Parental Experiences of the Berlin Heart as a Bridge to Cardiac Transplant

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Abstract

Due to advances in the identification, treatment and monitoring of end-stage heart failure in children, survival rates are increasing. Consequently, devices such as the Berlin Heart, a mechanical circulatory support device, are being used to support children in cardiac failure whilst they wait for a suitable donor heart. Although the medical benefits of these devices over other forms of mechanical support have been established, studies have neglected the psychological impact of this experience on parents and their children.

This study aimed to explore parents' experiences of supporting a child on a Berlin Heart as a bridge to cardiac transplant. Secondly, this study aimed to understand the impact these experiences had on parental quality of life, parental adjustment to their child's condition and family dynamics.

Semi-structured interviews were completed with eight parents of children who were supported on the Berlin Heart as a bridge to transplant. Interpretive Phenomenological Analysis (Smith, Flowers & Larkin, 2009) was used to identify themes and connections across parents' accounts. Three superordinate themes were identified: 'Loss of Control on the Berlin Heart', 'Life in the Berlin Heart Bubble' and 'Transitioning Forward'.

The findings highlight the complex process of decision-making for these parents and difficulties managing distress in a restricted and isolated environment. Loss of control was a defining feature of parents' experience. The importance of their support system in transitioning forward to a more positive and hopeful position with their child, was also emphasised. Impact on parental quality of life, adjustment to their child's condition and family dynamics throughout the experience are discussed.

Several research and clinical implications are recommended for healthcare professionals working with this unique client group.

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Chapter 1: Introduction

1.1 Overview

Chapter 1 introduces the Berlin Heart and its development from various other types of mechanical circulatory support, for use in young children, to support the failing heart until a suitable donor heart becomes available. The technical aspects of the Berlin Heart and its associated procedures are detailed to provide the reader with an understanding of its impact on parents and children and its associated risks. In the absence of literature on the psychological impact of the Berlin Heart, the parental experiences of having a child in intensive care, in hospital for a long period, dependant on technology or needing an organ transplant are reviewed. Theories of coping and adjustment to chronic illness are then discussed in relation to the experience of Berlin Heart parents. Studies exploring the experience of adults and children using similar devices and their impact on caregivers are reviewed, together with the limited data on the experience of parents. The rationale for the current study is then provided.

The research design including the rationale for choosing Interpretive Phenomenological Analysis, details of the sample, data collection and analysis are discussed in Chapter two.

Following this, a narrative account of the results are provided in Chapter 3 using quotations from parental accounts of their experience to illustrate 15 subthemes representing three superordinate themes: Loss of Control on the Berlin Heart, Life in the Berlin Heart Bubble and Transitioning Forward. The results are discussed in Chapter 4 with respect to the two research questions and in relation to existing literature and theory. The study is then critically evaluated and its implications for future research and clinical practice are discussed. Finally, the researcher's personal reflections are provided.

1.2 Background Information

Advances in the identification, treatment and monitoring of end-stage heart failure in child and adolescent populations have resulted in significant increases in survival rates in recent years (Jefferies, 2012). Currently, cardiac transplantation is considered for children experiencing end-stage heart failure (Imamura et al., 2009; Almond et al., 2013) where without intervention, life expectancy is less than 24 months (Berg, 2002). Increasing numbers of children are being listed for heart transplant without a corresponding increase in donors (Jefferies et al., 2012). Consequently, treatments capable of providing mechanical circulatory support (MCS) are used to stabilise and support patients whilst they wait for a donor heart (Jefferies & Morales 2012).

1.3 Mechanical Circulatory Support

1.3.1 Extracorporeal membrane oxygenation. One form of MCS, Extracorporeal Membrane Oxygenation (ECMO), is a procedure used in both adults and children with severe cardiac and/or respiratory failure (Jefferies et al., 2012). The ECMO machine is similar to the heart-lung bypass machine that is used in open-heart surgery. Cardiac ECMO is typically indicated after open-heart surgery following cardiac arrest, when the heart may be swollen, unable to maintain blood pressure or have an irregular rhythm. It may also be used following infections affecting the heart muscle (myocarditis) or heart muscle failure (cardiomyopathy) where the heart fails effectively to pump blood around the body (Jefferies & Morales, 2012). During this time the machinery takes over the function of the affected organ (heart and/or lungs) allowing organ(s) to rest and recover.

In paediatric populations, the cardiac ECMO procedure had been the primary source of MCS for a number of years for children awaiting heart transplantation, (Almond et al., 2013) but has been associated with high rates of morbidity and mortality. The effective period of ECMO support is typically restricted to 10-20 days, after which serious complications can occur including: bleeding, cerebral infarction, multi-organ failure and brain haemorrhage (Fraser et al., 2012). Such complications are frequently fatal or preclude transplantation (Imamura et al., 2009). Given the uncertainty around the availability of donor organs and their suitability, the short duration of ECMO support is frequently insufficient, with only 40-60% of children surviving the wait to transplant (Jeewa, Manlhiot, McCrindle, Van Arsdell, Humpl & Dipchand, 2010).

1.3.2 Ventricular assist devices. Consequently, alternative MCS methods including the ventricular assist device (VAD) have been used in children with end-stage heart failure. VADs are capable of supporting either side or both sides of the heart and may be implanted or external to the body. Left ventricular assist device - LVAD or right ventricular assist device-RVAD, where only one pump is required and the other side of the heart continues to work naturally or bi-ventricular (BIVAD) support, where two pumps are required, partially or completely replacing the function of a failing heart, are used (Fraser et al., 2012). VADs can serve either as a bridge to transplant, or as a bridge to recovery for individuals who improve and regain cardiac function (Almond et al., 2013). In contrast to ECMO, VADs can be used for extended periods, however, they are subject to many of the same complications as ECMO (Imamura et al., 2009).

Adult external VADs have been used in older children and adolescents (Reinhartz et al., 2001) but the larger cannula sizes and stroke volumes (the amount of blood ejected from the left ventricle in one contraction) have precluded their use in smaller children (Arabia et al., 2006). Furthermore, the use of implantable VADs is limited in paediatric populations due to insufficient mediastinal space, and thus, external VADs are most commonly used (Almond et al., 2013). To circumvent these difficulties, novel MCS devices such as The Berlin Heart EXCOR VAD (described in more detail below) have been developed and adapted specifically for use in paediatric populations (Hetzer et al., 2006).

Fraser et al. (2012) investigated survival and the clinical efficacy of the Berlin Heart EXCOR as a bridge to transplant in 48 children (<16 years) in the USA using a prospective design. Survival rates in two groups, stratified according to body surface area, were compared with two historical matched control groups who received ECMO support. Although serious adverse events such as stroke, bleeding and infection occurred across both the Berlin Heart and ECMO groups, survival rates were significantly higher in the Berlin Heart group, with 88% versus 75% and 92% versus 67% survival to transplant, in the smaller and larger body mass groups for Berlin Heart and ECMO groups, respectively. A further multi-centre prospective examination by Almond et al. (2013) in USA and Canada, used an unselected cohort from May 2007-December 2010 to assess 204 children supported by the Berlin Heart

EXCOR device. The median duration of support was 40 days with a maximum of 435 days. Survival at 12 months was 75%- 64% successfully received transplantation, 5% were alive on the device and 6% recovered with the device explanted. Nevertheless, neurological dysfunction occurred in 29% of the sample and comprised the leading cause of death.

Given the higher survival rates in children supported on the Berlin Heart EXCOR and its capability for longer-term use compared to ECMO, together with the uncertainty surrounding the availability of appropriate donors, the use the Berlin Heart EXCOR has increased significantly across the USA and Europe.

The number of children with end stage heart failure, actively listed for transplant, in the UK has significantly increased from 12 in 2006 to 31 in 2015 (NHS Blood &Transplant, 2015). From January 2005 to May 2016, 81 children were supported on a Berlin Heart at one of the two UK paediatric transplant centres with a survival rate of 83% (J. Wray, personal communication, May 27, 2016). Data from the second centre were not publically available, although is likely to be comparable.

1.4 The Berlin Heart Device

The Berlin Heart EXCOR is an external VAD, first used in the UK in 2005. Although an internal counterpart exists (INCOR), hereafter, reference will be made only to the EXCOR version using the term Berlin Heart. It is a simple air driven pump, which can support either the left ventricle of the heart (Left Ventricular Assist Device), or the right ventricle (Right Ventricular Assist Device) or both (Bi-ventricular Assist Device). It consists of a plastic pump, which sits outside the body, see Figure 1 below. A range of pump sizes are available, which enables support provision to children from 3-100kgs.

The polyurethane pump is separated into two chambers by a flexible membrane. One side of the pump is filled with blood which is connected directly to the child's own heart using two silicone cannulae (see Figure 1 and 2 below). The other side of the chamber is air filled and connected to an IKUS driving unit via two long plastic tubes known as a 'driving tube or 'compressor hose' (see Figure 1 and 3 below).

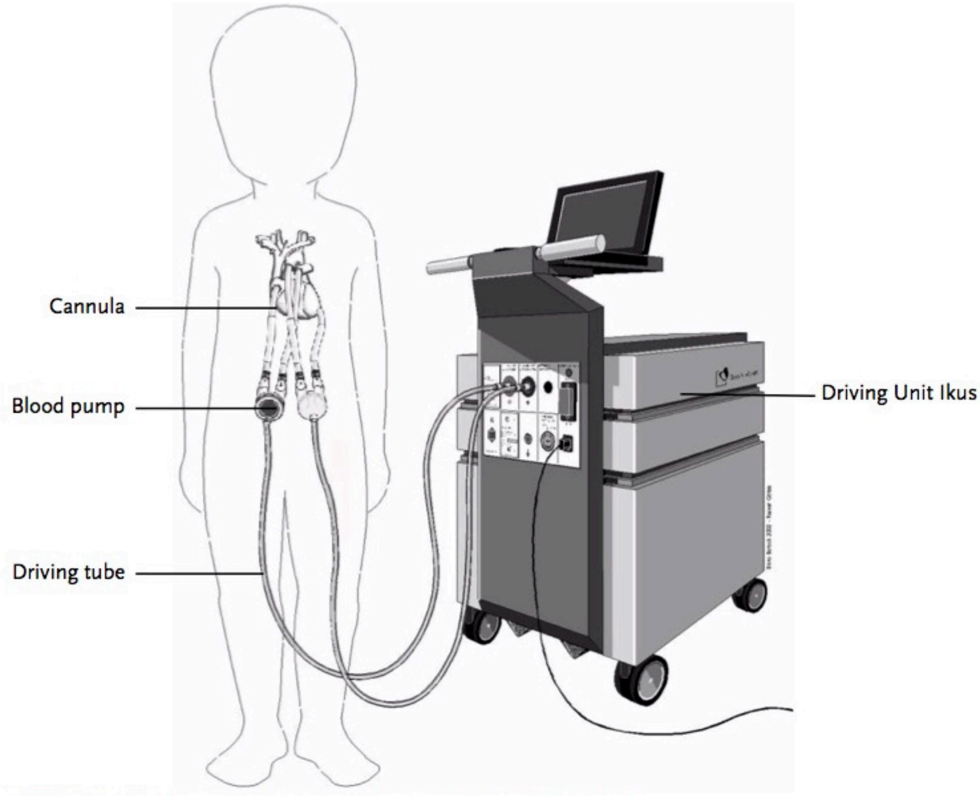

Figure 1. Diagram of a Child with Berlin Heart EXCOR BIVAD device, extracted Berlin Heart GmbH, (2008).

Figure 2. Photograph of a Child on the Berlin Heart EXCOR, extracted from Bridge to Transplant Team [NHS site], (2013).

The driving unit is attached to a laptop, which controls the parameters forcing air in and out of the pump. When air is drawn out of the pump, the flexible membrane is pulled back drawing blood into the pump's chamber from the child's own heart. Conversely, when air is forced back into the pump, the membrane separating the two chambers is driven forward pushing blood back into the child's main artery. Similar to a native heart, the Berlin Heart has valves, which ensure unidirectional flow of blood (Bridge to Transplant Team, [NHS site], 2013).

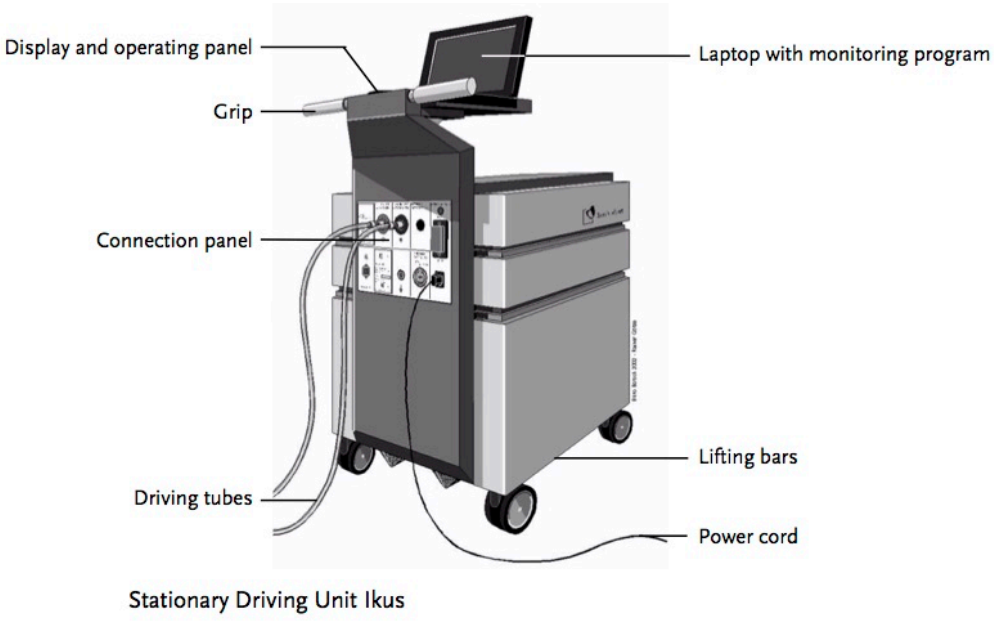

Figure 3. Diagram of the Berlin Heart EXCOR Driving unit, extracted from Berlin Heart GmbH, (2008).

Specifically, a LVAD drains blood from the left ventricle via a cannula inserted into the top of the ventricle and returns blood to the aorta via another cannula to circulate oxygenated blood around the patient's body. Conversely, an RVAD drains blood from the right atrium via a cannula and returns blood to the pulmonary artery via another cannula, sending deoxygenated blood to the lungs to collect oxygen. A BIVAD (see Figure 4 below) operated by using two pumps, an LVAD and an RVAD, supports both sides of the heart. Gas exchange occurs in the patient's own lungs in all support options.

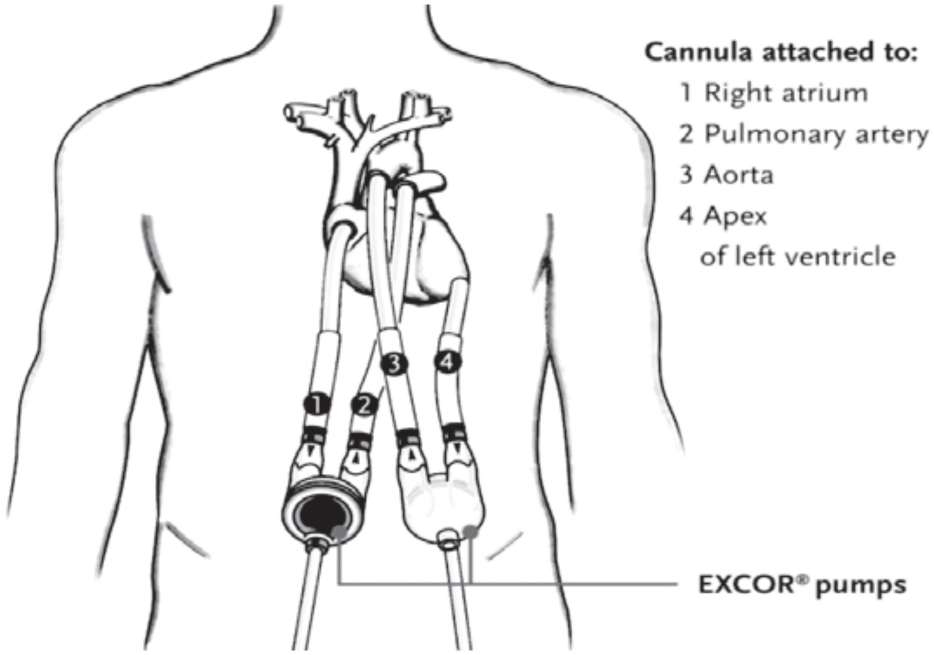

Figure 4. Diagram of the Berlin Heart BIVAD support, extracted from Bridge to Transplant Team, [NHS site], (2013).

1.4.1 Indications for the Berlin Heart. Although the use of VADs such as the Berlin Heart have become widespread and guidelines have been developed such as The International Society of Heart and Lung Transplantation (ISHLT) guidelines for management for paediatric heart failure (Kirk et al., 2014), the specific selection of suitable patients remains an area of active investigation and largely subject to individual clinicians and centre specific protocols (Feldman et al., 2013). At [NHS site] Hospital, although children with dilated cardiomyopathy, congenital heart defects and myocarditis are diagnoses commonly considered for Berlin Heart support (consistent with ISHLT guidelines), written referral criteria have not been formalised. Alternatively, indication for support is considered on a case-by-case basis at a weekly multidisciplinary Joint Cardiology and Cardiac Surgery meeting. Due to associated medical contraindications together with the limited donor resources, a list of exclusions have been developed (Appendix 1).

1.4.2 Implantation. Implantation of the Berlin Heart is completed on cardiopulmonary bypass, which takes over the function of the heart and lungs for the duration of the procedure. Following implantation, the child is transferred to PICU (Paediatric Intensive Care Unit) for a period of approximately two weeks, where they are closely monitored by specially trained staff (Bridge to Transplant Team, [NHS site], 2013).

1.4.3 Rehabilitation and continued care. Following the PICU phase of recovery, the child is moved to a high dependency unit (HDU) where a multidisciplinary approach to patient care is implemented. Given the evident psychological challenges this experience presents, psychological support is offered to all parents, children and siblings (where relevant) following an initial protocol driven clinical interview assessment, conducted by a Clinical Psychologist working in Cardiology. The format and type of support is variable, dictated by the family or individual needs and requests, and crucially the permitted time frame. An integrative approach is commonly used, employing Cognitive Behavioural, Systemic, Acceptance and Commitment and Mindfulness- based therapy models (V. Kelly, personal communication, May 5, 2016). Preparative materials are also provided to parents and older children to facilitate their understanding and adjustment and Play Therapists offer support to younger children.

Once stable, children are encouraged to mobilise and engage in developmentally appropriate activities promoting normal social interactions and adjustment to the device including play and education. Parents are strongly encouraged to complete training and education programmes (facilitated by nursing staff) so they can participate in caring for their child, performing wound care, thereby ensuring continuity of care and surgical site monitoring. Although restricted to the confines of the hospital most of the time, following completion of mandatory safety training (facilitated by nursing staff), parents and their children are encouraged to take carefully risk assessed visits following strict safety procedures, to local parks and coffee shops to promote quality of life.

1.4.4 Risks associated with Berlin Heart support. The relative efficacy and improved survival rates associated with the Berlin Heart have been recognised, however, it remains associated with several serious risks including: the surgery required to implant the device, infection, mechanical issues and stroke. Furthermore, removal of the Berlin Heart necessitates cardiopulmonary bypass (ECMO), associated with significant risk. Bleeding as a result of surgery is one of the most common complications (Bridge to Transplant Team, [NHS site], 2013) and transfusion and further exploratory surgery is often required.

Individuals supported on the Berlin Heart are at risk of stroke. When blood comes into contact with foreign objects such as plastic, it clots and thus anticoagulants such as heparin are used to thin the blood to prevent clots forming in the pump. This however, increases the risk of bleeding in other areas of the body and thus careful monitoring of blood and frequent observation and examination of the pump to check for clots, is required. If a clot is detected, the chamber must be replaced, which involves further surgery. Strokes occur in children supported on Berlin Hearts when clots leave the pump, entering the blood stream and are carried up to the brain where they cause damage to the brain tissue. Strokes occur in 20-30% of children on a Berlin Heart, the impacts of which range from impairments in: movement, speech, hearing, sight and personality, to death (Bridge to Transplant Team, [NHS site], 2013).

1.4.5 Impact of Berlin Heart. There are broadly two groups of Berlin Heart recipients who have suffered severe heart failure: those supported on medication for a period of time (chronic) and those who become acutely ill and require immediate intervention (acute). These groups are likely to have significantly distinct routes into support and thus divergent experiences of that support in terms of preparedness, their expectations and consequent adjustment.

Regardless of their chronic or acute status, patients receiving Berlin Heart support and their parents may be subject to prolonged hospitalisation whilst awaiting a heart transplant. During this time, patients and their families must process the need for their child to have a cardiac transplant and the known and unknown consequences of this. Additionally, they must manage the uncertainty surrounding the length of support they will require from the Berlin Heart and whether an appropriate donor will become available. Moreover, patients and their families must cope with the possibility and actuality of complications. Furthermore, they must adjust to an unfamiliar device, become acquainted with its novel, complex and technical routines and adapt to its intrusive noise, vibration and the physical restriction it imposes (Chapman, Parameshwar, Jenkins, Large & Tsui, 2007). Practical concerns such as being away from home, familiar roles and typical routines such as care of other children, work and other commitments may create significant strain on family dynamics, relationships and financial circumstances (V. Kelly, personal communication, August 27, 2013). Accordingly, parents may have to spend considerable time apart when they need one another's support the most. Conversely, estranged parents may have to re-connect and spend unusual amounts of time together.

Despite their widespread use, whilst research has established the clinical benefits of the Berlin Heart and its associated risks, there is a paucity of research available on the *psychological impact* of this invasive and high-risk intervention on both paediatric patients and their parents.

1.5 Importance of the Parental Experience

Understanding the psychological impact on parents is important not only for the parents themselves, but also because their influence is likely to impact both the medical and psychological outcomes of their children on the Berlin Heart. Children of distressed parents are at increased risk of depression and anxiety (Spence, Najman, Bor, O'Callaghan & Williams, 2002; Drotar 1997). An understanding of the parental experience is therefore imperative to explore. Parents are pivotal in the physical and emotional wellbeing of family members and thus their ability to adapt to their child's illness impacts the medical outcome of the unwell child (Gerson, Furth, Neu & Fivush, 2004; Stone et al., 2006; Johnston & Marder, 1993). The diagnosis of a chronic illness in a child generates a significant emotional challenge for the whole family system (Batshaw, 1991). The quality of parents' experience is likely to affect their behaviours and subsequent coping and adjustment to their child's condition. Given the restricted and emotionally laden environment of intensive and high dependency care wards, children's exposure to these experiences is arguably particularly influential, given the absence of other typical interactions. The experience of Berlin Heart parents therefore, proffers an important opportunity for modelling both effective and ineffective coping. Additionally, whilst parents offer a resource to support a child's coping and outcome, children exposed to ineffective parental coping experience greater distress and poorer outcome (Compas, Jaser, Dunn & Rodriguez, 2012). Furthermore, stress in parents of children with chronic illness has been associated with poor parental: psychological adjustment, depression and post-traumatic stress (Farley et al., 2007; Kronenberger et al., 1998; Young et al., 2003; Zelikovsky, Schast & Jean-Francois, 2007). This further underscores the importance of understanding the parental experience with respect to the Berlin Heart.

Given the lack of research attention specifically to the psychological experience of Berlin Heart parents, the broader literature evaluating parental experience and the psychological impact of several aspects inherent in the Berlin heart process including: having a child in intensive care, with a long-term hospital admission, dependent upon technology or requiring an organ transplant, will be reviewed. Theories of coping, adaptation and adjustment in chronic illness will then be outlined. Following this, studies relating to the specific use of VADs in both adults and children, and the consequences for their caregivers will be addressed.

1.6 Parental Experience of a Child in Intensive Care

Parents of children who are supported on a Berlin Heart are subject to a prolonged stay in an intensive care environment. The psychological impact on relatives of children who have intensive care admissions has gained significant research attention. An intensive care unit (ICU) admission is understandably very stressful for parents and has been associated with significant rates of persistent parental acute stress disorder (ASD) and post-traumatic stress symptoms. Using a prospective cohort design, Balluffi et al. (2004) found that ASD and post traumatic stress symptoms were widespread in parents of children requiring a stay longer than 48 hours in PICU, with 32% meeting symptom criteria for ASD at the initial assessment and 21% meeting criteria for post traumatic stress disorder (PTSD) at follow up at least two months after discharge. Lefkowitz, Baxt and Evans (2010) also established high rates of ASD and PTSD in parents of children hospitalised in Neonatal Intensive Care (NICU), with 35% of mothers and 24% of fathers meeting ASD criteria three to five days after admission. The negative impact of NICU was partially sustained 30 days later, with 15% and 8% of mothers and fathers, respectively meeting diagnostic criteria for PTSD. These figures suggest a vulnerability to PTSD in Berlin Heart parents when compared to prevalence estimates reported in epistemological studies of PTSD in the general population in the UK, which range from 1% in a nationwide study (Helzer, Robins & McEvoy, 1987) to

5.5% in a community sample in South East London (Frissa, Hatch, Gazard, Fear & Hotopf, 2013).

1.7 Parental Experience of Long-term Hospitalisation of Children

Berlin Heart parents are not only subject to the distress evidently associated with intensive care, but some are exposed to a prolonged period of hospitalisation. The stress experienced by parents of children hospitalised for major heart surgery has been investigated in a longitudinal study by Franck, Mcquillan, Wray, Grocott and Goldman (2010) using the Parent Stressor Scale-Child Hospitalisation, which measures parental stress in three domains: child's behaviour and appearance, parental role alterations and sights and sounds of the environment. The highest levels of stress were found in relation to the child's appearance and behaviour. Significantly, it was established that self-reported parental stress remained stable at a moderate to high level throughout a child's hospitalisation and was not correlated with illness severity or length of stay.

1.8 Parental Experience of Technology-dependent Children

Literature investigating the experience of families of technology-dependent children highlighted the significant emotional, social and financial implications on parents including social isolation and exclusion from work (Kirk, 1998; Wilson, Morse & Penrod, 1998; Tong, Lowe, Sainsbury & Craig, 2010). Kirk, Glendinning and Callery (2005) explored the parental experience of caring for a medically dependent child in a community setting using Grounded Theory analysis. The children's intensive and specialised care requirements had significant impact on parents' social and emotional wellbeing. Parents described a tension in their roles, assuming dual parenting and nursing capacities. It was concluded that parenting a technology-dependent child changes the meaning of parenting and underscores the importance of supporting parents in providing medical care to their children.

Carnevale (2006) qualitatively explored the parental experience of ventilator-assisted children in their home environment. Interviews were qualitatively analysed using a method based on Zaner's interpretive framework, which identified six themes: 'confronting parental responsibility', 'seeking normality', 'conflicting social values', 'living in isolation', 'the voice of the child' and 'questioning the moral order'. The challenge of adapting to their child's chronic illness, together with the perception of limited personal and social resources caused parents significant distress. This distress was emphasised in parents who assumed primary responsibility for the child's care needs.

The parental experiences of having a child with a chronic kidney condition (pre-dialysis, haemo or peritoneal dialysis, or had received a kidney transplant) was qualitatively explored by Tong et al. (2010) in 20 parents recruited from two Australian paediatric hospitals. The results from the Thematic Analysis were organised into four themes: 'absorbing the clinical environment', 'medicalising parents', 'disrupting family norms' and 'coping strategies and support structures'. Parents reported universal and profoundly negative experiences. Additionally, they reported feelings of uncertainty relating to their child's outcome, their own ability to cope and provide the necessary treatment. Furthermore, although feeling burdened by the care provided to their child and experiencing emotional and relationship difficulties, parents endeavoured to provide their parental and medical responsibilities.

1.9 Parental Experience of Organ Transplantation in Children

It is widely accepted that the process of paediatric organ transplantation is a complex longitudinal process, as opposed to a discrete event (Adams, Evangeli, Lunnon-Wood & Burch, 2014). This process of transplantation consists of several consecutive stages: identification of life-threatening illness, procedures to determine eligibility, decision regarding transplantation, waiting for a donor; then once an appropriate donor is found, the operative process, recovery and long-term follow up (Gold, Kirkpatrick, Fricker, Zitelli, 1986; Stubblefield & Murray, 1998). Each of these phases has been found to present distinct and unique challenges and adaptive tasks (Gold et al., 1986; Adams et al., 2014). These first four phases are inherent in the Berlin Heart process and thus the literature relating to the parental experience of other paediatric solid organ transplantation will be reviewed.

It has been established that the process of organ transplantation has a profound impact on parents (Gold et al., 1986). There is an emerging literature base exploring the psychological factors influencing paediatric heart transplant. However, much of this literature focuses on the child's psychopathology and concentrates on post-transplant adjustment, neglecting phases earlier in the transplant process (Adams et al., 2014), pertinent to the Berlin Heart procedure.

The emotional and behavioural impact of waiting for a transplant has been explored and psychosocial difficulties and psychiatric disorders have been identified. Using a sample of children awaiting heart and heart-lung transplantation, Wray and Raddley-Smith (2004) established that 24 and 21% of children and parents respectively, scored above clinical thresholds for depression on the corresponding versions of the Mood and Feelings Questionnaire (Angold & Costello, 1987).

There is emerging evidence examining the wider family implications of transplantation. Specifically, high rates of parental distress, anxiety, depression, and marital or relational difficulties are reported in parents of recipients of solid organ transplants (Higgins, Kayser-Jones & Savendra, 1995).

1.10 Models of Coping, Adaptation and Adjustment in Chronic Illness

Living with a chronic illness evidently presents challenges to the affected child, parents and wider family unit. Several factors have been purported to mediate the relationship between clinical stressors such as uncertainty, waiting, medical complications and restriction, and psychological outcome in the context of chronic and acute illness. Significantly, theory suggests that it is not the occurrence of an adverse event that is stressful, but the meaning an individual ascribes to it and how they consequently cope and mange that appraisal (Lazarus & Folkman, 1984). To enable understanding of parents' experiences of having a child on a Berlin Heart, it is important to explore their appraisal of the process, as the meaning and significance they ascribe to it will impact the individuals' emotional and behavioural responses. Several theories and models have been developed to help explain these complex relationships.

1.10.1 Cognitive models of coping and adjustment. Lazarus and Folkman's (1984) transactional model of stress and coping has been applied to understanding adjustment in chronic illness. A stressful experience is construed as an interaction between the person and their environment. This cognitive model suggests that these transactions depend on the perceived impact of the external stressor. An individual's adjustment to the stressors is suggested to be mediated by several factors. Initially, the individual evaluates whether the stressor is significant and constitutes a threat to their wellbeing- a primary appraisal. Following this, individuals assess the availability and efficacy of internal and external coping resources, and appraise the perceived controllability of the threat- a secondary appraisal. The interaction of these appraisal phases is suggested to influence the individual's perceived stress and the strength and quality of their subsequent emotional response and behaviour.

Applied to parents of children supported on the Berlin Heart, the environmental stressor could be construed as: being informed of the need for the Berlin Heart, the Berlin Heart procedure itself, experiencing complications whilst on it and the wait for a suitable donor. These stressors are likely to be primarily appraised as being highly threatening and significant. Where parents perceive the availability and efficacy of their coping resources, and thereby perceive control over the stressor, they are predicted to cope well and adjust. Conversely, where parents perceive an absence or an inefficacy of coping resources and thus lack of control over the stressor, they are predicted to cope and adjust poorly. Lazarus and Folkman (1984) purport that coping requires adapting behavioural and cognitive effort to minimise stressors, regulate emotion and thus assert control over the individuals' environment.

Lazarus and Folkman (1984) also suggest that characteristics of the individual and their situation impact their appraisal of stress and subsequent coping. These personal characteristics incorporate individuals' beliefs and are influenced by what is important to the individual. Self-efficacy beliefs are such an example and refer to an individual's belief in their own capability to respond effectively in a given situation. Thus, in circumstances that an individual attributes high value and importance to a situation, such as preservation of their child's life whilst on the Berlin Heart, and feels unprepared and poorly equipped to manage the situation (low self-efficacy beliefs), they are likely to experience feelings of hopelessness and thus experience difficulties coping.

Situational factors have also been identified which may influence an individual's appraisal of stress. If presented with a novel situation, given the absence of previous experience to draw from, individuals often struggle to evaluate their ability to cope. Thus, the unpredictability of events, together with feelings of uncertainty may impair an individuals' ability to use coping strategies and anticipate periods of security. Consequently, when an individual perceives their inability to influence and control their environment, feelings of hopelessness (Seligman, 1975; Abramson, Metalsky & Alloy, 1989) may impair their perceived accessibility of coping resources. In the novel situation that the Berlin Heart presents, parents may appraise their ability to cope as inadequate, thereby negatively impacting their coping responses.

The models outlined above highlight factors which mediate an individual's adjustment to their own experience of illness and their application to the experience of Berlin Heart parents. However, adjustment is also influenced by the social ecological context such as family functioning and social support. Although the importance of parent and family factors has been highlighted in select conceptual models of children's adjustment to chronic illness (Thompson & Gustafon, 1999 & Wallander and Varni, 1998), few models have incorporated the systemic impact of illness on adjustment in parents.

1.10.2 Systemic models of adjustment to chronic illness. McCubbin and Patterson's (1983) Double ABCX Model of Adjustment and Adaption and the more recently updated-The Model of Family Adjustment and Adaption (McCubbin & McCubbin, 1993), conceptualised stress within a family as a dynamic process of adjustment. Similar to the cognitive models outlined above, stress is defined as an imbalance of demands between the stressor event (A) and the families perceived resources (B). The family's definition of this imbalance (C) is purported to influence impact of the stressor, comparable to the aforementioned models. A crisis (X) is asserted to occur when a family is unable to balance the demands with coping strategies to resist the stressor and thus changes to the family structure or interactions occur. A family's ability to recover from a crisis is suggested to be influenced by four variables: multiple stressors, the acquisition of new resources, redefinition of the situation and the results of the implemented coping strategies.

Moss-Morris (2013) has proposed a working model of adjustment to chronic illness as depicted in Figure 5 below, which can be applied to parents.

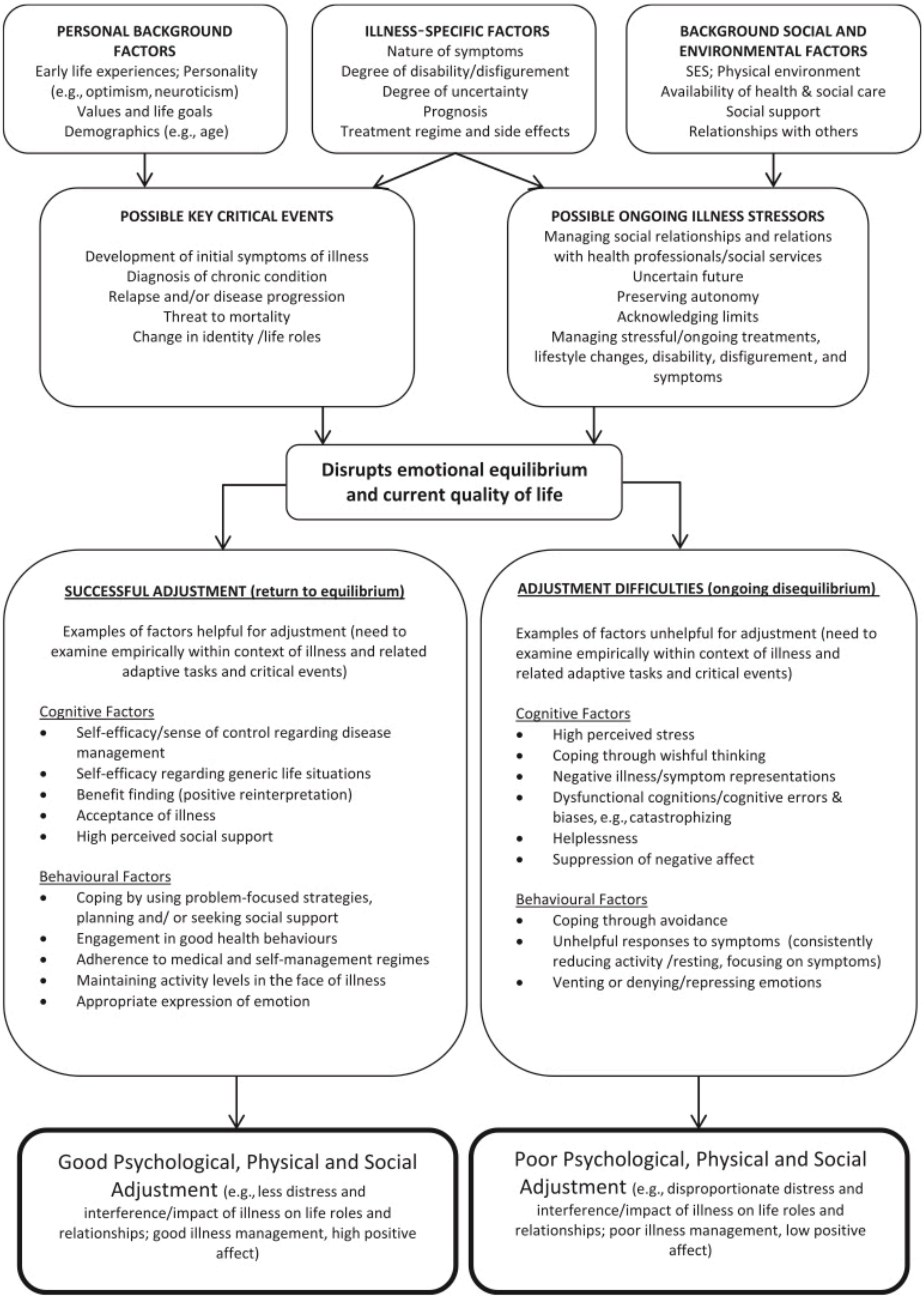

Figure 5. A working model of adjustment to chronic illness, extracted from Moss-Morris, (2013).

Moss-Morris's (2013) model suggests that personal factors (demographics and personality) and social environmental background factors (availability of social support and relationship with others) influences an individual's response to illness. Concurrently, factors particular to the illness such as uncertainty and treatment approach impact the illness stressor. Taken together these factors are proposed to disrupt an individuals' emotional equilibrium and quality of life. The adaptive task for adjustment in the case of a chronic illness is to maintain a sense of equilibrium, whereas, returning to equilibrium is the adaptive task for acute events such as diagnosis. Moss-Morris asserts that this equilibrium is associated with successful adjustment. Conversely, persistent disequilibrium is associated with difficulties in adjustment. Furthermore, although not empirically established for a cardiac population, the model suggests that successful adjustment is facilitated by the use of specific cognitive strategies (e.g. sense of control over illness and positive social support) and behavioural strategies (problem-focused coping strategies such as seeking support and sharing of emotions and concerns). Difficulties in adjusting to chronic illness however, are indicated by persistent distress, disrupted life roles, low positive affect and coping through avoidance.

This suggests that particular types of coping strategy facilitate successful or problematic adjustment.

1.11 Parental Coping and Adjustment

Coping mechanisms in the context of chronic illness have been recognised as a potential risk factors and protective factors, moderating the relationship between the illness stressor and adjustment (as indicated by psychological outcome) (Wallander, Thompson & Alriksson-Schmidt, 2003). The use of avoidant coping strategies has been associated with maladjustment in parents of children with chronic illness. Disengagement strategies were predictive of maternal depression and ruminative worry in children awaiting bone marrow transplant (Kronenberger et al., 1998). Additionally, avoidant coping strategies (denial and distraction) and high parental stress was predictive of depression in mothers of children with end stage renal disease awaiting a kidney transplant (Zelikovsky et al., 2007). Furthermore, in a pilot study of parents across organ transplant groups, Simons, Ingerski and Janicke (2007) found negative correlations between engagement strategies and psychological distress in mothers. Moreover, disengagement strategies and lack of social support were related to poor psychological outcome measured by the Brief Symptom Inventory. Emotion-focused coping strategies including distancing, escape and avoidance have been found to be used in parents of children with bladder extrophy, at times of particularly high stress (Mednick, Gargollo, Oliva, Grant & Borer, 2009)

The literature pertaining to parental coping and adjustment to having a child waiting for transplantation is scant. It is notable that paternal experiences are under-represented, with much of the research base focusing on maternal experience. Moreover, studies are drawn from small, heterogeneous samples (with respect to the child), compromising their internal validity and use diverse measures to assess numerous psychological and psychiatric domains, thereby complicating the interpretation of findings (Anthony et al., 2014). Nevertheless, broader findings have been established including: compared to fathers, mothers experienced greater stress related to their child's illness or transplant, greater levels of depression and were more likely to use engagement coping strategies and derive psychological benefit from social support (Simons et al., 2007; Zelikovsky et al., 2007).

Studies have highlighted the changeable nature of parental adjustment and coping throughout the transplant process. Conflicting findings have been presented concerning parental adjustment and coping over time. LoBiondo-Wood, Williams and McGhee (2004) reported decreased maternal stress and uncertainty and increased coping over time in a small sample of mothers of children pre and post liver transplant. Conversely, using a longitudinal methodology, a sample of mothers of children undergoing transplantation (kidney, live, heart or bone-marrow), Rodrigue and colleagues (1997) reported an increase in parental stress in the six months after transplant. These divergent findings may reflect the dynamic process of adjustment and the changing adaptive tasks confronting parents over time (Moss-Morris, 2013).

Having reviewed the complex relationships involved in appraisal of illness, utilisation of coping strategies and how these may contribute to adjustment to illness and the uncertainty inherent in waiting for a transplant, the literature relating to the specific use of VADs in both adults and children and the consequences for their caregivers, will now be reviewed.

1.12 Studies Exploring Experience of VADs

Although parents' narratives have seldom been reported, there is a small literature base exploring the impact of VADs in adults, children and caregivers.

1.12.1 VADs in adult populations. The ultimate benefits of transplantation on quality of life (QoL) in adult populations are well established with: improved social functioning, reduction in anxiety and sleep disturbance, enhanced vitality and engagement in more physical activities (Juenger et al., 2002; Dew et al., 1993; Deshields, McDonugh, Mannen & Miller, 1996). Nevertheless, investigation into adjustment and QoL in adults currently living with a VAD *in situ* has not received equivalent research attention. Although an early study in the USA concluded that the QoL and mood of LVAD patients was equivalent to that of transplant recipients (Dew et al., 1999), these findings have not been consistently replicated in the UK.

In a cross-sectional pilot study of 22 adults enrolled on an LVAD programme within the UK, QoL (World Health Organisation Quality of Life Assessment) (WHOQOL group, 1995) and psychological functioning (Hospital Anxiety and Depression Scale, HADS) (Zigmond & Snaith, 1983), were measured across three groups: eight patients with a LVAD (Heartmate1, 2 or Thoratec) *in situ,* six patients who had the LVAD explanted and eight patients who had undergone transplantation (Wray, Hallas & Banner, 2007). Although no significant differences in QoL or psychological functioning between the three groups were found, a significant trend was highlighted for poorer QoL and higher rates of anxiety and depression in patients with an LVAD *in situ*. Although it is difficult to draw firm conclusions given the size of the sample, potential confounding factors and clinical significance not being established, these findings are supportive and consistent with previous reports (Moskowitz, Weinberg, Oz & Williams, 1997; Grady, et al., 2003). Moreover, it could be argued that the small numbers employed may have impacted the power of the study to detect a difference between the groups. It should be noted that the LVAD patients were supported on a range of first generation devices and thus the further investigation in relation to newer devices is required. In this pilot study, QoL with an LVAD as an inpatient was significantly worse than that of outpatients, consistent with previous findings (Dew et al., 1993; Grady et al., 2003). The poorer QoL experienced by the inpatients may be attributable to the severity of their illness compared to the outpatients, or their lack of social support to enable their discharge. Equally, the hospital environment may have influenced their QoL directly, or influenced them to appraise their condition as more serious. This indicates that an understanding of the Berlin Heart parents' experience within the hospital environment is essential.

In a longitudinal study of 63 adult VAD patients who received heart transplants, physical functioning, emotional and cognitive wellbeing and social functioning was assessed at two, seven and 12 months post-transplant. Ninety control patients who had not received VAD support were matched on socio-demographic characteristics and cardiac difficulty (Dew et al., 2001). Whilst physical and emotional functioning post-transplant was largely comparable between the two groups across the study periods, VAD patients were found to have greater cognitive impairment and poorer social functioning outcomes compared with patients transplanted without VAD support (Dew et al., 2001). This difference between the two groups is likely accounted for by the adverse effects of the VAD support such as stroke.

Baba et al., (2006) explored psychiatric difficulties in 14 adult heart transplant candidates in Japan supported by LVADs between September 1997 and October 2005. Twelve of 14 patients were diagnosed with a psychiatric disorder, where adjustment and depressive disorders were most common. Furthermore, six of the 14 had more than one DSM-IV diagnosis.

A qualitative retrospective pilot study in the UK was conducted examining the impact of implantation of a VAD in adult patients and their relatives (Chapman et al., 2007). Six patients and three of their relatives were interviewed and the data analysed using interpretative phenomenological analysis (IPA) methods. Themes relating to impact on the patient's body, perception of self and trust were identified. Although it was understood that these effects are often successfully negotiated, some patients and their caregivers required supplementary support to process their experience.

In a Danish qualitative study of illness experience of patients with an LVAD, a convenience sample of 10 adult patients from 2008-2010 was evaluated using an 'in-depth interviewing' technique (Overgaard, Kjeldgaard & Egerod, 2012). Themes including 'ambivalence of gratitude and frustration towards the VAD' and 'ambivalence of hope and fear' were identified during the bridging and preparation for transplantation phases, respectively. Additionally, the authors identified divergent outcomes in relation to vocational adjustment between the younger and older participants within the sample, where the younger experienced greater difficulties. This study also highlighted patients' significant dependence on support from family members including spouses, parents and children.

1.12.2 VADs in paediatric populations. Using a retrospective cross-sectional design, QoL was assessed in children who underwent successful heart transplantation for cardiomyopathy (Wray et al., 2012). A validated self-report measure, the Paediatric Quality of Life Inventory (Varni, Seid & Rode, 1999), was employed and completed by children aged 5-18 years and the parents of children aged 2-18 years. Two groups were defined: 26 children bridged to transplant using a VAD (range of devices) and 58 transplanted without bridging. No significant differences were found between the two groups, with comparable QoL scores reported by both parents and children. Nevertheless, the small sample size, notably in the bridge to transplant group increases a Type II error rate (small-medium effect sizes were reported across the QoL domains). Additionally, the likelihood of error is arguably amplified by the exclusion of seven deceased patients and twelve who transitioned to adult services.

Some studies have highlighted negative effects associated with VAD support in children. A quantitative investigation of psychiatric symptoms in eight children (1-16 years) supported with a Berlin Heart VAD *in situ* was conducted by Ozbaran et al. (2012a) in Turkey. Psychiatric evaluations were conducted at two time points (1-2 months post VAD implantation and at 6 month follow-up) using validated self- and parent-report measures together with a semi-structured psychiatric interview (depending on the child's age). At the initial evaluation 62% of the sample had a psychiatric diagnosis including anxiety (not otherwise specified), major depressive disorder and adjustment disorder. Although these diagnoses were not sustained in all children at follow up, with some in remission and others developing new diagnoses, this study highlights the significant psychological vulnerability of children during this period. It is notable that these rates and presentations are comparable to those reported by Baba et al. (2006) in an adult population.

1.12.3 Impact of VADs on caregivers. As the use of VADs is becoming more widespread, a corresponding increase in demand for support from patients' close relatives has been noted (Maclver et al., 2009). Research exploring this phenomenon in adult populations is beginning to mature.

Phenomenological studies in the USA exploring the experiences of spouses and family caregivers of adult patients discharged home with LVADs have revealed issues pertaining to emotional distress, guilt, fear, anxiety, loss and care burden, thus highlighting the needs of the caregiver as well as the patient (Casida, 2005; Kaan, Young, Cockell & Mackay, 2010). Moreover, the experience of close relatives of adult LVAD patients during bridge to transplant was qualitatively explored using Grounded Theory in a Danish study. An interview with two members and a group interview (n=5) were conducted with close family members (parent, spouse or sibling. Results highlighted the significant importance and benefits of close family support on patients and care providers (Egerod & Overgaard, 2012).

The importance of the caregivers' experience has been further emphasised by two European quantitative retrospective studies investigating the prevalence of PTSD in partners of VAD patients who later received heart transplants. In a multicentre retrospective study, Bunzel, Laederach-Hofmann, Wieselthaler, Roethy and Drees (2005) established that 0% of patients but 23% of their partners met criteria for PTSD, measured by the Impact of Event Scale-Revised (IES-R) (Weiss & Marmar, 1997). Additionally, 2% of patients but 19% of partners and 4% of patients but 23% of partners reported mild to moderate levels of depression and anxiety respectively, on the HADS (Zigmond et al., 1983). More recently, Bunzel, Laederach-Hofmann, Wieselthaler, Roethy and Wolner (2007) have corroborated these findings in a cross-sectional study of 38 patients and 27 spouses investigating symptoms of PTSD, 6-135 months post-operatively. 26% of the spouses and 0% of the patients met criteria for PTSD. Additionally, spouses were found to report significantly higher scores across all IES-R dimensions and greater concern relating to pain, device malfunction, stroke and infection, when compared with the patients themselves. These findings may be partially explained by caregivers' distress associated with feelings of medical responsibility, carer burden and empathy for their partners' situation.

It is evident that the extant literature relates to the experiences of caregivers to adult VAD patients. However, as the number of children supported on VADs increases, the need to understand the parental perspective and experience is accentuated.

1.12.4 Impact of VADs on parents. The child-parent dyad presents a unique relationship dynamic. High levels of anxiety have been associated with having a child with a cardiac condition (Lawoko & Soares, 2002). Furthermore, it is well established that hospitalisation of a child for cardiac surgery is a significant stressor for parents (Franck, et al., 2010; Board & Ryan-Wenger, 2002; Shudy et al., 2006; Wray, Lee, Dearmun & Franck, 2011). This is particularly apparent when post-operative intensive care support is required (Board & Ryan-Wenger, 2000). Moreover, high levels of parental stress have been reported in relation to the child's appearance and behaviour (as measured by Parent Stressor Scale: Infant Hospitalisation (Frank et al., 2010), aspects particularly pertinent to VAD support. This suggests that parents will be impacted by the VAD itself, the transplant processes and also by their child's medical and emotional response.

During VAD support, parents are presented with a novel environment and have minimal control over their child's situation, whilst needing to provide an essential support role for the child (Ozbaran et al., 2012b). Studies have highlighted that individuals frequently feel overwhelmed by the burden of care and feelings of responsibility for the VAD regimens (Eshelman, Mason, Nemeh & Williams, 2009). Managing the uncertainty of this process together with contending with the loss of typical parental roles and balancing new requirements (Board & Ryan-Wenger,2000; Shudy et al., 2006), frequently resulted in emotional distress and burden. These findings highlight the complex and extensive support needs of the parent and family unit and warrant further research attention.

A quantitative study by Ozbaran et al. (2012b) examined depression and anxiety levels in eight mothers of children with LVADs in Turkey. Although mean self-reported rates of depression and anxiety were found to decrease six months post-VAD implantation, 75% of the mothers reported high levels of depression and 100% reported moderate levels of anxiety at the initial evaluation (1 month post implantation). Furthermore, a positive relationship between VAD duration and parental distress was identified.

One qualitative study of the experiences of children being supported on a VAD as a bridge to transplant and their respective parents' experiences has been published (Gilmore & Newall, 2011). This Australian retrospective study employed purposive sampling of six parents and four children (aged 13 years and greater) from July 2005 to February 2008 to explore their informational needs during their respective experiences of VAD support. Semi-structured interviews were conducted and data from the parents and children were analysed separately using Thematic Analysis. The majority reported feeling ill-informed and inadequately prepared for the course of VAD support, particularly regarding associated risks and potential complications. Similarly, children reported that the information provided prior to implantation did not adequately equip them for the experience they later faced. The study is subject to several limitations. Primarily, the study focuses on the informational needs of the children and their parents, neglecting their actual lived experience and its systemic impact. Additionally, although not unique to studies of this nature, the authors comment upon parents' poor ability to recall events, highlighting the possible impact of recall bias. Although limited by the number of children supported at the institution within the specified timeframe, only one of the consenting parents experienced a negative outcome- the death of their child. Moreover, one of the children in the sample recovered thus the VAD was removed, adding to the heterogeneity of the sample. It is thus complex to determine the extent to which this cohort's experiences are transferable to other parents. Furthermore the authors fail to state the type of VADs, the duration for which they were supported, or the amount of time elapsed since support for each child. Finally, length the of the parent interviews ranged from 9-45 minutes, suggesting some were short and lacking detail.

1.13 Rational for the Current Study

To summarise, the above review highlights that parents of children in ICU, those who are subject to long periods of hospitalisation, who are technology-dependent or are awaiting organ transplant experience a variety of adverse psychological and social effects. Parents of children on the Berlin Heart are exposed to all of these aspects, the combined effects of which are unknown. Furthermore, the Berlin Heart is a unique device and thus factors associated with it may differentiate the parental experience from that of other VADs or conditions.

Consulting the wider adult literature, it has been established that VAD use (*in situ*) is associated with poorer QoL, inferior social functioning, greater cognitive impairment than those bridged to transplant without a VAD and high rates of psychiatric disorder. Furthermore, negative outcomes including emotional distress, PTSD and high rates of depression and anxiety have been both quantitatively and qualitatively established in caregivers and spouses of adult VAD patients. The transferability of these findings to parents of children on the Berlin Heart may be limited. The nature of the parent-child relationship represents a unique dynamic associated with an enhanced feeling of responsibility to protect given the child's developmental stage. Thus, studies specific to this relationship are required to elucidate the parental experience.

Two quantitative studies have identified high rates of anxiety and depression in parents of children with a VAD *in situ* and post-traumatic stress symptoms in the parents of children post heart transplant. However, the only qualitative study addressing the parental experience of having a child on a VAD, provides an understanding focused only on their informational needs. Consequently, currently, there is no comprehensive qualitative understanding of the parental lived experience and impact of having a child supported by a Berlin Heart as a bridge to cardiac transplant.

The following study is proposed to develop Gilmore and Newall's. (2011) work, building on its limitations. By expanding the scope, this study aims to gain an enriched understanding of the wider lived experience of a larger, more homogeneous, clearly defined sample of parents of children bridged solely to transplant, using a specified VAD- the Berlin Heart.

1.14 Adopting a Qualitative Approach

Given the absence of research focusing on the parental experience of the Berlin Heart, a qualitative approach with exploratory aims was selected. A qualitative approach was deemed appropriate to prevent imposing restrictions on the data by using hypothesis testing or quantitative methods. Additionally, a qualitative method was felt important to enable the emergence of salient idiographic experiences and their subjective meanings. Furthermore, a qualitative exploration permits a detailed examination of the evident complexity inherent in parental experiences of this nature (Clark, 2009), which is currently absent from the literature base. Moreover, a qualitative approach was felt to be appropriate as it would move beyond a distress or impairment focus and capture the wider experiences and perspectives of parents within a broader social, emotional and psychological framework.

IPA focuses on participants' perceptions in an attempt to understand how individuals make sense of their experience, using a subjective and reflective process of interpretation (Smith et al., 2009). The inductive and iterative procedures of IPA help the researcher develop an "insider perspective" on the topic being studied, whilst also providing an interpretation of what this means to the participant. IPA is grounded in phenomenological epistemology and was thus considered suitable for exploring the parental lived experience and how parents make sense of these experiences (Holloway & Todres, 2003). The specific rationale for using IPA is discussed extensively in the methodology chapter.

1.15 Study Summary and Research Aims

This study aimed to increase the understanding of parental experience of having a child on a Berlin Heart to inform the development of interventions to enable services to meet the needs of this unique but increasing population. In depth insight and understanding may enhance preparation of parents and their families prior to their support on the Berlin Heart and may thereby mitigate negative effects on the parent and child. Furthermore, the data may facilitate more effective targeting of psychosocial interventions to improve parental experience and the quality of care provided to children and their parents, whilst making a valuable contribution to the limited evidence base.

The study will aim to answer the following research questions:

1) What are the lived experiences of parents of children who have been supported on the Berlin Heart?

2) What is the impact of these experiences on: parental quality of life, parental adjustment to their child's condition and family dynamics?

Chapter 2: Method

2.1 Research Design

A cross-sectional qualitative design was used. Semi-structured interviews were completed with parents of children who had been bridged to transplant with a Berlin Heart to retrospectively explore their experiences of their child's support.

2.2 Epistemological Position

This research explores the lived experiences of individuals from their own perspective and the meanings they make (Larkin & Thompson, 2012). This study assumes a critical realist stance within a hermeneutic phenomenological epistemological position. The critical realist assumption asserts that there are associations between an individual's account and their subjective reality. Although a researcher can never have complete access to an individual's experience (Nightingale & Cromby, 1999), through interpretations made of their accounts, understanding can be inferred within the particular context. IPA is consistent with this epistemological position and the exploratory aims of the study.

2.3 Interpretive Phenomenological Analysis: Theoretical Underpinnings

IPA is a qualitative methodology developed by Jonathan Smith (1996) to systematically explore individuals' lived experiences. IPA focuses on participants' perceptions in an attempt to understand how individuals make sense of their experience, by using a subjective and reflective process of interpretation (Smith et al., 2009). The inductive and iterative procedures of IPA help the researcher develop an ‘insider perspective’ on the topic being studied, whilst also providing an interpretation of what this means to the participant.

IPA is informed by three philosophical principles: phenomenology- the study of lived experience and being, hermeneutics-the theory of interpretation underpinning the interpretative element of IPA and idiography-the study of the discrete at an individual level. A more detailed examination of these principles is beyond the scope of this research, however for further details see Shinebourne (2011) and Smith et al. (2009).

2.4 Rationale for Choosing Interpretive Phenomenological Analysis

Qualitative approaches enable researchers to examine perspectives and meanings about phenomena which are little known or understood (Marshall & Rossman, 1999). Due to the small and unique population to be studied, the exploratory nature of the proposed research and small population size, qualitative analysis methods were considered appropriate.

IPA permits an idiographic exploration of the parental experience and acknowledges the relational focus of the parent and child’s shared experience within the Berlin Heart context. Furthermore, IPA has particular utility in health psychology research because of its interest in experiences that provoke reflection, and its sensitivity to the context in which events occur (Smith et al., 2009). Moreover, numerous studies have successfully employed IPA to examine parental decision-making and experiences of caring for a child with chronic illness (Daniel, Kent, Binney & Pagdin, 2005; Glasscoe & Smith, 2011). It was therefore considered an appropriate approach to explore the experience of parents of children supported on a Berlin Heart.

IPA is also appropriate for under-researched areas and able to capture the perspective of untold narratives of parents of children supported on a Berlin Heart. No preconceived hypotheses are held, so that participants' voices are unconstrained, allowing new and often unanticipated features of a phenomenon to be revealed (Shaw, 2001).

IPA allows insight into the process of decision-making and experience of hospitalisation, many features of which would be lost through quantitative methodologies. Additionally, IPA provides a practical and theoretical framework for exploring the processes through which people make sense of and attribute meaning to their experiences (Brocki & Wearden, 2006).

From a phenomenological perspective, IPA can also help research move beyond an objective and observable conception of Berlin Heart support, to consider subjective and lived experiences. Importantly for a novice qualitative researcher, IPA offered clear guidelines, training and support groups to help ensure production of a high quality piece of research.

2.5 Excluding other Qualitative Approaches

Careful consideration was given when designing the study and developing the research aims to determine the most appropriate analytical method. IPA was selected after excluding several other qualitative approaches.

Thematic Analysis (Braun & Clarke, 2006) typically employs larger samples and adopts a nomothetic stance, concerned with the generalisability of findings. Thematic Analysis places less significance on the reflexivity of the researcher and the analysis is focused at a more descriptive level. It was concluded this approach would not produce an idiographic or sufficiently rich understanding of parents' experience, nor adequately attend to the role of social and cultural context through interpretations.

Discourse Analysis (DA) (Potter & Wetherell, 1995) emphasises the function and impact of language, and the construction of reality through language, rather than reflecting it. DA did not fit with the researcher's critical realist epistemological position. Whilst IPA acknowledges the role of language in understanding how participants understand their experience, DA would not attend to the cognitive and affective reactions and sense-making focus of the research questions.

Grounded Theory (Glaser & Strauss, 1967) is a sociological methodology used to describe and generate theories of social processes. This approach uses theoretical sampling, which ceases data collection when data saturation is achieved and new ideas cease to emerge (Willig, 2008). Thus, Grounded Theory is most suited to research which aims to develop a theoretical model using a large sample of individual accounts (Lingard, Albert & Levinson, 2008). Although it was plausible to use Grounded Theory to form a model of decision-making, this was inconsistent with the broader, exploratory focus on capturing previously unheard experiences of having a child supported on a Berlin Heart (Harper, 2012). Consequently, IPA's emphasis on individual experience was considered to be most compatible with the study's aims.

2.6 Ethical Approval

The study received funding from the International Society of Heart and Lung Transplantation (ISHLT) and was part of a larger study- 'Identifying which outcomes matter to paediatric patients with specific complex cardiothoracic health conditions receiving specialist interventions'.

This larger study received full ethical approval by the London Bridge National Research Ethics Service (NRES) Committee. Subsequently, a substantial amendment (to add the researcher to the study) was submitted to the NHS NRES Committee- London Bridge and approved in the Sub-Committee meeting on 02/10/2013 (Appendix 2). Following this, a further amendment was submitted to NHS NRES Committee- London Bridge relating to the participant information and consent form and approved on 14/04/2014 (Appendix 3). Approval was granted by the Research and Development Department of the NHS recruitment site (Appendix 4). The research was also approved by the Royal Holloway University of London (RHUL) Psychology Department Ethics Committee (DEC) in 2014 (Appendix 5) and extended in 2015 (Appendix 6) and by the Clinical Research Adoptions Committee (CRAC) at the NHS recruitment site. The study was conducted in accordance with the British Psychological Society ethics guidelines (British Psychological Society, 2014).

2.7 Sample Size

Eight parents of children who had been supported on a Berlin Heart were recruited from a single specialist NHS tertiary children's hospital site. The size and availability of the population under investigation was a primary consideration. The tertiary children's hospital at which the research was conducted is one of only two paediatric heart transplant centres in the UK. Given the evident specialist nature of the target population, the number of potential participants was limited. From January 2005 to May 2016, Berlin Heart support was used in only 81 children; 11 of whom died on the Berlin Heart and two died before hospital discharge having had a heart transplant (J. Wray, personal communication, May 27, 2016).

A small sample size is recommended for IPA to allow consideration of each individual's experience and elucidate meaning (Smith et al., 2009). Moreover, in the context of professional Doctoral research, a sample size of four to ten interviews is recommended by Smith et al. (2009) and is consistent with other relevant qualitative studies in health psychology (Hale, Grogan & Willott, 2010).

A sample of eight was considered feasible given the constraints of the size of the population under investigation and time frame for recruitment and analysis within a Clinical Psychology Doctorate. It was anticipated that the eight accounts would be sufficient to permit integration of the lived experiences across the parent group, whilst preserving individual differences.

2.8 Inclusion and Exclusion Criteria

The IPA literature recommends obtaining a ‘fairly homogenous sample’, particularly when a novice to the approach (Smith et al., 2009). Homogeneity refers to the selection of participants who provide an idiographic perspective, in a given context. A number of inclusion and exclusion criteria were established prior to commencing recruitment.

Parents of children who had been bridged to transplant with a Berlin Heart at the tertiary children’s hospital were eligible to participate if they met the following inclusion criteria:

- *They were a UK resident.*

- *They were able to comprehend and speak English fluently* to avoid biases in interpretation.

- *They self-identified as their child’s main carer.* To reduce the complexity of analysis and issues around power dynamics and confidentiality present in dyad interviews, (Taylor & de Vocht, 2011 & Valentine, 1999), the parent with most contact with the child at the time of intervention self-selected from parental dyads. It was proposed that in the event that both parents requested involvement, separate interviews would be conducted.

-Their child was currently under follow-up care with the Cardiothoracic Team at the tertiary children's hospital.

Parents were excluded if:

-They were unable to provide informed consent.

-Their children had an underlying diagnosis of congenital heart disease. The homogeneity of the sample would have been affected by congenital heart disease patient's divergent disease course, the presence of previous surgery, together with the established significantly poorer outcomes and survival rates reported for this group (Blume et al., 2006; del Nido et al., 1994; Gajarski et al., 2003; Fiser et al., 2003 & Stiller et al., 2003).

-Their children experienced significant and unexpected medical complications post transplant such as development of Post Transplant Lymphproliferative Disorder. Such complications, could influence recollections of their experiences of the Berlin Heart and consequently complicate later interpretation.

- *Their children received the procedure before 2005.* Subsequent changes to the Berlin Heart design and associated procedures could influence parents' experience and thereby the homogeneity of the sample. This exclusion criterion also aimed to minimise the negative impacts of recall bias.

2.9 Sampling and Recruitment

Participants were recruited from the cardiac transplant department at the tertiary children's hospital.

Potential participants were identified from patient databases by an identified Clinical Nurse Specialist, screening for their suitability in accordance with the inclusion/exclusion criteria. Purposive sampling was employed to select a homogeneous sample, thereby providing the researcher access to a particular perspective of a phenomenon (Smith et al., 2009)-paediatric support on a Berlin Heart. This sampling approach is theoretically consistent with IPA and its philosophy (Chapman & Smith, 2002).

Potential participants were sent letters of invitation and information about the study (Appendix 7) from the clinical team, at least two weeks before their child's scheduled annual review or clinic appointment. Prior to their arrival at their annual review or clinic appointment, a member of the clinical team asked potential participants whether they would be willing to speak to the researcher. For those who agreed to participate, the researcher explained what the study would involve, answered any questions, obtained written informed consent (Appendix 8) and scheduled a convenient time during the annual review/clinic appointment to complete the interview.

Due to structural changes within the clinical team and staffing shortages, difficulties were experienced in distribution of information sheets to potential participants and thus recruitment was initially slow. Consequently, an Assistant Psychologist was enrolled to facilitate recruitment, contacting potential participants by telephone. Individuals who expressed interest in participating in the research and who consented to being contacted, were then followed-up by the researcher directly and provided with an information sheet (Appendix 7). Following this, the researcher explained what the study would involve, answered any outstanding questions and arranged a convenient interview time.

Six parents requested for the interview to be conducted outside of the clinic appointment/annual reviews due to time pressures and thus home visits were conducted. This approach opened the opportunity to recruit families unrestricted by the timings of hospital appointments.

During the recruitment period 12 eligible families were approached. One was excluded due to previous service-user involvement, one did not take part due to logistical difficulties and ten consented.

In total ten interviews were conducted. One of these was a pilot interview and one interview was accidentally deleted and could not be retrieved. Both RHUL DEC and NHS NRES Committee were informed and their guidance adhered to. The study sample consisted of the remaining eight interviews.

2.10 Sample Characteristics

All participants self-identified as their child's main carer during the Berlin Heart support. Seven mothers and one father were interviewed. Four of the parents were aged between 31-35 years, three were aged between 36-40 years and one was aged between 46-50 years. Seven parents identified as white British and one as

Somalian. Six were married, one engaged and one was single. Five parents were in employment, one unemployed and two cared for their child at home. Two parents had only one child, whilst others had two, three or six children.

The sample consisted of five female and three male children aged between one month and six years at the time of the intervention. Seven of the children had diagnoses of dilated cardiomyopathy and one of myocarditis. Six were supported on LVADs and two on BIVADs. The duration of support ranged from eight days to 172 days and complications occurred in six of the children. The length of time elapsed since the support ranged from two months to eight years six months, with an average of three years eight months.

Information was gathered from a demographic information questionnaire (Appendix 9) completed at interview, and supplemented subsequently from the child's medical notes. Some data have been excluded or categorised to maintain participant anonymity.

2.11 Data Collection

2.11.1 Semi-structured interviews. In accordance with recommendations by Smith et al. (2009) and Reid, Flowers and Larkin (2005), face-to-face semi-structured interviews were conducted to obtain a detailed first person account of each parent's experience guided by the researcher's exploratory questions. Interpersonal style and non-verbal cues were observed and noted to aid interpretation. Prompt questions were utilised by the researcher to facilitate expansion of answers and enquire further into areas of interest or unforeseen areas (Robson, 2011).

2.11.2 Interview schedule. An interview schedule was constructed to guide the interview process (Appendix 10). This schedule was developed initially to include themes extracted from a review of the relevant empirical base. It was refined following review by three self-selected service-users, discussions with research supervisors, peers and advice from the London IPA group to ensure questions were relevant, phrased clearly, sensitively and in an accessible format. Published IPA guidance was also adhered to, ensuring consistency with the theoretical framework and epistemological position (Smith et al., 2009).

Interview questions were open-ended to elicit an unbiased account of parents' perceptions and experience (Smith & Osborne, 2003). As recommended by the London IPA group, the first questions were open, exploratory and felt to be less challenging, to help build rapport and provide a platform from which participants could share their experiences. Following recommendation by the reviewing service-users, questions were structured chronologically as this was felt to assist in the interview's logical flow and aid participants' recall by reflecting phases in intervention support.

A pilot interview was conducted with a parent to assess the content and clarity of the questions and its perceived flow. Upon review of this interview, prompt questions were further refined to ask specifically for thoughts, feelings and examples within participant's experiences. This pilot interview enabled the researcher to experience interaction with a parent in a research rather than a clinical context and to become more familiar with the interview schedule.

2.11.3 Interviewing procedure. The first interview was conducted on 05/09/14 and then, following a period of maternity leave from 27/11/14-12/10/15, the remaining interviews took place between 15/01/16 and 09/03/16. Two interviews took place in a private clinic room on the NHS site and six were arranged as home visits at the participant's request. The researcher followed the NHS site lone worker policy and discussed a safety plan with supervisors prior to each home visit.

Interviews were conducted with the parent alone, at a time and date convenient to them. Interviews conducted as home visits were completed during school or childcare hours to enable the participants to speak openly about their experience.

Prior to the commencement of the interview the researcher reviewed the information sheet with the participant, providing an opportunity for them to ask questions and highlight pertinent ethical issues. Participants were reassured that the interview could be stopped at any time if they wished. Participants then signed the consent form (Appendix 8).

The interviews varied in length from 57 minutes to 141 minutes, with an average of 88 minutes. All participants were verbally debriefed by the researcher following the interview (Appendix 10). Feedback about the interview process was requested and participants were reminded of the support services available to them.

Interviews were recorded on a personal audio-recorder and later transcribed verbatim by the researcher, removing all identifying information. Following this, the audio files and transcripts were downloaded onto a secure storage device pending analysis.

2.11.4 Measures. A demographic information questionnaire (Appendix 9) was developed by the researcher in conjunction with supervisors, which parents completed at the interview.

2.12 Procedural and Ethical Considerations

2.12.1 Informed consent. All parents were over the age of 18 years and deemed to have capacity to consent to their participation. All participants received an information sheet (Appendix 7) at least 24 hours in advance of the interview. The researcher only made contact with the participants following their consent to do so, either by return of the slip, email, or via confirmation from the Assistant Psychologist. The information sheets were checked for content and accessibility by three supervisors. Prior to the interview, participants were reminded of the details outlined in the information sheet and provided a further opportunity to ask any questions.

All participants signed the consent form (Appendix 8) prior to the interview, which was countersigned by the researcher.

2.12.2 Confidentiality and anonymity. Confidentiality and anonymity was outlined in the information sheets and reiterated by the researcher when gaining informed consent prior to the interview.

Data collected was held in accordance with the Data Protection Act (Great Britain, 1998). All identifying information was removed and participant's anonymity protected through assigning each participant with a number identifying audio files and interview transcripts. Pseudonyms were allocated to each participant and their child to protect their identity and improve readability. Consent forms were stored separately in a secure place on the NHS research site. Paper data including the demographic information sheets were stored securely in a locked filing cabinet at the NHS research site. Electronic data was stored securely on an encrypted USB memory stick and audio recordings deleted following transcription and analysis, adhering to NHS confidentiality standards. Participants were permitted access to their data upon request and could withdraw their information from the study should they so wish.

2.12.3 Participant distress and well-being. It was not anticipated that the interviews would cause harm to the participants and extensive previous research suggests that families of children with chronic health conditions may find it beneficial to discuss their experiences (Murphy, Christian, Caplin & Young, 2007). However, it was recognised that participants could become distressed when participating in interviews focussing on their child's health and the impact of the Berlin Heart. This is consistent with Brinkman and Kvale (2008) who assert that human interaction, inherent in qualitative studies, emotionally impacts the participant.

A sensitive approach was adopted by the researcher to help the participant feel comfortable and build rapport. Interviews were conducted in a private consultation room or at their own home to ensure the participant felt as comfortable as possible when discussing sensitive issues. The researcher responded sensitively and empathetically to participant distress and reminded them of the support options available. Following the interview, two parents were referred to the hospital's Cardiac Psychosocial Team for follow-up support.

Brinkmann and Kvale (2008) assert that qualitative interviews can negatively impact the researcher themselves. Throughout the data collection process the researcher had access to supervision to reflect on the interview process.

2.13 Service-User Involvement

Three self-selected parents of children who had a child supported on a Berlin Heart were consulted on the development of the interview schedule. Parents were provided with a draft copy of the schedule and asked for feedback on relevance of the questions, the schedule's readability and accessibility, and the schedule amended as described above. It was felt that many parents would welcome the opportunity to share their experiences and that it would be important to elicit both positive and negative experiences.

As described above a pilot interview was also conducted with a father of a child supported on a Berlin Heart and the interview schedule amended accordingly.

2.14 Data Analysis

Interviews were analysed according to the principles of IPA (Broki & Wearden, 2006; Smith, 1996; Smith, Jarman & Osborn, 1999) and guidelines proposed by Smith et al. (2009). Analysis was also guided through supervision with research and academic supervisors who were experienced in qualitative methodologies and support from the London IPA peer support group.

Due to the length and richness of the interview transcripts, it was agreed that the analysis of accounts should focus on the time between the point at which the Berlin Heart was discussed as a support option to its removal. All interviews were transcribed verbatim through a process of listening and re-listening (Tilley, 2003). Non-verbal communication (e.g. crying, laughing and gesturing), significant fluctuations in volume or pitch and pauses were recorded (Smith & Osborn, 2003) to aid interpretation and understanding. All transcripts were transferred into a landscape table in Microsoft Word to permit recording of exploratory coding and emergent themes. In accordance with recommendations by Smith et al. (2009), each transcript was subject to the following procedure.

2.14.1 Reading and re-reading. The researcher read the transcript a number of times to gain familiarity, actively engage and immerse in the data- entering the participant’s world. Rich and conflicting areas were identified. The researcher remained open to the development of new thoughts and perceptions throughout this phase.

2.14.2 Initial exploratory coding. Remaining close to the data, initial notes were recorded, carefully reviewing the data line by line. The researcher recorded descriptive, linguistic and conceptual comments in the right hand column. Descriptive comments focused on the content and subject of the participants account. Linguistic comments attended to participants' use of language (e.g. pronoun use, tense, repetition and metaphors) and non-verbal communication (e.g. hesitation). Conceptual comments included interpretive thoughts and abstract concepts requiring a higher level of abstraction and ability to question the underlying meaning of the experience.

2.14.3 Developing emergent themes. Emergent themes were developed from the researcher's initial exploratory codes. The emergent themes captured the content salient to the participant and connections between exploratory codes were mapped and recorded in the left hand column. These interpretations required a higher level of abstraction, whilst also remaining close to the data to ensure interpretations were grounded in the participant's experience.

2.14.4 Clustering and collapsing emergent themes. Emergent themes were then listed chronologically, and patterns and connections between themes were noted to aid the organisation of clusters of related themes represented on mind maps. These subthemes were further refined and taken to a higher level of abstraction, discarding some themes. Subthemes were given a descriptive title to capture the conceptual nature of themes they represented. This process was iterative, checking that the subtheme and the group of emergent themes were connected and evidenced in the quotations.

2.14.5 Moving to the next case. The four previous stages were repeated for the remaining seven transcripts. Each transcript was considered individually and the researcher tried to bracket out emerging ideas from previous transcripts, to retain idiographic focus.

2.14.6 Cross-case analysis. Subthemes were compared and contrasted across cases, exploring convergences and divergences within the data (Smith, 2011). Subthemes were re-organised and superordinate theme labels developed to capture a more abstracted and synthesised overall representation of participant experience. A master table of themes (see Table 1) was created to depict the subthemes within superordinate themes. A coherent narrative of the findings is presented in the results chapter.

2.15 Validity and Quality in IPA

Guidelines developed to assess the validity and quality of qualitative research (Elliot, Fischer & Rennie, 1999; Yardley 2000, 2008) have been reviewed and carefully consulted throughout the phases of the research to ensure its reliability and rigour. The researcher's consideration and efforts to preserve Yardley's criteria and their application to IPA (Smith, 2011) are detailed below.

2.15.1 Sensitivity to context. An extensive review of the literature was conducted to ensure that the study was sensitive to the context of the relevant empirical base and to increase the researcher's understanding of relevant theory and to inform the research aims. Sensitivity to the participant's experience was vital and thus service-user involvement was incorporated together with a flexible interview structure to encourage the participants to share what was important to them. The iterative process of analysis ensured themes were grounded in the data and transcript extracts were used to support subthemes, available both in the results chapter and Appendix 13. Consideration was also given to the influence of characteristics of the researcher on the research process (see Owning one's perspective and personal reflexivity).

2.15.2 Commitment and rigour. Commitment was demonstrated through in-depth understanding of the topic and attentiveness to the participant's account using prompt questions to enhance the richness of the phenomenological data. Furthermore, idiographic engagement and interpretive analysis was ensured through careful analysis of individual accounts, their convergences and divergences. The researcher consulted published IPA literature, attended an IPA London training course and the London IPA support group to ensure methodological competence. As recommended by Smith (2011), extracts from at least half of the participants were represented in each theme, thereby ensuring rigor of the IPA (see Table 1). A practice interview with the researchers supervisor and a pilot interview were conducted to enhance the researchers skill and competence.

2.15.3 Transparency and coherence. The analysis of the first transcript was independently coded by the internal supervisor as a credibility check. To promote the validity and credibility of the analysis, the external supervisors reviewed the data for discrepancies, overstatements and errors (Elliot, et al., 1999) and to ensure the themes reflected their clinical experience. Derived themes were compared with the original transcripts to ensure that interpretations were grounded in participants' accounts, thus reducing researcher bias in the selection of themes for analysis. A final list of themes was agreed with all three supervisors following discussion of which themes best captured the data, to ensure the credibility of the final account.

A paper trail evidencing how the interpretation emerged was retained to ensure transparency of the development from the transcript to the finalised report. A coded extract from a participant's transcript and table of emergent themes is provided to allow the reader follow the analytical process (Appendix 11) (Yardley, 2008). The researcher demonstrated transparency and reflexivity by presenting her prior experience see 'owning ones perspective and personal reflexivity'. A reflective journal (Appendix 12) was recorded throughout the research process to promote reflexivity and identify how the researcher may have influenced data collection and analysis (Meyrick, 2006). The researcher also recorded reflections before and after each interview to enable identification of preconceptions, so bracketing could be used prior to analysis.

2.15.4 Impact and importance. Given the current absence of relevant research exploring the parental experience of the Berlin Heart, it was felt that this study held considerable importance, particularly as the population under investigation is growing. In the discussion chapter, the findings are examined in relation to previous literature and theory, and implications for clinical practice and future research are made. The research will be submitted for publication and shared with the clinical teams to ensure its dissemination and clinical value.

2.15.5 Owning one's perspective and personal reflexivity. Reflexivity, central to the qualitative paradigm, recognises the complexities inherent in objectivity in qualitative research. Acknowledgement of the researcher's values and beliefs and how these may have influenced interpretations made was critical (Elliot et al., 1999). The researcher's position, relative to the phenomenon under investigation, was carefully reflected upon to facilitate consideration of factors unintentionally influencing data collection and analysis (Willig, 2008).

The researcher is a 30-year-old white British female Trainee Clinical Psychologist. She had a child during the data collection phase in December 2014. She did not have any previous personal experience of children. The researcher had no personal or familial experience of heart failure or being supported on a Berlin Heart.

Furthermore, the researcher did not have any personal experience of chronic health conditions.

The researcher had some professional clinical experience working with parents and children with a variety of chronic health conditions. Prior to DClinPsy training the researcher worked clinically with children with heart conditions at the NHS site, some of whom had been supported using VAD devices including the Berlin Heart. The researcher's experience working with families supported on the Berlin Heart highlighted the psychosocial impact on the family and sparked an interest in the area. During training the researcher had worked in two paediatric settings- Cystic Fibrosis and Gastroenterology. These professional encounters afforded the experience of working closely with parents, their children and systemic networks from diagnosis, through adjustment and management of long-term health conditions. This insight had highlighted the significant stress on the child, their parents and wider support network.

Participants were aware that the researcher was not part of the NHS site's clinical team, which may have enabled participants to speak openly about their experiences, sharing both positive and negative aspects. The personal circumstances of the researcher were not disclosed which allowed the parents to take the expert position regarding their experience and facilitated curiosity in the researcher. The researcher's reflections were recorded in a reflective journal throughout the process to assist open mindedness and note preconceived ideas and assumptions (Coyle & Wright, 1996). The transparency of the researcher's fore understandings and the reflexive process is considered to increase the integrity of the research (Maso, 2003).

Chapter 3: Results

Interpretive Phenomenological Analysis revealed 15 subthemes, grouped into three superordinate themes as represented in Table 1 below. The essence of each superordinate theme is encapsulated within the subthemes, which can be found within the majority of participants' accounts. A summary table and representation of themes across participants is provided in Appendix 13, together with additional supportive quotations.

Table 1. *Master Table of Themes*

Superordinate Theme	**Subtheme**	**Number of transcripts contributing to theme**
1) Loss of Control on Berlin Heart	Do or Die	7
	Conflict of the Berlin Heart-Sitting on a Bomb or a Saviour	8
	Relinquishing the Parental Role	8
	Like a Bus Stop-The Unpredictability of Waiting	7
2) Life in the Berlin Heart Bubble	Restriction and Solitary Confinement	6
	Dedication and Sacrifice	7
	Strategies for Coping in Crisis	8
	Trauma, Brutality and Imperfection	6
	Burden of Care- Isolated or Shared	8
	Isolation from Normality- Home Bird to War Zone.	7
3) Transitioning Forward	Reinstating the Parenting Role	8
	Integration and Embedding- A Berlin Heart Family	7
	Managing an External Support System-Transference of Distress	7
	Hope of a New and Normal Child	7
	Donor Dilemma	5

The themes are translated into a narrative account of the data presented below. Descriptions of the parents' experiences and interpretative analytical commentary is interspersed with verbatim extracts from different participants to evidence each theme. These quotes aim both to illustrate the theme and highlight convergences and divergences between the parents' lived experience and how the theme was manifest in different ways. The quotations were selected as most representative of the theme to allow the reader to evaluate the correspondence between the interpretation and the data (Elliott et al., 1999). Furthermore, consistent with Yardley (2008), themes were extracted that were relevant to the research aims to provide 'impact and importance'.

Some quotations have been edited to ensure the confidentiality of the participants and pseudonyms have been used to maintain participant anonymity. To maintain clarity, some extracts have been edited and the omission of less relevant information is indicated by '……'. The researcher's explanatory notes are noted as [text]. Pauses are denoted as [..] with each full stop representing one second. Where the extract includes dialogue from the interviewer, it is denoted as '*I'*.

3.1 Superordinate Theme 1: Loss of Control on the Berlin Heart

The first Superordinate theme 'Loss of control on the Berlin Heart' is comprised of four subthemes entitled: 'Do or die', 'Conflict of the Berlin Heart-Sitting on a bomb or a saviour', 'Relinquishing the parental role' and 'Like a bus stop- The uncertainty of waiting', each relating to a different aspect of an apparent sequential loss of control felt by all the parents.

3.1.1 Do or die. The accounts of seven of the eight participants were punctuated by the evident distress and turmoil relating to the 'choice' of whether to accept the Berlin Heart as a support option for their child. Many parents felt that if they did not consent to the Berlin Heart, their child would die. Parents described a sense of intense desperation and conveyed feelings of powerlessness in their language, emphasis and tone. They appeared to feel trapped by their decision-making due to their perception of the absence of any real choice or alternative options as illustrated by Maria and Clare.

> The only possibility we have is a Berlin Heart. But I'm telling [emphasised] you that that we never put that on a child so small. We have absolutely [emphasised] no idea what will happen. So it's your choice [medical team]. So we were in between a rock and a hard place. But [emphasised] we knew that, he's still our child, so we said whatever you need- I sign anything. Just try. *(Maria)*

> So I had really fixed it in my mind, as I thought he'd never really cope with it, being awake and moving around, with with that. But they basically said, yeah, he's got to have it. We felt, I think by the end of that day he was kind of dying right in front of us, and we had no choice. *(Clare)*

The metaphor and evocative imagery, exemplified in Maria's excerpt- 'between a rock and a hard place', in which she recounts a discussion with a clinician, highlighted the distress she experienced, faced with the two inconceivable options- probable death of her son and the risks and complications associated with the Berlin Heart. For Clare, the very real and visible threat of her son's impending death reinforced the lack of choice she felt in her decision-making.

Gemma's extract below highlighted the perceived lack of parental input and influence and the impact of professionals in the decision-making process, as illustrated by her description of 'going along with it'. Gemma's extract also conveys a distinct lack of agency and evokes a sense of impending doom, highlighting the time-pressure she felt relating to the decision-making process.

> And I think because we had no sort of say in anything leading up to it, because we were told if she doesn't have this they said she would die, and as if she was running out of time, so we were running out of options really, so we just went along with it, so we didn't really have any control. *(Gemma)*

Helen used dramatic language and gestures to communicate the intense level of emotion she felt (gesticulating cutting her neck). A disconnect was evident between her matter of fact style and use of very categorical language, seemingly inconsistent with what appeared to be a very difficult experience for her, as evidenced in other areas of her account. This striking incongruity could suggest that it was easier for her to confront and share her experience through verbalising, than reprocessing the associated emotions.

> I I I don't, I don't at that time, I don't think we were really looking at it as it was a choice, because it was either that ECMO machine that you only, like it's only a certain amount of time you can go on the machine. '….' There's only a certain amount of time you can be on the ECMO machine and if your hearts not available then you're more less [gestures cut throat]-aren't you! Or, it was the Berlin Heart which was quite the new thing that they've got and we just said we've got to take that chance, you've got to take it if it's your kid. What you're going to say, I'll forget it-go home?! *(Helen)*

Conversely, Helen's experience could be interpreted to be using dark humour as a means to minimise the distress and possible trauma she may have been experiencing. Common to the seven parents was the sense that the risk of losing their child by not opting for the Berlin Heart, equated to allowing their child to die- something which was inconceivable, as illustrated by Clare and Helen.

3.1.2 Conflict of the Berlin Heart- sitting on a bomb or a saviour. The majority of the parents' accounts conveyed a struggle between the perceived positive and negative aspects of the Berlin Heart. A preoccupation was evident with its either offering hope and the opportunity for life, or conversely the challenge of the risk of death and negative implications on other organs and social development. For those parents who expressed these opposing experiences, there was a feeling of agonised frustration at being dependent on a device that could cause their child significant harm.

Both Maria and Clare expressed polarised positions within their accounts- the threat the Berlin Heart posed in terms of risk of stroke or perceived rudimentary technology and its later portrayal as a saviour. This switching may reflect the struggle they faced to remain positive and hopeful for her child, in spite of the ever-present risk of complications, common to many parents' experiences.

> He sometimes have eight, nine, or ten clots in his chamber. Literally visible [emphasised]. [….] He was sitting on bomb and one of them goes in the heart [snaps fingers] that's it. '……' going to burst in the brain or something.
> So you know, the Berlin Heart saved his life in the long run. If there be no Berlin Heart, Tom would not be here. Period. *(Maria)*

> I mean, it just feels, it just feels a bit medieval to me. I don't mean that in an insulting way, because obviously it's amazing technology and surgery and they saved [emphasised] him. *(Clare)*

Maria's powerful and evocative imagery used in 'sitting on a bomb' and 'burst in the brain' conveys the felt treacherousness of the experience and the sense of anticipatory anxiety, awaiting the threat to materialise. Furthermore, her use of clicking her fingers reinforces the immediacy and potential devastation of the threat posed by the Berlin Heart. Nevertheless, the reflective language used 'in the long run' suggests that this trade off was worthwhile and depicts the Berlin Heart constructively in a positive light. Clare's quote highlighted a possible mistrust of the device and underscored her feeling of lacking control.

Laura emphasised how she was reminded by members of the team, of the threat of the Berlin Heart in moments of comparable felt safety. This may have created a sense of insecurity, which could have served to reinforce the threat posed by the Berlin Heart.

> Your daughter is living on a knife-edge at the moment, so we want her to have as many experiences as possible, so enjoy what she's doing. '………' you kind of get a bit complacent, because you think she's OK, she's running around, as much as you can run around '……'. And that, […] we didn't want to be reminded that she was living on knife-edge, as you kind of block that away. *(Laura)*

The use of the terminology 'knife-edge' is suggestive of a threatening balancing act and highlights the fragility of the experience. The quotation also highlighted her desire to focus on the positive attributes of the device, possibly acting to counterbalance her distress. Similar to Maria's account, Laura also shared her fears about the persistent nature of the threat of the Berlin Heart in relation to the risk of stroke. This risk of stroke, combined with this threat being realised (as her child had had a stroke), appeared to trigger heightened anxious thinking. She described these fears 'playing on my mind' which evokes ideas of being persistently haunted by these uncontained fears.

> I think after that happened, that was one of the really huge fears around every single day after that, in terms of Jessica being on the Berlin Heart she risked having another one that could be more severe. '……' It was just like if it doesn't happen soon, the next one could be a lot worse, so that was something that was always playing on my mind after the first one. *(Laura)*

Helen’s account focused on the positive associations of the Berlin Heart as evidenced in her quote below.

> So as soon as she got hooked up to that, the difference in her, […….] were amazing. *(Helen)*

For Helen, there is a sense that the Berlin Heart was put on a pedestal, where its threat and negative consequences were minimised or not acknowledged, and thus not expressed.

3.1.3 Relinquishing the parental role. All eight parents conveyed a feeling of losing or having to alter significantly their parental role whilst their child was supported on the Berlin Heart. Although this theme was prominent and heavily emotionally laden, the way it manifested between parents varied. The majority of parents conveyed a deep sadness and helplessness. Their language and tone evoked a sense of reminiscence, suggesting they may have been grieving for their lost role.

> The things you associate with having a young child in terms of reading stories and taking them out to the park and fixing them a meal and bath and dinner and those very kind of routined parts of your day that you’ve done every day, you know, since they were tiny. It’s very weird to have a day when you don’t do it. You weren’t putting anyone to bed because he was just lying there like he had done for the last 24 hours, and would do for the next. *(Clare)*

> Um, finding it difficult not not not being able to do certain things for your daughter, like going and making her tea, you know, they bought all the meals, not being able to be able to be a mum [voice breaking]. You know, give her a bath, I think […..] you know, little things like giving her a bath, giving her a big squeeze, un all the things that you normally do. *(Helen)*

Both Helen and Clare’s extracts indicate that maternal role was integral to their identity and their new positions were egodystonic. This could explain the level of emotion expressed when describing their felt loss of the maternal provider role.

Clare described a shift from previous parenting to nursing, something she appeared to find uncomfortable and unsettling.

> So yeah, it wasn’t really parenting, we were just nursing really, I think it’s what we were doing. I mean you can’t hug them because they’re covered in stuff [emphasised], you can’t really get near them so you’re kind of holding their hand, or yeah, or rubbing their head. I mean that’s all you can really do. And yeah and really quickly it just felt like we were his nurses [disbelief]. *(Clare)*

Common to Laura and Sophie’s experience was their feeling of enforced relinquishment of a protective parenting role to engage with necessary treatment. A sense of powerlessness and hopelessness was common to these accounts.

> But you know the whole logic of your parents, [….] I suppose of being with nurses and doctors and pinning your child down while they're hurting them is quite a difficult thing to come to terms with. But it's just one of those things that you have no choice about really. *(Laura)*

> I felt like a really bad mother, because I couldn't-I can be here, but I can't go near. *(Sophie)*

The quotations from Laura and Sophie both emphasise a conflict, about their ability to protect and keep their children 'safe' whilst engaging in treatment. The emotions this conflict evoked appear distressing for them to acknowledge. Inferences are also made regarding the implications their actions had on their maternal abilities and identity.

In contrast to the other parents, 'Relinquishing the parental role' was perceived by Abshir and Sindy as a positive transition. For these parents, their roles were associated with unwanted additional responsibility.

> The nurses were doing Morgan's medication, so I didn't have the stress of the burden of my normal life, of having to play that role of a nurse-that was taken away from me. So, I could just concentrate on enjoying Morgan, because for the first time in his life he had a mechanical device that was giving the rest of his body a break. *(Sindy)*

> I did not think about it, [loss of role] because I believe in Allah and that anyone can die and secondly I am in best hospital in the world, so by any

> chance if that person is still has to live in this world, they will survive.
> *(Abshir)*

Sindy conveys a sense of relief regarding relinquishing her previous responsibilities. She perceived the Berlin Heart as providing an interval of rest for Morgan, whilst also providing her a break from ‘playing’ her adopted role of nurse. This relief was liberating for Sindy and enabled her to relate and interact with her child in a more positive, maternal way. Similarly, Abshir appeared to derive comfort from handing over responsibility to the hospital staff and crucially, putting his faith in his religion.

3.1.4 Like a bus stop- the unpredictability of waiting. Seven parents shared their anguish resulting from the unpredictability of waiting for a donor heart. The distress conveyed relating to this indeterminate period was likely to have been heightened due the criticality of its end point.

Both Maria and Clare draw comparisons between waiting for the donor and waiting for a bus, highlighting the unpredictability and lack of control over the wait period. This comparison emphasised the parents’ sense of powerlessness and helplessness in the face of uncertainty.

> It’s like a bus stop in a way for the heart transplant. We were waiting for a long long long time. And they were just not come, not come, and then one day it just comes and then you know, my child’s life it going to change.
> *(Maria)*

Some parents (Helen and Clare) experienced ‘false alarms’ whilst waiting for a donor, which may have reinforced their sense of lack of agency whilst waiting.

> All that getting ready, and then that call came back later saying no that wouldn’t be a suitable donor. ‘….’ Then you have that huge sense of disappointment that it didn’t work out, but yeah, it’s and you can’t, you have no control over it do you. ‘…’ There’s nothing- they can’t make it happen, you can’t make it happen you’re just waiting for, you know, you get that call and it does work out. *(Clare)*

The sense of total lack of agency and frustration is highlighted in Clare’s quote where no one could ‘make it happen’. A similar sense of nervous anticipation is conveyed by Gemma in the extract below.

> When you’re on the Berlin Heart, you're just waiting for the call. And then each day it doesn't come, you think […] well maybe it'll be tomorrow. *(Gemma)*

The tone of Gemma’s extract suggests she was feeling helpless because of the unpredictability of the experience. Similarly, Laura’s quote below underscores the lack of control she felt, to the point she seemed to fleetingly question whether it would indeed happen at all. Nevertheless, she was able to reflect more positively on the reassurance and hope she derived from others’ previous experience.

> It's just you have no idea, you have literally no idea whether it can happen and if it's going to happen, when [emphasised] it's going to happen. So I suppose you're always on alert, but everyone who I've spoken to after it has always said that you get told when you least expect it, in a way when you've given up is when it tends to happen. *(Laura)*

The level of desperation some parents experienced in the unpredictability of waiting was evidenced by Abshir in the quotation below, where he expressed suicidal thoughts.

> I believe that this is the last of my life, you know, because because I don't know when it [waiting for donor] is going to end. At that time, I say that this is the end of my life, that OK- I will end my life. *(Abshir)*

Abshir and his daughter's wait for a donor (146 days) was significantly greater than the other parents in the sample, which may contribute to his more extreme expression of this theme. Conversely, Sophie, who experienced the shortest wait for a donor (8 days), is not represented in this theme.

3.2 Superordinate Theme Two- Life in the Berlin Heart Bubble

This theme reflects the contained and unreal elements of life on the Berlin Heart. It is composed of six subthemes: 'Restriction and solitary confinement', 'Dedication and sacrifice', 'Strategies for coping in crisis', 'Trauma, brutality and imperfection', 'Burden of care- isolated or shared', and 'Isolation from normality- home bird to war zone'.

3.2.1 Restriction and solitary confinement. Six parents experienced feelings of restriction and confinement whilst their children were on the Berlin Heart. Maria and Clare's accounts focused on the physical restriction and lack of mobility imposed on their child by the Berlin Heart and the implications for them as parents.

> Urrm [name of older daughter] when she was little I could pick her up all the time and have her in my arms and cuddle her. With Tom it was much more harder there always be someone be put Tom into my arms. I can't really move him so much. It was not that movable. So mobility is not very good. *(Maria)*

> I think it was noticeable that when he had all this stuff on him I couldn't hold or cuddle him or anything. There were so few parts of him that were free and actually looked like him. *(Clare)*

Both extracts emphasise the limited physical contact that the device permitted and suggested that parents perceived bonding opportunities to be limited. This may have been particularly salient for Maria as Tom was only one month old at the time of the support. Additionally, Maria appears to reflect on how her experience interacting with her son was different from that of her older child.

The intensity of the restriction felt by parents is highlighted by Laura and Helen's quotations.

> She was too poorly to interact and if one of the children in the ward got any sort of infection, Norovirus and C.dif and all those sorts of things, that meant that she wasn't allowed visitors apart from us. As well, we weren't allowed to take her out of her room, so it's like solitary confinement in a way. *(Laura)*

> When we're on the Berlin Heart, we visited her every day. Obviously, we were both there, and we used to just visit her she would be drawing, watching DVDs. Obviously you get cabin fever, don't you. *(Helen)*

The language of 'solitary confinement' and 'cabin fever' suggest that the experience was unwanted, inescapable and isolating.

Both Gemma and Maria highlighted the lack of environmental stimulation for their children, synonymous with 'solitary confinement'.

> Four months, I think it was four months I think since she had seen daylight, since Harriet had seen daylight. *(Gemma)*

> Imagine if you were always inside, inside the building. Also for the child who never saw outside. So when he was born, he was at home for two and a half days then he went straight back to the hospital. So, to see Tom's face when we went for the first time to the park. He looked around you know,

> because when he was lying down when he was sitting he would just see white, you know. *(Maria)*

It is conceivable that this reported lack of environmental stimulation reinforced parents' feelings of confinement in this physically restricted environment.

Gemma shared her sense of restriction even when permitted to leave the ward with her child. This experience appeared to provoke feelings of anxiety and responsibility, which may have served to incapacitate her sense of momentary freedom.

> Yeah we only got out once, that's hard I think, not being able to get out. We went for a walk around the hospital with Harriet after we'd done all our training and things. And that was very nerve-wracking, because we were responsible because of course she was attached to a machine and was in a buggy, so we had to manoeuvre lifts and things and not go too far in front and stuff like that. '…….' Then of course you go back and it's reality again, your stuck in this Berlin Heart bubble because there's nothing left we're on the Berlin Heart. *(Gemma)*

The majority of parents experienced the feelings of restriction as oppressive and negative. Nevertheless, interestingly, Laura suggested she derived a sense of security at times from the level of restriction placed on her child, perceiving she was in less danger in her cot.

> Because she was quite full of energy you felt a massive relief every time she went back into her cot, because it meant she was less likely to fall on her face, or do something silly, [laugh] because she was susceptible to bruising and internal bleeding because of her blood being thinned. *(Laura)*

3.2.2 Dedication and sacrifice. Seven of the eight parents identified with the subtheme of dedication to their child and/or sacrifice of other relationships. This could be interpreted as a reaction to the stressors impacting on parents, leading them to focus on engaging in their parental role. Positive and negative manifestations of the theme were identified among the parents.

Many parents communicated dedication and sacrifice to their child through their consistent physical presence and devotion.

> A certain part of you as a mum has to say it’s only Rosie, stuff everybody else that's it- Rosie. Although I am a caring person, don't get me wrong, but you've got tunnel vision and that's it- Rosie. *(Helen)*

> I never left. I never went home- not even once, I was living in [name of NHS site] hospital. Not even once, I was living in [name of NHS site] hospital. *(Maria)*

> I didn't know whether we would ever get home with Jessica and for the whole almost six months that we were there, I refused to come back here, until I came through the door with Jessica. *(Laura)*

Helen's extract highlights how she attuned to her daughter's needs, to the exclusion of everything else in her life. Her assertive tone suggests that this devotion was egosyntonic and congruent with her definition of her maternal role, seemingly integral to her identity.

It is conceivable that the parents' presence reaffirmed their parental role in this stressful environment and provided them with a sense of agency.

Sophie, Gemma and Abshir all described the negative impact their experiences' had on their marriages, which could be construed as a sacrifice. The extracts from Gemma and Abshir below demonstrate how their focus on their child became all consuming, to the detriment of their other relationships.

> We weren't husband and wife, we were just parents, just parents and Harriet was our main priority, [….] always until, well until the end of our journey I suppose. *(Gemma)*

> My relationship with my wife, there is no relationship, there is no enjoying life, we left that along time like one year and something. There is no life like normal husband and wife, there is nothing. *(Abshir)*

Parental sacrifice was also expressed in terms of balancing the parenting needs of siblings, a theme which was common to many parents' experience, notably in Sophie, Abshir, Helen and Maria's accounts. To care for their child on the Berlin Heart, many parents were separated from other children for extended periods of time to dedicate themselves to their sick child.

> She [sibling] still needed her mum, but I wasn't able to. Just on the weekends. *(Maria)*

> Yes split. Because because my mind is not there and I was not with my other family and other children.
>
> *I: So did you have to go back to X?*
>
> Yes [home city] [NHS site], [home city] [NHS site], [home city] [NHS site]. Yes sometimes twice a week, three times a week depends how they need me. *(Abshir)*

> I mean obviously because it was a daunting prospect [being separated from other children] because I had my son, and my auntie took my son when we were at the [name of hospital]. *(Sophie)*

All three extracts contain negative language including 'daunting' and 'wasn't able to'. It is apparent that this balancing of parental responsibility, where contact with other children was significantly restricted to provide care to their sick child, was very complex and distressing for parents.

3.2.3 Strategies for coping in crisis. This subtheme was present in all eight parents' accounts and featured frequently and potently. Parents reported using a broad range of strategies to cope with the distressing situation they faced. Rather than using a single strategy, multiple strategies were used, perhaps indicating their inefficacy and/or parents' motivation to alleviate distress. Interestingly, some parents used opposing coping strategies such as emotional detachment and a more mindful present moment focus.

Emotional detachment was a commonly reported strategy used to manage emotions. It was also most commonly associated with at least one other strategy. Clare's extract below describes her using an emotional and cognitive strategy to disengage with her reality. She described 'pretending' which could suggest wanting to regress to a more protected time of her life. Disengaging in this way appeared to be a functional strategy for many parents in the face of an uncontrollable stressor.

> I would have some nights when I would come home for my night with [name of sibling] and I would put her to bed and then I would not even think about it. I wouldn't answer phone calls and just kind of text my family and say I'm not really in the mood to talk this evening, or whatever, or watch something on Netflix. Literally pretend nothing was happening and I think that's how I, [….] that's how I, that kind of helped. *(Clare)*

Many parents sought comfort and clarity in ascertaining information. Knowledge (usually derived from the team) seemed to clarify their understanding and alleviate (if only temporarily) some of their concerns and anxieties as illustrated in Helen's extract. Although this strategy was commonly portrayed as a positive approach, some parents did find the acquisition of information overwhelming. As reflected in Sindy's account, adopting a more present moment focus was a containing strategy for many of the parents.

> And I’ve always been like that, I think if you don't ask, you won't know, until always worrying and you're go away worrying, to make yourself poorly. *(Helen)*

> I thought to myself OK, I know the risks, but let's just focus on him having it and just try and think of the positives. And if that kind of stuff comes up, then we’ll deal with it then, but I’m not going to deal with it when it hasn’t even occurred yet. So that was just exactly what I done. Exactly the same approach. *(Sindy)*

Thinking positively about their situation was a coping strategy used by some of the parents and is illustrated by Gemma below. Although some parents perceived this strategy as useful, it is conceivable this may have been difficult to implement realistically at the time, due to the serious condition of their children.

> Yes, we could see the positives of it. So I think we just hung on to those really, and put the worry to the back of our mind, and if she was happy during the day, we took that on-board that she was doing well. *(Gemma)*

3.2.4 Trauma, brutality and imperfection. This subtheme related to their child’s appearance whilst on the Berlin Heart and was conveyed very powerfully by six of the parents.

Parents graphically described their child’s appearance following the Berlin Heart surgery, depicting them as dehumanised and brutalised. They emotively expressed the distress they felt when they looked at their child.

> He just looked awful [emphasised]. And I was totally thrown by that, couldn't handle it all, I found it really hard to look at him. Urrm, to look at all the stuff on him, he looked liked he'd been tortured. It's like, I thought- they've tortured him. I know that's ridiculous as they're trying to help him. '….' I still remember just walking in, [….] I'll never forget that, and walking in and being told that he's back and we can go and see him now and he just looked like a corpse […….] covered in tubes and there was just stuff [emphasised] everywhere and his eyes were held open so he looked dead already. '…..' It was like some big horrible tragedy in front of us. *(Clare)*

> She was like a blown up balloon, blood was coming out of everywhere, blood was coming out of her eyeballs, her mouth, her nose, '….' so she was just bleeding from everywhere. *(Sophie)*

Some parents appeared to continue to find recalling this information challenging. This is illustrated in Clare's extract through her language, tone, hesitation, and prolonged pauses (inconsistent with other areas of her transcript), which could indicate that she continued to find it a difficult image to process. Similarly, Sophie's use of evocative descriptions conveyed her distress and struggle during the interview. The language used in Clare's account including: 'corpse', 'tortured' and 'he looked dead already', together with her reported difficultly looking at her child, could be suggestive of a trauma response. Clare's hesitation and difficultly expressing how she felt when she looked at her son may also indicate that she experienced shame for expressing these thoughts and being unable to attend to her child unconditionally. As illustrated in the extracts above, many parents' descriptions depicted a brutally assaulted child. It is conceivable that they may have felt guilty for consenting to the Berlin Heart having seen their child's subsequent condition.

Both Sindy and Helen expressed their anguish regarding the appearance of their child's body. The conveyed sense of assault and the destruction of perceived perfection seems connected to a feeling of loss and having let their child down, being unable to protect them.

> It's like you make that child and they're kind of perfect, in the sense that they don't have any scars on them their body looks normal. It's smooth, it just looks like a normal body, even though Morgan was very sick inside, on the outside you never know that Morgan was an unwell child. '………' Now these surgeons are going to cut my perfect looking child, you know. It's like you're going to destroy something like that I created, that was perfect. *(Sindy)*

> I just thought that's my girl with all them holes in her now. I used to think, oh she spoilt. I didn't tell anyone, only in here [pointing to head], I don't tell anybody. Just my little thoughts. *(Helen)*

Helen's account suggests that she was ashamed of these thoughts and that they were somehow unacceptable.

3.2.5 Burden of care- isolated or shared. All parents felt burdened by caring for their child whilst on the Berlin Heart, however the management of this burden was divergent across the group.

Maria, Clare, Laura and Sophie all used their partner, extended family, friends or staff to effectively share the burden of caring for their child. The support offered by Sophie's family and Helen's husband appeared to act as an essential supportive container during their experiences:

> And you kinda feel like, if you've got a big family, it was like everyone said we're all in this together, it's not just your problem, it's all our problems. So that was quite comforting. *(Sophie)*

> You've got to be there together and you've got to hold each other, I mean hold each other up. And you know when one's had enough, to take over and say Mum had to go to loo and go for a break, because it does get, it does get hard. *(Helen)*

> You don't want it to spoil yer relationship, if you've got one. That's worth keeping. '……..' A family is nowt if you're broke. *(Helen)*

Helen quotations emphasised her reliance upon her husband, the importance of this strong partnership and the significance of maintaining it.

Some parents' experience highlighted the significance of supportive relationships with staff members. Maria and Clare's interactions with staff members appeared particularly pertinent to their experience and illustrated their sharing of the caring burden, as shown in the quotations below.

> I mean, urrm, look Dr T was crying the same like [name of husband] was crying, you know.
>
> *I: Umm.*
>
> And they were doing things, when Dr M and Dr B they were feeling [emphasised] things. Not just being there, and like a mechanic they could, I feel the connection between Tom and the doctors. *(Maria)*

> But, at the end of the day they're kind of caring for them and that's all you know, you want the best person looking after them and they were great in that respect, but when you had a nurse that was really amazing for caring for them and was really, not mothered him, but you know really cared for him and cared for us, and understood it, that was amazing because they did both things. *(Clare)*

Maria expressed significant gratitude and amazement at the team's willingness to offer holistic and personal care and the positive impact this had on her and consequently, her caring for her son. The interaction she described could suggest that through their emotional presentation, they offered her a model of emotional expression.

Laura's account highlighted a very interesting caring dynamic. She described feeling a complex conflict regarding her maternal position, calling into question her ability to protect her child.

> So if sometimes [name of husband] said he would do the dressing change today I will be like- good! If I don't have to be there to witness the distress then you know I'll do that. And then feel guilty about it, because I'm not there for her when she distressed. '……' And feeling like you've abandoned her because you're not there for her. But then you're not there for her, but you also not colluding with people to hurt her as well. So yeah, it's completely a double-edged sword in that respect. '…….' I still would sit outside the room and listen because, I don't know. Maybe it's just that way of saying I'm not completely getting out of the distress of it myself, because I'm still there and you know, as soon as it's done, to comfort her. *(Laura)*

Laura uses the metaphor of a 'double edged sword' to convey the conflict she felt. This conflict she felt about colluding in her daughter pain, highlights the complexities around sharing, or not, the burden of care with others.

Conversely, Sindy, Gemma and Abshir shared their feelings of isolation and the heavy responsibility they felt being unable to share the burden of care.

> And when you haven't got anyone else here with you, you don't have a second opinion. You don't have anyone to look at and say- what do you think, does it look funny to you? And I think so that was really hard for me**.** *(Sindy)*

> Um I don't know, um I guess it was only me and my husband in [NHS site location], so that was difficult. He was working while we were down there, so he wasn't there all the time. But I was there like from breakfast till late at night and then all over again. (*Gemma*)

> I did not have family to advise you [him], or to tell you [him] to myself this is the right way, this is the best way to have like um, to advise you. *(Abshir)*

3.2.6 Isolation from normality- home bird to war zone. Seven of the parents connected with the theme of ‘Isolation from normality- home bird to war zone’ in which parents described being separated from their normal home life, which was replaced by an alien environment.

> Every aspect of my life has been taken away from me: like my home, my dog, my car, my job, my friends. Well my friends did come up, but every kind of home comfort I couldn't even go back in the evening and watch Coronation Street or something, I didn't have a television in my room or, my son. Everything had been taken away, everything had been stripped away and it was just me and Alice in the hospital room. *(Sophie)*

> We were alone, away from home, and all that […] all that concrete building. When you see what, where we come from, and then suddenly go to [NHS site location]-dropped in the middle of [….] it felt like a war zone to me, when it's that big, when it's that big um you like [breath out]. It's so big. ‘……’ But it's that initial, it's massive, it's daunting and I want to go home [emphasised].

> And if you're like myself, I'm a home bird, and I hate being away from home. *(Helen)*

Sophie conveyed a sense of isolating exposure, being stripped back of everything that was familiar and comforting to her. Her description conveys a feeling of unsettled anxiety and the impression that the things that she no longer had access to, previously provided stability. Similarly, Helen's quotation highlighted how she felt out of her comfort zone. She likened the experience to a 'war zone' which conveys the level of fear she felt being confined within a daunting unknown city, the scale of which was very different from that of her home.

Helen and Abshir also shared an experience of feeling bereft and dispossessed of their home environment and its associations. Surprisingly, this experience appeared unrelated to the length of time spent on the Berlin Heart or parents' perceived ability to share the burden of care. Nevertheless, this subtheme was most pronounced in parents who had relocated the farthest distance.

> Sharing [accommodation] with another family is quite difficult when you're going through that. So that's a bit difficult because you can't make it your family home, and it's not your home, but it is while you're there. But, you can't make it your family home, because you've got to share it all with other people as well. *(Helen)*

> It was a big thing for me because she's she's not the only child that I have, I have other children. So you have to stick and hold your time you have with

> her. So the other children are left behind. I live in [name of home city], so it was a very very hard time. *(Abshir)*

3.3 Superordinate Theme 3- Transitioning Forward

This superordinate theme comprised five subthemes: ‘Reinstating the parenting role’, ‘Integration and embedding- a Berlin heart family’, ‘Managing an external support systems- transference of distress’, ‘Hope of a new a normal child’ and ‘Donor dilemma’, central to the majority of the samples’ experience. Each of the subthemes represented a transition point for the parents.

3.3.1 Reinstating the parenting role. This theme was prominent across the accounts of all parents. There appeared to be a transition from earlier relinquishing the parental role and corresponding sense of loss of control, to a position whereby parents felt able to reassert their parental role once again. For many parents this transition appeared to be a positive, empowering and therapeutic experience. For some this manifested through assertive communication, as illustrated in Helen’s quote.

> Because you do, cuz it's your girl and so I’d say, can't you do it any easier than that! Different nurses do different ways and when a plasters stuck so tight, you say- so and so did that, so put some of that there, and rub that there and- almost get to the point almost doing this job [proud tone]! *(Helen)*

> Because at the end of the day, doctors have always got your child at their best interests, but she's yours as well. And if you can't work together, because for how much they might come and have fancy words for stuff, your daughter’s only ever going to listen to you. *(Helen)*

Helen’s account portrays a sense of pride in regaining control from the team through her confident, direct and open communication style, enabling her to assert her wishes and redress the apparent power differential.

Some parents (Sindy, Clare and Helen) demonstrate this theme by reinstating their previously normal interactions and the practicalities of everyday parenting.

> He said to me mum, seriously like fish fingers everyday, sausages everyday, so like mash potato everyday- I'm bored of it! I want you to cook something for me. I think he wanted to some home cooked food that he’s used to, you know. ‘…….’ And yeah yeah and so that was good and I was making him his food and stuff and taking it in for him. *(Sindy)*

As illustrated in Sindy’s extract, for some parents, re-engaging in these practicalities enhanced their self-esteem and sense of worth, which may have faded when they relinquished their parental role.

Common to both Maria and Gemma’s accounts were vivid descriptions of their first ‘outing’ with their child whilst they were on the Berlin Heart. Both accounts conveyed a sense of how emotionally significant the event was for them as parents.

> We left in January when there was snow here, and we went outside with Harriet and it was sunshine- it was completely different. And she was just fascinated with all the trees blowing, all the things we take for granted, she had never seen but she was just mesmerised by, so I always remember our first little outing. We took lots of photographs, just nice nice to get out, it wasn't very long, but it was nice. *(Gemma)*

Gemma's reminiscent tone suggests that the walk was momentous and may have signified a transition point in the staff's perception of her capacity to care for Harriet, having completed the mandatory parent training programme.

Sophie highlighted the conflict and struggle she faced reinstating her parenting role with her other child who was being taken care of by her aunt.

> The hardest thing, it really was going in, taking him away from her, after he had been there four months. So my Mum and I went and stayed for the whole weekend, so we did it gradually with a transition. The following weekend I took him back up there, you know, and we did that for a few weekends and we were trying to say to her-now you've got your life back now [laugh]! And go and do whatever you want you now, but she sees alot of him now, they've got that nice bond now. *(Sophie)*

A sense of guilt at reinstating her role is conveyed, perhaps that she was disrupting a newly formed bond coupled with guilt regarding the length of her absence and need for her aunt’s involvement.

3.3.2 Integration and embedding- a Berlin Heart family. The subtheme integration and embedding- A Berlin Heart family, was present in seven parents’ accounts. There was a sense that the process of integrating and embedding into their new environment, either through relationships with other families or members of staff, was integral to their support system and ultimate survival of the experience.

The value, strength and support parents’ derived from having shared the experience with other families was striking. Laura, Sindy, Gemma and Abshir all expressed the importance of a shared community experience whilst on the ward:

> I think that's one of the things that kind of keeps you sane is the fact that you've got other families in the same room as you, going through the same thing as you. ‘…..’ When people were asking about that we wanted from the ward, I said just for us, having families in the same room as us almost made it bearable. *(Laura)*

For these parents it is possible that being surrounded by other families normalised their experience, they were no longer isolated in their fears, but had others who were able to truly empathise with their concerns. A sense of camaraderie and mutual understanding is conveyed. The adopted Berlin Heart family may have provided a means of more consistent and accessible support as they were in a shared space.

Sindy’s account was positive throughout and there is a sense that she integrated into the ward life more readily than the other parents. The quotation below highlighted how she tried to reconcile and regain some control over this shared experience.

> We used to have cinema days, they used to use to bring a big TV, I used to go to the shop and get all the popcorn for the kids, and they turn off the lights and they stay there and have popcorn and stuff and we just watch movies. We would have discos, they turn on the lights off and get flashing lights from the sensory room, they’d bring them in, then we have to stereo and we bring CD’s with all our music on and all the kids would have a disco, in the middle of the afternoon. But that's because we made it like that. *(Sindy)*

> It's like the Walton’s kind of thing. Yeah he had an amazing time. *(Sindy)*

Compared to other parents’ experience, Sindy conveyed an unusual level of positivity, which could indicate she was portraying an idealised view of events. The evident contrast between the trivial and jovial party atmosphere and the seriousness of the situation, may suggest she was temporarily withdrawing from reality.

Other parents, notably Clare and Maria, appeared to integrate more readily with the medical team.

> Some nurses made it a million times better and some nurses made it slightly worse- totally unintentionally. You're really, they become like family because you spend all your time with them you're in a small bay together. And yeah some of them we became good friends with, they really carried us through lots of stuff and cared for him like he was their own and would give us lots of reassurance about what was happening. *(Clare)*

> The staff is amazing. They are literally angels, without the wings. *(Maria)*

Clare described the staff becoming 'good friends', 'like family' which illustrates her embedding into the staff team and the significance of this in her experience. Both Maria and Clare shared strong gratitude for the staff.

3.3.3 Managing an external support system- transference of distress. This subtheme was endorsed by seven of the parents. It incorporates parents' experiences of managing the expectations and reactions of their own family and friends or the hospital team and also the associated reciprocity and infectious quality of distress. Parents acted both as protectors and were themselves protected. The act of managing in this way may have provided parents with a sense of control over what to share or conceal, but for others added yet another layer of distress.

> Yes, [name of husband] didn't tell me lots. He was keeping the troubles for himself. '….' He was protecting me from the outside world. He was always thinking and taking care of the fact that I'm living in a hospital. Friends and girlfriends of mine, they come and I just said which ones I needed to have

> the most. '….' And [name of husband] will say please don't go to the hospital that often, as its really hard for Maria. He knew how to manage them, he managed them really well. *(Maria)*

Maria described her husband as 'protecting me', which suggests she may to have internalised his actions as a positive and supportive act to help prevent further distress.

Similarly, a hierarchy of protection and distress was also apparent in other parents' accounts, needing to protect their loved ones from the distress. This emphasised the infectious nature of pain and distress, something which was common to many parents' experience.

> I don't know, [….], protecting them from it, not wanting them to worry about us, and maybe just partly because not wanting not having to deal with the emotions of it, with them as well, possibly. And that whole thing about, you know, not being able to kind of do anything about the pain that your child is going through and things like that, and I kind of didn't want him [her father] to have to do that as well. So, I think a part of it is about wanting to protect people around you as well. *(Laura)*
>
> Oh no, my mum's a worrier to as well. She tried not to be, but she said to me it was a double whammy for her because she was obviously very worried about Alice, but then also very worried about me as well. (*Sophie)*

> My dad was very close to Ben and found it really, just really struggled with the whole thing. '….' He came in pretty regularly to visit and to read to him and play with him and stuff when he was well, but when he went into ICU he didn't cope with it, he hates anything medical and then we said to him you know you need to come as we don't know how long this will go on for and he came up and was absolutely distraught, sobbing his eyes out. '…..' So I suppose you have to manage other people's reaction and handling it as well as your own. Sometimes that's hard because you're just trying to survive and you're having to manage the fall out of the situation. *(Clare)*

Laura's extract highlighted the need she felt to protect her parents from the distressing information, which may have inadvertently served to protect herself from their distress. Clare's use of the language 'managing the fall out' suggests that this was an onerous task.

Exclusive to Maria's account was the impact she felt her experience and her son had on the hospital team.

> They had urrm you know tears in their eyes and I'm thinking this is us, OK. Imagine, they have so many bad things, and so many children, trying hard so much to help them.
>
> *I: Yeah.*
>
> It's massive, it [the team] can be made of stone and still it [caring for her son] makes you cry. To be feeling something. I feel so sorry for them. So amazing. *(Maria)*

This dynamic was unique to Maria's account, and may reflect something about relationships between parents and staff in longer-term admissions.

3.3.4 Hope of a new and normal child. This subtheme was endorsed by seven of the parents. Binti, Abshir's daughter had been most recently transplanted and was still recovering from postoperative infections at the time of the interview, which could explain his lack of endorsement of this theme.

For all parents this theme was associated with positive emotion. The majority of the parents expressed this theme in terms of a physical transformation from which they derived hope and positivity.

> And she was warm, because all her legs and arms were cold where her circulation was bad. So to see her have colour and for her to feel warm, was lovely. '….' We just gradually, each day, seemed to be getting our child back. *(Gemma)*

> He was much more alive, he start to move hands. It was the first time I actually see him do this since he was sick. And the day after he was really [emphasised] moving hands and communicating, starting to smile. *(Maria)*

> Yeah, so for the first time he put on weight, proper weight, not just fluid. He was eating more than he did and um he had an appetite, he used to have a fry up every morning [laugh]. *(Sindy)*

Gemma's extract conveys an emotive image of her warm baby and she reflects on this positive change from her child feeling previously cold. A cold baby may typically be associated with death or illness, thus this reported change appears to be striking and emotive moment for Gemma. Similarly, Maria conveys a sense of physical transformation once Tom had been stabilised on the Berlin Heart. The language and emphasis she used 'he was much more alive' suggests that the process was transformative and filled with hope.

Maria and Sophie both derived hope and solace through others' experience, which appears to have meaningfully connected with their own experience:

> But on the other side they told us some of the children when they are on Berlin Heart, they actually walk [emphasised- shocked tone]. *(Maria)*

> To go up there and see those children were really well, in comparison to Alice, it you know that was quite encouraging. *(Sophie)*

Both of these extracts indicate that they were trying to imagine their child in a more hopeful position. The emphasis Maria used suggests that she may have previously doubted whether walking would be a possibility for her son and was somehow central to her conception of being normal and healthy.

3.3.5 Donor dilemma. The subtheme of donor dilemma was conveyed by five of the parents.

Clare and Gemma both verbalised their struggle regarding the ethical conflict they felt about organ donation, as illustrated below.

> I really struggled with the concept that you're sort of willing someone to die so that you can harvest their organs and that's a horrible, horrible thought. You're there desperately [emphasised] wanting life for your person, but you in wanting the heart transplant to come sooner, you're kind of wanting someone to lose their life, which feels really horrible. I can't, I found that really really hard to get my head around. *(Clare)*

Gemma conveyed a similar sense of guilt when considering the implications of transplantation. These emotions were tempered for some parents following resolution of this internal conflict, as illustrated by Clare, which seemed to have assisted in the process of reparation and helped to work through this dilemma.

> I remember thinking that if they didn't want to donate, then they wouldn't have done. So they want us to be happy, and they wanted the family not to go through what they're going through. So I think once I'd realised that and thought about it more that way, that that's what they wanted, we just took it as a great gift. *(Gemma)*

> It wasn't a cause and effect thing. *(Clare)*

Both Clare and Helen experienced another manifestation of the theme, whereby they felt a sense of envy at another child receiving their transplant ahead of their child. Both extracts suggest that the parents experienced a temporary feeling of resentment towards the transplanted child, a feeling which later left them feeling immensely conflicted and guilty- jarring with what might be considered socially acceptable.

> Someone got there transplant while we were there, and you feel this just weird sense of envy that they've moved forward, and then you hate yourself for thinking about it in those terms. *(Clare)*

> She might not have been strong enough at the time to deal with it, so that were comfort for them to say she might not have pulled through because she might not have been strong enough, she needs more weight on her, she wouldn't have been able to fight it and go through with the procedure, and I am a great believer in things happened for a reason, which I know it's not always nice because I don't think the girl survived. And that's another thing it wasn't right for Rosie then, then shoot me down there's a better one, and she'd be alright. *(Helen)*

Helen appears to be trying to convince herself that Rosie was not ready for transplantation. This could indicate that this is how she tried to cope with these strong emotions during the experience.

Chapter 4: Discussion

4.1 Overview of the Discussion

This study explored the parental experiences of eight parents of children supported on the Berlin Heart as a bridge to cardiac transplantation. Data were analysed according to the principals of IPA (Smith et al., 2009) and aimed to explore the following research questions:-

1) What are the lived experiences of parents of children who have been supported on the Berlin Heart?
2) What is the impact of these experiences on: parental quality of life, parental adjustment to their child's condition and family dynamics?

This chapter reviews the findings of the current study by considering the results in relation to each of the research questions and reviews the findings in terms of the current literature. Following this, the strengths and limitations of the study will be appraised and the implications for research and clinical practice will be outlined. Finally, the researcher's personal reflections will be presented.

4.2 Evaluation of the Findings

Due to the exploratory nature of this study and the breadth and interrelatedness of the research questions, they will be addressed by theme. The analysis revealed three superordinate themes:

1) Loss of Control on the Berlin Heart
2) Life in the Berlin Heart Bubble
3) Transitioning Forward

Figure 6 is provided below to supplement the discussion chapter and aid readability.

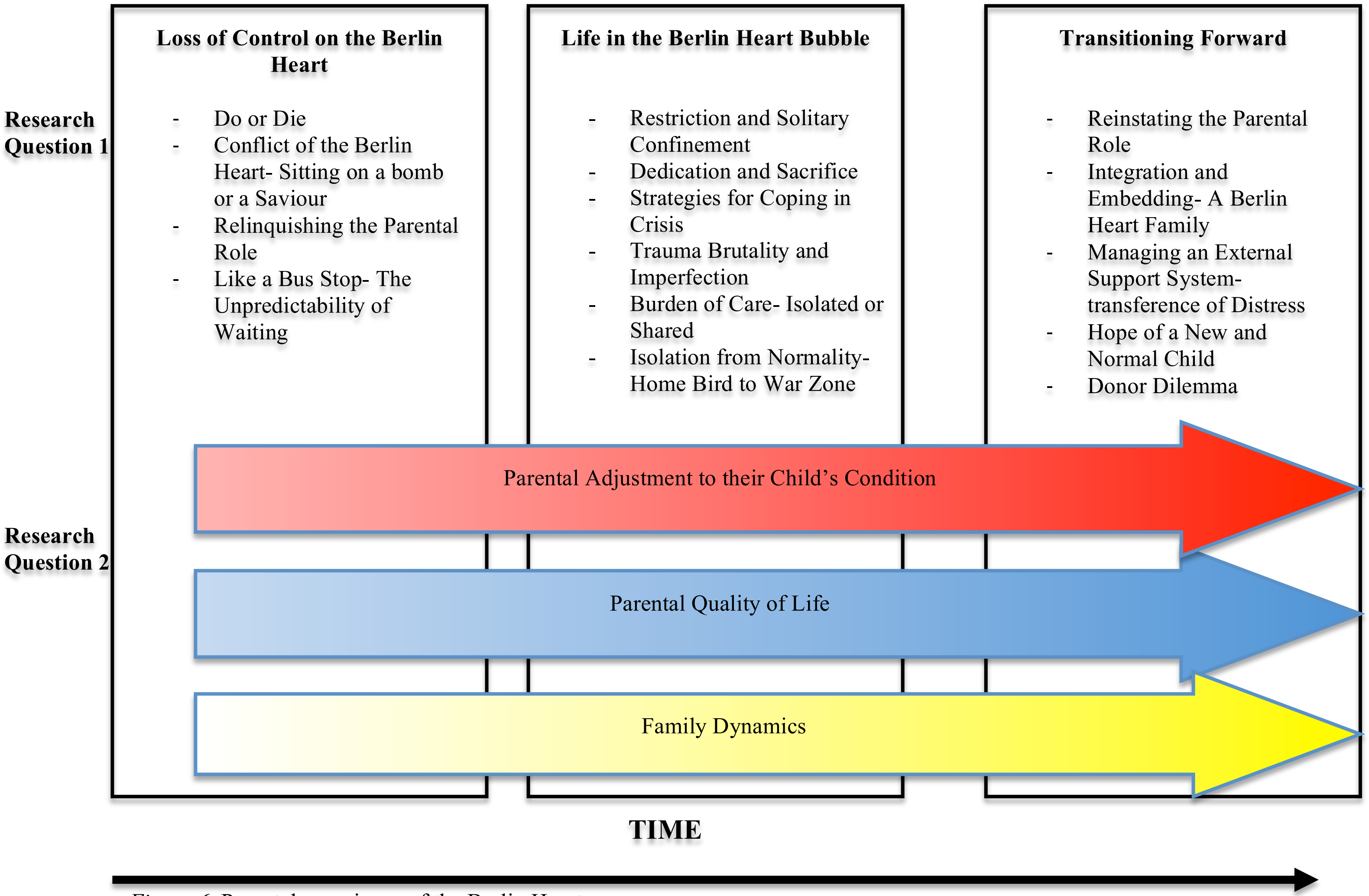

Figure 6. Parental experience of the Berlin Heart

4.2.1 Research Question One: What are the lived experiences of parents of children who have been supported on the Berlin Heart?

The parental experience was marked by three sequential phases- loss of control, living in an extraordinary environment, followed by transitioning forward in their experience, as depicted in Figure 6.

4.2.1.1 Loss of control on the Berlin Heart.

This superordinate theme was characterised by parents' experience of diminished ability to influence or control their environment and its perceived negative impact on their child, a loss of their typical or expected parental role and the unpredictability of waiting for a donor heart.

The Berlin Heart experience was novel to all parents. Consistent with Lazarus and Folkman's Transactional model of stress and coping (1984), it is conceivable that parents' ability to select and use coping strategies was impaired as a result of the absence of previous parental experience, their appraisal of their ability to cope (situational factors) and their likely consequent low self-efficacy beliefs (individual factor) (Lazarus & Folkman, 1984). Furthermore, the perceived loss of control over their environment appeared to contribute to feelings of hopelessness, which may have further incapacitated their use of coping strategies and thus increased their experience of stress (Lazarus & Folkman, 1984).

Parents reported significant distress relating to their decision to consent to the Berlin Heart support. Many parents' accounts conveyed a perceived lack of choice in the decision-making process, consistent with Vanvik and Førde's (2000) findings in mothers of children with hypoplastic left heart syndrome. Due to the lack of alternative support options and the perceived threat to their child's life, the majority of the Berlin Heart parents described feeling that failure to consent amounted to allowing their child to die. One parent emphasised the powerful influence the healthcare professionals had over their decision-making, consistent with Lipstein, Brinkman and Britto (2012). There is limited literature relating to decision-making processes in paediatric surgical procedures. Research exploring decision-making in life-threatening conditions, as opposed to elective surgery, has highlighted: parental respect for the child's views, parental anxiety and the child's expected quality of life as significant considerations (Daniel et al., 2005). Interestingly, the results of the current study suggest that parental decision-making was ultimately driven more by parental anxiety relating to the potential death of their child and current poor QoL, than to consideration of the child's views or parental duty. This discrepancy may be explained by the critical condition of their children and their young age (1 month to 6 years).

The parents described a loss of, or significant change to, their role as a parent during the Berlin Heart experience. The results suggested this period was predominantly associated with distress, a sense of loss and helplessness. This experience of loss and lack of 'normal' parenting is consistent with findings from Niven et al. (1993) in the parents of preterm babies during their time in hospital. Similarly, studies have established that parents of infants in NICU experienced a loss of control over their newborn's care and a change in parenting practices during their child's admission (Charchuck & Simpson, 2005). Furthermore, studies have shown that when mothers are admitted to NICU, their altered or relinquished role resulted in them feeling unable to protect their child from pain or provide sufficient support. Parents' inability to perform normal parenting resulted in feelings of helplessness and incompetence (Callery, 2002; Gale, Franck, Kools & Lynch, 2004). In the current study, it is therefore likely that the lack of control perceived by the parents, together with feeling unable to perform their typical parental role in this unusual environment, impaired their use of coping strategies and contributed to their reported distress during this time (Lazarus & Folkman, 1984). Feelings of helplessness related to their decision-making, the conflict posed by the Berlin Heart (conceived as a threat or a saviour) and the uncertain time scale of support, may have served to further reinforce parents' feelings of loss of control.

In relation to the loss of the parental role, this study's findings are consistent those of Kirk et al. (2005) who qualitatively explored parents' experiences of caring for a technology-dependent child. Using Grounded Theory, they established that parents' constructions of parenting altered whilst caring for their child and described a tension between parenting and nursing roles. This tension was also experienced by this study's participants. Although Kirk et al's. (2005) study was conducted whilst care was provided in the home environment with parents responsible for performing many clinical procedures, there are clear commonalities in experience and responsibility with the Berlin Heart parents. In a review article, Christie and Khatun (2012) describe a process of adjustment through development of a new normal. As family roles are reorganised and the meaning of illness appraised, feelings of anger and grief are frequently reported. Although feelings of loss and frustration were evident in some Berlin Heart parents' accounts, their experiences did not reflect feelings as intense as anger or grief. Additionally, Christie and Khatun (2012) reported that families of children with chronic health conditions may experience: restriction of activity, a loss of spontaneity, a sense of loss of how life used to be, and a threatened future (long-term disability or death). The results of the current study are consistent and supportive of these suggestions, however, parents' accounts focused on their Berlin Heart experience and thus did not discuss implications for their longer-term futures.

Although the majority of parents struggled with their experience of lack of agency, this finding was not universal. Two parents emphasised the benefits they felt when relinquishing their role. This divergence in parental experience may be explained in terms of locus of control (LoC) (Rotter, 1966).

LoC beliefs refer to the extent to which an individual believes they can impact the outcome of events affecting them (Ogden, 2001). When applied to health settings, LoC has been used as a model to ascertain whether an individual alters their health behaviours and requires a change in the style of communication from professionals (Ogden, 2001). Relationships between LoC and adjustment to illness and access to coping resources have been researched. An internal LoC has been associated with an individual's adaptability and positive health behaviours (Bradley, 1994; Pires-Yfantouda & Evangeli, 2012; Maltby, Day & Macaskill, 2007). Individuals with an external LoC tend to place control for change on situational factors they cannot control such as medical professionals. An external LoC has been associated with poorer medical adherence and outcomes in diabetes (Bradley, 1994). More recent conceptualisations of LoC include a third category as a subset of external LoC- chance, where individuals place control for change on chance. This has been associated with particularly poor adherence and adjustment in chronic health conditions (Weiner, 1980; Schlenk & Hart, 1984). Nevertheless, recent studies have highlighted the benefits of holding both internal and external LoC beliefs for adherence to treatment in diabetes (Pires-Yfantouda & Evangeli, 2012; Hummer, Vannatta & Thompson, 2011). Specifically, these studies emphasise that adherence was improved when an external LoC is held, associated with a positive relationship between the individual and the professional, together with an internal LoC and feelings of personal responsibility for care. These findings may explain Sindy and Abshir’s positive experience. Their parental roles were assumed by individuals with whom they had positive relations and trusted- the medical staff and Allah, however, they also maintained some feelings of responsibility towards their children. Alternatively, this transition may have been perceived in a positive light due to relinquishing a responsibility which they had felt to be unmanageable.

Parents’ reports of loss of control associated with feelings of uncertainty and unpredictability of their child’s situation could be contextualised within Mishel’s Transactional theory of Illness Uncertainty (1988, 1990). Illness uncertainty refers to an individual’s difficulty in attributing meaning to their illness. This uncertainty is particularly prevalent where an illness or prognosis is unpredictable or unknown or where treatments are undefined, highly complex and thus poorly understood (Brasher, Neidig, Reynolds & Haas, 1998). Illness uncertainty is suggested to be moderated by the accessibility of support, confidence and trust in care providers and the individual’s educational level and cognitive ability. These moderating factors may help to explain subtle divergences in parents’ accounts of the unpredictability of waiting in this phase of their experience.

4.2.1.2 Life in the Berlin Heart bubble. The results suggested that this phase of the parental experience related to living within an extraordinary environment, restricted and isolated from normality, dedicated to the care of a child, whilst suffering from the trauma associated with the Berlin Heart and distressed by the burden of caring.

The parental experience of imposed restriction and isolation from normality, powerfully expressed by the majority of parents, could be viewed as situational factors in terms of Lazarus and Folkman's (1984) model. These factors were likely to have been appraised negatively by the parents and thereby increased the perceived stress and strength of their emotional response. Although the feelings of restriction reported in parents' accounts are not unique to Berlin Heart parents and their children (Christie & Khatun, 2012), the intensity and quality of the restriction experienced, in which parents are confined to a hospital setting for an indeterminate period, appears different from that previously reported in the literature.

The overwhelming nature of the burden and responsibility of care experienced by the majority of parents is consistent with research by Eshelman, et al., (2009) in an adult LVAD population. The social support resources of the Berlin Heart parents dramatically altered when their child was hospitalised. Whilst some parents reported feeling isolated with this burden, others were able to draw on the support of their partner, extended family and staff to share the burden. The significant influence of support from a partner has been demonstrated in a study of breast cancer patients and their partners. These findings highlighted that perceived unsupportive behaviour from partners was predictive of women's distress over time (Manne et al., 2005). Similarly, in a sample of parents of children with chronic illness or physical disability, positive parental adjustment was associated with: positive family relations, marital satisfaction and a strong social support network (Cadman, Rosenbaum, Boyle & Offord, 1991). Furthermore, eliciting advice and engaging social support structures have been established as adaptive coping strategies in parents of children with insulin dependent diabetes (Azar & Solomon, 2001).

The importance of support structures to individual parents was emphasised in the current study in relation sharing the burden of care, consistent with the above findings.

This group of parents reported a variety of methods to cope with their distress and many parents used multiple strategies. Both emotion- and problem-focused strategies (Moss-Morris, 2013) were used. Congruent with the model, the use of emotion-focused strategies, such as emotional avoidance and pretending, appeared to be related to parents' perceived lack of control. Parental use of emotion-focused or avoidant strategies was unsurprising given the context and is consistent with previous findings in parents of children with bladder extrophy (Mednick et al., 2009). Conversely, problem-focused strategies, such as information seeking, which has been associated with reduced psychological distress (Simons et al., 2007), appeared to be implemented at times of greater perceived control, associated with periods of apparent stability of their child. It was however notable that some parents used avoidant strategies concurrently with adaptive coping strategies, consistent with findings in parents of children awaiting kidney transplant (Zelikovsky et al., 2007).

Avoidant coping strategies such as denial, distraction and disengagement have been found to be predictive of depression in mothers of children awaiting: kidney transplant (Zelikovsky et al., 2007), bone marrow transplant (Kronenberger et al., 1998) and across transplant groups (Simons et al., 2007). Although no measure of psychological disorder was used in this study, distress evident in parental accounts could be inferred to relate to their adopted coping strategy, as exemplified in Clare's account.

Although previous research has established gender differences in parental experience of stress and use of coping strategies in the context of chronic illness, (Simons et al., 2007; Tarbell & Kosmach, 1998; Zelikovsky et al., 2007) there was no apparent such difference between the seven maternal and one paternal accounts in this study.

The subtheme ‘Trauma, brutality and imperfection’ highlighted parents’ experience of distress related to the appearance of their child whilst on the Berlin Heart irrespective of the duration of support. These findings are consistent with literature from the congenital heart disease population, in which parents reported the highest levels of stress in relation their child’s appearance and behaviour (Franck et al., 2010). Parents’ accounts conveyed profound distress at their child’s appearance, suggesting they may have been inadequately prepared. Gilmore and Newall (2011) found parents felt unprepared for their child’s VAD support because they lacked adequate information. However, this study’s findings do not suggest parental unpreparedness was necessarily related to a lack of information.

All parents had been exposed to the threat of death to their child by virtue of requiring Berlin Heart support. This experience of threat was sustained for many parents by the on-going risk, and actual experience of, infections and stroke. Furthermore, parents’ evocative descriptions, their evident distress and emotion-focused coping strategies (pretending, avoiding) may indicate symptoms of post-traumatic stress or acute stress disorder (APA, 2013). This interpretation would be consistent with findings: in parents of children staying more than 48 hours in paediatric intensive care (Balluffi et al., 2004), in parents of children hospitalised in NICU (Lefkowitz et al., 2010), in parents of paediatric heart transplant recipients (Farley et al., 2007) and in partners of adult VAD recipients (Bunzel et al., 2005; Bunzel et al., 2007). Although there was variation in measurement, rates ranging from 32-35% for ASD and 8-26% for PTSD were found across these studies.

Significantly, some Berlin Heart parents' accounts were suggestive of on-going symptoms of post-traumatic stress, (including difficulty recalling the trauma, efforts to avoid associated thoughts and feelings, significant emotional distress and on-going impact on social, emotional and occupational functioning), which although not formally assessed by this study, would not be inconsistent with findings from spouses of adult VAD recipients with 26% reporting symptoms of PTSD 6-135 months post-operatively (Bunzel et al., 2007).

Although the specific influence of traumatic symptoms on an individual's adjustment to illness has not been modelled, it is conceivable that these symptoms would further complicate parents' disrupted emotional equilibrium and quality of life (Moss-Morris, 2013) and impair their ability to adjust successfully.

Some parents reflected on the imperfection of their child's body following the implantation of the Berlin Heart. Although concerns relating to physical scarring have been reported in a qualitative study of adult VAD patients (Chapman et al., 2007), the parents reflection on the their child's appearance, relative to their previous perceived perfection and their associated feelings of shame appear to be unique to this study.

The results suggested that parents dedicated themselves physically and emotionally to their child. This all-consuming care became a way of life to the extent that many sacrificed other relationships including their marriages and contact with other siblings. Although some parents derived a sense of agency from their dedication, others experienced distress at their sacrifice. These behaviours may represent a problem-focused coping strategy, as they were engaging in practical ways to reduce the cause of their distress. These features of the parental experience are consistent with findings in parents of children in intensive care who reported feeling powerless and similarly needing to stay close to their infant (Obeidate, Bond & Callister, 2009). These findings are also consistent with research by Holditch-Davis (2003) who established that parents of medically fragile infants provided greater responsivity, attention, social stimulation and commitment than parents of children without acute medical conditions. Although dedication to their child appeared to provide short-term alleviation of distress for some Berlin Heart parents, others struggled to implement their desire to dedicate. In addition, this desire caused feelings of conflict, guilt and distress in some parents because of the impact of their dedication on other children and relationships, which were also of central importance to their life. Consistent with the Berlin Heart parents, Tong et al. (2010) found that despite feeling burdened by their caring responsibilities and experiencing emotional and relationship difficulties, parents of children with a chronic kidney condition nevertheless fulfilled their parental and medical responsibilities.

4.2.1.3 Transitioning forward. The results suggested this phase of parents' experience was characterised by a feeling of reclaiming control, reasserting their parental role, adjusting to their situation and looking forward with hope. It is possible that parent's engagement with problem-focused coping strategies such as seeking information and social support, together with an internal LoC facilitated the apparent cognitive reappraisal of previous difficulties consistent with McCubbin & McCubbin's, (1983) model. This appeared to enable them to reaffirm their role and value in parenting.

The reinstatement of the parenting role experienced by parents in this study, did not necessarily correspond with their previous typical role, but required an adjustment to a new normality in which their concept of parenting was reconstructed.

Nevertheless, this element of their experience appeared to be positive for the majority. The apparent transition from positions of relinquishing to reasserting their parental roles has also been reflected in a phenomenological study by Heermann, Wilson and Wilhelm (2005), in which a theme of passive to active caregiving was reported over time in mothers of babies in neonatal intensive care.

Rempel and Harrison (2007) describe parents of children with hypoplastic left heart syndrome engaging in strategies which included: maintaining closeness, engaging in complex nursing care duties and remaining positive, which they refer to as ‘extraordinary parenting’, to simultaneously safeguard the precarious survival of their child, themselves and their couple relationship. The results of the current study appear consistent with Rempel and Harrison’s findings and their concept of extraordinary parenting. It is probable that parents’ experience of reinstating their role, often through the decision to engage in care duties, may be interpreted as fulfilling their need for protection and survival of both their child and themselves.

Engaging in the care of a sick child on NICU, has been found to enhance parental understanding and decrease psychosocial distress, thereby promoting more effective parenting (Hall, 2005). Additionally, Phillips and Tooley (2005) found that mothers of infants in NICU often felt distressed when they did not have proximity or ability to touch their babies. Moreover, Gale et al. (2004) found that parental distress was reduced by their involvement in providing care to their infant. Many parents in the current study initially experienced significant distress and difficulty in engaging in caring for their child, such as changing their dressings. The use of emotion-focused coping strategies such as disengagement, denial, distraction and pretending may have prevented the opportunity for reducing their distress. Some parents did opt to engage in the care routines, however, it was notable that this was predominantly following a period of adjustment to the device and the environment.

Parents’ engagement in and assertion of their parental role and their integration and embedding into new support systems, may have provided feelings of increased self-esteem, a sense of mastery over their environment and personal growth. These attributes are consistent with elements of Cognitive Adaption Theory (Taylor, 1983). The theory proposes that, following a threatening event such as chronic illness, individuals can respond by adaptively shifting their focus to something controllable, thereby permitting a return to previous psychological functioning.

It is well established that good social support makes an important contribution to an individual’s health and wellbeing (Wilkinson & Marmot, 2003). Social support provides individuals with emotional and practical resources together with a sense of community and belonging, from which people derive care and value.

During this phase of transition, parents in this study appeared to adjust to their novel situation and take comfort from the support provided by the staff and other families of Berlin Heart children, consistent with Mishel’s theory (1988, 1990). Parental integration and embedding was less apparent in the experience of parents of children with shorter support duration. Parents reflected on the importance and positive impact of sharing their experience with other families in the same situation. This finding is consistent with Hartman, Radin and McConnell (1992) in which the importance of mutual social and emotional parental support between families of chronically ill children was established. Additionally, the Berlin Heart parents reported the need to maintain their own family support systems and expressed the desire to limit the exposure and transference of distress onto their family.

Social resources and interpersonal support has been purported to effect adjustment and adaptive outcome in chronic illness by influencing emotional, cognitive and physiological pathways (Wills & Fegan, 2001). In a review of adjustment in chronic health literature, Stanton, Revenson and Tennen (2007) asserted that social support could promote an enhanced understanding of illness and thereby facilitate the use of effective coping strategies. Additionally, discussing concerns in a supportive social setting, free from criticism, was found to facilitate improved adjustment to adaptive tasks in chronic illness. It is conceivable that these beneficial outcomes of social support may have been inherent in the experience of parents who integrated into a 'Berlin Heart family'. Consistent with the results of this study, positive social support has been found to contribute to the process of adjustment to illness in spouses of adult heart disease patients (Bennett et al., 2001) and adult cancer patients (Helgeson et al., 2004).

Integration into a Berlin Heart family was prominent in the accounts of the three parents who had the least social support by virtue of being single (Sindy) or having absent partners (Gemma and Abshir). Given the established importance of social support and reliance on partners, it is conceivable that for these parents, the need for support and the benefits it brought were fulfilled by the adopted 'Berlin Heart family'.

Prominent in the parents' accounts was noticing signs of positive physical change or the hope that the Berlin Heart would ultimately provide positive change for their child. This theme 'Hope of a new and normal child' suggested that the parents were acutely aware of, and distressed by, the abnormality of their child's situation and were seeking any signs of normality. It is likely that this process itself alleviated some of the distress attributable to the conflict between a typical parental expectation and the reality of their child's condition. Parents' apparent vigilance to these changes further exemplifies their search for normality. These findings are consistent with existing literature in which parents have been found to seek normality (in caregiving, feeding and noticing developmental progress) in their unwell child (Nelson, 2002).

Related to this phase of the experience, some parents appraised small signs of their child's improvement as highly significant. In doing this, they perhaps position their child as having special attributes, consistent with previous reports of parents with congenital abnormalities (Drotar et al., 1975).

Parents' experiences in this final phase could be contextualised as representing post-traumatic growth (PTG) (Tedeschi & Calhoun, 1995). Research by Joseph, Murphy and Rengel (2012) purports that PTG is associated with strategies including: acceptance, seeking social support, positive reframing and problem solving. Tedeschi and Calhoun's (1995) theory of PTG explains individual's adaptation to traumatic events and the positive psychological changes resulting from their experience of adversity. The theory of PTG is defined by three domains. The first domain is characterised by: the increased importance of familial relationships and friendships, enhanced compassion towards others and the need for intimacy. Parents in this study reported changes in this area, noting the critical importance of support from their partners, extended family members and the positive impact of their adopted Berlin Heart family. Their embedding within the medical team and ward family also illustrated their need for intimacy in the form of shared experience. The second domain outlines personal growth through appreciation of an individual's vulnerabilities, thereby developing improved self-reliance and self-efficacy. In the final phase of their experience, many parents asserted their control both in respect of their parental role and in managing their external support systems. This indicated enhanced self-reliance and self-efficacy compared with the initial phase of their experience, which was characterised by loss of control and reliance upon others. The final domain includes growth in philosophy of life. The parents in this study appeared to gain a new perspective on their child's health as illustrated by their hope for a normal child, their gratitude towards staff members and their resolution of the ethical conflict they described in relation to the process of organ donation.

At the time of these interviews, one child who experienced a stroke and a second who had most recently received their transplant, appeared not to have derived the same level of benefit from the Berlin Heart support as other children. Consequently their parents shared an on-going experience of distress and comparably heightened sense of risk, compared to other parents' accounts. This apparent on-going distress is likely to have affected their appraisal and description of their experience and thus may have portrayed it more negatively. A study by Janoff-Bulman (1989) suggests that the impact of a traumatic event can negatively affect an individual's view of their world and themselves several years after the event. Given this finding, together with the likely absence of PTG for these two parents, their experience is likely to be appraised through a more negative lens. Importantly, it is conceivable that the current situation and condition of their child may have influenced the way in which *all* parents spoke about their experience at the time of the interview.

Some parents' experiences were marked by feelings of conflict and guilt relating to the process of organ donation. These experiences could be understood using Cognitive Dissonance Theory (Festinger, 1962). Parents reported distress at holding beliefs and or feelings that were contradictory, consistent with this theory. Parents' feelings of envy of others receiving suitable donors and experiencing guilt associated with the implications of waiting for a donor heart, are consistent with existing literature in paediatric transplantation (Gold et al., 1986). Attempts were made by some parents to reduce this incongruence by rationalising that donor families had opted into the donation programme or, in cases where donors were provided to other families, that their child was not yet appropriately prepared for the transplant. This process of rationalisation is suggestive of resolution of this aforementioned dissonance.

Appraising this study's findings in the broader context of childhood chronic conditions some convergences and divergences are apparent. The parental experience of loss of control and altered parenting roles are broadly supportive of the literature from parents of children who are technology-dependent including requiring: tracheostomy, oxygen therapy, mechanical ventilation, on-going intravenous drugs, parenteral nutrition and peritoneal dialysis due to chronic conditions (Kirk et al., 2005), ventilator assisted children (Carnevale, 2006) and parents of children with a chronic kidney condition (Tong et al., 2010).

In a review of parenting stress among caregivers of children with chronic conditions including: asthma, cystic fibrosis, diabetes, juvenile rheumatoid arthritis, cancer, epilepsy and/or sickle cell disease, a positive association was established between parenting stress and responsibility for treatment management, irrespective of illness duration or severity (Cousino & Hazen, 2013). This finding is consistent with the overwhelming burden of care and stress experienced by some of the parents in this study.

In a Nordic qualitative study exploring parent's experience of having a child with chronic asthma, four themes were established including: feelings of uncertainty, helplessness and guilt; the need for support; adaptation to everyday life; and the development of coping strategies (Trollvik & Severinsson, 2004). These findings are analogous with the themes found in the current study. Although beyond the scope of the current research to draw comparisons with a wide range of other chronic childhood conditions, themes such as ‘Do or die’, ‘Like a bus stop- the unpredictability of waiting’, Trauma, brutality and imperfection’ and ‘Donor dilemma’ found in this study are likely associated with elements of the Berlin Heart experience absent in many other chronic childhood conditions, which may not share the combination of components including: surgery, intensive care admission, being technology-dependent, confined to a hospital environment for an unknown time period and awaiting organ transplantation.

4.2.2 Research Question Two. What is the impact of these experiences on: parental quality of life, parental adjustment to their child’s condition and family dynamics?

4.2.2.1 Parental quality of life. Although no consensus exists as to the definition of QoL (Ogden, 2001), it has been defined by the World Health Organisation as ‘a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships and their relationship to the salient features in their environment’ (WHOQOL Group, 1993, p.1). Parental QoL was significantly impacted throughout the Berlin Heart experience, however the degree of its impact varied. The distress associated with: parental lack of control over decision-making, the perceived risks of the Berlin Heart, the loss of the parental role, and the unpredictability of waiting, experienced by the majority of parents implies a significant negative impact upon their QoL. Furthermore, the experience of restriction in the hospital environment, the dedication many parents gave to their child and the related sacrifices to their marriages also indicate a negative impact on their QoL. Moreover, the sense of trauma associated with life on the Berlin Heart common to many parents' accounts, the burden of care and their isolation from normality, which was emotively conveyed, strongly suggest that their QoL was negatively impacted. Interestingly, for many parents, QoL seemed to improve towards the end of their experience. It is likely that this transition was associated with feelings of increased control, ability to assert their wishes and parental role, integration into their support system and a degree of adjustment to their child's condition.

Although QoL has been examined in a sample of adult LVAD recipients with a significant trend for poorer QoL, (Wray et al., 2007), no such investigations have been conducted in parents of children supported on VADs. Due to the qualitative nature of this study, no formal measurements of QoL were used, thus further inferences about the impact on parents QoL cannot be drawn.

4.2.2.2 Parental adjustment to the child's condition. The literature base on adjustment to chronic illness is vast. Although it is widely accepted that chronic illness is associated with significant social and psychological consequences, which in turn require psychological adjustment, no consistent definition or measurement of the construct is used. Despite this, numerous theoretical frameworks and conceptualisations of adjustment have been developed in relation to an individual's chronic illness (Lazarus & Folkman, 1984, 1991; Moss-Morris, 2013; McCubbin & McCubbin, 1983). These have highlighted substantial heterogeneity in the concept of adjustment both between individuals and across the course of the illness or disease (Stanton et al., 2007). This evident variation presents significant challenges to the interpretation of the literature on adjustment to chronic illness (Stanton, et al., 2007).

Traditionally, adjustment to chronic illness had been defined relative to the presence or absence of symptoms indicative of psychopathology, notably anxiety and depression (Moss-Morris, 2013). Contextualised in terms of psychopathology, the findings from the current study would infer initial poor parental adjustment to their child's condition as significant distress and anguish is expressed. However, it is arguable that the reported distress is appropriate and realistic given the enormity of the situation. Although the intensity of distress appears to reduce over the course of their experience, transitioning to a more positive and hopeful position, parents' accounts retain a sense of anxiety and in some parents, possible symptoms of post-traumatic stress.

More recently, adjustment to chronic illness has been conceptualised as multifaceted, encompassing numerous life domains (Stanton, Collins & Sworowski 2001; Hoyt & Stanton, 2012), and an on-going and dynamic process that manifests differently across individuals (Stanton, et al., 2007; Stanton et al., 2001). Furthermore, Moss-Morris (2013) highlighted the importance of differentiating the process of adjustment from the outcome and also that at different points in the illness trajectory, the 'desired outcomes' may change.

Initially, parents experience was characterised by feelings of distress and a marked lack of control. At this stage of their experience, it is arguable that parents appraised their situation as significant and highly threatening (Lazarus & Folkman, 1984). As the experience was novel to all parents', it is probable that they assessed their coping resources as inadequate and inefficacious, resulting in feelings of uncertainty and lack of control, further impairing coping and adjustment (Lazarus & Folkman 1984; Moss-Morris, 2013). Similarly, emotional disequilibrium is predicted by the Moss-Morris model, given the parents' altered role, the threat to their child's life and the uncertain future (Moss-Morris, 2013).

The next phase of parents' experience seemed to be marked by a struggle to adjust and maintain emotional equilibrium as illustrated by their reported feelings of: restriction, dedication and sacrifice, a mixture of emotion- and problem-focused coping strategies (Moss-Morris, 2013), their behavioural responses to trauma, burden of care and isolation from normality.

The third phase of parents' experience indicated a transition towards adjustment to their child's condition and to their experienced adversity. This phase was characterised by a more constructive appraisal of their situation (Lazarus & Folkman, 1984; McCubbin & McCubbin, 1983) and was predominantly accompanied by increased control, engagement with social support and problem-focused coping strategies such as engaging in care duties (Moss-Morris, 2013).

LoC, once thought to be a stable personality characteristic, has been found to change in response to a significant life event (Legerski, Cornwall & Oneil, 2006). The experiences of parents in this study may reflect a changing LoC. Parents' initial shock and lack of control over their decision-making, the threat of the device, relinquishing their parental role and the uncertainty of waiting for a donor may be associated with an external LoC. As their experience progressed, parents appeared to build in confidence, assert themselves and their role, integrate into a new environment and manage their support systems, indicative of a more internal LoC and a more adjusted position.

4.2.2.3 Family dynamics. Family dynamics was evidently negatively impacted in all parents' accounts. Initially, parents' experience was characterised by grief at the loss of their traditional parental role or the reluctant adaptation to a more medicalised role, as described in relation to research question one.

Parents emphasised their dedication to their child often at the expense of contact with siblings and relationships with partners. The results suggest that siblings experienced both the direct impact of the additional demand on their parent's time and physical availability, together with the likely indirect impact of their parent's changed emotional responsivity, consistent with previous suggestions (Edwards &Titman, 2010). The burden of care described by many of the parents also illustrates the impact on family dynamics as several parents reported feeling isolated and unable to access their accustomed family support network. Conversely, other parents benefited from sharing this burden with extended family members, thereby altering their relationships with family members.

Interestingly, there appeared to be a positive transition in respect of 'family' dynamics over the course of time. The majority of parents reported embedding into the medical system and adopting a 'Berlin Heart family' whether this was other families or the medical team. All parents appeared to derive benefit from this transition. As described in relation to research question 1, this process appeared most significant to Sindy, possibly because she was the only single parent. This process may be indicative of adjustment to their adversity and reconciliation to the loss and sacrifices made relative to their biological families.

Specific to the only father's experience was a struggle with being unable to provide for his family. It is possible that being unable to provide financially conflicted with his values and cultural norms, thus causing him significant distress.

4.3 Critical Evaluation

4.3.1 Strengths. The main strength of this study is that it addresses a clinically significant gap in the literature. It provides a unique insight into the parental lived experience of having a child supported on a Berlin Heart as a bridge to cardiac transplant through the collection of rich narrative data.

The study was subject to numerous measures to ensure the production of high quality IPA and thus the validity of the results. The service-user involvement and consultation with the London IPA group regarding feedback on the draft interview schedule ensured questions were pertinent, clear and sensitive. Moreover, an initial practise interview with one of the supervisors together with the pilot study, permitted further refining of the researcher's interview style to ensure effective and sensitive collection of data.

A key strength of the study was the use of credibility checks to maintain the validity and quality of the final themes (Yardley, 2008), as outlined in the method section. Cross validation across three supervisors, ensured themes were grounded in the data, mutually exclusive and coherent. Additionally, the researcher clearly outlined the sending and receiving contexts in the method so that the influence of fore understandings and preconceptions could be identified. As recommended by Smith et al. (2009) and Morrow (2005) the researcher diligently kept a reflective journal capturing preconceptions, concerns and thoughts throughout the process. This reflexive process was found to be particularly helpful given the interviews were emotionally laden and it enabled bracketing of biases, such as assumed parental reaction to their perceived loss of role, during the analysis.

Prior to recruitment, consideration was given to the sampling strategy and criteria for inclusion to ensure the homogeneity of the sample. All parents experienced the same phenomenological experience of having a child supported on a Berlin Heart as a bridge to transplant. Although some variability in parent and child characteristics were present, due to the small size of the clinical population, some variability was inevitable. Furthermore, the characteristics of the sample were felt to be representative of the clinical population at the NHS hospital site (V. Kelly, personal communication, April 6, 2016), which may increase the likelihood that the themes are reflective of the broader population. Moreover, the relative homogeneity of the sample strengthens confidence in the findings drawn from this select sample. There was a good response rate for participation, with 10 of the 12 parents approached taking part.

4.3.2 Limitations. The retrospective study design meant that the parents' accounts of their experience were subject to potential recall bias (Schwarz & Sudman, 2012). Although efforts were made to minimise recall bias by setting an upper limit of 11 years since support, it was considered that further restricting of this criterion would impede recruitment. The time elapsed since the Berlin Heart procedure ranged from two months to eight years six months, which may have affected the quality of parents' recall.

Moreover, some heterogeneity of both parent (gender, age, ethnicity, marital status, occupation and number of children) and child characteristics (gender, age at time of intervention, diagnosis, type of Berlin Heart, duration of support and length of time since VAD support) was present.

Gender differences in parental experience of stress and use of coping strategies in the context of childhood chronic illness have been reported in a small number of studies. Compared to fathers, mothers experienced greater stress related to their child's illness or transplant, greater levels of depression and were more likely to use engagement coping strategies and derive psychological benefit from social support (Simons et al., 2007; Zelikovsky et al., 2007). No such gender differences were evident in this sample of one paternal and seven maternal accounts. Although difficult to specifically isolate the effects of gender in a qualitative study, it is possible that if more fathers were recruited, differences may have been apparent. The greater proportion of maternal compared to paternal accounts is common to much of the extant literature exploring parental experience of childhood chronic illness, where the vast majority employ a self-selected sample comprised exclusively of mothers.

Given the finding that the one father and the respective partners of the interviewed mothers in this sample all appeared to adopt a more traditional provider role, it is conceivable that this may represent a gender difference which could be explored with a paternal or a larger, more balanced mixed maternal and paternal sample.

Although it is conceivable that the duration of the exposure to the Berlin Heart may have impacted both the quality of the parents' experience and their ability to recall it, there was no evidence of difference between parents' accounts relative to either the amount of time elapsed since support or to the duration of support.

Heterogeneity was also evident with respect to the nature of the child's heart failure and the consequent care provided prior to Berlin Heart support. Only one of the parent's children had chronic heart failure, the remainder of the sample having acute heart failure. Similarly, this variable did not appear to result in divergent experiences. Although the introduction of some heterogeneity was required due to the small population size, this complicated the analysis of convergences and divergences within the sample and created challenges relating to the confidence in attributing findings to the shared lived experience, as opposed to variation within the sample. It is probable that the findings best represent the experience of mothers who identify as White British at one hospital site and thus further generalisation of the findings would not be well founded. Nevertheless, there are only two sites offering Berlin Heart support in the UK, and the majority of the British population identify as White (Office for National Statistics, 2011), therefore it is likely that these findings could be applied with caution to the other site.

This study failed to capture the lived experience of parents of deceased children. It is conceivable that bereaved parents would report their experience through a more negative lens than parents whose children were successfully supported and survived. It could be anticipated that it would be complex to differentiate the extent to which their reported experience reflected the death of their child, their experience of the Berlin Heart, or their combination. Gilmore & Newall's (2011) Australian study exploring the informational needs of both children and parents supported on a VAD did include one bereaved parent in its sample of six parental accounts. They noted that this parent's account demonstrated a predominantly negative experience and reported difficulties in its interpretation.

In the current study, although there was not a clear effect across all participants, a more negative experience was shared by the two parents of children who, at the time of the interview, appeared not to have derived the same level of benefit from Berlin Heart- one whose child had a stroke whilst supported and another who had most recently received their transplant. These parents shared an on-going experience of distress and comparably heightened sense of risk compared to the other parents' accounts. Further research would be required to elucidate the lived experience of parents of deceased children supported on the Berlin Heart.

The methodology of data collection, together with the nature of the research, may leave a vulnerability for socially desirable responding from parents. Although the researcher tried to minimise this risk by emphasising and reiterating their anonymity in the study, it is plausible that parents were responding in a socially desirable way, as found in a study by Durgel, van de Vijver and Yagmurlu (2013), which explored maternal reports of parenting practices.

4.4 Research Implications

There are several implications for future research which arise from this study and warrant further investigation.

The parents in this study self-selected as being the main carer for their child whilst they were supported on the Berlin Heart. Seven of these were mothers and only one was a father. It was notable that the one father and the respective partners of the interviewed mothers all adopted or strived to adopt a more traditional provider role. This would suggest that exploration of the paternal experience would be a valuable contribution to the evidence base, as supported by Clark and Miles (1999). Although paternal perspectives are predominantly underrepresented in parenting literature (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000), given the shift towards paternal caregiving roles in modern society, understanding paternal lived experience is essential.

Furthermore, many of the mothers reported their relationship with their partner as being critical to their coping. Conversely, for some parents, an apparent relationship between child illness and marital dissatisfaction was evident, consistent with previous findings (Berant, Mikulincer, & Florian, 2003), highlighting the significant role of partners on their experience. Thus although complex to analyse, parental dyads could be interviewed, similar to those conducted by Adams and colleagues (2014), to facilitate exposure of the systemic and relational factors.

Although beyond the scope of this research, using a prospective longitudinal methodology, incorporating both an interview at diagnosis of the heart condition, during support and follow-up interview six to twelve months post transplantation, could address the limitations identified relating to recall bias and permit a comprehensive understanding of how parental experience and adjustment may change over time. This methodology would also assist in the identification of families at risk of distress and complicated adjustment.

Direct exploration of children's experiences of being supported on the Berlin Heart also seems important to investigate. Given the importance of the parent-child dyad, the reciprocity of emotion and dependence inherent in this dyad, together with difficulties investigating child experiences through parental experience (a triple hermeneutic), further underscores the importance of exploring the child's account directly.

Given the established highly stressful and emotionally laden environment in which the staff provide care for the Berlin Heart children and their families, exploring the experiences and perspectives of nursing and medical staff is indicated. Qualitative investigation would permit understanding of their current support structures and facilitate the implementation of further support provision where required.

One of the limitations of this study is that it provides a predominantly western maternal perspective. Future research could incorporate the exploration of other ethnic minority groups and religious and cultural contexts where parenting practices and the impact of disease, illness and organ donation may vary and significantly impact parents' experience.

Recruiting a 'clinical' sample of families referred to the hospital's psychosocial services, or with current mental health input from Community Mental Health Team or Child and Adolescent Mental Health Team could elicit the possible differential experiences when mental health or attachment difficulties are present and formally recognised. This approach could also help highlight experiences detrimental to psychosocial distress and adjustment. Nevertheless, further restriction of the sample in this way could create significant challenges to recruitment.

Finally, collecting psychometric information such as the HADS (Zigmond & Snaith, 1983), or a measure of QoL such as WHOQOL-BREF (WHOQOL, 1998) may aid contextualisation of the sample and facilitate inferences about the findings.

4.5 Clinical Implications

This study provides an understanding of the parental experience and meaning, previously absent from the literature, of having a child bridged to cardiac transplantation on a Berlin Heart. A number of clinical implications for the transplant and VAD team within the NHS site are presented below.

4.5.1 Preparation for uncertainty.

The results validate the use of the psycho-educational leaflet developed by the NHS site to help prepare parents. This leaflet aims to reduce parental anxiety and normalise emotions. Similarly, a video was developed by the NHS site providing: parent testimonials, a description of the hospital environment and coping strategies other families have found useful. It is notable that the majority of the parents in this study experienced the Berlin Heart before the implementation of these resources. The study's findings strongly support the on-going use of these preparative materials. Moreover, a sibling support leaflet or video with service-user input may be beneficial.

4.5.2 Decision-making process. It was evident across parental accounts that distress was experienced regarding the decision to consent to the Berlin Heart. Some parents reported feeling able to conduct their own research informing their decision, whereas, others did not. Therefore, it might be helpful to consider providing parents with a written accessible executive summary of current validated research findings to provide parents with a sense of agency and information in the decision-making process, consistent with recommendations to promote shared decision-making by Elwyn et al. (2012). Ample opportunity should be provided to parents for discussion of the risks and benefits and to normalise the experience of complexity inherent in the decision-making process (Elwyn et al., 2012).

The findings also validate the importance of current protocols and procedures relating to staff-parent communication during the decision-making process. Conversations with parents should be clear, informative and provide realistic expectations so the parent is fully informed. Ambivalence about consenting and or perception of lack of alternatives, experienced by some of the parents, may be associated with feelings of vulnerability. Professionals should thus be mindful of the significant power dynamic inherent in decision-making conversations between parents and medical professionals (Charles, Gafni & Whelan, 1997). Furthermore, careful consideration should be given to the number of meetings with parents at this time, as several parents reported feeling overwhelmed and unable to process information. It may be beneficial to recommend that parents are joined by another family member or friend to support these meetings to manage feelings of overwhelm and recall of content. Additionally, compiling a written summary of conversations for parents, which could be supplemented at each subsequent meeting over their journey, may provide a reassuring record of conversations.

The results of the study validate current procedures in which, where viable, parents are provided access to a Berlin Heart, pictures and videos and where possible meeting another parent supporting a child on the Berlin Heart. These experiences not only assist in the decision-making process, but also aid the preparation of parents.

4.5.3 Assessment and on-going support. This study highlighted and further validates the importance of offering routine and on-going assessment to families of children supported on the Berlin Heart, to identify individuals requiring psychological support. Furthermore, it is clear that these assessments should consider the wider systemic factors influencing the parents, child and the social, emotional and longitudinal aspects of their heart condition.

Given the significant impact of partners, wider family members and siblings, on parental experience, the study underscores the importance of the current procedures adopted to support adjustment within the family at a systemic level (Kazak, 1989). Furthermore, the results of this study highlight the on-going importance of this approach to support the maintenance of positive relations within parental contexts and support structures e.g. with their children and their own parents. Moreover, the results support the on-going implementation of psychological interventions such as Acceptance and Commitment therapy, mindfulness based approaches or Cognitive Behaviour therapy to improve parental adjustment and coping.

A parent-mentoring programme could be implemented to provide a more informal support structure for families. Some parents reported benefitting from speaking to other parents who had been through the same experience. Specifically, it seemed that this was most helpful when the other parents had successfully completed the experience. This may have allowed time for reflection and sharing of a more balanced experience. All parents reported deriving a sense of positivity from sharing their experience with the researcher. Furthermore, many questioned whether such a mentoring programme existed and offered their support and involvement to such a programme. Thus, it is probable that a mentoring approach model, in which volunteers are co-opted into a mentoring pool, could be mutually beneficial as established in mothers in HIV populations- ‘mother2mothers’ (Futterman, et al., 2010).

Presently, self-report measures are not routinely used by the service. Routine inclusion of measures including parental QoL such as WHOQOL-BREF (WHOQOL, 1998) and HADS (Zigmond & Snaith, 1983) could provide valuable information at initial assessment and a useful comparison, for both parents and clinicians, as an evaluation of support at follow-up. Additionally, given the likely prevalence of post-traumatic stress symptoms, and in some cases disorder, implementation of the IES-R could be valuable to identify parents appropriate for trauma-focused intervention.

4.6 Personal Reflections

Throughout this process I have been struck by parents' willingness to openly share their experience with a stranger, and in some cases in an unfamiliar environment. The sense of openness and frankness offered by the parents underscored the importance of reflective psychological support and follow-up. I was honoured that for many this was the first time they had reflected on and shared their journey. At times, prompting parents to recall difficult experiences felt exploitative due to the vulnerability the parents conveyed however, all parents expressed that they derived benefit from the interviews.

This research experience has underscored the importance of systemically appreciating the needs of parents within a paediatric setting, which is frequently child focused and dominated by a medical model.

As a novice IPA researcher, my own experience and journey with the methodology was often difficult to navigate. During the analysis phase, I was aware of the striking parallels between my own feelings of uncertainty and concern about the accuracy of my findings, and that reported by the parents.

Having embarked on the journey of parenthood myself during the process of completing this research, I have felt privileged to hear parents' stories and challenged emotionally and cognitively by their recollection of pain and uncertainty and the fact that this continues for some. Personally, their experiences highlighted the importance of appreciating every day, and underscores my gratitude for mine and my family's health.

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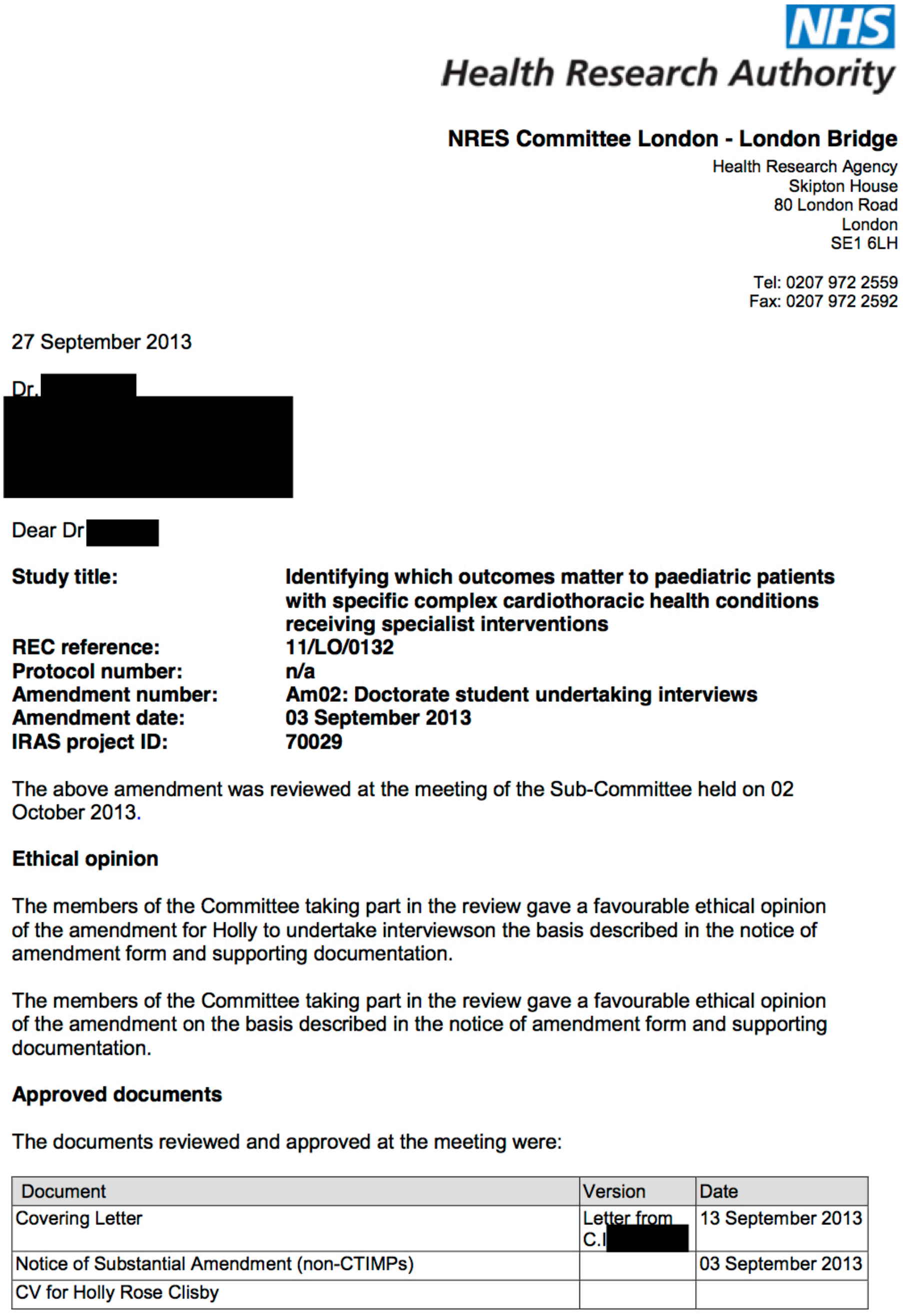
Appendices

Appendix 1: List of Contraindicating Conditions for the Berlin Heart

The following conditions contraindicate the use of a Berlin heart (M. O’Callaghan personal communication, January 20, 2016):-

- Presence of mechanical aortic valve
- Significant Aortic and/or Pulmonary valve Insufficiency
- Greater than single organ failure (except in association with acute heart failure)
- Documented heparin induced thrombocytopenia (HIT) or idiopathic thrombocytopenia purpura (ITP) or other contraindication to anticoagulant/antiplatelet therapy
- Documented coagulopathy (e.g. Factor VIII deficiency, disseminated intravascular coagulation) or thrombophilic disorder (e.g. Factor V Leiden mutation)
- Hematologic disorder causing fragility of blood cells or hemolysis (e.g. sickle cell disease)
- Stroke within past 30 days prior to enrollment, or congenital CNS malformation syndrome associated with increased risk of bleeding (e.g. arteriovenous malformation, moya moya)
- Psychiatric or behavioral disorder with a high likelihood for non-compliance
- Coexisting terminal condition
- Significant, or recent/still evolving neurological insult

Appendix 2: NHS Ethics Approval Letter Substantial Amendment- Favourable opinion (2013)



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27 September 2013

Dr. [redacted]

Dear Dr [redacted]

Study title: **Identifying which outcomes matter to paediatric patients with specific complex cardiothoracic health conditions receiving specialist interventions**
REC reference: **11/LO/0132**
Protocol number: **n/a**
Amendment number: **Am02: Doctorate student undertaking interviews**
Amendment date: **03 September 2013**
IRAS project ID: **70029**

The above amendment was reviewed at the meeting of the Sub-Committee held on 02 October 2013.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment for Holly to undertake interviewson the basis described in the notice of amendment form and supporting documentation.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter	Letter from C.I [redacted]	13 September 2013
Notice of Substantial Amendment (non-CTIMPs)		03 September 2013
CV for Holly Rose Clisby		

Participant Consent Form: For parents	5	27 August 2013
Participant Information Sheet: Information sheet for parents or carers	5	27 August 2013
Cv for [redacted]		
Cv for Dr. Michael Evangeli		

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

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

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

11/LO/0132: Please quote this number on all correspondence

Yours sincerely
PP

C Beckles

Professor David Bartlett
Chair

E-mail: claude.beckles@nhs.net

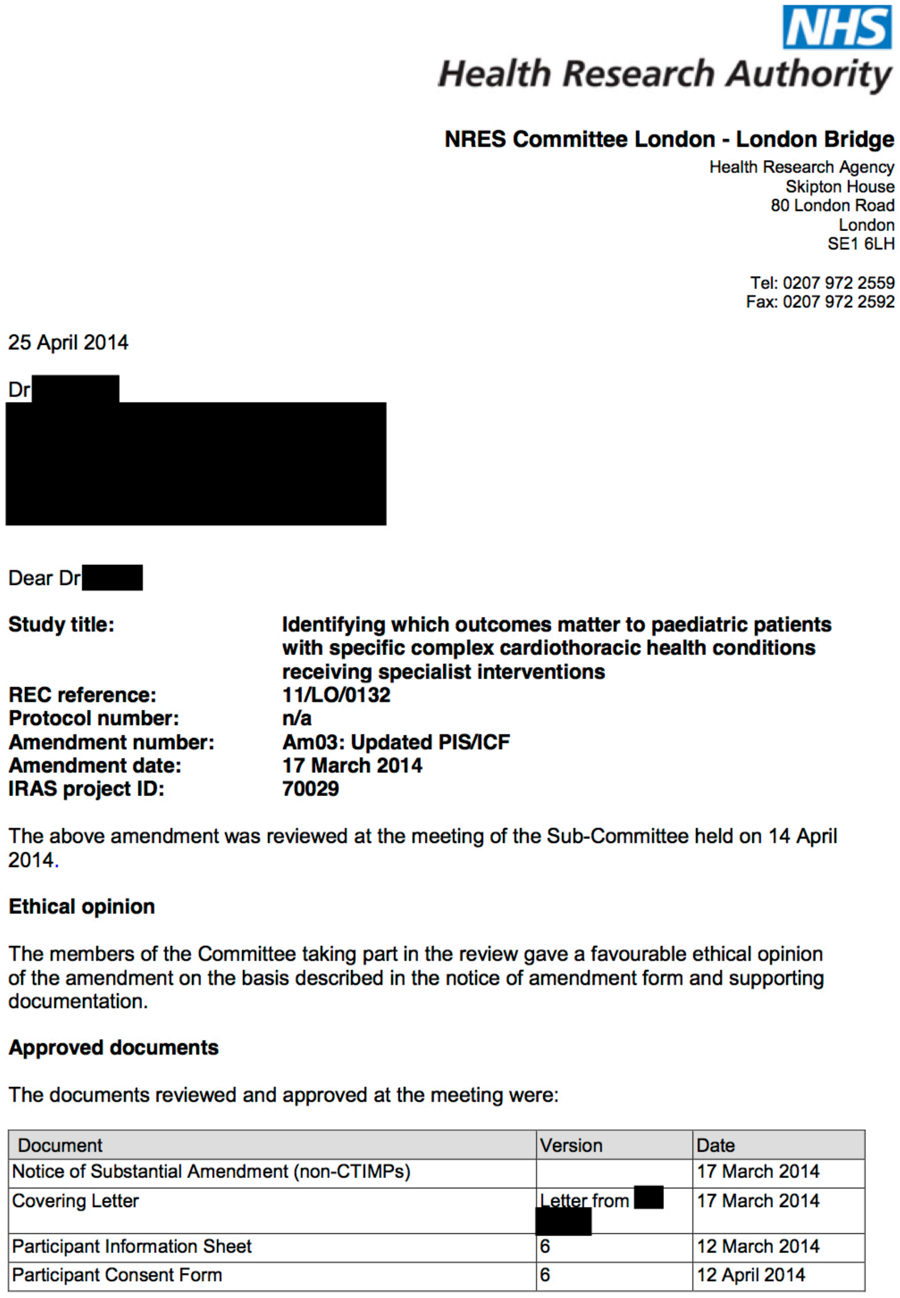
Enclosures:	*List of names and professions of members who took part in the review*
Copy to:	*Dr [redacted] Children's Hospital NHS Trust*

NRES Committee London - London Bridge

Attendance at Sub-Committee of the REC meeting on 02 October 2013

Name	*Profession*	*Capacity*
Professor David Bartlett	Honorary Consultant	Expert
Ms Karen Sanders	Senior Lecturer Nursing, Health Care Ethics & Law	Expert

Appendix 3: NHS Ethics Approval Letter Substantial Amendment- Favourable opinion (2014)



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25 April 2014

Dr [redacted]
[redacted]

Dear Dr [redacted]

Study title:	**Identifying which outcomes matter to paediatric patients with specific complex cardiothoracic health conditions receiving specialist interventions**
REC reference:	**11/LO/0132**
Protocol number:	**n/a**
Amendment number:	**Am03: Updated PIS/ICF**
Amendment date:	**17 March 2014**
IRAS project ID:	**70029**

The above amendment was reviewed at the meeting of the Sub-Committee held on 14 April 2014.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)		17 March 2014
Covering Letter	Letter from [redacted]	17 March 2014
Participant Information Sheet	6	12 March 2014
Participant Consent Form	6	12 April 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

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

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

11/LO/0132: **Please quote this number on all correspondence**

Yours sincerely
pp

Professor David Bartlett
Chair

E-mail: nrescommittee.london-dulwich@nhs.net

Enclosures:	*List of names and professions of members who took part in the review*
Copy to:	*Dr* [redacted] *Research and Development Office*

NRES Committee London - London Bridge

Attendance at Sub-Committee of the REC meeting on 14 April 2014

Name	*Profession*	*Capacity*
Professor David Bartlett	Honorary Consultant	Expert
Ms Sarah Kaiser	Diversity Practitioner	Lay Plus

Appendix 4: Email Approval from X Hospital Research and Development (2014)

Substantial amendment notification

X <X.X@X.nhs.uk>
Reply all|
30/04/2014
X <X.X@X.nhs.uk>;
X X <X.X@X.nhs.uk>;
Evangeli, Michael;
Clisby, Holly (2012)
Inbox

Dear Dr X,

PROJECT TITLE
Identifying which outcomes matter to paediatric patients with specific complex cardiothoracic health conditions receiving specialist interventions
REC Reference
11/LO/0132
R&D Reference
10CC17
Amendment Number
3
Amendment Date
17th March 2014
Date of Favourable Opinion
25th April 2014

Notification of host site amendment approval

Thank you for your correspondence with regards to the amendment(s) for the above named study. The Joint Research & Development Office can confirm that this/these amendment(s) do not affect current local approval for the study, conditional to approval from all other regulatory bodies.

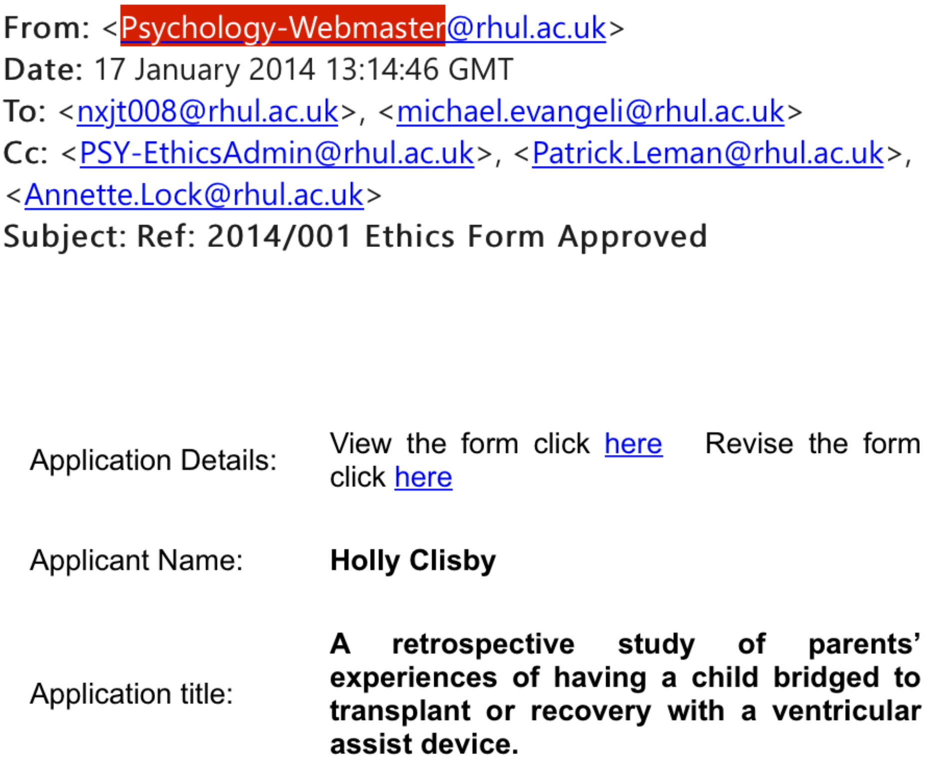
Thank you for keeping us informed.

Yours Sincerely

Dr X
Research Management and Governance Officer

Joint Research and Development Office
Address
Tel: XXX XXXX XXXX
Fax: XXX XXXX XXXX
Email: X.X@X.nhs.uk

Appendix 5: Email Approval from RHUL Departmental Ethics Committee (2014)



From: <Psychology-Webmaster@rhul.ac.uk>
Date: 17 January 2014 13:14:46 GMT
To: <nxjt008@rhul.ac.uk>, <michael.evangeli@rhul.ac.uk>
Cc: <PSY-EthicsAdmin@rhul.ac.uk>, <Patrick.Leman@rhul.ac.uk>, <Annette.Lock@rhul.ac.uk>
Subject: Ref: 2014/001 Ethics Form Approved

Application Details:	View the form click here Revise the form click here
Applicant Name:	**Holly Clisby**
Application title:	**A retrospective study of parents' experiences of having a child bridged to transplant or recovery with a ventricular assist device.**

Appendix 6: Email Approval from RHUL Departmental Ethics Committee (2015 Extension post maternity leave)

2014/001R1 Ethics Form Approved

psychology.it.support@rhul.ac.uk

12/10/2015

nxjt008@rhul.ac.uk; +5 more

Flag for follow up. Start by 29 April 2016. Due by 29 April 2016.

Application Details:	View the form click here Revise the form click here
Applicant Name:	**Holly Clisby**
Application title:	**A retrospective study of parents' experiences of having a child bridged to transplant or recovery with a ventricular assist device.**
Comments:	Approved.

Appendix 7: Participant Information Sheet

ROYAL HOLLOWAY UNIVERSITY OF LONDON

NHS HOSPITAL SITE LOGO

A retrospective study of parents' experiences of having a child bridged to transplant or recovery with a ventricular assist device

INFORMATION SHEET FOR PARENTS OR CARERS OF CHILDREN IN THE BERLIN HEART PROGRAMME

We would like to invite you to take part in a research study. Before you decide if you would like to participate it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish to help you decide if you would like to take part.

Why is the study being done?
The main aim of the study is to help us understand more about the experiences of parents/carers of children who have had a Berlin Heart. This information will be gained through interviewing parents/carers of children who have been supported on a Berlin Heart at X Hospital (X). If we can understand more about parents' experiences during this time we hope that it will help us to provide better care for children and their families.

Why have I been chosen?
We would like to speak to parents/carers of children who have been supported on a Berlin Heart at X Hospital from 2005 onwards and who are currently under follow-up with the Cardiothoracic Team at X Hospital. We hope to interview up to 10 parent/carers in total.

Do I have to take part in the study?
No. Your participation in the study is completely voluntary and it is up to you to decide if you would like to take part. Your decision will not affect the standard of care your child receives from the NHS. If you decide that you would like to take part, you will be asked to sign a consent form to show you have agreed to take part and will be given a copy of this. You can change your mind at any time and stop participating in the study. You do not need to give a reason for this. If you choose not to take part in the study this will not in any way affect the care received by you or your child, now or in the future.

What will I be asked to do?

If you decide to take part, we will ask you to meet with the researcher (Holly Clisby) on one occasion for approximately 90 minutes. This meeting can take place at X Hospital, co-ordinating with your child's outpatient appointment, or at your home if you would prefer, at a time that is convenient for you. The exact length of the interview will vary depending on how much you feel you wish to say.

At the meeting you will be asked to fill out a brief questionnaire asking you to provide some background information, which will include questions such as; your child's educational level, current use of support services, your family composition and your employment status.

An interview will then take place, in which the researcher will ask about your experiences of having a child on a Berlin Heart, the impact on you and your family and what aspects of the Berlin Heart treatment were most important to you/your child. There are no right or wrong answers, and you are free to decline to answer any question. With your permission the interview will be audio recorded so that the researcher can have a record of what you have said.

Expenses and payments

Taking part in this study is voluntary and you will not be paid for your participation.

Are there any disadvantages or risks?

We do not anticipate there to be any risks in taking part in the study, although some people may feel uncomfortable when talking about their experiences. This is an understandable reaction to discussing a personal subject. If you become upset or distressed at any time, you can take a break or end the interview completely. If you feel you need to speak to someone after the meeting, the researcher will refer you to a member of the clinical team who can help you.

What are the possible benefits?

This study will not have any direct benefit for you but by taking part in this research you will be providing valuable information regarding your experiences of being a parent of a child who has been supported by a Berlin Heart. Additionally, you may find it useful to share your experiences. We believe that what we learn from this study will help improve the care of families when children go to hospital in the future.

Will my taking part in the study be kept confidential?

Yes. All information which is collected about you and your child during the course of the research will be kept strictly confidential and known only to the research team.

All data collected during the course of the study will be held in accordance with the Data Protection Act (1998). This means that we keep it safely and cannot reveal it to other people, without your permission. You will not be identified in any report or publication of the results of the research.

Disclosure of information gained from the study will be shared only in exceptional circumstances. If the researcher is concerned about any risk of harm either to yourself or anyone else, then she is legally obliged to share this information with the appropriate people, (a contact person from the clinical team, and your GP). The researcher will always try to discuss these concerns with you first before doing anything.

How long will information be kept?
Information which is collected about you and your child during the course of the research will be kept for 6 to 12 months after the end of the study and will then be destroyed. Interview transcripts will be kept securely at X Hospital for up to 5 years, after which they will also be destroyed.

What will happen to the results of the study?
The results of the study will be written up in a thesis by the researcher (Holly Clisby) as part of a Doctorate in Clinical Psychology. Anonymised quotes from your interview may be used in the final report to help explain the key findings. The research may also be published and shared with professionals at scientific conferences. You will not be identifiable in any of these.

At the end of the study, a summary of the results can be sent to everyone who took part if they wish and we also hope to make a summary of the findings available on the Internet. The results of the study will be reported for the group as a whole and you and your child will not be identified in any report/publication.

Who is organising and funding the research?
The study is part of a larger study that has received funding by the International Society of Heart and Lung Transplantation (ISHLT). The study is being organised by the Cardiothoracic Unit at X Hospital NHS Foundation Trust. The study is being carried out by Holly Clisby who is a Trainee Clinical Psychologist at Royal Holloway, University of London. She will be supervised by Dr X (Health Psychologist) and Dr X (Clinical Psychologist), both at X Hospital, and Dr Michael Evangeli (Clinical Psychologist) at Royal Holloway, University of London.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed by the NRES Committee – London Bridge.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (see contact details below). If you wish to speak with someone independent of the study please contact the Patient Advocate and Liaison Service (PALS), X Hospital, telephone XXXX XXX XXXX extension XXXX for support and advice.

How do I contact members of the research team?
If you would like further information about taking part, please do not hesitate to contact Holly Clisby or X. Contact details are below.

Researcher:

Holly Clisby, Trainee Clinical Psychologist
Department of Clinical Psychology
Royal Holloway, University of London
Egham Hill,
Egham,
Surrey,
TW20 0EX.

Tel: 01784 414012 (Please note: Please state that it is intended for Holly Clisby)

holly.clisby@X.nhs.uk

Dr X (Chief Investigator):

XXXX XXXX XXX

X@X.nhs.uk

If you are interested in taking part:
If you would like to take part, please contact Holly Clisby using the contact details provided above. Alternatively, if you would prefer Holly Clisby to contact you instead, then please complete the participant reply slip overleaf and return it using the prepaid envelope. She will then call you and will answer any further questions that you may have about the study. If you want to participate in the study, Holly will then arrange a convenient time to meet with you and conduct the interview.

Thank you for taking the time to read this.

PARTICIPANT REPLY SLIP

- -

A retrospective study of parents' experiences of having a child bridged to transplant or recovery with a ventricular assist device.

Please tick the box to show your response and give your contact details.

I have read the Participant Information Sheet and I would like to be contacted to arrange a time to meet with Holly Clisby ☐

My name is:_______________________________________

I would like to be contacted by (telephone, email, post?)______________________

My telephone/mobile number is:____

My email address is:____

My address is: ____
____
____

Please return this reply slip in the pre-paid envelope, or alternatively you can contact Holly Clisby on 01784 414012 (Please note: Please state that it is intended for Holly Clisby).

Appendix 8: Consent Form

NHS HOSPITAL SITE LOGO

CONSENT FORM

A retrospective study of parents' experiences of having a child bridged to transplant or recovery with a ventricular assist device.

Name of Chief Investigator: Dr X (Health Psychologist)

Name of Researcher: Holly Clisby (Trainee Clinical Psychologist)

Patient Identification Number for this study:…………………..

Please Initial Box

1. I confirm that I have read and understand the information sheet for the above named study dated 12/03/14 (version 6). I have had an opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw myself from the study at any time, without giving any reason, without my child's medical care or legal rights being affected. ☐

3. I consent to an audio recording of the interview being made and understand that it will be destroyed after the research is complete. ☐

4. I am aware and understand that direct quotations said by me during the interview may be used in the thesis report or subsequent publications or presentation, but that these will be anonymised. ☐

5. I understand that relevant sections of my child's medical notes and data collected during the study may be looked at by responsible individuals from regulatory authorities or from X Hospital, where it is relevant to my child's taking part in this research. I give permission for these individuals to have access to my child's medical and electronic records. ☐

6. I agree to take part in the above study. ☐

7. I would like to receive a brief summary of the research findings following the completion of the study. ☐

____

Name of parent/guardian (Print name)	Date	Signature

____

Name of person taking consent (if different from researcher) (Print name)	Date	Signature

____

Name of Researcher (Print name)	Date	Signature

When completed: 1 for participant; 1 for researcher file; 1 for your child’s medical/electronic records.

Appendix 9: Background Information Questionnaire

A retrospective study of parents' experiences of having a child bridged to transplant or recovery with a ventricular assist device.

Demographic Questionnaire for Parents
To be completed by a parent about themselves and their child

About Me	**About My Partner (if applicable)**
1. Age (please circle one):	***1. Age (please circle one):***
<20 20-25 26-30 31-35 36-40 41-45 46-50 >50	<20 20-25 26-30 31-35 36-40 41-45 46-50 >50
2. Relationship to child	***2. Relationship to child ....***
3. Marital status	***3. Marital status ....***
4. Ethnicity (please tick one):	***4. Ethnicity (please tick one):***
White	**White**
British ☐	British ☐
Irish ☐	Irish ☐
Any other white background	Any other white background ....
Mixed	**Mixed**
White and black Caribbean ☐	White and black Caribbean ☐
White and black African ☐	White and black African ☐
White and Asian ☐	White and Asian ☐
Any other mixed background	Any other mixed background ....
Asian or British Asian	**Asian or British Asian**
Indian ☐	Indian ☐
Pakistani ☐	Pakistani ☐
Bangladeshi ☐	Bangladeshi ☐
Any other Asian background	Any other Asian background ....
Black or black British	**Black or black British**
Caribbean ☐	Caribbean ☐
African ☐	African ☐
Any other black background	Any other black background ....
Chinese ☐	**Chinese** ☐
Any other ethnic group	Any other ethnic group ....
5. Education level (Please circle one): **Primary Secondary / Graduate / Post-graduate**	***5. Education level (Please circle one):*** **Primary Secondary / Graduate / Post-graduate**
6. Occupation: .... Full time Part time	***6. Occupation: ....*** Full time Part time
7. How far from the hospital do you live? **Approximate travelling time: ……………………**	***7. How far from the hospital do you live?*** **Approximate travelling time: ……………………**

About my child...

1. Gender (please circle one) Male Female
2. *Date of birth:* ..../..../.......
3. Position of child in family (please circle one): oldest youngest middle/other only child
5. Attending school? Yes No
6. If yes, what year is your child currently completing: ....

Does your child have any special needs or problems at school? Yes No
If yes, please describe:
....

7. Please describe your child's medical condition
....

8. How old was your child when they were diagnosed?..

9. How often has your child had an overnight stay in hospital?

Never ☐
Once ☐
2-5 times ☐
6-10 times ☐
11-20 times ☐
more than 20 times ☐

10. Does your child have any other health problems? If so, please list them.

…………………………………………………………………………………………………..

……………………………………………………………………………………………………

11. Does your child take any medication regularly? Yes No

If yes, please list the medicines ………………………………………………………………….

…………………………………………………………………………………………………..

About my other children... ☐ No other children

12. How many other children under 18 years are living at home?

How many boys? .... Ages: .... How many girls? .... Ages: ....

13. Do any of your other children have any health problems? Yes No

If yes, please describe………………………………………………………………………

Appendix 10: Interview Schedule and Debrief Guide

Semi-structured interview schedule

Interview Process:-
1) Introductions
2) Interview process and Confidentiality
- Review Information Sheets-Opportunity to ask questions
- Consent Forms x3
-Background Information Questionnaire
3) Warm up questions
4) Interview Schedule
5) Debrief and endings

N.B. Example Experiential Follow-up questions to use throughout interview:-
*Can you tell me a bit more about X
*What did you mean by X
*Can you give me an example of X
*You mentioned X, Y and Z are any of these more salient to you?

* It is anticipated that the schedule would be used in a flexible manner to allow the researcher to be responsive to participants' comments, change the ordering of the questions or follow up novel insights or reflections, in accordance with IPA techniques.
Possible prompt questions are indicated (P)

*****I've got some questions for you, but this is all about your experience… a bit of a one-sided chat. I might ask some questions, which seem silly or obvious, but I need to ask so that I don't assume anything- I hope this will be OK?**

1. **I wonder if we can start off with you telling me a little bit about (insert name of child)?**
   P-Can you tell me about the history of (insert child's name) diagnosis/health experiences that led them to the point of needing mechanical support?

2. **Could you describe in as much detail as possible how the Berlin Heart was first discussed as a possible support option?**
   P-How did you feel/what were your initial reactions?
   P-How did you feel about the risks and benefits?
   P-How did you feel about the potential wait and idea of living in hospital?

3. **Can you tell me about your experience of having a child on the Berlin Heart?**

P-Can you tell me about your experience on the cardiac intensive care unit (CICU) following the insertion of the Berlin Heart?
P-Can you tell me about your experience on Bear/Ladybird Ward when (insert child's name) was on the Berlin Heart?
P-Did (insert child's name) have to move between the two wards during the admission? If so, what was that like?
P-What impact do you feel the Berlin Heart had on your child?
P-What were the challenges on you as a parent when (insert child's name) was on the Berlin Heart?

4. In your own words, what things that made your experience (in either location) better or worse?

P-Staff
P-Ward layout, e.g. bay or cubicle
P-Closeness to family and friends
P-Accommodation
P-Own coping resources
P-Waiting
P-Features of the device itself
P-Worries about infections/bleeding/other risk
P- You mentioned X, Y and Z- are any of these more salient to you?

5. What were your expectations post (insert child's name's) transplant?

6. Can you tell me about your experience when (insert child's name) had the Berlin Heart removed/transplant?

7. What impact, do you feel having a child with a Berlin Heart had on your family?

P-Your adjustment to your child's condition
P-Your quality of life
P-Family dynamics and relationships
P-Practical and social circumstances, e.g. employment
P-Siblings, other close family members

8. What things did you value/were important for you and your child during (insert name of child's) time on the Berlin Heart?

P-What advice would you give to another parent/carer of a child on a Berlin Heart?

***End of Interview Schedule.**

Reflect on the interview and opportunity to ask questions:-
Example questions:

Was the interview OK?
Was there anything that didn't come up, that they were expecting?
Is there anything you would like to add?
What has it been like discussing these issues today?

Do you have any questions you would like to ask me?

Debrief:-

We have now reached the end of the interview. I would like to thank you for taking the time to talk to me. I have very much valued hearing your thoughts and experiences.

If distressed:
-Would they like to talk to a member of the Transplant Team about anything? If you aren't sure now you can always contact her later on.
-Make a referral to Psychosocial Services?
-Reiterate Hospital Site PALS contact details on Information Sheet if required?

Risk disclosed?
-Contact Hospital Site Deputy Social Worker?
-Contact participants G.P?
-Contact Dr X an Dr X to inform and make referral to Psychosocial Services?

Contacting me: Tell the participant that they can contact me by telephone or email (on Information Sheet) if they think of anything they would like to ask me, or if they are worried about anything related to the interview.

Report summary: Ask the participant if they would like to receive a copy of the main findings from the research and indicate on the Consent Form.

Thank you for taking part.

END OF INTERVIEW.

Appendix 11: Example Participant Coding Extract and Emergent Themes for Maria’s Transcript

Emergent Themes	**Transcript 1** **NB- English not first language** P- Participant; *I*- Interviewer	**Exploratory Coding**		
		Descriptive	**Linguistic**	**Conceptual**
	I: And what do you feel some of the challenges were for you as a parent, when Tom was on the Berlin Heart?			
Restriction of movement	P: The Berlin Heart, the movement of the child is restricted. I was doing, I had been taught by the team how to do the change of the dressings.	Restriction of moment on Berlin Heart.	Definitive statement	Confinement and restriction
	I: Ummhumm.			
Threat of Berlin Heart Relentlessly positive- avoiding emotional implications of complications Struggle to accept	P: And that was obviously quite a challenge for Tom, and for us. They try to taught us how to change the dressing and sometimes there were a bit more infected, it was more scary. So that was probably. […] But Tom was urmm, it was just happened one day, a little bit of red, I heard from another parent that this can get infected. Tom had big problems with it. Movement is very restricted, but soo, actually [emphasis] quality of life on Berlin Heart is not so bad. You are in a very bad position already as you are waiting for a transplant, it’s very sad, but your child in the mean time is moveable you can [hesitant] go out. You can talk to them, you can understand them; you can develop them, their personality. They [parents] are sad that is happening, but when they accept the fact that they are in hospital. Tom didn’t know any better. He didn’t know home, he was so little. He was happy. You know, he was sitting, he had bath, he went- of course he was in pain, allot especially with the belly.	Challenges of dressing changes. When dressing site infected, it was more scary. Relatively, QoL on a Berlin Heart is good. Conflicting statements about QoL. Child unaware of home environment. Happy child- developmental milestones in hospital.	‘scary’ ‘big problems’ ‘bad position’ ‘Actually’- trying to convince herself ‘sad’- unusual use of word, given context ‘happy’ vs ‘pain’	Fear of infection Conflicting feelings towards Berlin Heart- keeping alive but restricting Life is still positive- things could be worse- defending child’s quality of life. Balance between pros and cons. Trying to convey a positive picture.
Ignorance of outside world protective for	*I: Umhum.*	Child not knowing		Contradiction- movement is restricted

child, but emphasised difficulty for parents.	P: But he didn't know any better so he was really happy child. It was more for me and [name of husband], because we know what is life outside the hospital.	outside word.		on Berlin Heart, but they are moveable. Child is oblivious, protected
Importance of physical proximity- need to protect.	*I: Of course.*	Living in hospital accommodation.	'Didn't move'- emphasis- conveying the difficulty	Needing to remain close to child.
	P: For us that's the big difference. As I said, I didn't move [emphasised] from hospital, I was living across the street from the hospital.			
	I: Yeah.	Grateful of hospital accommodation.		
Strength of relationship in adversity. Joint focus on child strengthened relationship.	P: And urm, urmm [name of accommodation] was really great and urm I was coming to back and forth living in here. What's hard for parents was a wait for the transplants. And everybody will say to you. And urmmmm we, me and [name of husband], people said that your separate from your partner, like lots of families separate. It make us even closer, it is strange as we were already very close [laugh]. It was very strange we have this thing, we talk about and find the team talk about Toms future, and finding that we can make it bigger and better and stuff and it is working that way. And you know I had the vision of Tom sitting and eating popcorn when we were in hospital and he was tiny tiny tiny. And recently, that happened. Oh wow, I saw that when Tom was very little. Things like that you know.	Hard experience to wait for the transplant. Closeness of the couple relationship. Working though the adversity with husband and team. Strength of relationship Vision of child eating was recently realised.	'everyone will say to you'-its not just us (suggests she's spoken to others) 'strange' I had a vision- a need for hope? Normalising language.	Strength, adversity bringing relationship closer together. Imagined future with child. Portraying positivity of the experience.
Strength and togetherness	*I: Yeah.*	No issues in relationship regarding their child.	Pause for reflection.	
	P: Urm me and [name of husband] are, we have obviously issues, as every married couple have.			
	I: Of course.			

	P: But, we don’t have, when it comes to Tom we are […..] it makes us much more stronger.			

List of Emergent Themes from Maria’s whole Transcript

Superordinate Theme	Emergent Theme	Page (Line number)
Desperate Decision-making	Influence of the team	1(17-19); 3(2-3); 18(13-14)
	Medical improvisation	2(6-8); 2(10-14); 2(16-17); 2(19-21); 6(14-17); 8(7-9); 9(18-21); 10(1-4)
	Between a ‘rock and a hard place’- The only choice	6 (17-19); 3(1-2); 5(26-27)
	Desperation in the face of death	3(5-9); 6(18-20)
	Acceptance of illness	27(9-14); 27(18-19)
Impact of the Berlin Heart	Threat of the Berlin Heart- sitting on a bomb	5(18-20); 9(2-3); 9(6-7); 21(18-23)
	Gratitude toward the Berlin Heart	20(3-5); 28(5-7)
	Living with uncertainty- ‘like a bus stop’	16(10-14); 17(3-7); 17(18-20); 17(23); 26(9-10); 26(12-16)
	Ethical dilemmas	18(2-5)
Coping with Adversity	Mechanisms of support	22(21-23); 23(5-6); 33(1-4); 36(15-20); 39(9)
	Complexities of staff relationships-critical vs. idealising	8(11-13); 8(21-25); 12(16-20); 19(12-15); 28(10-14); 28(27-30); 29(1-7); 29(9-12); 29(18-19); 37(3-5); 38(10-14); 38(16-21); 39(2-5); 40(9-11)
	A special child- strength and resilience	4(9-10); 4 (19-22); 5(1-6); 8(15-18); 19(21-25); 20(17-19)
	Coping through denial, detachment and minimisation	13(9); 13(26-28); 14(1-2)
	Reliance on others	23(13-16); 35(10-14)
	Knowledge as power	6(21-23); 6(25-27); 7(1-3); 12 (13-15); 27(19-23)
	Hope of a different future	7(7-8); 7(9-10); 14(4-5); 15(23-24)
	Protective role of others	34(9-17) 34(19-26)
	Findings positives	22(1-3); 30(15-19); 31(1)
Loss of normality	Life on hold	9(9-12); 31(4-7)
	Changing role of a mother	22(12-13); 24(2-5); 24(7-8); 24 (12-16)

	Restriction	21(14-16); 21(24); 23(17-18); 30(7-10)
	Dilemma of compromised sibling care	23 (23-25); 24(18-19); 24(22-24); 25(5-6); 25(16-17); 26(3-7); 33(5-9)
	Family dynamics and financial implications	31(12-15); 31(19-23); 32(9-11); 36(3-5)

Appendix 12: Extract from Reflective Journal

Interview 2 (15/1/16) Reflections Before the Interview:

This is first interview back following the birth of my son. Recruitment has been difficult following my return and thus I am happy to have an interview scheduled, but also apprehensive that there had been such a long gap since my last interview. I have spent some time reviewing my last interview transcript to try and boost my confidence. This is another interview with a mother and I'm wondering how this interview may be similar and/or different to the first interview. I have tried to schedule this interview with the child's father on several occasions, but have had to be cancelled due to the child being unwell, so have been wondering what the current and on-going impact of the heart transplant is on this family. This is my first home visit interview. I have spent some time considering how the dynamics may be similar and different, the power differential being altered and how I may have to adjust my approach or style being in the participant's home. I was acutely aware of the difference in risk management being away from the NHS site and this has increased my anxiety levels somewhat.

Interview 2 (15/1/16) Reflections After the Interview:

She arrived late to the interview and was visibly flustered by this- I reassured her there was no problem and suggested delaying if this would be more convenient. She noted that her son had just had a "meltdown" at school when she had dropped him off on the school run. I wondered how much this was impacting her thoughts throughout the interview, although she did not seem distracted by this when the interview commenced. She sat across the room from me on a sofa in the family room and appeared to adopt a comfortable position. She reported being very tired as one of her children was not sleeping at night. She spent time looking straight ahead when she was recounting what appeared to be more difficult parts of their experience as though she was trying to disengage, making minimal eye contact during these times. Risks to the child were disclosed during the interview, which was distressing and confirmed my initial apprehension about conducting home visits. I was struck by the on-going difficulties this family were experiencing post-transplant and wondered how this may be impacting her account of their time on the Berlin Heart. The reported risks were managed according to the risk plan as per the procedure in the ethics application and information sheet. She appeared grateful for the offer of support and follow up at the NHS site. Her emotive account and on-going struggle with her son's health, prompted me to reflect on my own child's and families health and my gratitude for this.

I felt that the interview went well and the mother was engaged in the interview and that rich data may have been collected. The mother was able to speak very eloquently and conveyed her emotional experience as well as the factual information with minimal prompting, which felt more natural than previous interviews. The difficulties she and her son continue to experience have highlighted the process of the Berlin Heart and its longitudinal impacts. Not only was this distressing to hear, but it highlighted that I had held assumptions about life after transplant being comparably positive. This emphasised the importance of on-going reflection to increase awareness of assumptions I may not be aware of prior to interviews. The narrative conveyed in her account was different to the previous interview and the pilot. Her account felt honest and raw and I was grateful for the level of emotion she conveyed. I wondered whether being in her own home enabled her to share a seemingly honest and emotional account, unrestricted by the connotations of the hospital and its inherent power imbalance. Given the apparent differences in emotion expressed between interviews, I was curious as to how the next interview would go.

Appendix 13: Summary Table of Themes with Additional Extracts

Subtheme	**Participant**	**Quotation**
Superordinate Theme 1: Loss of Control on Berlin Heart		
Do or Die	Maria	Basically, for me, for us [emphasised] for me and [name of husband]- It was the only way- there was not another way.
	Clare	I think we just had no choice, so. The benefit had to outweigh the potentially really rubbish risks because you know, your working with what you've got and that was all you know. If there was any other way, we'd have done that option.
	Laura	Anyway so we knew the risks and we knew the benefits of it, but at the end of the day the decision was taken out of our hands if we wanted her to live, it was the only option we had.
	Sophie	And I think me, a little bit, when people talk about things like that I just stick my fingers in my ears and go on because, I have no choice.
	Sindy	Not represented.
	Gemma	And then we went um but we weren't expecting for her to go onto the Berlin Heart when it was first mentioned. Umm we tried to stay positive, thinking that we know she'll be ok, but she did then deteriorate and then they said she needed to go down to [name of NHS site] to be fitted with a Berlin Heart and it was her only option really.
	Helen	But with Rosie we really had no option, it's either you let your child die or are you go to try this one and and I think to be honest she went on the Berlin Heart and as soon as she was on that Berlin Heart, she was so tiny and so weak and frail and she couldn't function properly.
	Abshir	Because I suffering very very hard, and I was not sure that maybe she would not live. Because of how she was struggling struggling very hard, that she might die if she did not put this Berlin Heart. So, so I say if if that makes help, then if the Berlin Heart makes help, then why not try.
Conflict of the Berlin Heart- Sitting on a Bomb or a Saviour	Maria	And that's when they started to tell me that it was going to be really hard for us. There are several different chambers, the smallest chamber urmm is really hard to coagulate, to try and find out how the coagulation is going to work. And heparin drug is really hard to see how much they're supposed to put, not damage him.
	Clare	And then urmm it would alarm quite often, and you would hear this really ear piercing

		alarm and people would come running and think oh this feels so flimsy I suppose like what if the battery runs down!
	Laura	I think the stroke in lots of ways was the most terrifying thing in terms of a risk, because you know you worry about losing the kind of person Jessica is, I suppose. So, you know if she has a stroke and she's not recognisable urm in terms of her personality- that Jessica that you know, that is really like scary.
	Sophie	And I thought she so sick at the moment, we can get her on this build her up, and get her better and then she'll be strong for the heart transplant.
	Sindy	And I spoke to his mum and she just said to me she said-yes fine. He is much better than but he was when, you know before the Berlin Heart, he was so so sick um and she said so we did have a tough time in recovery, but at this stage now he's doing really well- he's eating what he wasn't doing before and stuff like. So I come away from there thinking that sounds like OK, that I can almost be there with a bit more positive outlook on it, but at the same time I was still terrified.
	Gemma	I think it just reminded us the Berlin heart was keeping her alive and kicking keeping her going, and also how dangerous it is having like a foreign object attached to your heart and things and how it it just kind of reiterated the dangers of it, that we were told before.
	Helen	You know because that machine there, it's going to save your child's life.
	Abshir	It was very nice she recovered and she changed when she was on Berlin Heart the whole heart job, the Berlin Heart was doing it, and I was happy with it and she was getting better […] and it was just better.
Relinquishing the Parental Role	Maria	She will be living nine month away from me, and she was living at [name of husband's] mum and dads and a nanny who is still with us till today- thank goodness. She is with us from before, as I had to work lots before. Then I stopped when I had Tom. But when I had [name of daughter] I used to travel with [name of daughter] with my nanny because I was travelling and working all over the world. And urm it stopped when I had Tom, because everything stopped.
	Clare	It felt like this thing you were kind of tending to and needed certain things, but in no way did those things related to what you would normally do with your child.
	Laura	Urm and yeah I guess it was kind of quite shocking, but I think at that stage I think we were would just focused on whatever was needed you just had to put our trust in the people there really and the experts.
	Sophie	I remember saying to him like whatever you suggest to me, whatever you think her

		treatment should be, I'm going to go with what you say, because you're the expert not me.
	Sindy	And it was hard because I'm looking at my child lying there in complete like distress and their kind of just taking their time of it, and that would irritate me. So you kind of get a bit irritated with each other as adults, tension would build between you and some of the nurses, you know. Um and yeah it was really you had to really had to work together, but there was hard and it was irritating because sometimes you knew how your child liked it done, and how the dressing is best for them to be put back on and stuff like that and those times were some of them they didn't really listen and they want and they thought they should do it their way and that is really frustrating.
	Gemma	We weren't even allowed to touch her, because her heart rate would go crazy.
	Helen	He washed her, he sponged all her hair, washed her down and he he said, ‘I’ve just freshened her up’, and he was so gentle and I think the first sight of him upset me, because I thought I thought I'm not having him looking after Rosie- he won't know what to do.
	Abshir	They need me, and I need them, so I have to be there with them, so if anything happened to them they can’t without father it will be hard for them. I was trying to stay with them, to go with them.
Like a Bus Stop- The Unpredictability of Waiting	Maria	We waited so long for the heart and then one day, before they told us, there is a possibility that Tom he going to have his own heart works. *I: Yeah.* P: [Laughs] imagine that! That was the one day, and the next day, he got his heart.
	Clare	You know, it’s like buses or something, you wait for ages and then they all come at once. It’s a very strange and surreal situation to be in. It’s not a normal.
	Laura	So you know it is uncertain, you have no idea, but you have no idea how long it's going to last, but I don't know how I felt about- it it's just one of those sort of uncertainty things.
	Sophie	Not represented.
	Sindy	And um just waiting for them because I always said at [name of NHS site], when donors come, the majority of the time they will come in the night, so I was always waiting for that call in the night. So I was always waiting for that call in the night. Which is weird, as I actually got that call in the daytime when it actually finally did come. So I was actually not expecting it when it did come, I was completely taken back. It sounds stupid, because when you prepare yourself for something to happen in the night, so when it happens in the daytime, we don't think it's going to happen to so, when someone comes to you and says we've got a heart for Morgan, it was in the daytime, I wasn't prepared- it's

		so stupid, but yeah.
	Gemma	Yeah, yeah, it’s like a constant overwhelming feeling of I don't know what's going to happen tomorrow, whether I she will get the call tomorrow, or something will happen.
	Helen	But you think she’s stuck here, think she's just she can't go out, but you know you just thinking, hopefully and we used to go home on a night and think maybe tonight, maybe tonight when you get that call.
	Abshir	Um we don't know where they will get the heart, and we were just waiting.
Superordinate Theme 2: Life in the Berlin Heart Bubble		
Restriction and Solitary Confinement	Maria	The Berlin Heart, the movement of the child is restricted.
	Clare	That was one of the things I found hard about it, and I thought Ben would really struggle with, not having that freedom to move around in the same way.
	Laura	It's boredom which in its own way is quite difficult to deal with kids, what to do with an active kid in a restricted space with the restriction on the type of things I can do. Urm and luckily she was still at the age where she had a couple of hours nap in the afternoon, as well. But you know, you long for visitors and then sometimes the visitor thing is taken away from you because because of infection and things like that. And you think oh how are we going to get through the next couple of weeks without having anyone to come [desperate tone] and visit and stuff like that.
	Sophie	Not represented.
	Sindy	Not represented.
	Gemma	I think just a restriction really of what you could do and where we could go out. If you want to go outside you couldn't just take her outside, you had have nurse with you and then you have to backup battery and all these things we have to think about. I think once we got outside for the first time we just thought that was probably we won't get another opportunity like that for a while so we made the most of it, but I think just your isolation really. The constant just being kind of stuck either in the X ward or in the coffee shop, there wasn't really anywhere you could go.
	Helen	But you think she’s stuck here, think she just she can't go out.
	Abshir	And also one thing was the hardest time for me, whenever your child have flu or bugs they isolate you. That isolation was very hard, the other kids that don’t have they go walking and she has to stay there, and that makes it unhappy and demoralised because of how she is.
Dedication and Sacrifice	Maria	She still needed her mum, but I wasn’t able to. Just on the weekends.

	Clare	Not represented.
	Laura	You don't really get any financial support while you child is in hospital, and I think my work and all of that kind of got put on hold.
	Sophie	I was thinking oh my goodness he’s [son] going to be used to be crawling around and learning to walk, and you can't go off that ward. But I didn’t think about it too much, you just think after a while you've got to get on with it so this is what we've got to go and having seen the children. If it's moving towards getting Alice better, then it doesn't really matter, and you feel like that is my life now.
	Sindy	And I think for me and Morgan, we kind of just had as much fun as we could, and we had a lot of fun. Because he was there for seven months in total and it's like when you're there and you don't know how long you going to be there for, you need to just make the most of it ‘…..’.
	Gemma	There’s no real break times, I didn't really leave her, apart from when she was asleep, just sneak off grab sandwich and come back [laugh].
	Helen	It's like this is it, this is the world, this hospital, this Berlin Heart, this whole situation is our life. And it's gone is everything else, because yer just forget.
	Abshir	It was a big thing for me because she's she's not the only child that I have I have another child children. So you have to stick and hold your time and have with her. Yes, so the other children to leave behind. I live in [name of home city], so it was a very very hard time.
Strategies for Coping in Crisis	Maria	I just literally study it. So it was me in hospital and me on computer googling, worst type of parents. We know just a little, little knowledge is a very bad thing [laugh]. We always wanted to know. They told us about Berlin Heart, we Google it. We wanted to know where it come from, how it works. We wanted to know everything.
	Clare	I would try and literally pretend nothing was happening and be like, OK I’m out on my own in [NHS site location], this is great!
	Laura	It was more about focusing on keeping Jessica alive really, until we possibly got an offer. You know the anxiety levels are still so high, yeah so it's the fact that you just don't know, there's always time for an infection or a stroke or something happening that you focus on. You think, I’ve got a dressing change today, and the wait almost sits in the background.
	Sophie	I think I mainly concentrated on the positive side of things, which is unusual for me, because I normally focus on the negative and am pessimistic. But as I said, because she’d been so sick we were just really happy that they were doing something which was

		positive.
	Sindy	So we just had a walk around outside, we had a look round the hospital, we went to a restaurant, we-it sounds really stupid, but we had something to eat, we had a drink
	Gemma	I think we were just numb the whole time, to be honest and just to power through and just pretend that everything was fine, when deep down we knew it's not. But you just want the best for your child and we certainly didn't want her to notice that we were upset or anxious about anything.
	Helen	I just had to take real interest in to how they used to do the dressing and watch how they did it and each time they did it and things.
	Abshir	I'm not sure it was day by day and life change day by day [laughing].
Trauma, Brutality and Imperfection	Maria	Not represented.
	Clare	It just seems in some respects just such a basic and crude set up. It's a really I mean, I couldn't get my head around it that your attached to a filing cabinet sized machine and you can see all this blood and I mean it just seems so …. almost medieval. Do you know what I mean, compared to this amazing slick surgery that you hear of or see that you know with these tiny little scars and you wouldn't know.. this just seems so-in your face, is a really bad term. It's just very obvious.
	Laura	Not represented.
	Sophie	I mean, at the time, she just looked like she had all the life taken out of her. For a child that was normally so chirpy, she just looked so …. deflated which was quite hard to see. But I knew she was on a lot of drugs and her personality was not back because she's on a lot of drugs, and you know she's obviously still slightly sedated.
	Sindy	So for the first time I actually got to see his real body, and it was horrible.
	Gemma	Because she looked like spaghetti junction, there were cables everywhere, she was just totally covered.
	Helen	I'm asking them questions especially thinking, there there's a great big tube in there, quite thick, you think, if you touch it- you think that will hurt [shocked tone].
	Abshir	It was difficult for her because I was changing her dressings. I was changing it every week, cleaning all the dressing I changed I feel very really hard, very hard to accept how she is with this Berlin Heart- the blood goes here and through this one and this one. [emotional] [……]. It comes this demoralising how she is suffering, I feel pain myself when I see her with the tubes and the Berlin Heart.
Burden of Care- Isolated or Shared	Maria	My mum flew in she was with us for four months. So we were basically all living together. In fact four or five months they were living together when Tom was in CICU. They were sharing [name of daughter] with both of the grandparents. My Mum and

		[name of husband’s] mum and [name of husband’s] dad and Adja. So she was really taken care of lots.
	Clare	I think we felt all the way through that we were hugely lucky that we lived just close enough by that we could get there and back in the day, so someone could go home every other night urrm, or you know one of us going home every night, you know alternating it.
	Laura	We did our little rosta. I used to dread Thursdays [laugh], because Thursday was the day I would be on my own, although my Sister and my Dad, my Dad he's like he's nearly 80 now, every single Thursday or every other Thursday if my sister came down, he would get a train down to [name of NHS site] Hospital, to just spend the time with Jessica.
	Sophie	And then he would go into work all day and then he would come back and I would go in intensive care and stay there all day and then he would come back about five. He would come up and relieve me, so I could go for a cup of tea or something and then we go back and have dinner together in the evening.
	Sindy	You know, and don't get me wrong I had a lot of support family and especially friends coming up and seeing me every every other every few days, there be someone coming to visit, so we weren't just left completely on our own. But, we was on our own, because when them people went home, we was on our own, you know. So yeah it was really really hard.
	Gemma	There’s no real break times, I didn't really leave her, apart from when she was asleep just sneak off grab sandwich and come back [laugh].
	Helen	Because it's tough and it’s hard and I was lucky to have [name of husband], because we’re like each other's rock when were feeling down.
	Abshir	But for me it’s harder, my mind is not there, my family not there, so in my mind make it a big thing a big thing for me.
Isolation from Normality- Home Bird to War Zone	Maria	Not represented.
	Clare	I found it weird at the beginning and around five o’clock or kind of five to seven time in the day, where I mean were not particularly routine, but that bit we’ve always been quite routine with we have dinner at a fairly similar time and we will have a bath and pretty much always been in bed by 7 unless something’s going on. So, it’s very weird being in hospital doing none of those things. [….] You weren’t putting anyone to bed, because he was just lying there like he had done for the last 24 hrs, and would do for the next.
	Laura	But you know, you long for visitors and then sometimes the visitor thing is taken away from you because because of infection and things like that. And you think oh how are we going to get through the next couple of weeks without having anyone to come [desperate

		tone] and visit and stuff like that.
	Sophie	And so when we were up there it was like all of my aspects of my normal life has been taken away.
	Sindy	But then when it gets to the second week um for me it just felt like I just missed him. Like my life is just me and him at home. Yeah I just missed him cuz it's just like the other half of me, is here, but he's not here.
	Gemma	But probably just going down into the restaurant and having a coffee together probably took us an hour to get there, but it was just normal, that is that normal and a nice change from where we've been. And then of course you go back and it's reality again.
	Helen	If I had to go there again, I would I want my blanket, so it were like, if it were winter and want my blanket there, just my comfort. You know, if I want to have a cry, I've got something that can remind me of being at home. You need them [crying]. Home comforts you need.
	Abshir	There is no husband wife how they enjoy with the family and how you are happy, there is nothing like that. No any more. Not any more. Even how I used to be, how we used to be and how things were and no [laughs] we don’t see each other even. It’s hard to see each other. There is not emotion there is nothing, just problem problem problem.
Superordinate Theme 3: Transitioning Forward		
Reinstating a Parenting Role	Maria	Then we were worst kind of parents as I said. Ask way to many questions, always waiting, always there always doing everything. I know all the medications exactly you know what. If he didn’t get it I was going to ask why he didn’t get it.
	Clare	So we were having to do, you know, his nappy changes and bed changes and we got really good at learning the nurses technique from rolling from one side because he couldn’t move or do anything.
	Laura	She started to every time she came to sit on my lap, she was afraid that someone’s going to come up with a needle so it was like we said, I think this is something that the nurses have to do while we're out of the room because I don't want her to associate her sitting on my lap with someone coming to stick something into her. So there was some things that we kind of pulled ourselves back from, because I don't, I didn't really see the benefit in doing that, and neither did the nurse is really as well.
	Sophie	And then at the weekends I would go and see [name of son], which was a bit of light relief, but nice to get out, leaving the hospital. But, I hated leaving later because I was worried about what was going to find when I came back.
	Sindy	But when you know when he said, you know I'm sick of the food and whatever, um and

		he stopped eating, I thought well now I think now's the time for me to go into accommodation, just so that I can have a kitchen to cook in to bring food in for him, because I didn't want him to start going down hill.
	Gemma	I just think it's whatever any parent would do, I didn't have a distraction, I just wanted to do everything that I could really. And know that I've done everything, so if I could help her anyway, I just wanted to do that really.'….' Which made me feel good, I was being a good mum, by helping her.
	Helen	But when she wanted her mum, she wanted her mum. But she she was really good and we'd go out and will always try and bring a treat back or buy any DVD or get a get her something, so she would like that of it.
	Abshir	But I was if I was not there I knew she was not feeling well and not feeling it would be much harder for her, so I was there for her.
Integration and Embedding- a Berlin Heart Family	Maria	He's [Dr] my friend, until today we are friends now and he's in Slovakia now, so I call him and he asks me all the questions. To make sure that all the Slovak hospital know him- he's amazing. I will never say anything bad about Dr D, never ever.
	Clare	Urmm, I think they arranged a mini MDT urm on a Friday night when we were on X ward at [name of NHS site] hospital.
	Laura	And um just you know just chatting with the nurses and other families that were around, I think really helps.
	Sophie	And having [name of Psychologist] to talk to, because she was like she's the psychologist for the parents of the children who were on the Berlin Heart and that was very helpful and knowing that she'd seen other people to the same process. And meeting other parents who had been through it, to see the children on the Berlin Heart that was really useful.
	Sindy	There were four kids all with Berlin Hearts and we became a bit of a family. *I: Yeah.* P: We all had our routine, like. *I: Umm.* P: We would all come up in the morning, and everyone would say morning, morning, morning, you know.
	Gemma	There was just three [children] in there, which was small, cosy, and obviously they have to have a nurse per Berlin Heart, well they had a nurse in there looking after all of us. But no, it was nice to be in company of others going through the same thing.
	Helen	Not represented.

	Abshir	The, it it was the friends and family that I was with that makes my life easier. *I: Your own friends and family?* P: No, the friends and family on the ward, those ones make my life easier.
Managing an External Support System- Transference of Distress	Maria	Some of the people who react, how they react. One of my Italian friends she is one of my really good friends- [name of friend], she came in and she saw Tom. She starts to scream and cry and ran out.
	Clare	And some people don't totally get it, I mean I understand that because it's such a weird situation and it's so medically complicated and it's hard to explain to people. And some people would be totally amazing and be really appropriate and sensitive in what they say and urrm. Yeah, so I think you do manage other people's expectations of it, and how you're coping with it and things like that.
	Laura	Say some sort of crisis would happen with Jessica and I'd mention it after the main crisis had dissipated a little bit. And urm, and kind of watered it down a little bit, so they didn't have to deal with it.
	Sophie	As a wider family, because I'm very close with my parents and my auntie, my cousin's. I think, I mean, I never saw anybody else get upset, but then they are all obviously affected very deeply by it because we are so close, and my mum said it was like a double whammy for her.
	Sindy	Even though my family wouldn't let on to me, that it's not nice for them, because they like to be strong for me, I knew that must have been very hard for them.
	Gemma	So I don't think they [child's grandparents] could ever really grasp the concept of what it actually was, really. Because they hadn't seen it. I mean, they may have gone away and Googled it, I don't know. But I certainly know my parents probably wouldn't have done and just because I just think they were scared, and they would rather kind of not imagined it and concentrate on the fact that she's OK and doing well.
	Helen	Lucy [sibling], [hesitant] she was just starting school when Rosie went to [NHS site location], so we decided that she should stay at my mum's and go at school and try and keep her normal. In a normal environment at school. '…..' But I think it's had side effects on Lucy [sibling], emotionally and because she always used to cry when we'd go for check-ups, thinking we're leaving her all time.
	Abshir	Not represented.
Hope of a New and Normal Child	Maria	He survived everything, you throw something at him and he will survive it. He's amazing. He's really amazing. He really had the will to live.
	Clare	I think we were just riding on a wave of he's here, and we've got a second chance and

		that kind of kept us going, I suppose.
	Laura	Urrm, but, I think in terms of what happened and how we felt' it was a huge relief that we had kind of escaped you know scot free, as much as you imagine, from a stroke really.
	Sophie	Yes not seen all these children on the ward looking normal and I thought she so sick at the moment, we can get her on this build her up, and get her better and then she'll be strong for the heart transplant.
	Sindy	It was really really hard to see your child go through that, but you know you just have to try and get through it. And um everyday was just getting stronger and stronger um and until eventually he got to the point where he was doing quite well.
	Gemma	So we kind of thought this is a good thing, she would be off life support and maybe she be able to do things that, still develop as a normal child.
	Helen	We we just, you've got to think Rosie is in a good place at the moment, she's getting better, and she's gaining weight.
	Abshir	Not represented.
Donor Dilemma	Maria	So we were sitting there like what should we do? Should we not take the heart and see if his own heart do fine? It was really hard. Till today, I'm thinking about this. Till today.
	Clare	That we weren't causing them to die, you know. Yeah. But that we were getting something positive from that awfulness, and that they would have requested it, otherwise it couldn't have happened. That helped a bit.
	Sophie	Not represented.
	Sindy	Not represented.
	Laura	What an awful decision for the doctors to make, do you go for a heart that's maybe too far away, but when might the next offer come, because you know it had been five months.
	Gemma	And it was just a mix of a of emotions, you're relieved that…. then you're sad at the same time, you're not sure whether you allowed to be happy because obviously somebody else has gone through hell.
	Helen	The situation was they told us afterwards she was a match, but she was the same at the girl from [name of other hospital] and it was a girl that was on the news, she'd had so many heart attacks or something-she got it.
	Abshir	Not represented.