

## DOCTOR OF PHILOSOPHY

### Parents' experiences of transitioning from hospital to home with their infant, following first stage cardiac surgery for complex congenital heart disease

Gaskin, Kerry

*Award date:*  
2016

*Awarding institution:*  
Coventry University

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**Parents' experiences of  
transitioning from hospital to  
home with their infant, following  
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disease.**

**By  
Kerry Louise Gaskin**

**PhD**

**April 2016**



**Parents' experiences of the  
transition from hospital to home  
with their infant, following first  
stage cardiac surgery for complex  
congenital heart disease.**

By

**Kerry Louise Gaskin**



**A thesis submitted in partial fulfilment of the University's  
requirements for the Doctor of Philosophy (PhD)**

**April 2016**

## NRES Committee West Midlands - Solihull

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06 December 2012

Ms Kerry L. Gaskin  
Faculty of Health & Life Sciences  
Coventry University  
Coventry  
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Dear Ms Gaskin

**Study title:** A Feasibility Study of Parental Home Monitoring and Early Assessment of Infants with Complex Congenital Heart Disease  
**REC reference:** 12/WM/0375  
**IRAS project ID:** 92184

Thank you for your letter of 04 December 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Laura Hewitt, [laura.hewitt1@nhs.net](mailto:laura.hewitt1@nhs.net).

### Confirmation of ethical opinion

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

### Ethical review of research sites

#### NHS sites

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

## Non-NHS sites

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

### Conditions of the favourable opinion

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

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

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

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

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

### Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		18 October 2012
Covering Letter		03 December 2012
Evidence of insurance or indemnity		01 August 2012
Interview Schedules/Topic Guides	Telephone Interview Schedule Group A and B version 1	06 November 2012
Interview Schedules/Topic Guides	Interview Schedule	06 November 2012

	Telephone Interview Group C version 1	
Interview Schedules/Topic Guides	Interview Schedule Pre Discharge Group A and B version 1	06 November 2012
Interview Schedules/Topic Guides	Interview Schedule Pre Discharge Group C version 1	06 November 2012
Investigator CV	Kerry Gaskin	
Investigator CV	David Barron	
Investigator CV	Gill Furze	
Investigator CV	Tim Kilner	
Letter from Sponsor		11 October 2012
Other: Baseline data to be collected	version 1	01 November 2012
Other: Theoretical Approach	1	16 July 2012
Other: Letter from David Barron - Consultant Cardiac Surgeon		29 November 2012
Participant Consent Form	4	03 December 2012
Participant Information Sheet: PIS Staff	3	05 October 2012
Participant Information Sheet: Participant Information Sheet	4	03 December 2012
Participant Information Sheet: Information for GP and other Health Care Professionals	4	03 December 2012
Protocol	4	17 October 2012
Questionnaire: PHQ-9 Depression		
Questionnaire: GAD-7 Anxiety		
Questionnaire: Maternal Confidence Questionnaire		
Questionnaire: Staff Online Survey Schedule/Half Way	1	06 November 2012
Questionnaire: Staff Online Survey Schedule/End of Study	1	06 November 2012
Questionnaire: Staff Online Survey Schedule/Pre Project	1	06 November 2012
REC application	92184/37552 6/1/13	18 October 2012
Response to Request for Further Information		04 December 2012
Sample Diary/Patient Card	Daily Diary Group A version 2	05 October 2012
Sample Diary/Patient Card	Daily Diary Group B version 2	05 October 2012

### 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.

#### **After ethical review**

##### Reporting requirements

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

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

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

##### Feedback

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

Further information is available at National Research Ethics Service website > After Review

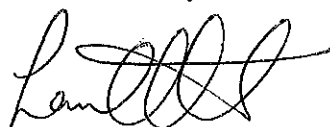
**12/WM/0375**

**Please quote this number on all correspondence**

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/>

With the Committee's best wishes for the success of this project.

Yours sincerely



**Dr Rex J Polson**  
Chair

Email: [nrescommittee.westmidlands-solihull@nhs.net](mailto:nrescommittee.westmidlands-solihull@nhs.net)

Copy to:

*Professor Neil Forbes*  
*Dr Carole Cummins, Birmingham Children's Hospital NHS Foundation Trust*

fp

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Our Ref: KR/SS/R&D Approval

10<sup>th</sup> June 2013

Mr David Barron  
Consultant Lead for Cardiac Services  
Birmingham Childrens Hospital  
Steelhouse Lane  
Birmingham  
B4 7NH

Dear Mr Barron

**Re: Birmingham Children's Hospital NHS Foundation Trust R&D Approval**

**Project Title: A Feasibility Study of Parental Home Monitoring and Early Assessment of Infants with Complex Congenital Heart Disease**  
**REC Ref: 12/WM/0375**  
**IRAS ID: 92184**

Thank you for complying with the Birmingham Children's Hospital NHS Foundation Trust's R&D approval process.

I am now happy to approve the above study, however please note that recruitment cannot commence until Mr Barron and Kim Jones provide copies of their current GCP certificates to the R&D office.

You will note from the Research Ethics Committee (REC) approval letter dated 6 December 2012 that the favourable opinion is subject to obtaining management permission or approval at each host organisation prior to the start of the study. This letter constitutes that approval.

Approval of the study is subject to the following conditions:

1. That you inform the R&D Office and the REC of any significant protocol amendments, sending copies of correspondence with the REC and also sending us copies of your REC annual progress and safety reports
2. That you notify the R&D Office and the Governance Support Unit of any adverse events arising from this piece of research
3. That you provide the R&D Office with interim reports as requested by the R&D Office and a final report of your research
4. That you conduct the research in conformity with the Research Governance Framework and with clinical trials legislation where applicable.

Yours sincerely



Miss Katie Roebuck  
R&D Business Innovations Manager



**Coventry University**  
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Coventry CV1 5FB  
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**Professor Ian M Marshall**  
Pro-Vice-Chancellor (Research)



**TO WHOM IT MAY CONCERN**

RRU/Ethics/Sponsorlet

11 October 2012

Dear Sir/Madam

**Researcher's name: Kerry Gaskin**  
**Project Title: Parental Home Monitoring and Assessment of Infants with Complex CHD**

The above named researcher has successfully completed the Coventry University Ethical Approval process for her project to proceed (ref: 5680).

I should like to confirm that Coventry University is happy to act as the sole sponsor for this researcher and attach details of our Public Liability Insurance documentation.

With kind regards

Yours faithfully

**Professor Ian Marshall**  
**Deputy Vice-Chancellor, Academic**

Enc

**Pro-Vice-Chancellor's Office**  
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<b>Candidates Signature:</b> K. Gaskin	<b>Date:</b> 15/4/16	

## Abstract

**Aim:** To explore parents' experiences of the transition from hospital to home with their infant, following first stage cardiac surgery for a functionally univentricular heart or systemic shunt dependent cardiac lesion.

**Background:** The process of monitoring a fragile infant at home, in between stage 1 and 2 of cardiac surgery, takes the philosophical perspective of holistic care beyond the borders and boundaries normally expected of parents going home for the first time with their new baby. This neo-transition of becoming a medical parent is superimposed upon the multiple transitions already experienced during the birth and whilst in hospital (new baby, new to parenthood, sick baby, cardiac surgery, ongoing and lifelong care needs). The impact of these transitions, on parents' wellbeing and the influence of parents' demographics on their ability to effectively monitor their infant at home, has not previously been studied.

**Methods:** A mixed methods study was conducted in two phases. Phase one was a retrospective survey of 22 families (35% response rate). Phase two prospectively explored parents' experiences using semi-structured interviews and 3 self-report tools to assess anxiety, depression and confidence; with 13 mothers and 4 fathers of 13 infants. The qualitative data was thematically analysed; descriptive analysis of the quantitative data was undertaken using the Statistical Package for the Social Sciences (IBM SPSS Inc.) version 22 for Windows

**Results:** Most parents felt unprepared for their infant's discharge home; numerous physical, emotional and social boundaries and borders were evident during the transition from hospital to home, which impacted upon parents' knowledge and preparedness. Traversing the physical boundary of leaving the hospital for the first time with their infant, was loaded with emotionally traumatic experiences that could not be separated from the specific physical transition of going home. For a while parents were in an uncertain place where they could not visualise what was ahead and how it would feel. This created anxiety and fear, at the same time as excitement to be going home. Liminality as a concept emerged during transition from hospital to home; a crossing point from a comfort zone, safety and security (the ward) into the unknown uncertain place (home). Adjusting to the situation; developing confidence; becoming comfortable with new skills was a threshold concept to mastery of a new normal.

**Conclusion:** Discharge strategies need to be more consistent locally and nationally to ensure that parents are prepared physically, psychologically and socially for discharge home with their infant. Local and community health care professionals need to be better prepared to effectively support these infants and their parents at home.

## Acknowledgements

I dedicate this thesis to my Grandfather Norman Arthur Greenfield, who would have been so proud.

The completion of this thesis would not have been possible without the support and guidance of many people; I am extremely grateful for that ongoing support. Firstly, I thank my children Imogen and Francesca, my partner Pete, my parents Patricia and Philip and other members of my family who have encouraged me tirelessly. Special thanks go to my Uncle Peter who carefully proof read the final draft. I also thank those close friends that have supported me in many ways throughout this journey.

I thank my supervision team Dr Charlotte Hilton, Professor Gill Furze, Dr Martin Bollard and Dr Penney Upton; as well as Dr Tim Kilner and Professor Malcolm Woollard who encouraged me at the beginning of my doctoral journey. I have been intellectually challenged through this iterative process with enthusiasm and dynamism, coaching and guiding me to think and write at doctoral level.

I thank my employers: Coventry University (2005-2013) and the University of Worcester (2013 ongoing) for the valuable periods of study leave; and my colleagues who supported me in my academic role to enable me to reach this stage. I also thank my mentors and peers in clinical practice who over the years shared their wisdom, passion and dedication to congenital cardiac nursing empowering me to have the vision to succeed; but especially to Caroline Hinton, Tracy Freame, Angie Scarisbrick, Di Robertshaw and Rebecca Hill.

Finally, I thank Heart Research UK for funding the feasibility study; the support of NIHR through the Comprehensive Clinical Research Network as the Feasibility Study was adopted to the NIHR Portfolio; Mr David Barron for his clinical research support and encouragement; Lucy Cooper, Mel Rooney and Needa Mohammed for their excellent day to day management of the study as the research nurse team; Suzie Hutchinson at Little Hearts Matter; the External Advisory Group including Dr Jo Wray, Isabel Baumber and Gill Harte and of course all of the families who agreed to take part and shared their journeys with me and the team; without them this study would never have happened. I am indebted to them all.

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# Chapter 1. Introduction and Background to the Study

## 1.1 Introduction

Parenting a fragile infant at home, in between the first and second stage of complex cardiac surgery, takes the philosophical perspective of parenting beyond the borders and boundaries normally expected of parents going home for the first time with their new healthy baby. This neo-transition of becoming a parent of an infant with a chronic condition is superimposed upon the expected transition of having a baby, such as becoming a parent; and the unanticipated transitions experienced during the birth and whilst in hospital, such as having a sick baby requiring cardiac surgery who has ongoing and lifelong care needs (Messias et al 1995; Svavarsdottir and McCubbin 1996). Successful transition requires support (Messias et al 1995; Svavarsdottir and McCubbin 1996; Rempel and Harrison 2007, Rempel, Harrison and Williamson 2009, Rempel et al 2012a, 2012b) and varies depending upon the individual resilience of family members (Patterson 2002) and their adaptation to cumulative, situational and normative stressors and strains (McCubbin and McCubbin (1993) and McCubbin, Thompson and McCubbin 1996).

Family resilience is dynamic and develops with the family as they experience significant sources of stress during the life course (Patterson 2002). Non-normative sources of stress, such as the diagnosis of a congenital heart disease (CHD), push families to the extremes of their family functioning, resulting in either improved or poorer functioning (Patterson 2002). The degree to which a stressor impacts on the stability of the family unit or places considerable demands on the family's resources and capabilities, verifies the severity of the stressor; and the family's integrity and well-being can be threatened over time by the stressor (Patterson 1988, McCubbin and McCubbin 1993). Maladaptation to stressors has been linked to vulnerability; whereas bonadaptation has been linked to resilience (Patterson 2002; McCubbin and Patterson 1983). The processes within which a family functions are what describe the resilience of that family (Patterson 2002). However, the primary factor in resilience is thought to be having caring and supportive relationships within and outside the family (APA 2015). Family relationships that create love and trust and provide role models that offer encouragement and reassurance are believed to help bolster the resilience of individual family members (APA 2015). Furthermore, parental coping, in parents of infants with CHD, has been

positively related to perceived social support, such that those who perceived greater social support were likely to report a higher level of coping. The level of family stress has also been suggested to significantly influence the relationship between perceived social support and coping (Tak and McCubbin 2002).

Psychological functioning plays a part in an individual's ability to adapt and adjust to a crisis, such as having an infant with CHD (Davis et al 1998; Pelchat et al 1999) and individuals respond to trauma using various strategies (APA 2015). Adjustment mechanisms depend on the timing and type of crisis; the stressor or transition; the environment and daily stressors; gender and role; and the type of family and their resilience (Davis et al 1998; Pelchat et al 1999). Factors impacting on a parent's ability to adjust include uncertainty, lack of control and a lack of confidence in their ability to care for their infant. The *uncertainty* surrounding the child's health condition and survival, as well as the relatively little control that parents have over the medical treatment explains the perception of threat, uncontrollability and stressfulness for parents of infants with CHD (Pelchat et al 1999; Rempel et al 2012a; 2012b; Meakins et al 2015). Modes and variations in adaptation and adjustment, in parents of infants with CHD, therefore, need to be considered by Health Care Professionals (HCP) as part of the process of transition (Messias et al 1995; Svavarsdottir and McCubbin 1996) especially the transition from hospital to home for the first time.

Parents' experiences of discharge planning for the transition from hospital to home following their infant's first stage of complex cardiac surgery, and the impact of parents' wellbeing and demographics on their experiences of going home, has not previously been studied.

## 1.2 The aim of the research

The aim of this study was to explore parents' experiences of their transition from hospital to home; when going home with their infant for the first time, following first stage cardiac surgery for complex congenital heart disease (CHD).

The topic was identified in 2010 following informal discussions with the Chief Executive of a national CHD charity, who had been receiving an increasing number of phone calls from parents requiring support after their first discharge from hospital with their fragile

infant. Around the same time discussions with my MSc students, who were experienced clinicians, revealed a lack of evidence to support their academic assignments regarding parental home monitoring for this group of infants. A collaborative venture was subsequently instigated with local and national clinicians, the charity and parents, to consider the feasibility of a research project exploring home monitoring after discharge, within which the topic for this doctoral study emerged. The background to this study is presented through a contextual overview by considering: my professional background; the empirical framework, an overview of CHD and the social, political and historical background. The synthesised review of the literature (Holloway & Walker 2000), is presented in chapter 2, along with the underpinning theoretical approach (section 2.8). The philosophical background is presented in chapter 3.

### 1.3 Background and rationale for undertaking the study

#### 1.3.1 Professional background

To explore the influence of parents' demographics, values and beliefs on their experience of going home, it was necessary to recognise that my position in terms of my beliefs, political stance, cultural background (ethnicity, gender, age, employment, educational background, marital status) and professional experiences could impact on the research process (Thomas 2013).

Prior to the study commencing it was perceived that professional experience and understanding of working with children with CHD and their families would assist in establishing a rapport with the parents. My professional experience of working with these children and families began in 1994, firstly as a paediatric student nurse, where I was to experience caring for the first infant to have surgery for Hypoplastic Left Heart Syndrome in Oxford; and subsequently as a staff nurse, senior staff nurse and nurse practice educator in three specialist children's cardiac units in the UK (Oxford, London and Birmingham). I felt that having insider knowledge through my professional experiences would be beneficial in terms of understanding the language and the nuances of the clinical environment (Maltby et al 2010). However, it was recognised that this professional knowledge and understanding might introduce a certain professional bias to the data collection and subsequent analysis. I also recognised that in my role as a

PhD student and academic I might be perceived as an outsider by the parents, which also could have been either advantageous or disadvantageous. I felt that not being part of the clinical team might encourage some parents to share their experiences more readily, as there was no threat to the care that they were receiving; conversely, I recognised that some parents might be less inclined to talk openly with a stranger.

My position as the researcher was central in the exploration and interpretation of the knowledge that arose from the associations between the people involved in the study (Thomas 2013). Positionality represents a space between objectivity and subjectivity; however, achieving complete objectivity is unattainable, as we are unable to totally separate ourselves from subjectivity and this is what represents positionality (Bourke 2014). The research represented a shared space that was shaped by the parents as participants and by me as the researcher (England 1994). I recognised that my beliefs and values have been created and moulded by my personal and professional experiences of transition.

It was necessary, therefore, to accept my subjectivity and to recognise how this might influence the way I collected data and interpreted the results. There were two ways that this subjectivity could impact on the interpretation: firstly, the way that I as researcher interpreted the experiences of the parents and those of myself; and secondly, the way parents made meaning of their own experiences (Bourke 2014). An additional component was recognising the way in which my voice would be evident within the reporting of the research findings. This would be the way in which I left my own signature on the project; resulting from the use of 'self' or subjectivity. The strength of the dominant qualitative strand of the research process would develop from the relationship between myself as the instrument and the parents as participants (Bourke 2014). I will reflect on the impact of my position as researcher as the study progressed, at the end of this thesis.

### 1.3.2 Overview of Congenital Heart Disease

CHD refers to a range of defects of the heart that are present at birth. CHD has recently been estimated as occurring in about 5.6 per 1,000 births in the UK, which equates to approximately 1 in every 180 babies being born with some form of CHD (Townsend et al 2013). Of the 5,000 babies born with CHD every year in the UK about half of these presentations are major and life-threatening, requiring surgery and life-long follow-up

(CHD Working Group 2008). The success of paediatric cardiology, medical interventions and surgical techniques, along with improved nursing care has resulted in an increase in the survival rate of children and young people (CYP) with CHD over the last 40 to 50 years (DH 2006). The first year of life is a critical time for infants with complex CHD, as around half of all those who died from CHD in 2011, were under the age of one year (Townsend et al, 2013).

Whilst some types of CHD can be repaired either through interventional procedures, where instruments are inserted through the skin to treat structural heart defects, or surgically and therefore considered 'cured', for example Atrial Septal Defect; those with complex CHD will require ongoing surgical 'palliation' into adulthood. 'Palliation' refers to the range of surgical techniques employed, which remain palliative rather than curative for the individual involved.

For the purposes of this study complex CHD refers to functionally univentricular hearts, where there is only one functioning ventricle, and defects that are dependent upon a shunt between the systemic and pulmonary circulations. A functionally univentricular heart condition, for example hypoplastic left or right heart, is one of the most frequently encountered life-threatening cardiac deformities present at birth (Jaquiss and Imamura 2009) and requires several surgical operations over two to three stages. However, whilst advances in medical and surgical care have resulted in improved prognosis, the number of infants with hypoplastic left heart syndrome (HLHS) dying between the first two surgical stages has remained a concern with mortality rates of up to 15% (Barron et al 2009, Checchia et al 2006, Cua et al 2005, Hansen et al 2012, Ghanayem et al 2003, Simsic et al 2005).

Conversely, there appears to be a paucity of research evidence relating to infants with a hypoplastic right heart. However, it has been suggested that death rates between the surgical stages in these infants was roughly two times higher than that of infants with a heart in which the left side has not developed fully (Fenton et al 2004). Multi-centre outcomes of infants palliated with systemic-pulmonary shunts; for example, those with pulmonary atresia, severe tetralogy of Fallot, tricuspid atresia; have also been reported as poor (Bauhofer et al 2001). It could, therefore, be suggested that these infants also need closer monitoring in between surgical stages. Because of the mortality rates between the first and second surgical stage, home monitoring programmes (HMP) have been developed to enable early recognition of deterioration in infants who are at risk of

potentially life threatening events (Ghanayem et al 2003, 2004, 2006; Fenton et al 2004; Steury et al 2010). Yet, whilst these studies have predominantly focused on evaluating HMPs for infants with HLHS, there is a lack of empirical evidence regarding implementation of HMPs for infants with other complex CHD, despite the risk of sudden unexplained cardiac death.

A reduction in inter-stage mortality has been reported following implementation of these HMPs (Ghanayem et al 2003, 2004, 2006); however, these three studies were conducted in a single centre and used historical data as control subjects. Despite the methodological limitations, the innovative intervention and subsequent research influenced the implementation of HMPs in numerous centres worldwide, to reduce mortality for this very fragile group of infants (Fenton et al 2004; Furck et al 2010; Steury et al 2010; Petit et al 2011; Siehr et al 2014). Successful home monitoring necessitates careful management by parents and effective collaboration with HCPs as parents are responsible for measurement and documentation of their infant's oxygen saturations and weight daily. Interestingly, a recent retrospective cohort study using prospectively collected data from the National Pediatric Cardiology Quality Improvement Collaborative (Oster et al 2015) from 2008 to 2012 found no association between oxygen saturation or weight monitoring with mortality or readmission; thus, one could question why we are asking parents to do this.

Research has highlighted that one of the roles of home monitoring is to ensure early detection of clinical deterioration by parents through careful clinical monitoring of these infants at home (Ghanayem et al 2003, 2004, 2006; Fenton et al 2004; Furck et al 2010; Steury et al 2010; Petit et al 2011; Siehr et al 2014). The studies did not consider the responsibility placed on parents at a time of heightened vulnerability. Furthermore, there is no evidence within these historical control HMP studies, that HCPs have considered parents' resilience or psychosocial functioning, or the impact of adopting a medical role at home on the parents, siblings or wider family. At this time, the multiple transitions already being experienced by these families, such as adapting to a new baby, parenthood, a sick baby, cardiac surgery, ongoing and lifelong care needs, are superimposed by the transition of becoming a medical parent at home (Messias et al 1995). Whilst daily monitoring and the intended outcome of reducing morbidity and mortality are important, what has not been considered empirically, is the additional impact on parents' wellbeing and the influence of parents' demographics on their ability to effectively monitor their infant at home.



Effective assessment by parents of their infant, is only achievable if parents fully understand their child's CHD; the signs of deterioration to look out for (Staveski et al 2015); and are adequately prepared prior to discharge for their transition from hospital to home (Jones et al 2009; Titler and Pettit 1995; Weiss et al 2008). Additionally, Kosta et al (2015) have identified a key area of dissatisfaction amongst parents as being the quantity and quality of information. In a study comparing expectations of cardiologists and parents regarding education and counselling (Arya et al 2013), parents consistently ranked topics as more important than cardiologists, further supporting this dissatisfaction. Parents of older children with CHD, would have preferred more counselling and education both prenatally and in the neonatal period than was perceived necessary by cardiologists (Arya et al 2013). Nevertheless, at the time of developing this doctoral study (2011) there was limited published research evidence regarding the effectiveness of discharge education and preparation for parents of infants with complex CHD.

### 1.3.3 Political drivers shaping children's cardiac services

Over the last 20 years the congenital cardiac speciality in the United Kingdom (UK) has been subject to scrutiny through several investigations following failures in the provision of care, which have changed the landscape of care for children and young people with CHD and their families. In 1998 a public inquiry was set up to investigate children's heart surgery at Bristol Royal Infirmary after the death of 29 babies between 1984 and 1995 (DH 2001). The inquiry reviewed fundamental issues of clinical safety, accountability, patients' rights and the professional culture within the hospital during that time; uncovering unsafe practice, secrecy regarding doctors' performance, lack of external monitoring and lack of information for patients and their families. In the report of this public inquiry Sir Ian Kennedy (DH 2001:4) recommended that the government learn from the lessons and make substantial changes within the NHS so that a case as large as this would not happen again. The most important of which for this thesis included:

- Putting patients at the centre of the NHS
- Improving children's health care services
- Setting, inspecting and monitoring standards of care
- Ensuring the safety of care
- Improving the regulation, education and training of health care professionals

- Improving the quality, reliability and range of information which supports decision making
- Involving patients and the public in health care

The government formally responded to the report in 2002 and published recommendations to address concerns (DH 2002). The National Patient Safety Agency was announced in July 2001 to coordinate the reporting of medical errors following a report about patient safety by the Chief Medical Officer (DH 2000; DH 2001a) and just weeks before the Bristol Inquiry Report was released. On the day that the Bristol Inquiry report was published Professor Al Aynsley Green was introduced as the National Director of Children's Services (Butler 2001). So, the immediate impact of the inquiry and the subsequent report was evident in terms of the implementation of national governing bodies that were to provide closer monitoring of clinical practice.

One of the long-term advantages of the healthcare reforms, resulting from the initial Bristol inquiry (DH 2001) has been the availability of performance statistics, not only for professionals to monitor and review but also because these statistics are open to public scrutiny. The National Institute for Cardiovascular Outcomes Research (NICOR) hosts the National Congenital Heart Disease Audit website which gives the 'overall survival percentage chance for common procedures at individual units and for the UK as a whole', as well as how many procedures are being performed at each centre (NICOR 2015). The availability of this information provides openness and transparency and potentially enables informed choice about the centre in which parents wish their infant to be treated. The reforms also impacted positively on the consent process; since 2001 the Department of Health guidance on consent for parents (DH 2001b) has required NHS Trusts to adopt a model consent policy. This has resulted in changes in practice, which ensure that those HCPs responsible for gaining consent now give detailed information about the treatment benefits and risks to parents before a decision is made about their child's treatment. The significance of these changes for this thesis relates to the potential impact on parents' experiences of having an infant with complex CHD in the current era.

In 2002 a paediatric cardiac services review group was set up to advise on the implementation of recommendations in the Kennedy Report (2001) of the Bristol Inquiry, with the aim of highlighting areas for improvement, such as considering the number of operations that should be performed by each centre each year. The group proposed that

surgery should be provided in a limited number of centres and that there was a need for more evidence based practice (DH 2002a). However, despite wider NHS reform, the proposed congenital cardiac service changes were not implemented at that time. The Safe and Sustainable (S & S) Children's Heart Surgery programme commenced in 2006, following a national workshop attended by representatives from professional and patient groups. The work of the S & S Steering Group additionally considered earlier recommendations made by the Paediatric and Congenital Cardiac Services Review (DH 2002a) following the Bristol Inquiry (DH 2001). In 2009, the 'S&S Children's Cardiac Services' national stakeholder engagement event, once again established that the configuration of children's heart surgery services in England were not sustainable (NHS Specialised Commissioning Group (NSCG) 2009: 5). There was concern that some of the smaller centres could not provide the best possible service as they did not see a wide enough range of cases and did not have 24hour cover. Fewer larger centres were expected to guarantee that experienced surgical teams 'used to performing complex operations' were available around the clock to respond to emergencies (NSCG 2010:3). Importantly for this thesis, and parents' experiences, the proposed changes meant that children's heart surgery centres would not be local for all children and families. It was proposed that all children requiring surgery or interventional procedures would be referred to one of the larger Specialist Surgical Centres (SSC); geographically meaning longer journeys for some families. Nonetheless, ongoing management and non-interventional procedures would take place in the Children's Cardiology Centres (CCCs), which may have been nearer home.

In 2011 the Health Impact Assessment (HIA) Steering Group for the S and S review of Children's Cardiac Services was convened and aimed to explore the impact of the proposed changes for everyone concerned, specifically including the impact of reducing the number of centres for children and their families (Mott MacDonald 2012). The HIA identified 'evidence to suggest that the concentration of surgical expertise onto fewer sites and the provision of more secondary services closer to home would be likely to create benefits in terms of better clinical outcomes for all children requiring paediatric cardiac services' (Mott MacDonald 2012:14). However, the review also found that the impact of the proposed changes would be significant for some families and patients (children); the main impact was felt to be the impact on the strong bonds and trusts that children and their families had developed with their specialist teams, and related to the potential change of staff and clinical environment due to relocation. Other potential impacts included: increased journey times and travel costs; distance from home and

impact on availability of local support mechanisms, particularly for vulnerable groups in deprived areas.

At the end of the four-year programme, in July 2012, a joint committee of Primary Care Trusts (JCPCT) proposed a new model of provision for children's heart surgery in England. However, the decision regarding configuration resulted in two separate challenges: a judicial review (JR), and referrals to the Secretary of State, who in turn asked the Independent Reconfiguration Panel (IRP) to consider the JCPCT findings (NHS England 2013:3). Following the outcome of the judicial review, the report by the Independent Reconfiguration Panel (IRP) and the Secretary of State's announcements relating to the safe and sustainable review of children's congenital heart services (NSCG 2011), NHS England became the responsible body for taking forward the process of reviewing congenital cardiac services (NHS England 2013:3). A change to service provision could have impacted on parents in this study had the NHS England review concluded earlier. However, the new CHD standards and service specifications were not published until April 2016 (NHS England, 2016) and, therefore, were too late to impact on the experiences of parents during this study. Nevertheless, the results of phase one of this study informed the development of clinical competencies for nurses (Gaskin et al 2014) and the new standards; specifically, the sections relating to communication with parents and children and discharge planning (NHS England 2016: H19, L13, L14, L15).

The implications of the standards (NHS England 2016) for future CHD nursing practice include the need to be proactive in providing appropriate information and education for parents, this may also require training and education for HCPs. HCPs also need to understand how parents of children with life-long conditions develop expertise and the characteristics of the expert parent, to engage in a more effective partnership and collaboration when making care decisions (Smith, Swallow and Coyne 2015). Parents need to be empowered and educated to participate effectively when taking their infant home for the first time; and some parents may be unable to clearly articulate their support needs due to the stressfulness of their situation. To help facilitate parent-professional collaboration Smith, Swallow and Coyne (2015) have developed a framework for involvement of parents in the care of a child with long-term conditions. This framework includes three domains: valuing parents' knowledge and experiences; supporting parents in their role as care giver and incorporating parents' expertise into clinical and

psychosocial care. However, a limitation of the framework is that it has not yet been evaluated in practice.

More specifically, the implications for children's cardiac nursing in terms of the support that parents require, focuses around the significant supportive role of the cardiac clinical nurse specialist (CCNS, previously known as the cardiac liaison nurse, Gaskin et al 2011). A key element of the CCNS role is to ensure that parents are appropriately prepared and empowered to adjust to the transition that occurs when they are discharged home with their infant (Gaskin et al 2014). Furthermore, discharge planning and advice should involve the multi-professional team (Jones et al 2009:122), additionally, it has been recommended that support and after care should be equally available across the UK for all parents of infants with complex CHD reflecting the NSF (DH 2004) and the principles and values of the NHS constitution (DH 2015). The results of this thesis will contribute to HCPs understanding of parents' needs, thereby informing the future implementation of supportive strategies.

#### 1.4 Chapter summary

This chapter has provided an introduction and background to the study by providing a contextual overview of the professional, empirical, social, political and historical background. The final aspect of the background to the study, as defined by Holloway and Walker (2000), is the critical review of the literature, and the underpinning theoretical approach, presented in chapter 2. Chapter 3 presents the philosophical and methodological approach, study design, and methods for both phases of the study. Chapter 4 presents the results of phase one; chapter 5 presents the results for phase two and chapter 6 presents the discussion arising from both phases. This study is concluded in the chapter 7, including a review of the implications for practice and recommendations for future research.

## Chapter 2. Literature Review

### 2.1 Introduction

Chapter one introduced the topic for this thesis and presented the rationale and background to the study. This chapter outlines the literature search strategy and appraisal methods employed, before presenting a critical review of the literature and synthesis of the findings. The chapter concludes by identifying the research and knowledge gaps arising from the review of contemporary evidence, providing a framework and justification for the research; and the basis for this thesis (Holloway & Walker 2000).

A 'systematised literature review' (Grant & Booth 2009; 102-3) was undertaken, which included a systematic review process. However, the resultant output fell short of a systematic review design, due to the lack of available resources required, such as two reviewers, within a post-graduate study. Undertaking a part-time PhD project over five years, meant that the literature review process needed to demonstrate awareness of the changing context of research in the field during that time and therefore a systematised literature review was undertaken at various time points along the journey.

The main systematised review took place during December 2011- July 2012 to provide a comprehensive review of the subject area including theoretical frameworks, existing research (including PhD theses) and methodologies; new publications and areas for review were identified as the study progressed. The literature was searched and reviewed again post phase two data analysis (July 2015) to consider the contemporary evidence; relevant theory and knowledge within this area of study and to identify key authors within the subject field to explore the relevance to the findings of this study (Holloway and Walker 2000). Final updating of the literature review was undertaken prior to submission of the thesis (November-December 2015) and again at the time of making final corrections following the VIVA (2016).

## 2.2 Research question

A question was developed for the initial literature search, using the mnemonic PICO (Sackett et al 1997) to guide the search:

- **P**opulation – parents of infants with complex CHD
- **I**ntervention – going home after cardiac surgery
- **C**ontrol (or comparison) – being in hospital
- **O**utcome – parents’ experiences, psychosocial functioning, parenting, transition, adaptation, adjustment

The resulting question was:

*‘What are parents’ experiences of going home from hospital for the first time with their infant following first stage surgery for complex congenital heart disease?’*

## 2.3 Literature Search Strategy

A systematic process was utilised to identify evidence from different research paradigms. From this question a range of search terms were identified (see table 2.1) and subsequently used in the searches that were conducted at various times as described above.

**Table 2.1 Search terms**

<ul style="list-style-type: none"> <li>• Congenital Heart Disease</li> <li>• Hypoplastic left heart syndrome</li> <li>• Hypoplastic right heart</li> <li>• Univentricular heart</li> <li>• Cardiac surgery</li> <li>• Parents, mother, father, family, parent experience, parent demographics</li> <li>• Parenting - styles, practices</li> <li>• Transition, adaptation, adjustment</li> <li>• Psychosocial factors</li> <li>• Discharge, home, going home</li> </ul>
--

Boolean operators were used to search the main healthcare databases Academic Search Complete, CINAHL, eBook collection, Medline, PsychArticles, PsycINFO [through EBSCO] and Cochrane database, as well as Google Scholar. The search strategy was originally broad to identify early work and then limited to 2001-2015 (see Table 2.2), the dates reflecting the ten years before this study commenced (2011), up to the year in which this thesis was completed to reflect current contemporary evidence. Papers written in English were sought as the cost and time of translation was prohibitive for a study with limited finances.

**Table 2.2 Inclusion and Exclusion Criteria for HealthCare Databases**

Inclusion	Exclusion
<ul style="list-style-type: none"> <li>- Research papers (including reviews, quantitative, non-experimental, qualitative)</li> <li>- Grey literature such as PhD Theses</li> <li>- English language</li> <li>- Full text</li> <li>- Early work pre 2001</li> <li>- Research 2000 – present</li> <li>- Age range 0-1 years</li> </ul>	<ul style="list-style-type: none"> <li>- Grey literature including conceptual, theoretical; anecdotal or opinion</li> <li>- Papers not written in English</li> <li>- Papers relating to:               <ul style="list-style-type: none"> <li>o Premature babies</li> <li>o Neonatal intensive care</li> <li>o children over 1 year</li> <li>o grandparents</li> <li>o siblings</li> <li>o transition from paediatric to adult services</li> <li>o surgical outcomes</li> <li>o Service improvements</li> <li>o Conditions other than CHD</li> </ul> </li> </ul>

The most successful searches, in terms of number of hits and relevance of papers, being 'Parent demographics and CHD and adaptation'; 'Parents and CHD and adaptation'; 'Parents and CHD and psychosocial factors'. Saturation was reached when the same articles were appearing repeatedly (see tables 2.3 and 2.4). Additionally, the reference lists of identified papers were hand searched. The British Library's electronic theses online service (EThOS) revealed one thesis, however, after review this was deemed not relevant for this review. There were no available resources in the Cochrane database. Personal contacts and attendance at conferences also enabled identification of other national and international research. After identifying and reviewing the abstracts, the full text of the relevant papers was obtained to establish the full methodology of the paper and therefore fully appraise the study being presented. All papers identified as suitable for review were obtained both from Coventry University and University of Worcester subscriptions.



Table 2.3 Search Results Search A

	Search Term	2011 Hits	1 <sup>st</sup> screen	New	2011 - 2014 hits	New	2014 - 2015	New
1	Parent Demographics (And limits Full text; English; 2002-2012)	<b>7100</b> 784			553	0		
2	1 AND Transition (Plus limits)	17			6	0		
3	1 AND CHD (plus limits)	1	1	1	0	0	3	3
4	1 AND 2 AND 3 (plus limits)	0	0		0	0		
5	Transition AND CHD (plus limits)	<b>17</b>	1	1	34	0		
6	Transition AND CHD AND Home (plus limits)	1	0		2	0		
7	Transition AND CHD AND Discharge (plus limits)	1	0		3	0		
8	Transition AND CHD AND Parents (plus limits)	1	0		4	0		
9	Discharge AND CHD AND Parents (plus limits)	<b>5</b>	1	1	7	0	1	1
10	Discharge AND CHD AND Adaptation (plus limits)	1	0		2	0		
11	Adaptation AND CHD (plus limits above)	<b>267</b> <b>42</b>	7	7	77	1		
12	Adaptation AND CHD AND Parents (limits as above) (Full text; English; 1992-2002)	14	6 2	No new 2	17	0		
13	Adaptation AND Discharge AND Parents (plus limits)	<b>5</b>	5	No new	32	0		
14	Adjustment AND CHD AND Parents (plus limits)	0	0		8	0		
15	Psychosocial factors AND CHD AND Parents (no limits) (with limits full text; English; 2002-2012) Google Scholar	<b>81</b> 17	9	6 1	30	1		
16	Parents experiences AND CHD (plus limits)				8	1		
17	Parents experiences AND going home (plus limits)				3	0		
18	Parents experiences AND Transition home AND CHD (plus limits)				3	0		
19	Parents AND HLHS (plus limits)				37	1	2	1
20	Parents AND HRH (plus limits)				0	0		
21	Parents AND univentricular heart (plus limits)				0	0		
22	Parents AND discharge from hospital AND CHD (plus limits)				4	0		
	<b>Total</b>			<b>19</b>		<b>4</b>		<b>5</b>

Table 2.4 Search Results SEARCH B

	Search Term	2011 Hits	1st screen	New	2000-2014 hits	New	2014-2015 (July 2015)	New
1.	Parents  (And limits Full text; English; 2000-2011/14)	<b>602,515</b>  77865			612,954  31,481			
2.	2 AND Transition (Plus limits)	2219			1065			
3.	2 AND CHD (plus limits)	182			95		24	3
4	1 AND 2 AND 3 (plus limits)	5	1	1	2	0		0
5	Transition AND CHD (plus limits)	<b>49</b>	1	0	13	0		0
6	5 AND Home (plus limits)	2	1	0	0	0		0
7	5 AND Discharge (plus limits)	3	1	0	0	0		0
8	3 AND Discharge (plus limits)	<b>6</b>	2	2	4	1		0
9	Discharge AND CHD (plus limits)	<b>180</b>			77		19	1
10	9 AND Adaptation (plus limits)	2	0	0	0	0		
11	Adaptation AND CHD (plus limits)	<b>65</b>	8	8	10	1	6	0
12	11 AND Parents (plus limits)	5	0	0	1	0		
13	Adaptation AND Discharge AND Parents (plus limits)	<b>9</b>	0	0	3	0	3	0
14	Adjustment AND CHD (plus limits)	<b>73</b>			37		18	0
15	14 AND Parents (plus limits)	6	0	0	4	0		
16	3 AND Psychosocial factors (plus limits)	<b>29</b>	12	7	10	2	1	0
17	Parent experience AND CHD (plus limits)	<b>26</b>	6	1	5	1		
18	17 AND Going home (plus limits)	<b>0</b>	0	0	0	0		
19	Parents AND HLHS (plus limits)	<b>28</b>	3	0	5	2	2	1
20	Parents AND HRH (plus limits)	<b>5</b>	1	0	3	0	3	0
21	Parents AND univentricular heart (plus limits)	<b>3</b>	0	0	1	0	0	0
22	Cardiac surgery AND parents (2005-2015, full text, English)						109	0
23	22 AND home (plus limits)						4	0
24	22 AND discharge (plus limits)						3	0
25	CHD AND family AND discharge (plus limits)						16	0
26	CHD AND family AND home (plus limits)						12	0
27	Mother and father AND CHD (2005-2015, English, Full text)						16	0
	<b>TOTALS</b>			<b>19</b>		<b>7</b>		<b>5</b>

## 2.4 Appraisal of the Literature

The literature obtained from the search included qualitative, quantitative and mixed methods study designs; therefore, a systematic method (Hawker et al 2002) was utilised to structure the heterogeneous appraisal of papers.

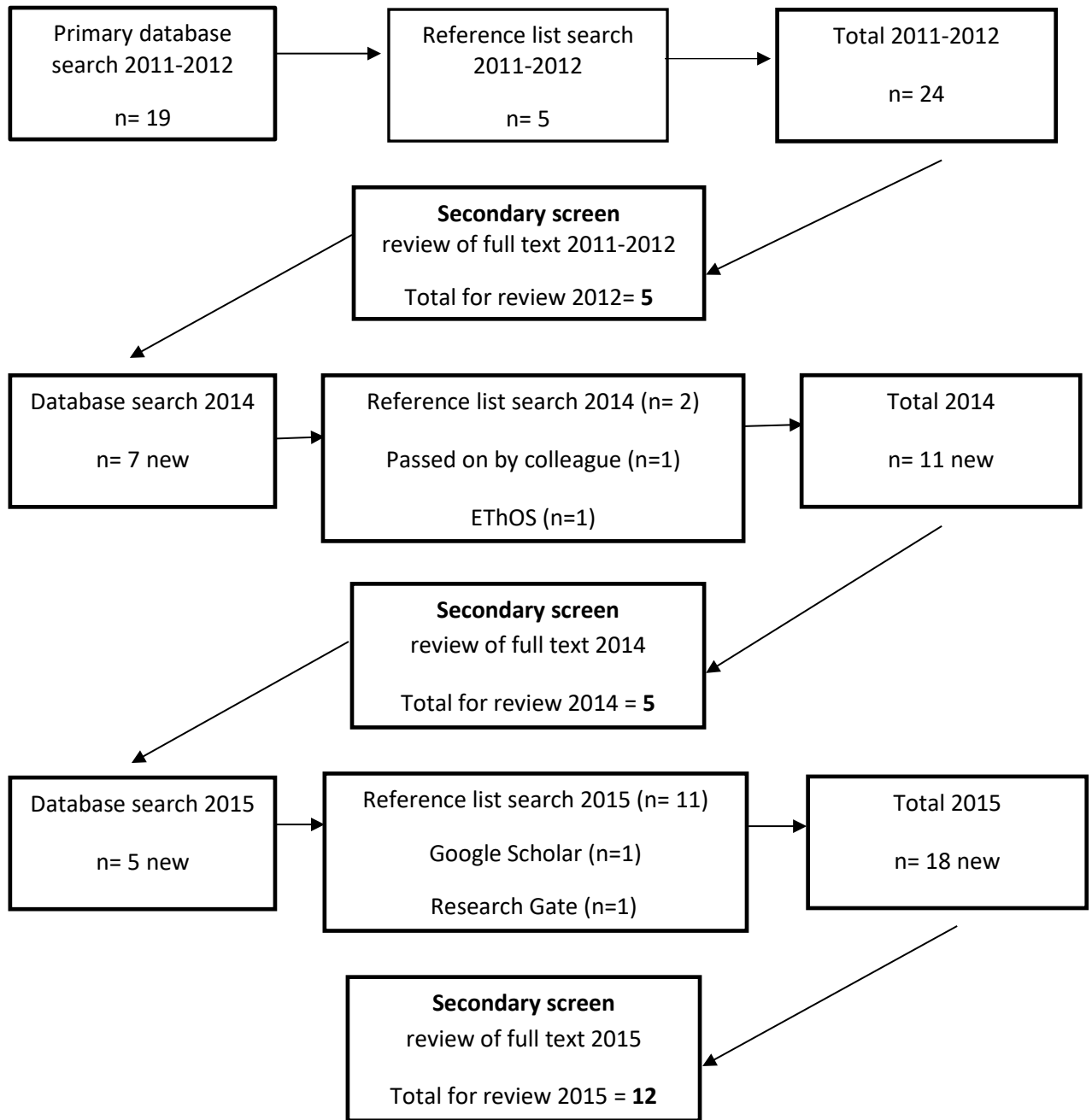
### 2.4.1 Critical Appraisal Stage 1 – assessment of relevance

In the primary search research studies were selected by reading the title and abstract; 53 papers were identified (see figure 2.1). A secondary screen using assessment form 1 (see Appendix 1) identified relevance to the research question; context of the material (age of infants; parents' experiences, type of CHD, discharge home); the source of the data (mothers, fathers) and the type of study. At this stage, each paper was colour coded as green (relevant); amber (partially relevant) or red (reject). Twenty-two papers were accepted and coded as green (n=11) and amber (n=11).

### 2.4.2 Critical Appraisal stage 2 data extraction

Data were extracted from the 22 studies using 'standardised assessment form' (Hawker et al 2002; Appendix 2) that was adapted, to enable specific interpretation of how the papers addressed the research question. I chose to use a traffic light system to code papers as relevant (green); possibly relevant (amber) and not relevant (red). At this stage five studies were coded as red and rejected; the remaining 17 papers were coded as green (n=8) due to the time period that the study explored (up to six-months post discharge) and amber (n=9) because they explored the experiences of parents of infants with HLHS, but the age of some children in the study was over 1 year.

Figure 2.1 Primary and secondary screens



### 2.4.3 Critical appraisal stage 3 – scoring for methodological rigour

The final 17 studies were varied in methodology, therefore, a critical appraisal tool for reviewing disparate data (Hawker et al 2002) was utilised (Appendix 3) that consistently assessed each empirical study, using a detailed protocol. The appraisal tool has nine categories, with scores ranging from good (40), fair (30), poor (20) to very poor (10); the maximum total score achievable is 360 (appendix 4). Scores for the appraised papers were 360 (n=8); 350 (n=6); 340 (n=1); 330 (n=1); 320 (n=1); the lower scores were due to limited information provided in the papers regarding the sampling, ethics and transferability or generalisability sections. One study (Hartmann and Medoff-Cooper 2014) scored 260 and was therefore excluded at this stage due to methodological rigour. Additionally, the focus of this paper related to one element of caregiving (feeding) and was not relevant to the research question. A précis of the final 16 papers is presented in table 2.5.

Table 2.5 Precis of the final 16 papers for review

Authors, Date, Country	Aim	Participants	Methodology, Design, Method	Key Findings	Strengths and limitations
Doherty et al 2009 Belfast, UK	To examine the mental health and coping styles in both mothers and fathers of infants born with severe CHD	70 families	Quantitative questionnaire	Mothers had a significantly elevated level of psychopathology than fathers ( $p=0.001$ ) at mean time of 2.8 months after birth ( $SD = 1.6$ ) 33% mothers and 18% fathers scored at the level of 'clinical caseness'	UK study therefore reflects service provision elsewhere in UK. Discussed cultural intricacies of the sample, including the historically high family support. Does not state whether all mothers and fathers took part. Recruitment methods and participant information inadequately described. Used 7 Self-report tools - potential responder bias relating to recent events. CHD diagnoses of infants were heterogeneous therefore not specific to parents of infants with univentricular hearts. Only 13% of parents had received an antenatal diagnosis, but the time of diagnosis was not entered into regression analysis – recognised as a limitation
McCusker et al 2010 Belfast, UK	To consider the impact of a new programme of early psychosocial interventions on infant development and maternal adjustment	<b>70 families</b> – same sample as Doherty et al	Quantitative Evaluative Design Pre and post intervention Questionnaire	Mothers that had undergone psychosocial interventions demonstrated enhanced positive appraisal strategies and reduced worry and anxiety, compared to mothers in the control group	Same as Doherty et al (2009) Do not disclose whether baseline measurements were before or after surgical or catheter interventions. Parents allocated in a non-randomised manner to the intervention or control; this along with the number of exclusions from the study raised concerns of bias. There was also a significant difference between the age of the infants at baseline.
Fischer et al (2012) Ohio, USA	To evaluate the anxiety level of parents at the time of hospital discharge and to determine if certain characteristics predict higher anxiety levels	24 fathers 35 mothers (of 38 infants)	Quantitative: Prospective cross sectional design Questionnaire	There was a relatively higher percentage of caregivers anxious in the state (here and now) score than in the trait score (how you feel generally)	No information provided about when the study took place or the recruitment timeframe, therefore difficult to ascertain whether the cross-sectional design was appropriate to the timeframe. The authors suggested influencing factors on anxiety scores could have been the relief to be going home and increased understanding of the situation due to education prior to discharge.

Authors, Date, Country	Aim	Participants	Methodology, Design, Method	Key Findings	Strengths and limitations
Brosig et al 2007 Wisconsin USA	To evaluate coping and psychological functioning of parents of children <b>prenatally or postnatally diagnosed</b> with congenital heart disease	10 couples prenatally diagnosed 7 couples postnatally diagnosed	Mixed Methods Quantitative: Questionnaire Qualitative: Semi-structured interviews Longitudinal: baseline (at time of diagnosis) and 6 months post birth	Both groups scored higher than test norms at the time of diagnosis, suggesting that receiving the diagnosis is a critical time for all parents. At six months' post birth the difference in anxiety levels between the two groups approached clinical significance (Postnatal having lower anxiety than prenatal group) In the interviews anger, disbelief, guilt and fear - key themes at diagnosis. Parents in the prenatal group felt they had been able to prepare, whereas those in postnatal group would have liked to know earlier. Emotional status of parents in both groups had improved at 6 months. Parents of infants with complex CHD had found it difficult to adjust and had not expected it to be so hard. Fears were related to impact of CHD on infants' development, on their relationships and on family.	No indication as to when the study took place or the timeframe for recruitment, therefore application of findings to contemporary practice can be questioned. Authors suggest that non-participation may have indicated that those not wanting to take part were in a worse psychological state. Statistical findings should be viewed with caution due to the small sample sizes. Also, parents in the post-natal group had infants with less severe CHD (57% of infants compared to 80% infants in prenatal group). Parents of infants
Rempel & Harrison 2007 Canada	RQ: what is the process of parenting a child with HLHS whose care and treatment includes the Norwood surgical approach?	9 mothers and 7 fathers of 9 infants and preschool children	Qualitative: Grounded Theory Longitudinal	Emerging theme that parenting was extraordinary, conceptualised as a core social process, demonstrated through concurrent safeguarding their child's precarious survival as well as their own and their relationship with their spouse.	Variation in parental and infant demographics including time of diagnosis. Homogenous diagnosis. Age range of child varied between 2-60 months at the time of first interview. Parents interviewed at different stages of surgical journey. 30 interviews over 13 mths, between Nov 2001-Dec 2002 when mortality rates for HLHS were high at this study site (50%) probably relating to the Norwood procedure being new, having only introduced 4 yrs earlier; therefore, this was early research into the experience of parents who had undergone this novel staged repair of HLHS. Applicability to current contemporary experiences may therefore be limited. Clear comprehensive explanation of constructivist approach and recognises researcher's reflexive role; discusses trustworthiness

Authors, Date, Country	Aim	Participants	Methodology, Design, Method	Key Findings	Strengths and limitations
Rempel et al 2009 Canada	<i>How do mothers and fathers manage their worry associated with uncertain outcomes for their child with HLHS who has survived through advanced technology?</i>	with 9 mothers and 7 fathers of infants and preschool children (same as Rempel & Harrison 2007)	Secondary analysis of previous study Qualitative Constructivist Grounded theory	Parents' normalised their child's development, which was not necessarily following a normal path, to balance their anxiety about the uncertainty of their child's future. Suggested that normalisation potentially had a detrimental effect on the child's developmental progress, especially when parents failed to seek appropriate resources to aid this development.	As above – very strong paper. Excellent overview of methodology and analysis. At the time of the study little was known about the long-term outcomes given that the surgery was a relatively new technique. Knowledge was being constructed whilst parents, medical and nursing staff were learning with from and about these children. Therefore, does not necessarily reflect current contemporary practice. Does not focus specifically on the 'going home for the first time' stage, therefore not entirely applicable to this study in this thesis.
Lee & Rempel 2011 Canada	To describe the relationship between the parental process of perceiving their child as vulnerable and normalising their child's outcomes in young children surviving HLHS	16 parents of children aged 0-5 years who have received treatment at stages 1-3 for HLHS	Deductive Secondary analysis of data from Rempel et al 2007, employing sensitising concepts	Normalisation was identified as a parental coping strategy whilst parents balanced their worries about the vulnerability of their children with their admiration of their child's survival	Does not focus specifically on the 'going home for the first time' stage, therefore limits applicability to the study in this thesis. Recommendations for practice were made promoting collaboration with parents to identify strategies that would encourage independence for the children, whilst enhancing the well-being of the parents



Authors, Date, Country	Aim	Participants	Methodology, Design, Method	Key Findings	Strengths and limitations
Rempel et al 2012a Canada	RQ: What is the process of parenting young children with HLHS from the time of diagnosis through the survival of the first 2 surgeries and survival or anticipation of the 3 <sup>rd</sup> surgery	25 parents - 15 mothers, 10 fathers 28 grandparents 17 grandmothers, 11 grandfathers Of children aged under 5 years who have received treatment at stages 1-3 for HLHS	Qualitative Grounded Theory	Developed a theory called 'Parenting under pressure' – four phased process: 1. Realising and adjusting to the unconceivable 2. Growing increasingly attached 3. Watching for and accommodating to the unexpected 4. Encountering new challenges	Does not focus specifically on the 'going home for the first time' stage, therefore limits applicability to the study in this thesis. One family was recruited by one of the participants – raising questions about possible coercion. However, including grandparents was novel. The sample was not as diverse as their previous study, with majority of parents being of Canadian ethnicity, having middle and upper socioeconomic status and being well educated – recognised as a limitation. Participants were only interviewed once, recommendations for longitudinal research with the sample were made. This study included a later surgical cohort, where survival rate at 2 years had improved from 48-77%, attributed to an alteration in the first surgical procedure and possibly introduction of a home monitoring programme. Parents' experiences may have been different due to staff knowledge and skills and the improvement in mortality rates
Rempel & Rogers et al 2012b Canada	To conceptualise the needs of parents of young children with HLHS to provide a theoretical framework to inform development of future parent interventions	25 parents (15 mothers, 10 fathers) 28 grandparents 17 grandmothers 11 grandfathers	Secondary analysis of the 'parenting under pressure data (Rempel et al, 2012a)' Supra analysis and interpretive description Developed model 'facets of parenting'	Developed a conceptual model, five facets of parenting: 1. Survival parenting 2. Hands off parenting 3. Expert parenting 4. Uncertain parenting 5. Supported parenting This was mapped against the 'parenting under pressure' theory to identify guiding principles for developing parenting interventions across the three-staged course of surgery	As above – very strong paper. Excellent overview of methodology and analysis Included children aged under 5 years who had received treatment at stages 1-3 for HLHS; therefore, did not focus specifically on the 'going home for the first time' stage Same four authors as their previous paper, ensuring consistency.

Authors, Date, Country	Aim	Participants	Methodology, Design, Method	Key Findings	Strengths and limitations
Rempel et al 2012c Canada	RQ: what is the process of family management related to the dimensions of the FMSF in families of infants with HLHS who underwent the early era of the Norwood procedure in comparison to parents of children who underwent later era Sano procedure?	9 mothers and 7 fathers of infants and preschool children (Rempel & Harrison 2007) 25 parents (15 mothers, 10 fathers) (Rempel et al 2012a)	Secondary analysis of interviews (Rempel et al, 2007 and 2012a) Thematic content analysis and analytic expansion	Parents demonstrated an intense, dynamic and transforming process of family management throughout their child's journey. Parents whose children were given better survival rates (second surgical era) were more positive in their outlook regarding their child's illness and the family features.	Recognised that two samples had originated from distinct surgical series, where clinical outcomes for the infants differed and hence the treatment options and management strategies also varied. Data source, collection and analysis techniques were explained in detail and the limitations of secondary analysis were clearly recognised.
Meakins et al 2015 Alberta Canada	RQ: is the parenting process among parents of a child with HLHS characterized by exaggerated vigilant parental action, and if so, how does this influence parental response?	9 mothers and 7 fathers of infants and preschool children (Rempel & Harrison 2007) 25 parents (15 mothers, 10 fathers) (Rempel et al 2012a)	Secondary analysis of (Rempel & Harrison, 2007; Rempel et al, 2012a) Thematic content analysis, deductive analysis	Key finding was that 'vigilant parent action' and even 'exaggerated parental vigilant action' was necessary as parents mastered the complex care required by the child; some elements were out of their control, 'out of their hands'. This resulted in parents becoming more vigilant regarding the elements that were 'in their hands'	Analysis conducted by Rempel and Meakin, bringing consistency and credibility to the analysis based on knowledge of the original samples. Two of the other three authors had been involved in the previous grounded theory studies, therefore also enhanced credibility but assisted in monitoring bias alongside the additional experienced researcher. The paper explained rigour, transparency and the possibility of researcher bias well, whilst highlighting recognisable limitations of conducting secondary analysis

Authors, Date, Country	Aim	Participants	Methodology, Design, Method	Key Findings	Strengths and limitations
Pridham et al 2010 Wisconsin USA	To describe the motivations of internal working models (IWM) for parenting in general for a small sample of parents of an infant with a complex CHD through the infant's first year.	Parents of 24 infants with complex CHD – included data from a pilot study of 10 families	Qualitative longitudinal study Semi-structured interviews Video-assisted interview Demographics self-report form Directed content analysis guided by concept of IWM	Eight categories of parenting motivation with four key themes: 1. The infant, including the relationship of the parent and infant 2. The family 3. The parent him or herself 4. Parenting tasks or responsibilities Parenting motivations: <ul style="list-style-type: none"> <li>Supporting: promoting or facilitating the baby developmentally</li> <li>Protecting: guarding the baby's wellbeing or health</li> <li>Relating: interacting or being with the baby</li> <li>Building: Strengthening the family</li> <li>Guarding: protecting self</li> <li>Promoting or facilitating self</li> <li>Forming: promoting a parenting identity</li> <li>Doing: doing the needed</li> </ul>	Comprehensive explanation of the analysis strategy, relevant for the methodology and considered interrater reliability, descriptive validity and interpretive validity. Infants had a variety of complex CHD and therefore were not specifically univentricular hearts. Interview was developed during a pilot with three families to include specific parenting activities. Parents were interviewed in the home at 1-2 months, 4-6 months and 12 months. The data from all families was included in the analyses, however data collected at four months from the pilot families was grouped with the data collected at six months for the families in the final study, assuming similarity in the infants' development at this time.
Dale et al 2011 Norway	Comparison of well-being among mothers of children with CHD with mothers of children without CHD at pregnancy and 6 months' post-partum	Population 61,299 212 mothers of infants with CHD Recruitment 1999-2008	Quantitative Large longitudinal case-cohort design Satisfaction Life Scale (SWLS) Differential Emotions Scale (DES) Questionnaire	Mothers of children with CHD demonstrated the same level of satisfaction with life and feelings of joy as mothers in the control group, both at T1 (30 weeks' gestation) and T2 (six months' posts partum); although this was not significant ( $p=0.085$ ). However, having an infant with CHD significantly affected anger; mothers of infants with severe CHD reported more anger at six months ( $p=0.012$ ), whereas mothers of infants with mild and moderate CHD did not differ from the control group. At 6/12 mothers of infants with severe CHD reported slightly elevated feelings of anger compared with controls ( $p=0.006$ )	It was not explicit until reading the discussion section of this paper that the study was secondary analysis of data that had been collected by different institutions. Further information about the MoBa study was therefore sought (Norwegian Institute of Public Health 2015). Limitations included using self-report tools and the selection bias of the MoBa study which over represents mothers with higher education and positive birth outcomes. As this was secondary analysis of data, clinical assessment of the mothers was not possible. A further issue raised was the relatively low pre-natal detection rates of CHD in Norway and the potential impact of time of diagnosis on the psychological outcomes for mothers in the study; however, the researchers did not have access to time of diagnosis information for the sample.

Authors, Date, Country	Aim	Participants	Methodology, Design, Method	Key Findings	Strengths and limitations
Jordan et al 2014 Australia	Aim: to explore mothers' subjective experience of the mother-infant relationship after discharge from hospital following neonatal cardiac surgery Hypothesis: CHD mother-infant dyads might experience early relationship difficulties	Recruited 97 infants who underwent cardiac surgery under 3 months and their mothers 91/97 were interviewed 78/97 returned questionnaires	Mixed methods: Maternal postnatal attachment scale (MPAS) Edinburgh postnatal depression scale (EPDS) Interviewed 4 weeks after discharge – inductive thematic analysis	Four themes emerged: 1. The emotional tie 2. Bonding difficulties 3. Anxiety and worry about the infant 4. Caregiving behaviours towards the infant  Difficulty bonding was linked to time of diagnosis (prenatal), high EPDS and low MPAS On MPAS 15% of mothers (n=11), had scores lower than 85% of the community sample, which were clinically significant and indicated low attachment feelings. Mothers who described 'bonding difficulties' had lower MPAS scores than those who did not (mean 80.6 (SD10) vs mean 85.7 (SD 5.7), $p=0.0047$ ).	Transparently report findings from the same longitudinal study as Bright et al (2013) in one Australian tertiary centre. Parents recruited between February 2005 and September 2006; the study now being almost ten years old. Parents of 198 infants were identified as eligible, however, some of these infants died or were too sick and therefore 115 remained. 17 families declined to take part and one infant died after the parents had been approached, resulting in 97 families agreeing to participate The interview schedule was transparently reported in each paper as being the same for both mothers and fathers. Both (Bright et al 2013 and Jordan et al 2014) reported a mixed methods approach involving an interview and completion of self-report questionnaires. Bright et al (2013) examined the father-infant relationship whilst Jordan et al (2014) explored mothers' subjective experience of their relationship with their infant. There were more interviews with mothers (n=91), than fathers. Therefore, raising the question as to why the data from both sets of interviews, from within the same study, were not analysed in the same manner. Conversely, as each paper was reported by a different lead author from the same centre; the choice of analysis strategy may have related to individual preference or academic study, although this was not discussed. In this paper (Jordan et al 2014) the number of responses relating to each theme and the percentages were also calculated, however, Cohen's Kappa was not used. This paper generally presented more qualitative results than quantitative, reflecting a dominant qualitative stance and the aim of their study 'to explore mothers' subjective experiences'.

Authors, Date, Country	Aim	Participants	Methodology, Design, Method	Key Findings	Strengths and limitations
Bright et al 2013 Australia	To examine the father –infant relationship in infants with CHD. Reported on attachment relationship with infant within two months of hospital discharge	63/79 fathers completed the interview. 79% were telephone interviews. 19% were jointly conducted with the mother – see Jordan et al 57/79 (72%) completed the questionnaire (mean time after discharge was 58.37 days)	Mixed methods: Paternal Postnatal Attachment Scale (PPAS) Interviews thematic analysis	<p>Eight themes emerged:</p> <ol style="list-style-type: none"> <li>1. Feelings of relationship strength</li> <li>2. Behaviours to promote relationship strength</li> <li>3. Feelings of relationship strain</li> <li>4. Medical condition facilitated the relationship</li> <li>5. Conscientiousness about health and the future</li> <li>6. Desire to maintain normalcy</li> <li>7. Not enough interaction to affect relationship</li> <li>8. Respect and admiration</li> </ol> <p>PPAS scores Fathers reported lower levels of 'affection and pride' (second subscale); with 25% of fathers in the sample having lower scores than 85% of fathers in the community. For the third subscale 'pleasure in interaction with their infant', almost 30% had scores lower than 85% of fathers in the community. There was moderate clinical significance to this.</p>	<p>One of the limitations of interviewing parents together could have been that the responses, or lack of, were influenced by their partner being present, however, this has not been recognised as a limitation by the authors. The joint interviews were not referred to by Jordan et al (2014). Whilst the studies were both reported to be mixed methods, Bright et al (2013) was more dominantly quantitative as despite collecting qualitative data via an interview, the data were quantified. This choice of statistical analysis technique may have related to the number of interviews undertaken with fathers (n=63), although the rationale for choice was not identified. Fathers' responses were coded by one researcher who devised a coding template, which was subsequently used by two researchers to individually code the responses. Mean measures and standard deviations were calculated to test the likelihood of reporting a theme based on timing of diagnosis, type of cardiac condition and type of surgery. This was presented as 'qualitative measurement' but quite clearly the data were quantified, rather than presenting it concurrently as fully mixed synergistic data (Creswell and Plano-Clarke 2011).</p>
Franich-Ray et al 2013 Australia	To investigate the prevalence and nature of trauma symptoms in mothers and fathers of infants who had cardiac surgery	77/97 mothers, 55/79 fathers completed acute stress disorder scale 1 month after discharge	Quantitative Acute Stress Disorder Scale at 1-month post discharge Same sample as Jordan et al and Bright et al (above)	Nearly 1/3 of parents experienced trauma symptoms consistent with a diagnosis of ASD; 1/3 of mothers and almost 1/5 of fathers met the criteria for ASD. Most parents exhibited at least one trauma symptom and approximately 10% experienced one symptom at a clinical level. When reviewing the results of the subthreshold ASD items, dissociation symptoms (feeling numb, distant) were the most commonly exhibited in both parents.	Parents of infants who underwent cardiac surgery before 3 months of age recruited at time of surgery. One of the limitations of the study was that parents whose infants were gravely ill were excluded and therefore they may have missed the parents who were potentially at greatest risk of ASD.

## 2.5 Emerging Themes

Although several international studies had been published relating to the research question, at the time of the original search (2011) there were no studies published from the UK. Therefore, the findings were extrapolated, considering the potential differences in health care systems and population demographics across the world to identify knowledge gaps. Four themes were evident within the studies: parenting experiences, parent-infant attachment; psychosocial functioning of parents and the impact of parental demographics; these themes are considered individually in the next four sections of this chapter. Since the completion of this doctoral study, six papers have been published reporting a mixed methods study also conducted in the UK (Tregay et al 2015a; Tregay et al 2015 b; Crowe et al 2016a; Crowe et al 2016b; Tregay et al 2016; Brown et al 2016), which explored the discharge process following congenital heart surgery; parents' recognition of deterioration and decision making. As they were not included in the initial literature review, these papers will be discussed briefly in section 2.6 and referred to further in the discussion (chapter 6).

### 2.5.1 Parenting experiences

Eight studies explored parents' experiences of caring for infants and children with complex CHD. Seven of these were the result of two grounded studies undertaken by the same team and presented the theories 'parenting under pressure', 'facets of parenting' and the processes of family management (Rempel and Harrison 2007 Rempel, Harrison and Williamson 2009, Rempel et al 2012a, 2012b, 2012c, Lee and Rempel 2011, Meakins et al 2015). The eighth paper focused on parenting motivations (Pridham et al 2010).

The first grounded theory study, reported in two papers (Rempel and Harrison 2007, Rempel et al 2009), was conducted during 2000-2001 at a time when mortality rates for HLHS were high at their study site (50%) probably relating to the Norwood surgical procedure being new, having only been implemented at the centre in Canada four years earlier. Therefore, this was early research into the experiences of parents of children who had undergone a novel staged surgical repair for HLHS. Hence, the results of

Rempel and Harrison (2007) and Rempel et al (2009) may not truly reflect the contemporaneous experiences of parents.

To describe the parenting experience of mothers and fathers whose child with HLHS underwent treatment, that included a series of high risk surgeries starting with the Norwood Surgical procedure soon after birth, Rempel and Harrison (2007) interviewed 16 parents of 9 children. The emerging theme was that *'parenting was extraordinary'*. This *'extraordinary parenting'*, occurred alongside parents safeguarding their child's 'precarious survival' as well as their own and that of their relationship with their spouse. Their children had survived complex surgery in an era where surgical knowledge and skill was advancing rapidly and health care professionals (HCP) were learning alongside the parents. HCPs were unable to provide direction and, therefore, parents developed their own ways of managing the advanced care needs of their children. The extraordinary parenting reflected the extensive assessment and problem solving knowledge that parents utilised to safeguard their child.

In a subsequent paper, Rempel, Harrison and Williamson (2009) discussed the finding that parents *normalised their child's development*, who was not necessarily following a normal path, to balance their anxiety about the uncertainty of their child's future. It was suggested that this normalisation potentially had a detrimental effect on the child's developmental progress, especially when parents failed to seek appropriate resources to aid this development. However, at the time of the study, little was known about the long-term outcomes given that it was a relatively new technique. At that time, there were 32 survivors constituting a survival rate of 60%, from which the sample of parents of 9 children was drawn. Knowledge was being constructed whilst the parents, medical and nursing staff were learning with, from and about these children. Therefore, parents would have had few examples upon which to build their parenting response. Likewise, there was a lack of knowledge regarding why parents behaved as they did, supporting the rationale for the study and providing evidence to inform practitioners about the advice that was necessary.

Secondary analysis of the data from Rempel and Harrison (2007) was undertaken by Lee and Rempel (2011) to further explore concepts that had emerged from the original analysis, specifically around the role of *normalisation* and parental perception of child *vulnerability*. Normalisation was identified as a parental coping strategy whilst parents balanced their worries about the vulnerability of their children with their admiration of their child's survival. Recommendations for nursing practice were made, promoting

collaboration with parents to identify strategies that would encourage independence for the children, whilst enhancing the well-being of the parents.

The outcomes of Rempel and Harrison (2007) and Rempel et al (2009), including the finding that grandparents played an active role in the care of the child, informed the sample for the second study which is reported in two further papers (Rempel et al 2012a, 2012b). The resulting conceptualisation was a four-phased process of parenting young children with HLHS called 'parenting under pressure'. Rempel et al (2012a) explained that these phases overlapped and reoccurred throughout the patient's and parents' journeys from diagnosis, to first surgery, to discharge home, awaiting and experiencing further surgery. They also found that despite times of ease, parents remained uncertain about current and future outcomes.

Secondary analysis of data from the same study (Rempel et al 2012a) was reported by Rempel et al (2012b) and provided a theoretical framework to inform the development of future parent interactions. This framework, which included five facets, was mapped with the theory of '*parenting under pressure*' to provide guiding principles for developing parent interventions longitudinally across the course of the three-staged surgical approach to HLHS. One of the facets '*hands off parenting*' was described as parents feeling left out of their infant's care and that professionals were trying to help parents by disburdening them. It may have been that HCPs were themselves developing knowledge and skills of caring for these highly complex patients at the same time as parents. HCPs may, therefore, have lacked confidence in their own ability; resulting in a reluctance to empower parents to get more involved in their infant's care, because they were not sure of the consequences.

The outcomes of secondary analysis of both the first and second of their studies using the Family Management Style Framework (Knafl et al 1996) as a conceptual basis were presented by Rempel et al (2012c), to offer pathways for nursing interventions based on unique family situations and beliefs. It was also recognised that the two sets of data had originated from distinct surgical series, where clinical outcomes for the infants differed and hence the treatment options and management strategies also varied. Specifically, the researchers aimed to ascertain how family management changed over time from the initial diagnosis through the early period of home care; thereby reflecting the aim of this thesis. The main finding emerging from Rempel et al (2012c:54) was that 'parents demonstrated an intense, dynamic and transforming process of family management' throughout their child's journey. Interestingly parents whose children were given better



survival rates (the second surgical era) were more positive in their outlook regarding their child's illness and the family features. What is evident from the discussion in this paper is how much has been learnt from the two grounded theory studies about supporting these families, as well as from generic improvements in medical, surgical and nursing care of children with HLHS and the shift in beliefs and values over time around long term clinical outcomes.

A deductive secondary analysis of the data originating from Rempel and Harrison (2007) and Rempel et al (2012a) was conducted by Meakins et al (2015); using thematic content analysis to further explore sensitising concepts arising from a review of paediatric chronic illness literature [uncertainty, protectiveness, support and mastery]. The findings further support the work originating from the grounded theory studies, offering additional insight into parents' perceptions of mastery of skills as being '*in their hands*' or '*out of their hands*' (p.36-37). The key finding from this study was that '*vigilant parental action*' and even '*exaggerated parental vigilant action*' was necessary as parents' mastered the complex care required by the child; some elements were out of their control, '*out of their hands*'. This resulted in parents becoming more vigilant regarding the elements that were '*in their hands*', such as monitoring and caring for their child, especially when there was a risk of mortality at home (p. 38-39). Meakins et al (2015:39) summarised these findings as "collective influences that culminate in vigilant parenting and exaggerated vigilant parenting". Understanding parental vigilance behaviour has been identified as underpinning effective interactions between professionals and families (Meakins et al 2015). Moreover, implications for future practice and research were considered comprehensively in relation to their findings.

Likewise, Pridham et al (2010) presented concepts for a theoretical model developed to consider assessment and intervention elements of parental support. Pridham has written extensively about transition and parenting (such as Pridham et al 1991, Pridham and Chang 1992), however, here the authors describe how attachment-caregiving theory underpins the model developed, drawing on three concepts: the behavioural system of caregiving, the internal working model of parenting and motivation. Pridham et al (2010) conducted a qualitative longitudinal study to describe parenting motivations during the first year for a small sample of parents whose infants had complex CHD; including but not restricted to HLHS and tricuspid atresia. The aim was to explore internal working models of parenting to enhance understanding of the complexities and variations of parenting over time and relating to different roles or activities to develop guidance and

support for the future. The overall aim therefore being to develop evidence based theory and interventions to support parents of children with CHD, reflecting that of Rempel and Harrison (2007) and Rempel et al (2012a), although less specific than for parents of infants with HLHS.

Albeit conducted with parents of infants with broader CHD diagnoses, over a shorter period of time and not related to a staged surgical approach for one condition, there is some resemblance here between the parenting activities and the motivations identified by Pridham et al (2010) and those noted by Rempel and Harrison (2007), Rempel, Harrison and Williamson (2009), Rempel et al (2012a, 2012b), such as mastery of skills, vigilance, support, safeguarding survival of the infant, self, couple and family. Pridham et al (2010) also discuss ways in which some parents fostered independence and promoted their infant's development. There are differences in the samples between this study and the work of Rempel and Harrison (2007) and Rempel et al (2012a) and no detail is provided regarding the surgical 'eras' in Pridham et al (2010). However, Rempel et al (2009) made recommendations for nursing practice in terms of the need to promote collaboration with parents to identify strategies that would encourage independence and developmental progress for the children, whilst enhancing the well-being of parents. It would seem therefore that parenting a child with complex CHD poses challenges for parents related to seeking appropriate resources to ensure optimum development and growth. Furthermore, Pridham et al (2010) recognised that the motivational categories were not independent of each other and changed over time, again reflected by Rempel et al (2012a) where the process of 'parenting under pressure' was characterised by four overlapping and re-emerging phases.

The papers explored in this section demonstrated analogous findings within 'parenting infants with CHD':

- Safeguarding, protecting, safety, vigilance, monitoring, survival
- Uncertainty, vulnerability
- Normalisation, normalcy
- Supporting, promoting, facilitating, strengthening, building
- Realising, adjusting, accommodating

This section has considered the impact of having an infant with CHD, who requires neonatal surgery, on parenting. The following section considered papers that reported the impact on parent-infant attachment.

### 2.5.2 Parent-infant attachment

Two papers, Bright et al (2013) and Jordan et al (2014) transparently report findings from the same longitudinal study in one Australian tertiary centre, which examined the impact of infant cardiac surgery on infants' and parental adjustment. Additionally, 'attachment' emerged as a key theme within four other papers (Rempel and Harrison 2007, Rempel et al 2012a, 2012b, 2012c) and was the underpinning theory used by Pridham et al (2010) (table 2.5).

A mixed methods approach was reported by Bright et al (2013); Jordan et al (2014) and Pridham et al (2010) involving interviews, video assisted interviews (Pridham et al 2010) and completion of self-report questionnaires (Bright et al 2013; Jordan et al 2014). Bright et al (2013) examined the father-infant relationship; Jordan et al (2014) explored mothers' subjective experience of their relationship with their infant and Pridham et al (2010) explored internal working models of parenting.

Many fathers were found by Bright et al (2013:597) to '*appreciate their infant more*' because of what their infant had been through and the time they had spent together in hospital. Conversely some fathers were apprehensive to begin with about forming an attachment with their infant and reported '*feelings of relationship strain*', partially clarified by the minimum time '*spent at home*'. Potential impacting factors such as length of hospital stay and the severity of the infant's condition were suggested and further research in this area was recommended. Some of the fathers interviewed reported no impact on their relationship and described wanting to maintain a '*sense of normalcy*' for the family, whilst others reported a sense of '*admiration and respect*' for their infant (Bright et al 2013:596); reflecting two themes identified by Rempel et al (2009) and Lee and Rempel (2011).

In addition to interviewing fathers one month after discharge, Bright et al (2013) asked fathers to complete the Paternal Postnatal Attachment Scale (PPAS) at the same time point. This scale developed by Condon, Corkindale and Boyce (2008) has 19 items and three subscales:

1. The absence of irritability and negative feelings towards the infant (patience and tolerance) ( $\alpha = 0.72$ )
2. Feelings of pleasure, satisfaction and competence in interactions (pleasure in interactions) ( $\alpha = 0.69$ )

### 3. Sense of affection and ownership (affection and pride) ( $\alpha = 0.6$ )

The total score can range from 19 (low or poor quality attachment) to 95 (high or good quality attachment). The alpha coefficient for the sample is presented by the authors for the total score ( $\alpha = 0.91$ ) and each of the sub scores, as above. Generally, coefficients at or above 0.80 are considered sufficiently reliable to decide, based on the observed scores for an individual (Webb, Shavelson and Haertel 2006) and those below 0.7 may be questionable (George and Mallery 2003) therefore the internal consistency is lower for the third subscale, potentially impacting on the reliability of this scale.

Scores obtained for the total and first subscale were comparable to community norms; whereas scores on the other two subsets were significantly lower than community norms. Fathers reported lower levels of 'affection and pride' (second subscale); with 25% of fathers in the sample having lower scores than 85% of fathers in the community. For the third subscale 'pleasure in interaction with their infant', almost 30% had scores lower than 85% of fathers in the community. There was moderate clinical significance to this based on the Cohens *d* effect size (Cohen 1988). Furthermore, Bright et al (2013) explained that fathers with low clinical levels of 'pleasure in interaction' and 'affection and pride', had infants who had spent less time at home before their first hospital admission, potentially impacting on their ability to develop a relationship with their infant before hospitalisation and therefore influencing the results. Interestingly, the results of the PPAS did not necessarily reflect the qualitative findings, however, the authors suggested that this was because the interview measured elements within the father-infant relationship that were not measured by the PPAS, such as those specifically related to the infant's clinical diagnosis of CHD.

In comparison, Jordan et al (2014) thematically analysed the mothers' responses to the same question; using an analytical method widely used in qualitative research (Boyatzis 1998, Roulston 2001). In this paper (Jordan et al 2014) the number of responses relating to each theme and the percentages were also calculated, however, Cohen's Kappa was not used. This paper generally presented more qualitative results than quantitative, reflecting a dominant qualitative stance and the aim of their study 'to explore mothers' subjective experiences'. Eight mothers positively described their relationship with their infant and stated there had been no impact on the relationship. Intensified attachment feelings and receptive caregiving were associated with increased protectiveness in almost half of mothers with 'medically fragile infants' (Jordan et al 2014: 644). Conversely, difficulty bonding was evident for approximately a quarter of mothers and

was linked to time of diagnosis (prenatal), high Edinburgh Postnatal Depression scale (EPDS) scores and low Maternal Postnatal Attachment (MAP) scores.

The Maternal version of the Postnatal Attachment Scale developed by Condon and Corkindale (1998), is also a 19-item scale with scores ranging from 19 to 95. No further information about the tool was provided by the authors, which differed to the detail given by Bright et al (2013) as described above. Jordan et al (2014) reported that the mean score was similar to Australian community norms for mothers of four-month-old infants. However, 15% of mothers ( $n=11$ ), had scores lower than 85% of the community sample, which were clinically significant and indicated low attachment feelings. Furthermore, mothers who described 'bonding difficulties' had lower MPAS scores than those who did not (mean 80.6 (SD10) vs mean 85.7 (SD 5.7),  $p=0.0047$ ).

It was suggested by Jordan et al (2014) that these mothers may have been at higher risk of developing an insecure attachment with their infant. Furthermore, the authors suggested that the link between bonding difficulties and postnatal diagnosis may indicate that adjustment to the situation may not always be facilitated by knowing in advance of the birth and surgery. It was also recognised that the lack of bonding may be a protective mechanism for some mothers, either consciously or subconsciously. This protective mechanism was also identified by Rempel et al (2012a) as an integral element of the 'parenting under pressure' framework; where as parents grew increasingly attached, they balanced the nurturing of their child with protecting themselves, in case their child did not survive. Likewise, Pridham et al (2010) recognised a parenting motivation as guarding and protecting themselves from loss or harm.

There is evidence within the studies, therefore, of attachment between parents and their infants, as well as situations where having an infant with CHD impacts on the relationship such that the parent-infant attachment is insecure and may need professional support. Furthermore, an additional component emerging from the papers was the possible link between attachment and parents' psychosocial functioning. Psychosocial functioning is discussed in the next section.

### 2.5.3 Parental Psychosocial Functioning

Seven of the studies included in this review focused on parental psychological functioning (McCusker et al 2009; Doherty et al 2009; Brosig et al 2007; Dale et al 2012; Fischer et al 2012; Franich-Ray et al 2013; Jordan et al 2014). However, one of the limitations of these studies was that they focused on parents of infants with various types of CHD, rather than specifically a univentricular heart. Moreover, the findings of the studies (see table 2.5) could not be directly compared as data were collected at varying time points in the healthcare journeys of the infants, using different data collection tools.

Two of the European studies (McCusker et al 2009 and Doherty et al 2009) conducted at the same centre in Belfast, Northern Ireland by the same nine professionals. Given that the papers were published in the same year it is likely that the samples include the same patients, however, neither of the papers acknowledge the other. Doherty et al (2009) indicate that infants were recruited over a two-year timeframe whilst McCusker et al (2009) do not clarify the recruitment timeframe. Both report samples of 70 /73 invited families. The relatively small sample sizes (over two years) could reflect the size of the unit and number of patients being diagnosed and admitted with significant CHDs over that time period. Belfast was a comparatively small unit conducting less than 100 surgical procedures and less than 50 interventional procedures each year, whilst the largest units conduct over 300 operations annually; infants with more complex CHD were transferred from Belfast to either Dublin or larger units in England for surgery (Health and Social Care Board 2012). Unfortunately, this centre recently closed to cardiac surgery following review of paediatric cardiac services in Northern Ireland.

The mental health and coping styles of mothers and fathers of infants born with severe CHD were explored by Doherty et al (2009); whilst McCusker et al (2009:110) report on 'the impact of a new programme of early psychological interventions on infant development and maternal adjustment'. Therefore, the data collected and analysed in Doherty et al (2009) could have informed the development of the CHD Intervention Programme [CHIP] programme analysed by McCusker et al (2009). There is no mention of fathers' adjustment in the abstract or the study aims (McCusker et al 2009), yet data were also collected from 56 fathers. If the samples were the same, it is important to ascertain at what point the data were collected by Doherty et al (2009) in relation to the implementation of the CHD Intervention Programme (CHIP) by McCusker et al (2009). Doherty et al (2009) report that the inventories (detailed above), and the cardiac

symptoms checklist and parental demographics survey questionnaire used in their study were completed at a mean time of 2.8 months (SD= 1.6) following the infants' birth. Whilst McCusker et al (2009) took baseline information about maternal coping and adjustment (including the Spielberger's State-Trait Anxiety Inventory as well as the two tools used by Doherty et al 2009) before the intervention programme commenced and again at a 6 month follow up.

Only one of the seven studies measured anxiety prior to discharge in parents of neonates admitted with CHD, eight of whom had a single ventricle physiology and six of whom had been home before initial hospitalisation (Fischer et al 2012). This was a prospective cross sectional study and conducted in a tertiary paediatric hospital in Columbus Ohio USA. This study evaluated parental anxiety levels, using the Spielberger State-Trait Anxiety Scale (Spielberger et al 1983 cited in McCusker et al 2009:113) at the time of hospital discharge. It also aimed to determine whether certain characteristics predicted higher anxiety levels. No information was provided about when the study took place or the recruitment timeframe; therefore, it is difficult to ascertain whether the cross-sectional design was suitable or whether the sample was appropriate to the timeframe. Sample size calculations were made for categorical variables.

Caregivers were approached within 48hrs prior to discharge home and asked to complete a parental demographic questionnaire as well as the Spielberger State-Trait Anxiety Inventory (STAI). This tool differentiates between 'state anxiety' [which is classed as a transitory state experienced in specific situations] and 'trait anxiety' [a general tendency to perceive situations as threatening]. The *state-anxiety* scale evaluates how individuals feel 'right now/at this moment' measuring feelings of apprehension, tension, nervousness, and worry. The scores from this scale are likely to increase in situations of physical danger and psychological stress. The *trait anxiety* scale on the other hand measures how people feel 'generally' and will demonstrate high scores in individuals that are depressed or psychoneurotic (Spielberger, 2012). Fischer et al (2012) reference another CHD study (Jantien Vrijmoet-Wiersma et al 2009), in their explanation of which tool is being used and why, rather than referencing Spielberger et al (1983 cited in McCusker et al 2009:113), which suggests that they may not have accessed the original source of the tool.

Mothers and fathers completed the forms individually and a good response rate of 87% was achieved. 59 questionnaires were completed for 38 neonates (68 caregivers had

been approached); 24 questionnaires were completed by fathers and 35 by mothers. The results of the Spielberger State-Trait Anxiety Scale revealed a standard *state-anxiety* score of 54 (s.d. +/- 11); however, no comparisons are made with population norms for these scores, despite these being available for a variety of ethnic groups (Knight, Waal-Manning, Spears 1983). Any score two standard deviations above the norm was considered significant anxiety and one standard deviation above was borderline anxiety. 5% of the caregivers taking part reported significant levels of state-anxiety, 14% borderline state-anxiety and 81% denying state-anxiety. The standard trait-anxiety score was 48 (s.d. +/- 10), 5% of the caregivers taking part reported clinically significant levels of trait-anxiety, 2% reporting borderline trait-anxiety and 93% denying trait-anxiety. Again, no comparisons are made with population norms, making validity difficult to assess. The study found that most caregivers reported not being anxious before being discharged home, however, there was a relatively higher percentage of caregivers anxious in the state score than the trait score.

The authors recognised other factors such as relief to be going home and increased understanding of the situation due to education prior to discharge. However, there were a higher percentage of carers that demonstrated anxiety on the state (the here and now) score than the general trait score. This perhaps reflects the specifics of the situation or possibly as suggested by Fischer et al (2012) related to having a newborn baby. However, comparisons would need to be made with research of mothers of well babies being discharged from hospital for the first time. Unfortunately, not being a longitudinal study meant that changes in anxiety over time were not measured, unlike Brosig et al (2007) and McCusker et al (2009) who measured anxiety at baseline and again six months later.

Two papers (Jordan et al 2014 and Franich-Ray et al 2013), considered different elements of psychosocial functioning one month after the infants' discharge. Jordan et al (2014) reported on mothers' subjective experience of the mother-infant relationship, through an interview, the Maternal Postnatal Attachment Scale (MPAS) (see section 2.4.2) and the Edinburgh Postnatal Depression Scale (EPDS).

The EPDS (Cox, Holden and Sagovsky 1987 cited in Jordan et al 2014:642) is a 10-item screening tool for postnatal depression, over the last seven days; scores range from 0-30 and higher scores indicate more severe levels of depression. Community norms of a score more than or equal to 10 have been used to identify possible depression (Boyce, Stubbs and Todd 1993, Hiscock and Wake 2001 both cited in Jordan et al 2014:642). As



discussed in section 2.4.2 above, Jordan et al (2014) found that almost a quarter of mothers interviewed indicated difficulty bonding with their infant; this 'bonding difficulty' was associated with a prenatal diagnosis (OR 2.695% CI 0.89 to 8.9), and with high EPDS scores (mean 9.1 (SD 5.3) vs mean 6.2 (SD 3.9),  $p = 0.01$ ). Maternal depression was also associated with low MPAS scores ( $p=0.0001$ ). However, the authors recognise that caution needs to be taken when interpreting the results because of the wide confidence intervals (CI) present for the associations between prenatal diagnosis and the EPDS cut off scores and 'bonding difficulties'.

The prevalence of acute stress disorder (ASD), subthreshold ASD and types of trauma symptoms experienced by both mothers and fathers was investigated by Franich-Ray et al (2013) through completion of the Acute Stress Disorder Scale (ASDS). This tool was developed by Bryant, Moulds and Guthrie (2000) to measure responses during the acute phase of a traumatic experience. It is a 19 item self-report measure of ASD according to the American Psychiatric Association (2000) criteria (cited in Franich-Ray et al 2013: 495). Four clusters of symptoms are assessed: dissociation, re-experiencing, avoidance and arousal.

Parents in this study were asked to complete the tool based on how they had been feeling since their infant's surgery. Franich-Ray et al (2013) found that nearly a third of parents experienced trauma symptoms consistent with a diagnosis of ASD; one third of mothers and almost one fifth of fathers met the criteria for ASD; however, they found that it was uncommon for both parents within a couple to meet the ASD criteria. Furthermore, most parents exhibited at least one trauma symptom and approximately 10% experienced one symptom at a clinical level. The authors recognise that one of the limitations of their study was that they excluded parents whose infants were gravely ill and therefore they may have missed the parents who were potentially at greatest risk of ASD.

When reviewing the results of the subthreshold ASD items, dissociation symptoms (feeling numb, distant) were the most commonly exhibited in both parents. Franich-Ray et al (2013) note the significance of this finding given that another study (Hall et al 2006), albeit with parents of infants hospitalised with burns, identified parent dissociation symptoms as being predictive of future post-traumatic stress disorder (PTSD). Furthermore, Franich-Ray et al (2013) suggest that trauma symptoms may impact upon the parent's ability to understand medical information, which is significant in a situation where clinical decisions need to be made about care or where parents need to adopt a medical role on top of their parenting role, such as going home with monitoring

equipment. Additionally, these dissociative symptoms may prevent the parent from being available for their infant, or indeed other siblings, which could impact on the subsequent attachment relationship.

One study examined anxiety at approximately three months after birth (Doherty et al 2009). Doherty et al (2009) recruited 70 (96%) of the 73 families that were invited to participate. The parents of all infants born with significant CHD which required invasive interventions were invited to participate; however, those parents where the child's condition was so severe that they were unlikely to survive were excluded (n=6). Whilst it was recognised that the infants' diagnoses were heterogeneous, all fell within the definition of 'severe' CHD; 31% (n=25) of the infants had more complex CHD. Data were collected at a mean time of 2.8 months (s.d. = 1.6) after the birth of the infants. 13% of cases had an antenatal diagnosis however, prenatal and postnatal diagnosis was not entered into their regression analyses and is recognised as a limitation of the study.

Parental psychosocial functioning was explored using the Brief Symptom Inventory (BSI) (also used by Brosig et al 2007) and comparisons made between mothers and fathers. As the data, did not meet parametric assumptions the non-parametric Mann-Whitney test was used to compare between mothers and fathers, this showed that mothers had a significantly elevated level ( $p=0.001$ ) of psychopathology than fathers. Additionally, 33% of mothers and 18% of fathers scored at the level of 'clinical caseness' on the BSI. The authors recognise the limitations of using a self-report tool in that the results may be biased by recent events. They also referred to the regional population within which the research was undertaken and therefore the cultural intricacies of the sample. Specifically, they indicated that the population is one whereby family support historically tends to be high and therefore this may impact on the results.

Three studies explored psychosocial functioning at the six-month time point. Two studies examined parental anxiety at six months after birth: Brosig et al (2007) included both mothers and fathers whilst McCusker et al (2009), only studied mothers. In comparison one study (Dale et al 2012) considered maternal wellbeing, rather than anxiety, six-months after birth.

A mixed method study was undertaken by Brosig et al (2007) incorporating semi-structured interviews and the Brief Symptom Inventory (BSI), which is a brief psychological self-report scale (Derogatis 1993 cited in Brosig et al 2007: 689) at diagnosis, birth and six months later. The BSI is a 53-item self-report symptom inventory,

originally designed to assess the psychological symptom status of psychiatric and medical patients, as well as individuals who are not patients. Each item of the BSI is rated on a five-point scale of distress (0-4), ranging from 'not-at-all' to 'extremely' and relates to nine symptom dimensions: somatisation; obsessive-compulsive; interpersonal sensitivity; depression; anxiety; hostility; phobic anxiety; paranoid ideation and psychoticism. The BSI also includes a global index of distress called the Global Severity Index (GSI). This is considered the most sensitive indicator of the individual's distress level (Brosig et al 2007:688). These nine dimensions provide a profile of the patient's psychological status in psychopathological terms; communicating information regarding the 'nature and intensity of the patient's distress', and providing data relating 'to the pattern of the patient's symptomatology' (Derogatis and Melisarato 1983:596-7). The study was undertaken in Wisconsin, USA and aimed to evaluate coping and psychological functioning of parents of infants prenatally or postnatally diagnosed with CHD.

The aim was to recruit 10 couples in each group (prenatal and postnatal diagnosis) (Brosig et al 2007). The response rates differed dramatically between the two groups; 11 families prenatally diagnosed were approached within one week of diagnosis, 10 agreed to participate (91% response rate), 16 couples postnatally diagnosed were also approached within one week of diagnosis, only seven agreed to participate (44% response rate). Therefore, the goal of 10 couples per group was not achieved, the limitations of the study are addressed and potential reasons for this are considered. Whilst the study was published in 2007, there is no indication as to when the study actually took place or recruitment timeframe. Prenatal screening and information provision may have changed over the last 5-10 years and may also be different in the UK due to variance in health care provision, therefore application of the findings to a UK population may not be entirely appropriate.

It was hypothesised by Brosig et al (2007) that parents would have similar amounts of distress at the time of diagnosis but that those who had a prenatal diagnosis would experience less stress than those parents that received a post-natal diagnosis at the time of their infant's birth. They also hypothesised that both groups of parents would report lower levels of anxiety six months later. Whilst some comparisons were made between the results from the two groups of parents it was recognised that the parents in the post-natal group had infants with less severe heart defects (57% in the post-natal group compared to 80% in the prenatal group). Additionally, there was only a 44% response

rate in the postnatal group compared to a 91% response rate in the prenatal group. The most common rationale for not participating being that they were 'too overwhelmed' with what had happened to take part. In the discussion Brosig et al (2007:691) recognise that non-participation may have indicated that those parents not wishing to take part may have been in 'a worse psychological state' than parents of infants with equivalent diagnoses in the prenatal group, indicating important implications for practice.

In comparison, both groups of parents scored higher on the BSI than test norms at the time of diagnosis, but there was no significant difference between the groups on Brief Symptom Inventory (BSI) scores (small effect size  $d = 0.26$ ), suggesting that receiving the diagnosis is a critical time for all parents. Furthermore, the data were also analysed to ascertain clinical significance of the BSI scores for the individual participants. A BSI was considered clinically significant if the Global Severity Index (GSI)  $T$  score is  $>63$ , or if the  $T$  scores of two dimensions are  $>63$ . By considering the data in this way, it was identified that 58% of parents ( $n=11$ ) in the prenatal group had clinically significant ( $p=0.0001$ , medium effect size  $d=0.51$ ) BSI scores at the point of diagnosis, as did 71% of parents ( $n=10$ ) in the postnatal group ( $p=0.0001$ , medium effect size  $d=0.65$  and therefore a slightly more important correlation than the prenatal group). There was no clinical significance between groups for this finding.

In the semi-structured interviews Brosig et al (2007) identified the emergence of analogous themes in both groups, such as anger, disbelief, guilt and fear at the point of diagnosis. The prenatal parents reflected on the fear that remained with them throughout the pregnancy but also indicated that although it was stressful to find out about the diagnosis before birth they reported cherishing the pregnancy. Parents in the prenatal group felt able to prepare themselves, whereas some in the postnatal group wished they had known earlier about the diagnosis.

At the time of birth, Brosig et al (2007) found that 75% of parents ( $n=12$ ) in the prenatal group had BSI scores in the clinically significant range ( $p=0.001$ , medium effect size  $d = 0.48$ ), indicating that at birth (rather than at diagnosis) the number of parents that had BSI scores in the clinically significant range was almost the same as the post-natal group (71%,  $n=10$ ). However, the effect size was greater ( $d = 0.65$ ) for the postnatal group indicating a stronger correlation between BSI score and anxiety at birth (or at diagnosis in this group).

Parents' anxiety levels were measured again six months after birth (Brosig et al 2007), at this stage the difference between the two groups approached clinical significance ( $\chi^2(1) = 3.226, p = 0.072$ ). Only one parent (10%) in the post-natal group had a BSI score in the clinically significant range (small effect size  $d = 0.12, p = 0.354$ ) compared to 45% ( $n = 5$ ) parents (medium effect size  $d = 0.44, p = 0.006$ ) in the prenatal group. However, these statistics need to be viewed with caution due to the small sample sizes. In addition, the parents in the post-natal group had infants with less severe heart defects (57% of infants in the post-natal group compared to 80% in the prenatal group) potentially reflecting the results obtained at this stage. Brosig et al (2007:691) also identified that parents of infants with complex defects had ongoing stressors as they adapted to life at home and that 'parenting a child with CHD placed strain on their relationships as a couple as well as family life' as well as the 'multiple surgeries' that their infants faced; reflecting the multiple transition concepts highlighted by Meleis et al (2000).

The interviews conducted at six months by Brosig et al (2007) found that the emotional status of parents in both groups had improved however, many of them reflected on the difficulty of the first six months of parenting their infant; particularly for those parents whose infants had complex CHD. These parents had found it difficult to adjust and had not expected it to be so hard. The parents' fears at this stage were related to the impact of the CHD on their infant's development and on their relationships and family. Obtaining qualitative data about the parents' perceptions of their experiences as well as quantitative data regarding anxiety levels provided different types of knowledge about the impact of CHD for parents. Whilst Brosig et al (2007) do not discuss the merits of mixed methods research, the clinical implication of providing multiple standpoints regarding what is important, is that it enables practitioners to have a better understanding of the issue being researched than either approach would provide alone (Creswell and Plano Clarke 2007).

Likewise, McCusker et al (2009) explored maternal worry, anxiety and stress at baseline (up to two weeks after admission to the cardiology unit for surgical or catheter interventions) and again at six month follow up. What is not disclosed is whether the baseline was before or after the surgical or catheter interventions and therefore it is difficult to identify whether baseline stress, anxiety and worry scores are pre or post treatment, which could potentially have an impact on the findings.

Participants (70/73 mothers) were allocated either to the intervention group ( $n = 35$ ) or standard care (control  $n = 35$ ) in blocks of 10 [the final two cohorts in blocks of five] based

on the order of admission to the unit. Sixteen mothers were excluded from the study either due to infant mortality, failure to complete the intervention programme (CHIP) or failure to arrange the six month follow up. A greater number of mothers from the control group were excluded. This along with the non-randomised approach raised concerns of bias for the investigators and therefore the two groups were compared for confounding variables at baseline and six month follow up. Less biased randomised controlled trials usually follow the intention to treat rule (Fisher et al 1990), this includes analysis of the data for every participant according to the group that they were randomised to and regardless of their adherence to the intervention that they were assigned; participants are not excluded for failing to complete the intervention or failing to follow-up. The result is that overoptimistic estimates of the efficiency of an intervention by removing the non-completers are avoided, thereby reflecting clinical practice by recognising that some people do not comply or complete treatment (Gupta 2011).

The age of the infant at baseline assessment was the only factor that was significantly different between the two groups. Therefore, as age at testing was statistically different between groups, associations between this factor and the outcome variables of interest were explored and age was included as a covariate in the analyses where required. Three standardised scales were used at baseline and again at six month follow up, Spielberger State Trait Anxiety Inventory (also used by Fischer et al 2012), the Maternal Worry Scale (also used by Doherty et al 2009) and four subscales from the COPE inventory (also used by Doherty et al 2009). Maternal state-anxiety scores were compared at six month follow up with baseline anxiety scores as a covariate, using ANCOVA (ANalysis of COVariance). ANCOVA was used here to control for differences in the groups at baseline. The mean scores were elevated in the control group (mean 38.1; SD =9.3) compared with the intervention group (mean 32.5; SD=9.6), although scores were slightly more spread out around the mean for this group. ANCOVA indicated that this difference was statistically significant, controlling for baseline anxiety scores ( $P = 0.04$ ) with a moderate to large effect size (partial  $\eta^2 = 0.084$ ).

The Maternal Worry Scale scores were comparable between mothers in both groups at baseline (20.8 control group versus 21.6 intervention group). However, at six month follow up the mean worry score in the control group remained at 20.8 (SD=8.5) whilst the worry scores fell in the intervention group from 21.6 to 18.2 (SD=4.1); here the standard deviation is also lower such that the scores are less spread out around the mean, indicating less variability in the scores. The ANCOVA was statistically significant,

comparing maternal worry scores at six month follow up, while controlling for baseline scores ( $P=0.04$ ) with a moderate to large effect size (partial  $\eta^2 = 0.097$ ). The results suggested that the mothers that had undergone the CHIP intervention demonstrated reduced worry and anxiety and enhanced 'positive appraisal strategies' compared with the mothers in the control group; there was a moderate to large effect size of the difference (McCusker et al 2009). However, the results should be viewed with caution due to the non-randomised approach to allocation of groups and removal of non-completers.

A longitudinal case-cohort design study, was reported by Dale et al (2012), which differed from the other two studies in that it compared the wellbeing (rather than anxiety) among mothers of children with CHD with mothers of children without CHD (controls) at pregnancy and at six-months post-partum. In this study, prospective data from the Norwegian Mother and Child Cohort Study (MoBa), that was conducted between 1999-2008 by the Norwegian Institute of Public Health was linked with a nationwide medical CHD registry. From a sample of all pregnant mothers attending routine ultrasound examination between 17-18 weeks' gestation in Norway ( $n=61,456$ ), Dale et al (2012) identified 212 mothers of infants aged six months with mild ( $n=92$ ), moderate ( $n=50$ ) and severe ( $n=70$ ) CHD. It was not explicit until reading the discussion section of this paper that the study was secondary analysis of data that had been collected by different institutions. Further information about the MoBa study was therefore sought (Norwegian Institute of Public Health 2015) to make sense of Dale et al (2012).

The psychological variables life satisfaction, anger and joy, were constructed from questionnaire responses at two time periods: time one (T1), week 30 gestation and time two (T2), six-months post-partum; in addition to demographic information obtained from the Medical Birth Registry of Norway. Three questionnaires were utilised: the 'Satisfaction with Life Scale (SWLS) (Diener et al 1985), which comprises five items that are measured on a seven point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). The Joy and Anger scales comprising three items each are subsets of the Differential Emotions Scale (Izard et al 1993), with responses categorised into 1 (never) to 5 (very often). Finally, social support was measured by an item in the questionnaire at time one which asked 'do you have anyone else other than your husband/partner that you can ask for support in a difficult situation?'; the responses were 'no'; 'yes' (one to two people or more than two people). Cronbach's alpha was used as

a measure of reliability, these were 0.89 (T1) and 0.89 (T2) for SWLS; 0.80 (T1) and 0.83 (T2) for Joy scale and 0.79 (T1) and 0.78 (T2) for the anger scale.

The impact of time on SWLS, joy and anger was explored using ANCOVA, based on CHD diagnosis for three separate mixed between-within subjects: the within-subjects was time of measurement (T1 and T2); the between subject factor was severity of CHD and the control group. As the covariates, small for age and infant's gender differed significantly between the CHD groups these were controlled for within the analysis. The main finding of Dale et al (2012) was that mothers of children with CHD demonstrated the same level of satisfaction with life and feelings of joy as mothers in the control group, both at T1 (30 weeks' gestation) and T2 (six months' post-partum). Mothers of infants with severe CHD reported less joy at six months (T2), although this was not significant ( $p=0.085$ ). However, having an infant with CHD significantly affected anger; mothers of infants with severe CHD reported more anger at six months ( $p=0.012$ ), whereas mothers of infants with mild and moderate CHD did not differ from the control group. Limitations have been identified by Dale et al (2012) such as using self-report tools and the selection bias of the MoBa study which over represents mothers with higher education and positive birth outcomes. Additionally, as this was secondary analysis of data, clinical assessment of the mothers was not possible. A further issue raised was the relatively low pre-natal detection rates of CHD in Norway and the potential impact of time of diagnosis on the psychological outcomes for mothers in the study; however, the researchers did not have access to time of diagnosis information for the sample.

#### 2.5.4 The impact of parental and infant demographics on psychosocial functioning

Most of the seven studies specifically exploring psychosocial functioning, collected some parental demographic data (see table 2.6), however, the impact of these was not explicitly explored in most of the papers. The other nine studies reviewed were not included as the focus of these studies was not to explore psychosocial functioning. This final section therefore incorporates some of the broader evidence around the impact of parental demographics.



**Table 2.6 Parental demographics obtained in the seven studies exploring psychosocial functioning**

Parental demographic	Brosig et al (2007)	Doherty et al (2009)	McCusker et al (2009)	Fischer et al (2012)	Jordan et al (2014)	Franich-Ray et al (2013)	Dale et al (2012)
Mothers	*	*	*	*	*	*	*
Fathers	*	*		*		*	
Parent's Age		*		*	*	*	*
Marital status	*	*	*	*			*
Employment		*	*		*	*	
English Speaking		*	*	*	*		
Ethnicity					*	*	*
Education level				*		*	*
Socioeconomic status		*	*		*	*	

#### 2.5.4.1 Lesion severity

The severity of the heart lesion was found to be related to parental distress levels at diagnosis, where parents of infants with more severe defects had higher BSI scores (Brosig et al 2007). A higher percentage (81%) of parents who had infants with severe lesions had BSI scores in the clinically significant range compared to 33% of parents who had infants with less severe defects ( $\chi^2(1) = 7.483, p = 0.006$ ). These findings, albeit from a small sample, contradict the findings of other studies that suggest that the severity of lesion is not significant in relation to levels of anxiety (Doherty et al 2009, Lawoko and Soares 2006, Morelius, Lundh and Nelson 2002, Wray and Sensky 2004, Jantien Vrijmoet-Wiesma et al 2009; Werner et al 2014). These other studies explored parents of older children with CHD and therefore their recall about anxiety at the time of diagnosis may have been influenced by the amount of time that had passed since (Bradburn, Rips and Shevell 1987). Additionally, some studies exclude parents of seriously ill infants and

therefore may have missed those families who may have experienced the greatest uncertainty and perhaps anxiety (Franich-Ray et al 2013).

#### *2.5.4.2 Marital Status*

Marital status, whilst collected in five of the studies was not directly explored in terms of its impact on psychological functioning. However, marital status and perhaps more importantly the strength of the relationship, should be considered in terms of the social support received by married or single parents; particularly as Doherty et al (2009) found that mothers used more instrumental and emotional social support as coping mechanisms. They also found that social support did not predict mental health difficulties in either parents, but family cohesion was found to be a significant variable for mothers. A variety of other studies have considered the role of social support, Tak and McCubbin (2002) suggested that social support influenced family resiliency, whereas Werner et al (2014) found that lower levels of perceived social support predicted greater impact on the family, of the child's CHD. Hartmann and Medoff-Cooper (2012) explored parents' experiences of feeding their infant (with HLHS) at home, and identified that parents without family support nearby found the constant demands of parenting overwhelming. Families with a limited social support network of family and friends may therefore have the greatest requirements for supportive interventions from HCPs to prevent negative consequences occurring for the family (Werner et al 2014).

Furthermore, Lawoko and Soares (2003) in a study of parents of older children with CHD, found that an excess of time caring accounted for more variance in the availability of social support than the illness, severity or the parent's gender. Moreover, Goldbeck and Melches (2006) explored the impact of severity of disease and social disadvantage on quality of life in families of children with CHD. The most common manifestations (risk factors) of social disadvantage identified were single parent status; ethnic minority; unfinished parental education or professional training and unemployment. Whereas in another study of parents with older children with CHD, Wray and Sensky (2004) found increased marital satisfaction over time for parents that were satisfied pre-operatively; whilst those that were dissatisfied preoperatively remained so post-operatively.

#### *2.5.4.3 Birth order of the infant*

Franich-Ray et al (2013) found no relationship between the birth order of the infant with CHD and parental acute stress disorder, suggesting that first time parents and experienced parents were affected by their infant's surgery similarly. In a study exploring the impact on family life of having a child with CHD, Werner et al (2014) found that parents of infants with severe CHD, who had undergone cardiopulmonary bypass surgery during the first year of life, had considered not having any more children due to living with the 'roller coaster' of ups and downs that they had experienced with this child.

#### *2.5.4.4 Education*

Three of the studies collected information about educational backgrounds of the parents. Fischer et al (2012) considered parents' educational status and the link to anxiety. Interestingly Fischer et al (2012) identified that parents with a higher level of education were more likely to be anxious about going home, than those with lower levels of education. Additionally, Doherty et al (2009), identified knowledge and understanding as significant variables in relation to coping for mothers and fathers. However, educational status was not identified or explored further. Dale et al (2012) compared the number of years of education that mothers in each of the three intervention groups and the control group had and found no significance difference in length of education between groups; they did not explore education any further. Franich-Ray et al (2013) also collected demographic data about parents' education levels however, did not use this information in their analysis. In another study discussed earlier in the chapter, Bright et al (2013) found no differences in Paternal Postnatal Attachment Scale scores based on fathers' demographic characteristics, including education.

#### *2.5.4.5 Ethnicity*

The studies conducted in the USA (Brosig et al 2007, Fischer et al 2012) did not identify the ethnic backgrounds/nationality of the families. Given that there are a range of ethnic groups across the USA, incorporating more detail would have enabled consideration of

the findings in comparison to the ethnic populations in the UK. In contrast, Fischer et al (2012), Franich-Ray et al (2013) and Jordan et al (2014) only included English speaking parents who could also understand written English. Whilst neither of the Belfast studies (McCusker et al 2009, Doherty et al 2009) reported ethnicity of the families recruited, 98% of the population of Belfast is of white ethnic origin (Belfast City Council 2012), therefore it could be suggested that the samples included in the studies reflected this demographic.

In comparison 87.5% of the population of England are from a white ethnic origin (ONS, 2011) indicating that the two studies from Belfast may not entirely reflect the ethnicity of the whole UK. Furthermore, an old study by Sadiq et al (1995) estimated the prevalence of CHD requiring hospital admission in the West Midlands (the study site for phase two of this thesis) as higher in Asian infants than in non-Asian (9.45 per 1000 v 4.56 per 1000,  $p < 0.0001$ ), and that complex CHD were more common in Asian infants, suggesting a higher percentage of families from this ethnic group in the UK. It should be recognised that these two sources of data do not consider contemporary population statistics, which may have changed in recent years due to migration and immigration.

However, the highest rates of CHD are in populations with higher than average number of people from Black, Asian and Minority Ethnic (BAME) groups; where the average proportion of people from BAME groups is 13%; furthermore, five primary care trusts in England have proportions of people from BAME above 25% and three have proportions above 50% (Mott MacDonald 2012). In the Health Impact Assessment undertaken as part of the Safe and Sustainable Children's Cardiac Services review (Mott Macdonald 2012:41), a higher predisposition to CHD was revealed amongst the population groups identified in Table 2.7, potentially impacting on future service provision. Furthermore, Lawoko and Soares (2003) identified ethnicity as a factor impacting on social support, suggesting that some ethnic groups were likely to face social isolation. Therefore, ethnicity appears to be an important demographic to consider when conducting research around parents' experiences of going home with their infant post cardiac surgery.

**Table 2.7 Children's heart surgery - vulnerable groups (adapted from Mott Macdonald 2012)**

- Children (under 16s) \* who are the primary recipient of the services under review and, therefore, most sensitive to service changes;
- People who experience socio-economic deprivation;
- People from Asian ethnic groups, particularly those with an Indian, Pakistani, Bangladeshi and other Indian subcontinent heritage;
- Children of mothers who smoke during pregnancy; and
- Children of mothers who are obese during pregnancy

\* It is recognised that within this group there are subsets of children who are particularly 'vulnerable' and more likely to experience disproportionate effects (Mott Macdonald 2012: 41).

#### 2.5.4.6 Socioeconomic Status

The postcode deprivation index was used by Doherty et al (2009) and McCusker et al (2009) to determine socioeconomic status; using regression analysis socioeconomic status was found *not* to be a factor mediating mental health (Doherty et al 2009). Franich-Ray et al (2013) and Jordan et al (2014) used the Daniel Scale of Occupational Prestige (Daniel 1983 cited in Bright et al 2013:594) to assess socioeconomic status. However, only Bright et al (2013) explored the relationship between socioeconomic status and psychosocial functioning; although, they found no significant differences in Paternal Postnatal Attachment Scale scores based on fathers' socioeconomic status.

As described above, the Health Impact Assessment (Mott Macdonald 2012) highlighted that families living in specific areas within the UK are at higher risk of having infants with CHD. Therefore, it is important to consider the potential impact that geographical location may have on parents transitioning from hospital to home with their infants, such as service provision in that area, whilst also considering other demographic variables that may suggest vulnerability for these parents. For example, in a study by Hearps et al (2013), which explored psychosocial risk in families within four weeks of their child's cardiac surgery and before discharge; parental educational level was used as a proxy for the socioeconomic status and found that this was the sole contributing environmental

factor to the level of psychosocial risk; such that those with higher education levels were more likely to have lower psychosocial risk.

#### *2.5.4.7 Employment Status and Financial Stability*

Four of the studies collected information about education and financial stability, however, this information was not explicitly reported upon within the results. However, in a study of parents of older children with CHD who were compared to parents of children with other diseases and parents of healthy children, Lawoko and Soares (2002) found that employment status and financial stability explained more of the variation in distress and hopelessness in parents, than the child's disease. Additionally, in the same study but reported separately, the parents' financial situation independently explained greater variance in the availability of social support (Lawoko and Soares 2003) limiting parents' social activity and therefore impacting on the degree of social isolation.

## 2.6 Discussion

Parents' experiences of having an infant with CHD are multi-faceted and encompass the need to safeguard, protect and maintain vigilance through monitoring to enhance survival. Uncertainty and vulnerability are experienced, alongside the need for normalisation and parents pass through phases resulting in realisation, adjustment and accommodation. A protective mechanism exists within parent-infant attachment, balancing nurturing for their child and protection for themselves against loss or harm. Whilst attachment does exist; for some parents the relationship becomes insecure, impacting on parental psychosocial functioning and requiring professional support. The findings of the studies considered in this review, indicate that parenting these infants is challenging, traumatic and anxiety provoking, and further improvement of supportive interventions from HCPs is necessary.

It was notable that seven of the eight papers exploring parents' experiences of parenting, were written by the same Canadian team (Rempel and Harrison 2007 Rempel, Harrison and Williamson 2009, Rempel et al 2012a, 2012b, 2012c, Lee and Rempel 2011, Meakins et al 2015) and, therefore, implementation of the recommended parenting interventions in the UK would require UK evaluation of parents' needs and requirements. Furthermore, the original literature search failed to identify studies that only focused on parenting experiences during the discharge to home timeframe, for infants with

functionally univentricular hearts or systemic shunt dependent lesions (complex CHD) and after the first stage of cardiac surgery. Infants with complex CHD are recognised as being particularly fragile and significant mortality occurs within the first year (Townsend et al 2013). Although most deaths occur in hospital, around 20% of post-operative deaths may occur after these infants have been discharged from hospital (Hindocha 2010). Therefore, a recommendation arising from the literature review was that the timeframe between stage one and stage two of cardiac surgery for functionally univentricular hearts or systemic shunt dependent lesions, should be a key focus for future research exploring the experience of parents of these infants.

The review identified that parents of children with HLHS are under extreme pressure and pass through a series of parenting phases during multiple surgeries. However, some of the data presented (Rempel and Harrison 2007; Rempel, Harrison and Williamson 2009) was collected over ten years ago in North America, and could therefore be questioned in terms of its relevance to contemporary healthcare practices in the UK. More recently, a qualitative study in which 25 cardiologists and nurses from tertiary centres; 11 primary and secondary HCPs and 20 parents in the UK were interviewed, was published supporting the finding that parenting infants with CHD is challenging (Tregay et al 2016b). Not only was going home with an infant after cardiac intervention found to be a major challenge for parents, but also for professionals. Difficulties related to inconsistent pathways of care and the potential loss of information between teams involved. Parents, and professionals working in non-tertiary settings, were found to lack the information necessary to respond to a deteriorating infant; contributing to the stress of parenting these vulnerable infants at home (Tregay et al 2016b). This contemporary evidence would suggest that despite the ongoing medical, surgical and nursing advancements in tertiary care over the last 20 years, there remain opportunities for service improvement specifically relating to the provision of information for parents and the monitoring and assessment of vulnerable infants going home following complex cardiac surgery in the UK.

Whilst in the early surgical era post complex cardiac surgery 'extraordinary parenting', constituting extensive assessment and problem-solving knowledge, was applied by parents undertaking technologically advanced skills (Rempel & Harrison 2007); a more recent study found that some parents were unable to identify any early warning signs of their infant's deterioration (Tregay et al 2016a). Therefore, the decision-making skills of these two groups of parents may differ. Parents were invited to participate if their child

had undergone major heart surgery in the first year of life and had subsequently died or had been readmitted unexpectedly to intensive care following discharge to hospital (Tregay et al 2016a). This recruitment approach differed to that of Rempel & Harrison (2007) where all children of the participating parents had survived the three-staged approach to complex heart surgery. Both were retrospective reviews and therefore the possibility of recall bias or recall inaccuracy (Thomas & Diener 1990; Mogg, Mathews & Weinman 1987; Raphael 1987) must be considered, especially given the number of bereaved parents versus parents of survivors in the two studies. However, similarities exist between the two studies in terms of the lack of readily available and appropriate information for parents to aid decision making regarding their child's symptoms. This demonstrates little improvement in communication from HCPs despite more evidence being available about the potential consequences of this complex surgery now than 10 years ago. A synthesis of information obtained from Tregay et al (2016a; 2016b), was utilised by Crowe et al (2016) to identify ways to improve discharge and post-discharge care for this patient group including: structured discharge documentation; enhanced surveillance for patients with certain high risk cardiac diagnoses and an early warning tool for parents and community health professionals. These recommendations reflect the aims of this doctoral study, which was based on the knowledge gap identified following the original review of literature in 2011, and undertaken in parallel to the studies published by Crowe et al (2016) and Tregay et al (2016a; 2016b).

The studies included in the review were conducted in several countries across Europe, North America, and Australia. Considerable differences exist between the structure of healthcare systems and populations; but despite these differences the findings were consistent in that parenting a child with complex CHD is challenging and anxiety provoking. The implications of the findings from the seven studies exploring parents' psychosocial functioning (McCusker et al 2009; Doherty et al 2009; Brosig et al 2007; Dale et al 2012; Fischer et al 2012; Franich-Ray et al 2013; Jordan et al 2014) are significant for practitioners to consider for future practice in terms of the demonstrated need for psychological support for families (both mothers and fathers) of infants with CHD. The data in these studies was collected at varying time points during the infants' first year of life; however, it was identified that psychological functioning was affected at all time points explored, including at the time of diagnosis; after the infant was born; prior to discharge; one month after discharge and six months after baseline. However, despite these findings, clinical psychology support is one of the most under resourced services available in congenital cardiac centres in the UK. Therefore, psychological service



provision has been included in the standards developed within the children's cardiac services review (NHS England 2015) and the need for further research is evident.

None of the seven studies focused only on parents of infants with a functionally univentricular heart; instead the infants in these studies had a variety of CHD. Only four of the studies explored psychosocial functioning in both mothers and fathers. Fischer et al (2012) included both mothers and fathers as caregivers in their study; however, did not differentiate between mothers' and fathers' anxiety in their results. Brosig et al (2007) demonstrated that both parents experienced high levels of psychological distress at the point of diagnosis and birth; and for those parents with infants with more complex CHD, clinically significant BSI scores remained at six-month follow up. However, Doherty et al (2009) found that mothers had a significantly elevated level ( $p=0.001$ ) of psychopathology compared with fathers. Additionally, 33% of mothers and 18% of fathers scored at the level of 'clinical caseness' on the BSI; distress was also evident at a mean time 2.8 months' post birth with clinically elevated levels of psychological distress in one third of mothers and one fifth of fathers. Similarly, Franich-Ray et al (2013) found that nearly a third of parents experienced trauma symptoms consistent with a diagnosis of Acute Stress Disorder (ASD). One third of mothers and almost one fifth of fathers met the criteria for ASD reflecting the findings of Doherty et al (2009). However, Franich-Ray et al (2013) found that it was uncommon for both parents within a couple to meet the ASD criteria; although most parents exhibited at least one trauma symptom and approximately 10% experienced one symptom at a clinical level. The implications for practice indicate that support needs to be targeted at both parents before and after discharge from hospital.

None of the studies specifically considered parents' psychological functioning, longitudinally, during the intervening period from stage one to stage two surgeries for complex CHD. Furthermore, the impact of parent demographics on psychosocial functioning was not specifically considered in the identified papers. There remains a dearth of research considering the social, educational and economic factors that may impact on parents' experiences during the transitional period of going home from hospital with their fragile infant. The final recommendation from this review, therefore, is that the psychological functioning of both parents and the impact of their demographics is explored in between the first two stages of their infants' surgeries for complex CHD.

## 2.7 Statement of Objectives

This systematised literature search failed to identify studies that focused specifically on parents' experiences, during the transition from hospital to home timeframe, of caring for their infants who had recently had the first stage of cardiac surgery for complex CHD. Hence, the aim of this doctoral study emerged, which was to explore parents' experiences of the transition from hospital to home for the first time with their infant, following first stage surgery for a functionally univentricular heart or systemic shunt dependent cardiac lesion. Additionally, the aim was to find out more about the families to help gain an understanding of how they dealt with the transition psychologically, how they adapted to the new situation and whether the information that they were given helped in that transition.

### 2.7.1 Research Question and Aims

The overarching research question for this study was:

*'What are parents' experiences of the transition from hospital to home for the first time with their infant, following first stage surgery for complex congenital heart disease?'*

Phase one:

The aims of phase one were:

To retrospectively ascertain parents' views and experiences relating to the discharge information that they received when their infant was discharged home from the specialist heart hospital after the first stage of treatment. Additionally, finding out more about the family would help gain an understanding of how they dealt with the transition, how they adapted to the new situation and whether the information that they were given helped in that transition.

The secondary research questions were:

- Do parental demographics have an impact on the transition from hospital to home?
- Do parents perceive that the discharge strategy in their infant's cardiac centre met their needs?

- How confident or anxious did parents feel about taking their infant home (retrospectively) and how do they feel now about looking after their infant at home?

Phase two:

The main aim of phase two was to obtain a greater understanding of the experiences of a group of parents whose infants were being discharged home following first stage treatment for complex congenital heart disease.

The secondary research questions were:

- Did parental demographics and psychosocial functioning have an impact on the transition from hospital to home?
- How confident, anxious or depressed are parents before and after taking their infant home (at T0, T1, T2 and T3)?

Where T0 was at baseline (before discharge); T1 was two weeks after discharge; T2 was eight weeks after discharge and T3 was after stage two surgery.

## 2.8 Theoretical Approach

After undertaking the primary literature review the way in which ideas could be drawn together and links made was theorised. The key concepts arising from the review and the main themes identified from an initial parent consultation in September 2011 (see section 3.1) enabled construction of potential explanations for the forthcoming findings (Thomas 2013). Transition was identified as the theoretical foundation. At the time of designing the doctoral study only two studies were identified that focused on transition for parents of infants with CHD. The first study was an exploration of the experiences of parents of children diagnosed with CHD (Messias et al 1995) in terms of the impact of the diagnosis on the parents and the family dynamics and used *Middle Range Transition Theory* (Chick and Meleis 1986). The second study was undertaken by Svavarsdottir and McCubbin (1996) and incorporated the *Resiliency Model of Family Stress, Adjustment and Adaptation* (McCubbin and McCubbin 1993) as the conceptual framework, but focused on the transition to parenthood. Both studies are 20 years old and therefore did not meet the inclusion criteria for the literature search and were both

conducted in the USA, where health care practices differ to the UK and have changed considerably within children's cardiac care over the last 20 years. Furthermore, the transitions explored in these two studies were different to the transition being explored in this doctoral study. However, they provided guidance in terms of underpinning theories that may be relevant for this doctoral study.

Before exploring the two theories used in the studies above, my own conceptual framework was developed (appendix 5) which reflected a conceptualisation of how people's behaviours and characteristics would be affected by individual and environmental factors and, therefore, how they might adapt to change, or in this instance the transition from hospital to home. The concepts were shaped partly by my epistemological beliefs, as well as abstractions and phenomenon (such as the influence of parental demographics; historical, social, cultural, political and economic variables) that interested me as the researcher. This abstract generalisation of how the phenomena were interrelated helped me to understand the project in terms of developing the primary research question, reflecting my suppositions and philosophical perspectives as the designer and the principal researcher (Polit and Beck 2008). Having developed my own conceptual framework, these concepts were utilised to explore different theoretical perspectives, including family resilience, adaptation and adjustment (McCubbin and McCubbin 1993) and transition theory (Chick & Meleis 1986; Meleis et al 2000) to identify an appropriate theory to underpin the study. As transition was the key concept being explored in line with the research question and aims, the middle range transition theory (Meleis et al 2000) was chosen as the underpinning theoretical concept for the study, and because it explored the nature of transitions within a nursing context.

Transition is defined as '*the process of changing from one state or condition to another*' and is derived from the mid-16<sup>th</sup> century French and Latin verb '*transire*', meaning '*to go across*' (OUP, 2014). This definition was relevant to this study as it relates to the process of parents physically moving with their infant from the hospital to the home environment. Early published conceptual work around transition (Chick & Meleis 1985) drew upon models of nursing, but also recognised that future nursing research would inform further development of the theory; hence the emergence of the *Middle Range Transition Theory* (Meleis et al 2000) (figure 2.2). Middle range theories (MRT) were advocated in the 1950s to integrate theory and empirical research (Boudon 1991). MRTs are beneficial because they are narrower in scope than grand theories (Fawcett 2005: Liehl & Smith

1999; McKenna 1997; Meleis 1997; Parker 2001; Walker & Avant 1995); they are concerned with less abstract, more specific phenomena (Fawcett 2005; Meleis 1997); they are comprised of fewer concepts and propositions (Fawcett 2005; McKenna 1997; Walker & Avant 1995) and are more appropriate for empirical testing (Liehl & Smith 1999; McKenna 1997; Meleis 1997; Parker 2001; Walker & Avant 1995); making them relevant for a theory-practice based study. However, a potential limitation of using the MRT (Meleis et al 2000) for this study was that the transition being explored may not concur with the model, due to its uniqueness and complexity for the parents involved; potentially indicating a future need for further development and refinement of the MRT. Application of the MRT will be discussed further in section 3.5.3

**Figure 2.2 Middle Range Transition Theory (Meleis et al 2000)**

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## 2.9 Chapter summary

This chapter has presented the findings of the main systematised literature search that took place during December 2011- July 2012, to enable a comprehensive review of the subject area thereby providing a framework and justification for the research; and the basis for this doctoral study (Holloway & Walker 2000). This primary literature search failed to identify studies that focused specifically on parents' experiences, during the transition from hospital to home timeframe, of caring for their infants who had recently had the first stage of cardiac surgery for complex CHD. Therefore, the aim of this doctoral study was to explore parents' experiences of the transition from hospital to home for the first time with their infant, following first stage surgery for a functionally univentricular heart or systemic shunt dependent cardiac lesion. The theoretical approach underpinning the study was identified in section 2.8, this will be referred to further in the next chapter. Chapter 3 presents the methodology and methods adopted for this study.

## Chapter 3. Methodology and Methods

### 3.1 Introduction

This chapter begins by introducing the patient and public involvement throughout the design, development and implementation of the study. The methodology section is split into two parts to consider how the study was designed, including the underpinning philosophical approach, choice of paradigm and the resultant 'mixed methods' methodological approach. Part two of the methodology presents the overarching methodological design frame for each phase of the study (Thomas 2013). This is followed by the tools and methods used for each phase of the study, including ethics, participants, data gathering tools and materials used and the procedure followed (Thomas 2013).

### 3.2 Patient and Public Involvement

During the design stage of the research study a bursary was received from the NIHR West Midlands Research Design Service to support the involvement of patients and the public (in this case parents). The initial parent consultation took place during an annual summer family event hosted by a UK congenital heart disease charity, in September 2011 attended by families living in the West Midlands. The aim was to provide evidence to support an application to the NIHR Research for Patient Benefit, however, unfortunately this grant application was unsuccessful and the project took an alternative route. Patient and public involvement identifies what research is important; influences the way that research is planned and carried out; ensures that the research is focused and relevant to members of the public and assists in the dissemination of information about the research (NIHR 2014). It also ensures that studies are relevant for the those directly affected by the recommendations that are made (NICE 2013).

The choice of methodological approach and methods were informed through discussions with the parental consultation group and an external advisory group, that included clinicians external to the study site, parents and representatives from the charity. The external advisory group set up in phase one, continued to support the project in phase two. The research design and methods for phase two were discussed and decided upon in collaboration with this group. Phase two sat within a feasibility study of 'Parental Home

Monitoring and Assessment of Infants with Complex CHD', for which I was the Principal Investigator. The feasibility study was designed by me and is, therefore, my own work; the results of which will be published elsewhere and will not be covered in this thesis. To provide context a brief explanation of the feasibility study is provided here. The primary aim of the feasibility study was to obtain sample size calculations for a future multi-centre randomised controlled trial. The secondary aims included testing the feasibility of using an early warning tool as part of a home monitoring programme for infants with functionally univentricular heart conditions or those with systemic shunt dependent heart conditions. The equipment was funded by Heart Research UK as was the research nurse role (0.6 whole time equivalent); the role being to manage the day to day running of the feasibility study. There was a team of three nurses (covering the 0.6WTE) who were based in the Wellcome Trust Clinical Research Facility (WTCRF) at the study centre. Monthly meetings took place with the research team at the study site and six monthly meetings with the external advisory group throughout the recruitment phase. These meetings included discussions around recruitment, data collection and data analysis, enabling the members of the group (parents, charity representatives and external clinicians) to contribute to the decisions that were being made. The final meeting took place once the feasibility study had ended and all data had been analysed. The team acknowledge the support of National Institute of Health Research (NIHR) through the Comprehensive Clinical Research Network as the Feasibility Study was adopted to the NIHR Portfolio.

### 3.3 Methodology Part 1 – Research Design

#### 3.3.1 Philosophical approach

Whilst designing the study, exploration of the varying worldviews was necessary to define and fully articulate the epistemological and ontological assumptions underpinning the project. Worldview is a term often used synonymously with paradigm; paradigm being defined as a set of generalisations, beliefs and values of a community of specialists (Kuhn 1970:43-51). Paradigms as epistemological stances has been the prevailing definition in social sciences research and has had the greatest impact in mixed methods research (Morgan 2007). Conversely, Cryer (2006) separates paradigms into the 'traditional' and 'interpretivist' perspectives (Denzin and Lincoln 1994: 536), where a traditional paradigm represents research that obtains numerical data [quantitative research]; and the interpretivist and constructivist paradigm represents research where



the data collected is more descriptive [but can include quantitative data], the emphasis being on exploration rather than experimentation (Cryer 2006:77-79). The issues being explored in this doctoral study were complex and, therefore, the focus was on developing a mixed methods study combining both the traditional and interpretivist paradigms.

### 3.3.2 Best Paradigm Approach in Mixed Methods Research

Much debate has taken place by mixed methods researchers over which 'best' paradigm stance best fits a mixed methods study (Tashakkori and Teddlie 1998, 2003, Murphy 1990, Cherryholmes 1992, Mertens 2003, Sweetman, Badiee and Creswell 2010, Greene and Caracelli 1997, Morgan 2007, Denscombe 2008). However, whilst a pragmatic approach was officially associated with mixed methods research (Tashakkori and Teddlie 2003) other 'best' paradigm approaches have since been presented, see table 3.1 (Creswell and Plano-Clark 2011).

**Table 3.1 Best paradigms associated with mixed methods** (adapted from Creswell and Plano-Clarke 2011)

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It has been suggested that it is naïve to assume that mixed methods research ‘*combines and shares thinking at a paradigm level*’ Giddings (2006:200). There was initially a struggle to understand how an interpretivist, constructivist approach could be directly integrated with a positivist and pragmatic approach at the philosophical level. Moreover, the single paradigm approach as used in pragmatism did not sit well with my own worldviews. The pragmatic orientation to ‘*what works in practice*’ (Creswell and Plano-Clarke 2011:41) suggested an approach that is undertaken for its ease of use, rather than as a philosophical or methodological framework to look further than structured descriptive results. Whereas, a dialectical approach uses multiple paradigms. The art of a dialectical approach is that the truth is sought through the exchange of logical discussion of ideas and opinions; the differences cannot be disregarded or reconciled, but should instead be respected in order (Oxford University Press 2013).

After considering the underpinning epistemological assumptions of the study (interpretivism, constructivism and positivism), a dialectical perspective, (see table 3.1), where both qualitative and quantitative data collection methods work together (Greene and Caracelli 1997), was identified as the best stance to adopt. This was because each of the integral components was guided by a different epistemological stance; however, the interpretivist and constructivist paradigms were identified as the dominant assumptions.

It was necessary to consider both constructivism and constructionism within this study, as each infant had a clinical diagnosis of CHD that was personal to them and therefore their parents’ experience was real and individual, despite the impact of other forces. There is a variance in definition between constructivism and constructionism. Constructivism, being resistant of critical forces, focuses entirely on the way in which we independently make sense of situations and purports that this experience is exclusive to each of us. Conversely, constructionism encourages criticality, whilst considering the impact that our culture has on influencing the way in which we create and convey meaning (Crotty 1998). The ‘constructionist’ paradigm implies that as humans we construct meaning as we connect with the world that we are interpreting and that meaning only materialises when consciousness engages with it; so, the object that we see is shaped by our consciousness (Crotty 1998:42). The way in which we construct meaning is also influenced by the world that we were born into, our social world, our culture, the history of our culture and what we are surrounded by, this is referred to more

specifically as social constructionism (Crotty 1998, Geertz 1973). The effect and impact of socialisation in whatever sense, be that professional, organisational, cultural, political, economic or legal ideologies and influences, on an object or a subject, is central to the theme of this study.

However, social constructionists (considered to be realist and relativist) would say that the reality of the parents' situation and the way that they described or narrated their story should perhaps not be immediately accepted as real, because the reality of the situation also depends on the community around these parents (Crotty, 1998). It is, therefore, not a simple case of constructivism but perhaps should be considered more in terms of constructionism. Relativist theory suggests that 'the way things are' means the logic we make of them and this logic can be influenced by the history of culture and cross-cultural interpretation, as well as the time and place in which the situation or experience occurs (Crotty 1998).

It was appropriate to consider both the parent's personal culture and the associated culture of being a parent of an infant with CHD. There are so many other factors that affect how sense is made of situations and the world in which these infants and their parents exist, such as their personal demographics, the society within which they live, their resilience as a family and the support mechanisms that they utilise. Given that congenital cardiac services have been under review for many years, it was possible that the care that parents and their infants received during the time of the study would be influenced by some of the issues discussed in section 1.2.3. Therefore, it was essential that the potential impact of the ongoing process politically, legally, organisationally, economically, personally and professionally was taken into consideration during the analysis of the results obtained from the study.

Finally, everyone interprets 'language' differently and so, this subjectivity can be conscious or indeed unconscious and our research practices can be unknowingly oppressed by systems of race, class and gender (Kincheloe and McLaren 1994). Our interpretations are also bound by our own personal stance, the position which we adopt in life based upon our own personal and professional experiences (Salmon 1989). Furthermore, our personal stance is connected to the concept of reflexivity, not only for ourselves as the researchers but for those that are involved in the research. One of the reasons for maintaining reflexivity throughout this study was to ensure that I situated

myself in the research and its processes to acknowledge my own personal stance and the issues of value that emerged throughout (Savin-Baden 2004). A summary of my positionality and reflexivity is presented at the very end of this thesis in appendix 18.

### 3.3.3 Rationale for choosing a 'mixed methods' methodological design

Debates about the use of mixed methods to address healthcare research have emerged. Combining quantitative and qualitative methodologies has been suggested as having a shared objective that aims to understand the world in which we live from different perspectives (Haase and Myers 1988). Moreover, King, Koehane and Verba (1994) maintained that identical rules and inferences apply to both, and there is a mutual reason for both approaches. However, some believe that researchers cannot be both positivist and interpretivist or constructivist (Sale, Lohfield and Brazil 2002) and suggest that the rationale for mixing methods is instead to challenge the underlying assumptions of the paradigms. Additionally, it has been proposed that an 'either-or' decision is not required and that positivism should be embraced by qualitative researchers, informed by an element of interpretivism (Howe 1992). Furthermore, there appear to be two different reasons for integrating quantitative and qualitative methods, the first being to enable 'triangulation' through the amalgamation of two or more theories or sources of data to investigate the same phenomenon to acquire a more inclusive appreciation of it (Creswell 2003); here the research methods are interdependent (combinant) (Sale, Lohfield and Brazil 2002). The second rationale for legitimately combining methods suggests that the strengths of one method are engaged to boost the other to accomplish complementary outcomes (Morgan 1998); in this definition, the research methods are independent (additive) (Sale, Lohfield and Brazil 2002).

My own stance concurs with Sale, Lohfield and Brazil (2002) that interpretivist or constructionist researchers cannot also be positivist, agreeing with the former position that integrating methods enables triangulation otherwise described as holism. Within nursing, and more specifically this study, the complexity of phenomena necessitates the inclusion of data from broad and holistic standpoints (Clarke and Yaros 1988). Therefore, supporting the use of a combination of methods, whilst gaining 'depth and breadth' in attempting to solve the '*complex and multi-faceted questions*' that this study aims to answer (Clarke and Yaros 1988:147) and reflecting a synergistic stance using a dialectical perspective. This perspective regards the variations that exist between the

philosophical paradigms and the rationale for justifying this approach, as vital in designing research (Greene and Caracelli 1997:8). Moreover, these differences should be deliberately used to dialectically discover 'enhanced understandings, new and revisioned perspectives and meanings' (Greene and Caracelli 1997:8). Furthermore, obtaining a more complete understanding of immensely complex social issues requires a complementary analytic and systemic approach to inquiry (Salomon 1991), justifying the choice of a mixed methods methodological design in this study.

### 3.3.4 The 'mixed methods' methodological approach

Research studies range from non-mixed (mono-methods) at one end of the continuum, to fully mixed method approaches at the other extreme (Johnson and Onwuegbuzie 2004). Any study that combines both quantitative and qualitative methods either uses a fully or partially mixed approach, with the fully mixed approaches reflecting the highest degree of integration both at paradigm and technical levels. Fully mixed methods are suggested to engage quantitative and qualitative modes within one or more stages of the research process or across stages; whereas in partially mixed studies the quantitative and qualitative elements are not mixed within or across stages (Leech and Onwuegbuzie 2009:267). Alternatively, in partially mixed studies both the quantitative and qualitative elements are completely implemented either concurrently or sequentially prior to mixing at the analysis stage (Leech and Onwuegbuzie 2009:267).

Following review of the four mixed typologies proposed by Leech and Onwuegbuzie (2009:271) the typology that best represented this study was defined as a '*fully mixed concurrent dominant status*' (QUALquant) approach, where integration of the different methods occurred in addressing the research objective and during the data analysis and inference stages of the research process (Clarke and Yaros 1988, Leech and Onwuegbuzie 2009).

### 3.4 Methodology Part 2 – The Design Frame

The 'design frame' is described as the superstructure for the research study (Thomas 2013; 133). Two different design frames were used for each phase of the study to best answer the overarching research question.

#### 3.4.1 Phase One Design Frame

Phase one, used a retrospective survey design, to gather data from parents that had already gone home with their infant. Retrospective designs take less time and are more cost effective, however one of the disadvantages of a retrospective approach is the potential for recall bias, which exists wherever historical self-report information is obtained from the participants (Raphael 1987). The errors arising may occur due to differences in inaccuracy or completeness of recall to memories of past events (Last 2000). These disadvantages need to be considered in analysis of data.

The advantages and disadvantages of using an online medium to distribute the survey to participants were considered and compared to face to face and postal methods that the Charity had traditionally used. Several potential disadvantages of online surveys have been identified mainly by researchers in the field of market research; these include lack of internet experience or expertise; low response rate and the skewed attributes of participants (Evans and Mathur 2005). Evans and Mathur (2005) suggest that users of the internet may not be truly representative of the general population and whilst Fricker and Schonlau (2002) suggest that the differences between online and offline populations is decreasing, this may have changed more in the last 10 years, however, internet access may still vary across the country. It could also be proposed that internet access differs across certain districts or populations within the UK due to broadband availability and the cost of using the internet for families from lower socioeconomic backgrounds. Furthermore, Duffy et al (2005:638) concluded in their study comparing data from online and face to face surveys, that online surveys appeared to attract responses from individuals with a more knowledgeable viewpoint, which they suggested could have been because this was a prior characteristic of those who accessed the internet or those who joined online panels. Clear instructions were provided to help alleviate this problem (Evans and Mathur 2005:201). However, those with a lack of internet experience or expertise may have been less inclined to take part potentially causing the low response rate to the online survey. Additionally, the ability to access the online survey may have

depended on the respondent's internet connection and the configuration of their computer (Evans and Mathur 2005:201-202). Moreover, low response rates to online surveys have been identified by several researchers (Fricker and Schonlau 2002, Wilson and Laskey 2003), however, there is limited evidence as to the cause of this.

Since the sample being invited to complete the survey were geographically spread across the country an online approach was deemed more cost effective in terms of administration costs, ease of distribution, speed and timeliness, flexibility and convenience. Additionally, access to technological innovations in this case using Bristol Online Survey (Bristol University 2015), the ease of data entry and analysis, question diversity, control of answer order, required completion of answers and 'go to' capabilities were felt to be advantageous in the decision to use an online resource to collect the data (Evans and Mathur 2005, Fricker and Schonlau 2002). The advantages therefore seemed to outweigh the potential disadvantages hence the rationale for choice of an online survey as the design frame.

#### 3.4.2 Phase Two Design Frame

In phase two, a prospective longitudinal design was chosen rather than a cross-sectional design, to explore a cohort of parents over time who shared the same experience of being discharged from hospital to home with their infant following cardiac surgery for complex CHD (Thomas 2013). A cross-sectional study was inappropriate because too few infants and parents were discharged at the same time from the hospital due to the relative rarity of complex CHD. Parents' experiences of going home from hospital were explored at different time points, until their infant was readmitted for the second stage of cardiac surgery, to ascertain the effect of the transition over time.



## 3.5 Methods

### 3.5.1 Ethical Considerations

Ethical approval for phase one of this study was obtained through Coventry University Research Ethics Committee (Appendix 6). It was recognised that the online survey may elicit an emotional response as parents reflected on their infant's healthcare journey. The Charity could offer support to parents in need, therefore parents were reminded of the availability of this service in the participant information leaflet.

In phase two, permission to conduct the feasibility study was obtained from Coventry University Research Ethics Committee, the National Research Ethics Committee (NREC) (Solihull) and the Local NHS Research and Development approval (at the study site) (Appendix 7). I undertook the NIHR e-learning course 'An Introduction to Good Clinical Practice' (Appendix 8) to support my role as Principal Investigator and followed the Research Governance Framework for Health & Social Care (DH 2005). As Principal Investigator, I was required to have an Honorary contract with the study site.

It was recognised that being involved in the feasibility study may have elicited an emotional response in parents such as anxiety and distress. However, the level of emotional response was difficult to predict as parents were likely to be anxious taking their infant home for the first time. Some parents may have been more anxious than others and some may have felt depressed about the whole situation of having an infant with a complex CHD. Monitoring psychological functioning was therefore made an aim of phase two and the rationale for measuring anxiety and depression in all parents taking part in the study was to ensure that parents received appropriate support as soon as possible, where necessary. An additional monitoring time point (8 weeks' post discharge) was added at the request of the NREC.

It was particularly important to recognise the clinical reality of the situations that parents were experiencing and for some it was just not the right time to be involved. The risks of taking part and the availability of support were included in the participant information leaflets (appendix 9 and 10) that parents received before being recruited to the study and before signing the consent form (Appendix 11). Parents were advised that if they would like to talk to someone about their experiences, they should contact the research nurse, cardiac nurse specialist, general practitioner (GP) or a parent support group.

Parents who screened positive for heightened anxiety or depression were referred by the research team to the appropriate professional, such as the cardiac nurse specialist team or their GP for further advice and support, following gaining verbal consent to do so from the parent.

### 3.5.2 Participants

#### 3.5.2.1 *Study Population*

The study population was all parents in the UK that had an infant with a functionally univentricular heart, following stage one surgery for complex CHD. Approximately 200 children are born in the UK each year with a functionally univentricular heart (National Institute for Cardiovascular Outcomes Research (NICOR) 2015) therefore the population of parents with infants in this age group would be approximately 400 families (not excluding those that had died in their first two years of life).

#### 3.5.2.2 *Sample*

The phase one sample was a convenience sample of all parents (over 18 years of age) who were members of a UK Congenital Heart Disease Charity with children aged between 0-2 years and who had already been discharged home from one of eleven UK specialist heart centres, after the first stage of treatment for a univentricular heart. The total sample identified from the Charity's database that met these criteria was 62 families. The families represented a variety of ethnic groups and geographical areas. The sample was chosen because they had experience of the social situation being explored, which was the discharge from hospital to home time frame. The sample was not a representative sample because not every member of the population had an equal chance of being selected (Oppenheim 1992) and because not all parents of infants with single functioning heart ventricle (the 'Population') choose to become a member of the Charity.

In phase two, given that the study had a concurrent [convergent] design with the qualitative element taking priority over the quantitative for addressing the research question, it was necessary to decide who would be selected for the two samples, the size of the samples and subsequently the design of the data collection formats (Creswell and Plano-Clarke 2011). For example, the two divergent strands (qualitative and quantitative) could have contained the same samples or different samples of the

population. Where different samples are used, the rationale is normally that the researcher is attempting to analyse data about a subject but from different perspectives, which did not meet the aim of this study. So, for example, parents of infants from minority ethnic groups could have been included in one strand compared to only parents that comprehend English in another strand, to consider different cultural or religious perspectives.

However, a homogenous group of parents who comprehended written and spoken English, was decided upon because there was no funding available to employ an interpreter or to develop the written information in different languages. Conversely, when the aim is to compare or substantiate the two strands of a study, it is recommended that the same individuals are included in both aspects. So, as this reflected the aim of this study the same group of parents were included for each strand (Creswell and Plano-Clarke 2011:183).

### *3.5.2.3 Sample Size*

The next decision for phase two was about the size of the sample and whether the size of each strand should be the same or different. It is suggested that using different sized samples is a good choice as having a small qualitative sample assists in obtaining rich exploratory data, whilst having a large quantitative sample enables thorough statistical examination of the subject (Creswell and Plano-Clarke 2011:183). However, meaningful consideration, comparison and evaluation of the two strands of data can be problematic due to the variation in sample sizes. Researchers deciding upon this approach accept that the rationale for collecting each form of data is different (Creswell and Plano-Clarke 2011:184).

The second option and the one chosen for this study, was to use equal sample sizes for each strand of the data collection in phase two. The sample was all parents (who met the inclusion criteria) of infants discharged home from the study site following the first stage of treatment for their complex congenital heart disease, over a 15-month period. The rationale for the small sample size of 12 families in phase two reflected the dominant **qualitative** element of the concurrent mixed methods approach. A small number of participants were conveniently selected to obtain in-depth information about their perceptions of the transition from hospital to home. In qualitative research, samples are not meant to represent large populations. Small, purposeful samples of articulate respondents are used because they can provide important information, not necessarily

because they are representative of a larger group (Reid 1996). The limitation of choosing equal sample sizes for both the qualitative and quantitative strands of this study are recognised and there was an awareness that this would be sacrificing the use of rigorous statistical tests (Creswell and Plano-Clarke 2011:184)

#### *3.5.2.4 Recruitment*

In phase one, only parent members of the Charity (who met the inclusion criteria) were sent the invitation email with the Uniform Resource Locator (URL) link to the questionnaire. It would have been more difficult to gain access to parents from the non-charity member population in a timely and convenient manner and therefore this would have presented methodological dilemmas. Recruitment to the online questionnaire was initially available for one month during November 2012. However, this date was extended until the end of March 2013 due to a lack of early responses. A reminder email was sent by the Charity's team at the end of November notifying families of the extension to the deadline. Parents were informed, in the participant information leaflet (appendix 9) that it was up to them to decide whether to take part. If they decided to take part, they could access the questionnaire (appendix 12) via an online link provided in the email and they were free to withdraw at any time and without giving a reason. Parents were informed that taking part or not taking part in the study had no impact at all on their baby's care or on the support they could have from the Charity.

Recruitment to phase two of the study was an integral part of recruitment to the feasibility study and was, therefore, undertaken by the research nurse. Parents were recruited whilst their infant was an in-patient at the study centre. All parents of infants for whom discharge planning from the study centre had commenced, received a letter from the consultant cardiologist inviting them to consider taking part in the study, plus a copy of the Participant Information Sheet (appendix 10). Potential participants were given at least 24 hours to consider participation in the study. The parents who were interested in participating were asked to contact the research nurse, who explained the study further, answered any questions and provided all relevant information. Recruitment to the study took place over a 15-month period [August 2013-end of November 2013 (4 months); April 2014 until end of February 2015 (11 months)].

The research nurse checked inclusion and exclusion criteria (table 3.2) against information provided by the potential participant. The research nurse gained written informed consent to take part in the feasibility study, including the semi-structured

interviews for phase two, and then asked the participants to complete the baseline assessment questionnaire (appendix 13), with the medical details being completed by the research nurses from the infant's medical notes.

**Table 3.2 Phase two Inclusion and Exclusion Criteria**

Inclusion Criteria	Exclusion Criteria
1. All Parents of infants that have recently undergone stage 1 treatment for complex congenital heart disease at the study site, before discharge planning commences 2. Able to read written English 3. Able to comprehend spoken English 4. Able and willing to give informed consent.	1. Parents of Infants that have already been discharged 2. Currently involved in any other research study

The parents of 80 infants were screened during the 15-month recruitment phase, as having an infant with complex CHD. However, of these 19 were ineligible, mainly due to language barriers; 15 refused, mainly because they felt unable to take part due to being overwhelmed by their situation; 19 were missed whilst the study was suspended and 14 infants died in the intensive care unit shortly after surgery and before transfer to the ward where recruitment took place. In total 13 families were recruited into the feasibility study and all participated in phase two, which is presented here.

### 3.5.3 Data Gathering and Materials Used

The Middle Range Transition Theory (Meleis et al 2000) was used to design the choice of data collection strategies, tools and instruments to enable exploration of the **type, patterns and properties** (fig 2.2) of the parents' transitions (Creswell and Plano-Clarke 2011). Specific descriptive demographic data was collected in both phases to explore the **inhibitors or facilitators** (fig 2.2) such as: parity and parenting experience; demographics - gender, age, educational level, employment or professional status, ethnicity, language, home environment and social networks; parents' knowledge and understanding of the situation; and parents' ability to recognise clinical deterioration in their own infant. The study also explored parents' **patterns of response** (fig 2.2) to the transition, by identifying **processes** that moved them either in the direction of health or

toward vulnerability and risk. In phase two data was collected around psychosocial functioning to identify parents' confidence in caring for their infant at home; anxiety and depression. This allowed early assessment of the parents' responses and enabled intervention by the research team to facilitate healthy outcomes. Indicators of the **outcome** of the parents' transition could be explored through **mastery** of new skills and **fluid integrative identities** (fig 2.2) or identity reformation (Meleis et al 2000).

In phase one the choice of a questionnaire as the data collection instrument primarily arose from the design frame, the research question and discussions about the type of data that was to be collected. Additionally, it related to the sample that had been identified, who were geographically spread across the UK making it more difficult to use other methods. In phase two, the choice of data collection tools primarily arose from the concurrent mixed methods approach and discussions with the team about the parallel concepts of the research question and the type of data that was to be collected independently. A mixture of data collection methods was used, including collection of demographic data at baseline, semi-structured interviews and self-report tools. Early mixed methods researchers (Greene and Caricelli 1997) proposed broad agreement that mixing different types of methods at the data collection level was not problematic and could strengthen a given study, but must relate to the research question. However, whilst mixing the two methods may not be problematic, Creswell and Plano-Clarke (2011) indicated that data collection of each strand must remain comprehensive and meticulous, dialectically respecting the two approaches.

### 3.5.3.1 Questionnaire

The questionnaire (Appendix 12) was developed in collaboration with the CHD charity and sought to obtain the following categorical data to generate a descriptive picture of parents' discharge experiences:

*Demographics:* including parents' ages, ethnicity, education, employment, living arrangements, total household income, benefits; age of infant now; number of siblings.

*Medical Information:* time of diagnosis (antenatal or postnatal) and infant's type of congenital heart defect, length of first hospital stay; parents' and sibling health status

*Discharge Information:* feeding (frequency and method); medications (number, frequency, route of administration); other treatments or measurements to continue at home; type of teaching received (subject and general or specific to their infant); type of written instructions received (subject and general or specific to their infant); quality of information received from specialist heart hospital; who to contact about concerns.

*Parents' experiences of going home:* anxiety, confidence and support mechanisms.

*Anxiety:* Likert scales are the most extensively used scaling techniques and are frequently used in stress and health studies (Hasson and Arnetz 2005). The middle option (neither agree or disagree) can be removed from a five-point scale to remove the tendency for people to over choose it (Thomas 2013). Therefore, a 4 point Likert scale was used to measure parents perceived anxiety (at discharge [T0] and now [T1]), with answers being chosen from extremely, moderately, slightly and not at all.

*Confidence in the Parenting Role* was measured using the Maternal Confidence Questionnaire [MCQ] (Parker, Zahr and Cole 1992, appendix 14). Few tools have been developed and psychometrically tested to assess maternal confidence, hence the choice of this tool, which has been demonstrated to be valid and reliable (Badr 2005). It was developed in 1985 in a study investigating the efficacy of intervention in the neonatal intensive care unit in mothers and infants at eight months after their infant's discharge from the hospital (Parker, Zahr and Cole 1992). The scale consists of 14 items: each item is answered on a 5-point scale from 1=never to 5 = a great deal. The scale measures maternal confidence in parenting skills and the mother's ability to recognise her infant's needs. After reversing the two negatively worded items (items 10 and 12), a total score is derived from the mean of the totalled 14 item scores. Total scores vary from 14 (lower maternal confidence) to 70 (higher maternal confidence) and means vary between 1 and 5 for each question. The MCQ is uni-dimensional with a higher score indicating a higher perceived competence (Badr 2005:165). Face and content validity have been evidenced by previous studies (Zahr 1991), where measures for internal consistency (alpha coefficient) for the total items ranged between 0.89-0.93. The total mean score alpha coefficient was 0.89; reliability coefficients above 0.70 are considered acceptable. The scale has been used since in 40 research studies, establishing reliability and validity; it has also been translated into 9 languages (Badr 2005). Correlation coefficients of  $r = 0.66-0.69$  have been reported (Aracedo 1997, Zahr 1991) demonstrating a positive linear relationship between the variables.

*Support mechanisms:* parents were asked to indicate who supported them at home and professionally.

Open ended questions were embedded into the questionnaire to gain an understanding of parents' experiences at the time of going home, from their perspective. However, it was recognised that this type of question can make the respondent less inclined to answer because of the time it takes and therefore the number of open ended questions was limited (Maltby et al 2010:110). Careful wording of these questions was necessary to reveal high quality data as was the sequencing; therefore, only one open ended question was used at the end of each section, enabling participants to give their own perspective relating to the closed format questions that had been used before.

Appropriate sequencing was considered as this can dramatically affect the accuracy and reliability of the data collected; such that behaviour questions are generally asked first, because they are based on fact and easier to remember. Asking questions about attitudes first may have resulted in the respondent not thinking carefully about their response and so becoming contradicted by their behaviour; behaviours can then be misrepresented to justify their attitude (Brace 2008). Sensitive questions were asked later for numerous reasons. These questions can be perceived as intrusive and may, therefore, create a greater level of termination of the questionnaire; placing them later therefore allowed the respondent to build up a relationship with the 'questionnaire' and additionally, it ensured that some data were collected even if the respondent ended the questionnaire at that point (Brace 2008). Brace (2008) also suggested that classification data, such as age, gender, should be asked at the end of the survey because these questions rarely relate to the survey, probably because his works refer specifically to market research. However, for this study the classification information was important in terms of identifying relationships and patterns and therefore placing it at the end of the questionnaire may have implied that it was less important and could have resulted in the respondent not answering these questions. Gendall (1998) supports this view describing sequencing as a 'downward funnel' in which non-threatening questions are asked first, concluding with the more sensitive ones at the end of the questionnaire.

### *3.5.3.2 Semi-structured Interviews*

The semi-structured interview method was chosen because it combined the structure of a list of key issues to be explored, in addition to the freedom to follow up points raised as necessary (Thomas 2013). Furthermore, interviews are ideal for the exploration of



experiences, perceptions, attitudes, values and beliefs (Barriball and While 1994). Interviews enabled the researcher to adjust the words of the questions, without changing their meaning, recognising that participants had varying vocabularies and may have interpreted words differently (Treece and Treece 1986 cited in Barriball and While 1994:331). Therefore, the consistency of the interviews was related to assigning the same meaning rather than on the repeated use of identical words (Denzin 1989). This would have become more difficult if a heterogeneous group had been chosen, for example by including parents whose understanding of English was limited. Furthermore, interpretation of the meaning of words may have varied even more in such a group and therefore may have resulted in a much more challenging interview situation.

All the participants were asked to take part in semi-structured interviews at the time points identified in table 3.3, for phase two of this study. A face to face interview was chosen as the mode of interviewing before the parents were discharged home in order that the researcher could attempt to establish rapport with the family.

**Table 3.3 Interview Time Points for phase two**

Time	Time point/Place	Interview Schedule
T0.	Baseline assessment at time of giving informed consent/ Prior to discharge  In hospital	<ul style="list-style-type: none"> <li>• Baseline demographics completed by the research team after informed consent had been obtained</li> <li>• Semi-structured interview conducted to ascertain parents' perceptions of their infant's discharge</li> <li>• Measure potential parental anxiety using GAD7</li> <li>• Measure potential parental depression using PHQ-9</li> <li>• Measure parental confidence using 'Maternal Confidence Questionnaire'</li> </ul>
T1	Two weeks after discharge  Parents at home – telephone interview	<ul style="list-style-type: none"> <li>• Semi-structured interview to ascertain parents' perceptions regarding their infant's discharge</li> <li>• Measure potential parental anxiety using GAD7</li> <li>• Measure potential parental depression using PHQ-9</li> <li>• Measure parental confidence using 'Maternal Confidence Questionnaire'</li> </ul>
T2	Eight weeks after discharge  Parents at home – telephone interview	<ul style="list-style-type: none"> <li>• Semi-structured interview to ascertain parents' perceptions regarding their infant's discharge</li> <li>• Measure potential parental anxiety using GAD7</li> <li>• Measure potential parental depression using PHQ-9</li> <li>• Measure parental confidence using 'Maternal Confidence Questionnaire'</li> </ul>
T3	At the end of participation in the study (when their infant returns for stage 2 surgery)	<ul style="list-style-type: none"> <li>• Semi-structured interview to ascertain parents' perceptions regarding their infant's discharge</li> <li>• Measure potential parental anxiety using GAD7</li> <li>• Measure potential parental depression using PHQ-9</li> <li>• Measure parental confidence using 'Maternal Confidence Questionnaire'</li> </ul>

It was not deemed feasible to conduct subsequent interviews in the parents' own home, because of the distance, time to travel and costs that this would have accrued. Families could have lived anywhere in the West Midlands or much further afield. Additionally, interviewing in the parents' home may have been invasive for some parents, which may have impacted upon their decision to consent.

There are advantages and disadvantages to the two modes of interviewing chosen for this study. Whilst face to face semi-structured interviews give the researcher and the participant the opportunity to probe any words or phrases that are ambiguous for clarification or for additional information, further increasing the flexibility to validate meaning (Treece and Treece 1986, Barriball and While 1994:331); it has been suggested that probing is more difficult to perform during telephone interviews because of the lack of visual cues (Carr and Worth 2001). However, Carr and Worth (2001) also suggest that the lack of probing opportunities produces pauses in the conversation that enables the interviewee to respond in more depth because of the lack of interruptions from the interviewer. Assessing the silence is, therefore, a skill that was acquired over time to differentiate between the reasons for any silences occurring in each telephone interview situation.

In face to face interviews, the interviewee's replies can be observed alongside non-verbal behaviour, which may be advantageous when ascertaining perceptions around sensitive issues (Gordon 1975 cited in Barribal and While 1994:329) as well as identifying the possibility of a demand characteristic effect. Barriball and While (1994) applied the 'demand characteristic effect' that Orne defined in his seminal article in 1962, to semi-structured interviews. Whilst Orne's (1962) work focused on experimental situations, this effect could be suggested to reflect a situation where interviewees reply in a way that they perceive as the preferred social response despite whether it is truthful or not. Additionally, Denzin (1989) described the inherent demands of an interview as a perceived social desirability, where the interviewee endeavours to portray themselves in a manner that meets the perceived requirements of the interviewer. However, it has been suggested that probing in face to face interviews can assist in the reduction of socially desirable replies, through the development of trust and a rapport with the interviewee (Patton 1990).

Conversely in telephone interviews Novick (2008:5) identified that the absence of visual cues and body language had been linked to 'the loss of informal communication and contextual information and the misinterpretation of responses' (Chapple 1999, Creswell 1998, Opdenakker 2006, Sturges and Hanrahan 2004, Sweet 2002). Furthermore, the absence of visual cues may impact on the demand characteristic effect; as using the telephone can 'silence issues of privilege and power within an interview setting', for example because both parties are not able to see the ethnicity of the other (Holt 2010: 116). However, the example does not relate in this instance, as the researcher had already met the families, face to face, at the initial interview.

There is a lack of empirical data regarding the suitability of telephone interviews for semi-structured interviews (Novick 2008). This mode of interview is generally thought to be more suitable to structured interviews (Fontana and Frey 1994) indeed Taussig and Freeman (1988:418) suggest that even considering using a telephone to conduct clinical interviews "*invites clinical and methodological scepticism*". Telephone interviews, therefore, seem to be depicted by some researchers as 'second best' compared to face to face interviews for qualitative data collection (Taussig and Freeman 1988, Sturges and Hanrahan 2004); despite their research demonstrating that the data they collected using telephone interviews was comparable to that collected in face to face situations. However, the significance of mode differences could not be predicted before the interviews with these parents and so it was considered as a possible limitation when analysing the data. Recommendations have been made by researchers who have used telephone interviews, which were taken into consideration for the telephone interviews being conducted for this study. The first being to establish contact or rapport in person prior to conducting telephone interviews (Burke and Miller 2001, Carr and Worth 2001), this was planned as the first interview was face to face. Secondly Burke and Miller (2001) recommended using a script at the beginning of the first telephone interview to prepare the participants; this was built into the interview schedule (Appendix 15). Other advantages and disadvantages of face to face and telephone interviews are depicted in table 3.4. These were considered when analysing the data collected from both types of interviews, to ascertain the impact of the mode of interview on the responses obtained from the parents.

**Table 3.4 The Advantages and Disadvantages of Face to Face and Telephone Interviews (adapted from Novick 2008)**

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### 3.5.3.3 Self-Report Tools

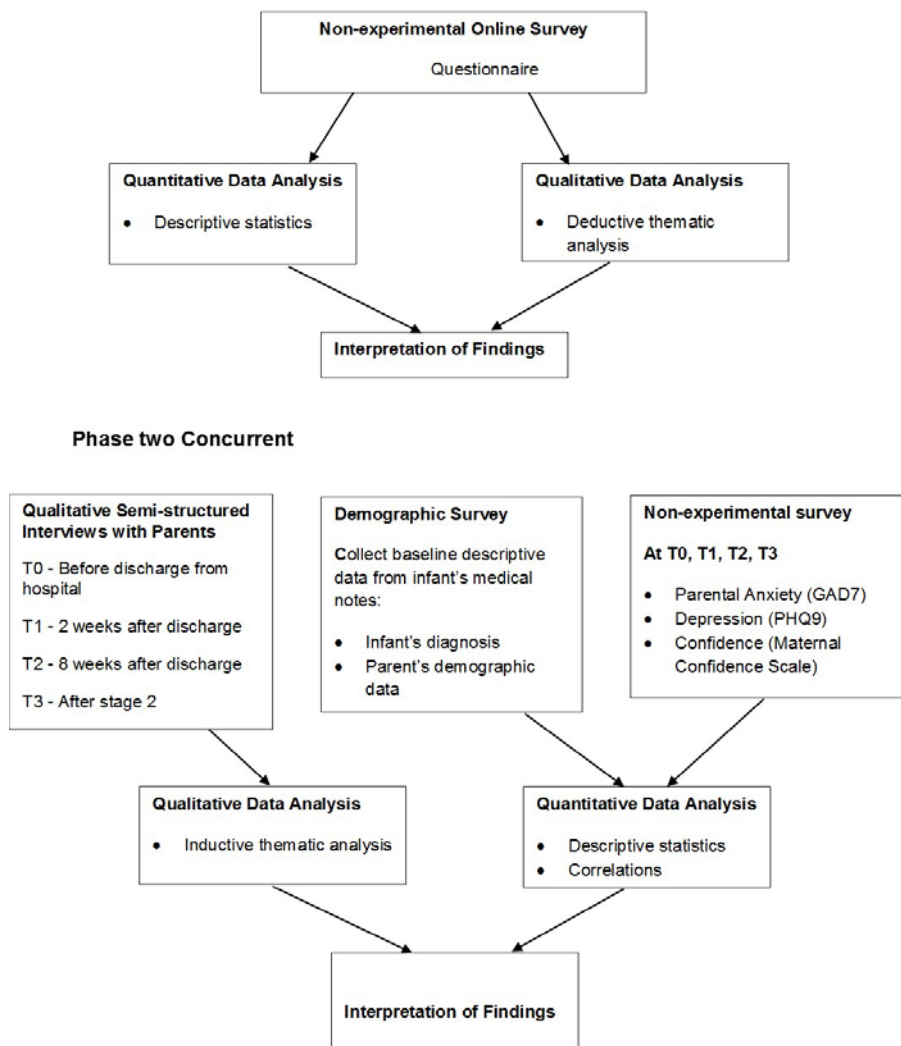
In addition to being invited to take part in the semi-structured interviews parents recruited to phase two of this study were asked to complete three self-report tools to assess: parents' confidence in looking after their infant (Maternal Confidence Scale; Parker, Zahr and Cole 1992 as described above), signs of General Anxiety Disorder (GAD7) (Spitzer et al 2006) and levels of depression using the Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer and Williams 2001) (see Appendix 16, 17). The online software application Coventry University Depression and Anxiety Support (CUDAS; Furze 2013) was used during the telephone interviews to calculate the score for GAD7 and PHQ9.

The GAD7 tool was developed as a brief self-report scale to identify possible cases of generalised anxiety disorder (GAD), which is one of the most common mental disorders (Spitzer et al 2006). The development took place during a criterion standard study, conducted during 2004-2005, and recruiting 2740 adults from 15 primary care clinics in the United States of America (USA). The study also aimed to identify probable cases of GAD and to evaluate its reliability and validity (Spitzer et al 2006). Spitzer et al (2006) found that internal consistency and the test-retest reliability was good (Cronbach  $\alpha=0.92$ ; intra class correlation= $0.83$ ). Convergent validity of the GAD7 was also good, demonstrated by its correlations with 2 anxiety scales: The Beck Anxiety Inventory ( $r=0.72$ ) and the anxiety subscale of the Symptom Checklist-90 ( $r=0.74$ ). Additionally, GAD7 had strong criterion validity for identifying possible cases of GAD. Furthermore, Spitzer et al (2006) found that a score of 10 or greater on the GAD7 was reasonable in identifying cases of GAD. Scores of 5-9 indicate mild anxiety, 10-14 moderate anxiety, and 15-21 severe levels of anxiety on the GAD7. The GAD7 was also identified as being appropriate for assessing symptom severity and monitoring change over time (Spitzer et al 2006) making this an appropriate tool to use with phase two of this study. This score has been successfully used to assess the psychological burden on parents of children with chronic illness (Khanna et al 2015), and cystic fibrosis (Quittner, Saez-Flores and Barton 2016).

The Patient Health Questionnaire (PHQ) is a tool used to make criteria based diagnoses of depression and other mental health disorders; PHQ9 is the PHQ depression scale, with 9 items representing the criteria upon which the DSM-IV depressive disorders are based (Kroenke, Spitzer and Williams 2001). Scores on the PHQ9 can range from 0 – 27; with scores between 0 and 4 indicating no depression, 5–9 mild depression, 10 –14

moderate depression, 15–19 moderately severe depression, and greater than 20 indicating severe depression (Kroenke, Spitzer and Williams 2001). The internal consistency of the PHQ9 was found to be high in a study involving two different patient populations and 6000 total participants; producing Cronbach’s alpha of 0.86 and 0.89, where  $\alpha$  values above 0.7 are desirable (Kroenke, Spitzer and Williams 2001). Furthermore, test–retest reliability had a high correlation at  $r = 0.8$ , with  $r$  values above 0.7 again being desirable (Kroenke, Spitzer and Williams 2001). This score has been successfully used to diagnose depression in parents of children with chronic illness (Resch, Elliott and Benz 2012; Khanna et al 2015) including cystic fibrosis (Quittner, Saez-Flores and Barton 2016). The mixed data collection methods used for each phase of this study are depicted in figure 3.1.

**Figure 3.1 Design frame; Data Collection Tools and Analysis at Each Phase**  
Phase one



### 3.5.3.4 Analysis Strategy

There are a variety of different approaches to data analysis commonly used in qualitative studies, such as content analysis, thematic analysis and interpretative phenomenological analysis (Maltby et al 2010). Content analysis was disregarded for this study as it primarily involves analysing the content, looking for patterns and grouping them accordingly. There is also debate around whether this method is more quantitative than qualitative; for example, some researchers utilising content analysis have predetermined criteria that they expect to find, resulting in counting the frequency with which the criteria appear in the data (Maltby et al 2010); this approach did not, therefore, meet the aims of the study. In comparison, interpretative phenomenological analysis seeks to explore people's perceptions of their experiences and aims to investigate the psychology underpinning their experiences (Maltby et al 2010). This method was carefully considered as an in-depth approach to the interpretation of data; however, given that this study was not only aiming to explore the psychology of the parents' experiences, but also to explore the potential impact of parents' demographics, this approach was also disregarded.

Thematic analysis was chosen because it is flexible and accessible, especially for novice researchers; it allows for social and psychological interpretation of data and can generate unanticipated insights (Braun & Clarke 2006). However, Braun & Clarke (2006) suggest several issues that can result in poor analysis including failing to analyse the data at all; using the data collection questions as themes; presenting a weak or unconvincing analysis and a mismatch between the data and the analytic claims that are made about it. These disadvantages were considered whilst Braun and Clarke's (2006) six phased step by step approach (summarised in table 3.5) was used for the qualitative analysis in both phases of the study; this was an iterative and reflexive process.

**Table 3.5 Step by step approach to thematic analysis (Braun and Clarke 2006)**

Phase
1. Familiarising yourself with the data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

The Statistical Package for the Social Sciences (IBM SPSS Inc.) version 22 for Windows was used for the quantitative data analysis in both phases. The sample in both phases was too small to undertake interpretive statistical analysis, therefore, descriptive statistics were employed to calculate the percentage and frequency of categorical variables. Means and standard deviations were calculated for continuous variables (anxiety, depression and confidence).

#### *3.5.3.5 Ensuring quality*

Methods of validating the quality of data, results and their interpretation are important components of good research; and whilst the procedures are different in qualitative and quantitative research, the purpose of checking the quality of the study remains the same (Thomas 2013). Discussions around quality in mixed methods research are in their infancy. However, Creswell and Plano-Clark (2011) state that in mixed methods studies, the action of merging quantitative and qualitative approaches initiates added validity issues that range further than those concerns raised for each approach individually. Having reviewed the perspectives of other mixed method researchers Creswell and Plano-Clark (2011) recommended that 'validity' was the best term to use in mixed methods studies and suggested strategies to address potential validity issues in data collection, data analysis and interpretation. These strategies outlined in table 3.6 were employed within this study.



**Table 3.6 Strategies for Minimizing Validity Threats (adapted from Creswell and Plano-Clark 2011: 240)**

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### Trustworthiness

The criteria for addressing trustworthiness proposed by Guba (1981) were used within the qualitative methods and corresponded to constructs utilised within positivist research (Shenton 2004). *credibility (relates to internal validity)*

This included adopting appropriate and well recognised research methods; random sampling of the participants in phase two; and triangulation using different data collection tools. Having worked at the study site previously, I was already familiar with the culture of the organisation. Debriefing sessions took place monthly at the study site and bimonthly with my supervision team; additionally, peer scrutiny took place within the research team at the study site. I kept a reflective diary throughout the study and updated it following each interview recording a thick description of the situation. My position and the influence of positionality has been described (Appendix 18). Finally, the findings were framed by examination of previous research.

*a) transferability (relates to external validity/generalisability)*

Background data to provide context for the study is provided in chapter 1 as well as description of the phenomenon being studied, which was the transition from hospital to home.

*b) dependability (relates to reliability)*

Overlapping methods were used as described earlier in this chapter to allow the study to be repeated

*c) confirmability (relates to objectivity)*

Triangulation was employed to reduce the effects of researcher bias. My beliefs and assumptions are described in section 3.1.1 Description of methods in chapter 3 allows the results to be scrutinised. The limitations of the study and the potential effects are discussed in section 7.6.2. An audit trail of the qualitative analysis is provided in section 3.4.8.

#### Validity and reliability

The measuring instrument used in phase one to identify parents perceived anxiety levels, the Likert scale, had primarily been chosen in collaboration and with guidance from the charity's statistician, for ease of use and understanding for the novice researcher and the participants. However, during data analysis the validity and reliability of the Likert scale was considered and evaluated. A change within the supervisory team brought with it different advice, support and knowledge of relevant validated scores. This resulted in a validated anxiety tool (GAD7, Spitzer et al 2006) being recommended and subsequently utilised for phase two of the study. Validity was addressed by examining the construct validity of the self-report tools that were used in both phases of the study to measure parents' psychosocial functioning. The validity of these tools related to the degree to which they measured what they claimed to be measuring (Polit and Beck 2008) and the reliability of the tools related to the consistency of data collection at each time point (Thomas 2013). The validity and reliability of the maternal confidence score (MCS), GAD7 and PHQ9 are explored in section 3.4.3.

#### Generalisability

Since this study explored the characteristics of parents, it was difficult to make generalisations because the parents were involved in the social phenomenon being studied. These parents had their own interests, motivations and enthusiasms; it was therefore recognised that the idiosyncrasies of the people being studied could have influenced the findings of this study (Thomas 2013). Furthermore, the small sample size

in both phases meant that the findings were unlikely to represent the wider population and therefore the extent to which generalisations could be made was very limited (Thomas 2013).

### 3.5.4 Procedures

#### 3.5.4.1 *Ethical Considerations*

In phase one, anonymity was maintained as the parent's personal details were not provided to me as the researcher. Instead an invitation email was sent to the Charity explaining the aims of the study and providing the URL to the online questionnaire. The invitation email included a copy of the participant information leaflet explaining what the study entailed. Consent was implied by parents completing and submitting the online questionnaire, however, an additional mandatory question was added following the ethics review, which asked parents to confirm that they consented to taking part in the survey. As the Charity's members are geographically spread across the whole UK, the likelihood that individuals could be linked back directly to the research was low. Additionally, future published information will not be linked to specific organisations (children's heart centres) as it will be presented anonymously. In phase one all information collected from parents was anonymous; each participant was given a response number in Bristol Online Survey (BOS) (Bristol University 2015).

The information collected via the Bristol Online Survey (BOS) website was kept secure as it was only accessible by me the Principal Researcher and was password protected. Only staff at the Charity had access to parent's personal information, email addresses and other details on the Charity's database, data protection was maintained as this information was not available to me as the principal researcher.

In phase two all information collected from parents was kept strictly confidential. Whilst confidentiality was maintained, if any potentially serious problems had been reported throughout the study, it was the professional and legal responsibility of the research team to refer the problem to the appropriate professional, so that something could be done about it. Confidentiality, privacy and anonymity was ensured in the collection, storage and publication of research material.

Only staff at the study centre had access to any other personal data not collected in the baseline information, data protection was maintained as this information was not available to me as the principal investigator. As the principal investigator, I had access to the parents' names and telephone numbers to undertake the telephone interviews. Data generated by the study was retained in accordance with Coventry University's policy on Academic Integrity. Data generated during the research will be kept securely in paper or electronic form for a period of five years after the completion of the research project.

In phase two, after reading the participant information leaflet and the measurements of anxiety and depression, some parents chose not to take part in the study, because some felt that being involved would make them anxious or depressed; or that they were too overwhelmed with the situation at that time. This self-selection may have meant that the families that were struggling the most opted out of the research. Alternatively, there was the possibility that a demand characteristic effect (Orne 1962) was being observed because of the nature of the study being undertaken. Some parents may have responded in a way that they thought the researchers wanted them to and may not have honestly answered the anxiety and depression tools because they did not want to be seen as being affected by the study. As there were not sufficient quantities of data, statistical analysis of this issue was not possible, however, this was considered as a possible data collection issue.

#### *3.5.4.2 Data Collection*

##### Phase One

This instrument and method of distribution (online) was economically viable and enabled a relatively fast turnaround in obtaining responses (Creswell 2003). The online questionnaire was piloted to test its effectiveness before being refined and developed for ease of completion and to ensure that participants interpreted meaning as intended (Oppenheim 1992). A poorly worded item may not have prevented participants from answering but may have produced results that were spuriously negative or positive (Oppenheim 1992). Every part of the questionnaire was piloted including the questions, the question sequence, the inventories and scales, the instructions given to participants, the answer categories and the number sequence.

Three families who were members of the Charity and had children aged between 0-3 years and one parent representative, a statistician on the Charity's Board with an older child with CHD, were invited to pilot the online questionnaire. Two parents participated, one mother and one father. Both found the questionnaire easy to navigate; the sequencing was felt to be appropriate; one parent felt that all questions were clear whilst the other felt that some were clear; one of the questions using a rating scale needed to be reworded as did the instructions for completing one of the questions. The feedback given by the two parents (see table 3.7) was useful and all comments were acted upon before the final version of the questionnaire was made available.

**Table 3.7 Feedback from the pilot questionnaire**

<b>Feedback received from parents piloting the questionnaire</b>
<p>I found questions 14, 20 and 30 quite hard to answer. Question 22 – continuous overnight feeds and 3-hourly during the day Question 30 – need to make it so you can only tick one box Question 33 – doesn't quite work at the moment - it needs rewording in some way so that it refers to first admission, second admission, etc. Hope this makes sense. Also, when I tried to submit my response, it comes up with an error message saying I need to complete each section of the question i.e. 33a through to 33l. I am about to put 'other' for all the sections I hadn't yet answered, to see if I can then submit my answers. Question 36 – I didn't answer as my baby is 10 and I couldn't give any meaningful answers trying to remember when he was 2. Questions 37 onwards – I didn't answer.</p>
<p>The survey doesn't ask overtly about the quality of written information received, or the source. It might be helpful to distinguish between information received at local hospitals compared to specialist units. Would it be helpful to include a 'deadweight' question - if you hadn't received this advice how do you think you would have felt? Happy to help further if required - I work for a research company</p>

## Phase Two

In phase two the data was collected from the point of discharge from hospital (T0) following the first stage of cardiac surgery, until their infant had been readmitted and was ready to go home following the second stage of surgery (T3).

All the interviews undertaken before discharge (T0) were conducted face to face, at the hospital. Parents were given a choice of location: either in the ward office or in their infant's room if the parents did not want to leave their infant. The interviews were undertaken by the Principal Investigator (me) or one of the research nurses, if I was unable to get to the hospital in time (if discharges were arranged quickly). Interviews at T1, T2 and T3 (see table 3.3) were conducted over the telephone by me, the Principal Investigator. A date was arranged for the interview at T1 before parents left the study centre. The interviews were audio-recorded with the consent of the interviewee and field notes were written at the time of the interviews and reflective notes throughout the study. At T1 most interviews were conducted on the telephone; one was conducted face to face at the request of the parents, during a visit to the hospital; all the T2 interviews were conducted via the telephone; four of the T3 interviews were conducted face to face, again at the request of the parents.

The reasons for non-completion of interviews being:

- Infants had been readmitted to hospital [at T1 (n=1), T2 (n=2), T3 (n=3)]
- Mothers not contactable or not returning calls at T1 (n=3), T2 (n=3), T3 (n=4)
- Father not available at T1 (n=1), T2 (n=1), T3 (n=2)

Parents were given paper copies of the MCS, GAD7 and PHQ9 at the first face to face interview to complete themselves. Responses to these and the MCS were recorded in Word documents and in the research diary.

Parent and infant demographic data was collected at baseline, because one of the secondary aims of this study was to explore whether parental demographics and psychosocial functioning had an impact on the transition from hospital to home. Furthermore, as the qualitative strand was dominant the constructivist (or interpretivist) approach aimed to understand the world in which these parents existed and how their reality was constructed socially, collecting demographic data helped to build up a picture of each family; whilst the constructionist approach maintained that their knowledge emerged from social interactions. Completed baseline questionnaires were only accessed by the research team.

The information collected from the face to face and telephone interviews was analysed by me the Principal Investigator to draw conclusions. As a constructivist researcher I relied upon the parents' views of the situation and recognised the impact of my own

background and experiences on the research and on the constructionist interactions with the parents as participants. As the researcher is the tool of data collection in qualitative research (Holloway & Walker 2000) I had to be aware of the potential of introducing an experimenter effect, such as the Hawthorne effect, where people's behaviour changes because of the interest that is being taken in them (Thomas 2013) when conducting interviews. This effect was named after an iconic study that was undertaken in the Hawthorne factory, Chicago in 1924 (Roethlisberger and Dickson 1939). My expectations as the researcher could also have influenced the research participants, who could consciously or unconsciously have confirmed to the lead that I may have appeared to be giving through gestures, tone of voice or the actual questions that I was asking (Thomas 2013).

### *3.5.4.3 Analysis*

#### Analysis of Qualitative Data

##### Stage 1- Familiarising yourself with the data

The qualitative data for phase one was downloaded from the Bristol Online Survey (Bristol University 2015) website into a Microsoft Word document; printed and read and re-read to familiarise myself with the data. Initial notes were made in a wide right hand side margin as thoughts and ideas emerged relating to the data. For phase two this stage was ongoing throughout the data collection as the interviews from phase two were undertaken longitudinally beginning in August 2013, until January 2015. Transcription of the first 8 interviews from T0 was undertaken using Microsoft Word. Initial thoughts and mind maps were generated and recorded on hard copies of the transcribed data. Interviews were transcribed on an ongoing basis, so I returned to familiarise myself with the data at regular intervals. Nvivo10 was used from March 2014, six months after Phase two had commenced recruitment. By this time the first (T0), second (T1), third (T2) and some of the final interviews (T3) had been conducted with 8 of the 13 families. The audio files and transcriptions already conducted for phase two were imported into NVivo 10, as well as phase one data. Once using NVivo 10 all interview audio recordings were imported into a project within NVivo 10 and those that had not already been transcribed in Word were transcribed directly within NVivo 10 and saved to this project.

## Stage 2 Generating Initial Codes

For phase one the data were initially colour coded by hand to identify initial codes. After importing the data from phase one and the interview transcriptions into NVivo 10, 'free nodes' (stand-alone nodes that had no clear logical connection with other nodes) were created by reading through the imported transcripts from both phases. Subsequently transcribed interviews for phase two were also coded, into free nodes or broad themes, creating 749 free nodes in total. The creation of free nodes occurred less frequently as the coding progressed because the references in the data began to fit into the existing free nodes. The number of references coded to each free node varied, at this stage some of the free nodes with very few references were combined with other small free nodes to create 63 parent nodes. Parent nodes contained child nodes, for example 'not getting enough sleep' and 'postoperative'. This stage generated combined initial codes for the data from phase one and phase two.

## Stage 3 Searching for themes

After transcription and coding, the next stage was to search for themes. In phase one the data were themed deductively as the analytic interest was to ascertain key points that could be taken into consideration for the development of phase two. This approach to analysis is recognised as providing a less rich description of the data overall, however, it enabled a more detailed analysis of an aspect of the data focusing on discharge home (Braun and Clarke 2006). In phase two an inductive approach was undertaken, whereby the themes are highly connected to the data itself; I aimed to code the data without fitting into any pre-existing model or my own pre-conceived ideas specifically based phase one findings (Braun and Clarke 2006:12).

At this stage five separate projects were created in NVivo 10, one for phase one and four separate projects for T0, T1, T2, T3 for phase two, creating a structured framework for chronological analysis. Each of these projects were reviewed individually and empty free nodes were deleted, reducing the number of parent and child nodes; these were renamed and merged to cluster the codes into broader categories. In retrospect, had I been more proficient with NVivo 10, it would have been beneficial to create individual projects at the beginning of analysis. The benefit of not doing this earlier was the consistency in coding across the data, however, as more interviews were coded the disadvantage was coding into pre-existing nodes rather than developing new nodes; resulting in the potential to miss new or varying themes.



The software was easy to use to create free nodes and tree nodes, a hierarchical structure was constructed, creating a general parent node at the top and moving to more specific child nodes within this. These broader categories of codes enabled reconstruction of the data into a framework that made sense to further develop the analysis for each 'project', whilst addressing the research question(s).

#### Stage 4 Reviewing themes

This phase involved the refinement of themes that had initially been identified during earlier coding of the data. At this stage, each of the projects for phase one and phase two (T0, T1, T2, T3) were reviewed separately to reconsider the themes emerging from the coding and from my preconceived ideas of transition based on my early conceptual framework and the middle range transition theory (Meleis et al 2000).

In each of the projects, the parent nodes were opened to show the child nodes to review (drilling down) and re-code them to new child nodes or link them to different parent nodes, to better understand the meanings embedded within them. The original hard copies of coding for phase one were reviewed to compare initial coding with that emerging within NVivo 10. Reassuringly, the original themes reflected those identified within NVivo 10; however, despite potentially being influenced by the initial hand coding, there were additional codes not identified previously. Coding in NVivo 10 also enabled quantification of the number of references to a node, thereby identifying the most frequently occurring nodes and therefore the most prevalent nodes within themes (box 3.1), albeit content analysis was not the chosen method.

#### Box 3.1 Key themes originally arising from Phase one

- |  |
|--|
| <ol style="list-style-type: none"> <li>1. Mixed emotions about going home: fear versus excitement</li> <li>2. The need for effective discharge preparation for parents</li> <li>3. The need for effective discharge planning and preparation of community staff and local hospital teams</li> <li>4. Gaining control: The need to return to family functioning</li> <li>5. The need for access to information and advice [once at home]</li> </ol> |
|--|

#### Stage 5 defining and naming themes

Stage 5 was to define and rename the themes. The final framework for Phase one emerged following presentation of the 5 key themes identified in stage 4 (box 3.1) at two different events. First at the University of Worcester's Research Seminar Series on 24<sup>th</sup>

February 2015; the attendees included two Professors, four Children's Nursing Students, several Senior Lecturers and Research Assistants. The questions arising encouraged consideration of the themes in alternative ways. Whilst the questions did not raise anything new within the data; these factors had not been presented within the 5 themes. A week later the same slides were presented at a networking event for congenital cardiac nurses at the Royal College of Nursing in London. The questions arising from this presentation were very different and referred to clinical practice rather than the research, therefore did not progress analysis any further. These two experiences enabled reflection on the analysis to further reduce the data to 4 key themes and to consider the constructivist sub themes within these.

The reduced themes from Phase One were subsequently presented at the RCPCH/RCN conference in Birmingham on 28<sup>th</sup> April 2015 (table 3.8). Some of the questions arising related to the provision of support for parents clinically, including psychological support and specifically what support we should be providing and for which parents. This had already been included in the discussion, however, it encouraged broader thinking about my recommendations. I was also asked whether any parents had demonstrated maladaptive behaviours; my presentation had focused on adaptation and adjustment and so this question reminded me to consider maladaptation in the discussion.

**Table 3.8 Final framework for Phase One**

<b>Key themes</b>	<b>Sub themes</b>
Mixed emotions about going home: fear versus excitement	Novice parents Experienced parents Distance of specialist hospital from home
Knowledge and preparedness	Of parents confidence Of community and local hospital teams
Support systems	Family Friends HCPs Support groups Other cardiac parents
Gaining control: The need to return to family functioning	

Stage 5 was initially the most difficult for phase two, as the parent nodes had been created based on the underpinning middle range transition theory (Meleis et al 2000). I stared at the themes in the first project (T0) and could not see anything new or

different. Of course, because the data had originally been coded together in one large project the same parent nodes occurred in each of the individual projects, however, upon closer inspection the child nodes were different. Whilst reviewing T0, phase one themes were explored to identify whether the same themes had emerged for phase two. A memo created on 6<sup>th</sup> June 2015 (box 3.2) demonstrates reaching a threshold concept. The similarities to Maslow's (1943) work had not been previously identified, however, I was also aware of other research that had identified safety and survival, vigilance and uncertainty as key elements of parents' experiences (Rempel et al 2009, 2012a, 2012b). Additional reading was undertaken around subjective wellbeing, emotions and feelings, which became tangential, whilst enabling abstract and inductive consideration of T0 nodes to reduce the data further. This also enabled exploration of ordinary, expected and unexpected themes.

Reviewing the extant literature obtained throughout the course of the study (and since the initial literature search in 2011) was avoided until completion of phase two data analysis. However, I was unable to completely ignore my theoretical and epistemological pledges, and therefore the "data were not coded in an epistemological vacuum" (Braun and Clarke 2006:12).

#### Box 3.2 Memo Extract from NVivo 10 project T0

*"Today I looked back at the results of phase one to guide the definition of themes for phase two T0. It suddenly struck me that the last theme 'gaining control', linked to Maslow's hierarchy of needs - basic physiological needs, safety and security and love and belonging. I undertook a quick Google search for a diagram of Maslow's hierarchy to remind myself of the content and then for a website that explained the theory and found <http://www.simplypsychology.org/maslow.html> This led me to look for evidence around these human needs and highlighted the word 'well-being'. The website referenced this article,*

*Tay, L., and Diener, E. (2011). Needs and subjective well-being around the world. *Journal of Personality and Social Psychology*, 101(2), 354. This looks more objectively at human needs than Maslow's hierarchy, which was developed based on biographical accounts of 18 people - all prominent white males"*

By looking more carefully at the data four main themes became evident for T0:

- Safety and security
- Survival
- Love and support
- Mastery

The same four themes were used as a framework to structure the free nodes within the other three time points, recognising that they may or may not fit. The analysis at this stage included reviewing the content of the proposed framework, by looking at individual nodes to identify *what was said* and *how it was said* to ensure that the coded annotation matched the node and the theme. As well as being tracked through the annotations in NVivo 10, it was also cross linked to the observations made within my field notes. I also considered *who had said it*, by tracking through case nodes linked to each participant's unique identifier code and their demographic information set up as attribute values for a person in NVivo 10. Again, this was cross referenced to my field notes.

As the analysis progressed linked memos in NVivo 10 within each of the projects were used to document thoughts and propositions regarding the framework that was emerging and notes were kept in my field journal. This was to provide reminders that could be referred to later when writing the discussion. The order of prevalence for the four key themes was found to be different at each time point and in addition the sub themes were different for each time point also.

Phase 6 producing the report

The next stage was to write a first draft of findings. Phase one findings were analysed and written up about a year before phase two findings were written. Having time away from the writing enabled objective thinking about the findings and field notes and how it linked to the extant literature. Notes were made from which conclusions were drawn enabling a draft plan of the discussion.

A blog from QDA (posted in December 2014) about using NVivo 10 to support the analysis and demonstration of rigour was useful as it matched well to Braun and Clarke's (2006) 6 stages of thematic analysis.

<http://qdatraining.com/forums/topic/nvivo-tools-to-support-relationships-in-a-qualitative-framework-2/>

The blog identifies five key areas to address the analysis:

1. The content of the framework - what was said and how it was said (by which parents). This was tracked through annotations in NVivo 10 which were also linked from field notes and observations (recorded in a notebook following each interview and through reflections and memos in NVivo 10).
2. Who said it – this was tracked through case nodes linked to profiling or demographic information in NVivo 10 (these has been set up for each parent)
3. Coding patterns –visualisations in NVivo 10 were created to view patterns emerging from the data
4. A formal documenting process which challenges the researcher and participants alike. Questions that arose during the analysis were documented and linked using memos in NVivo 10. These memos were synthesised into the story arising from the parents' narratives
5. The extant literature – some of the literature was loaded into NVivo 10 and coded to the same 'patterns of experience' that were developed from the primary data. However, this was not employed as effectively as it could have been, mainly because of my limited knowledge and experience of NVivo 10. Instead what parents had said was manually compared with the extant literature, by referring to the literature review chapter and notes previously made. A limitation here was that because all the extant literature was not loaded and coded into NVivo 10 the findings could not be tested for congruence with the literature and therefore did not identify gaps through NVivo 10. This is a learning point for future use of NVivo 10.

## Analysis of Quantitative Data

The quantitative data in both phases, was analysed using the Statistical Package for the Social Sciences (IBM SPSS Inc.) version 22 for Windows at the end of data collection. Descriptive statistics were employed to calculate the percentage and frequency of categorical variables. Means and standard deviations were calculated for continuous variables (anxiety, depression and confidence).

### 3.6 Chapter summary

In summary, this chapter has explained the methodological approach, and the methods employed for both phases of this study. The next chapter will present the findings for phase one.

## Chapter 4. Phase One Findings

### 4.1 Introduction

This chapter presents the findings from phase one of this study including: the descriptive data in terms of parental demographics and the family's medical information and the descriptive statistics arising from the categorical data, which are presented alongside the qualitative findings. The chapter concludes with a discussion, relating the findings to the contemporary evidence. The aim of phase one of the study was to retrospectively explore parents' preparedness relating to the information that they received when their infant was discharged home from the specialist heart hospital after the first stage of surgery for a univentricular heart (right and left sided). Additionally, the aim was to find out more about the family to help gain an understanding of how they dealt with the transition, how they adapted to the new situation and whether the information that they were given helped in that transition.

### 4.2 Parental demographics

Twenty-eight parents participated in the online survey, twenty-one mothers and 7 fathers. There was a total of 22 responses, (35% response rate) from 6 couples (27.3%), 15 mothers (68.2%) and 1 father (4.5%). The questionnaire was structured so that both parents could contribute to the answers independently therefore in total 7 fathers and 21 mothers responded (n=28 participants). Whilst it was mostly mothers that completed the questionnaire, the father's demographic data had been completed in 20 responses. Care had been provided in 11 different specialist cardiac units across the UK and 1 parent commented on their care in Australia. The responses from this parent were reviewed from an international perspective as the surgical treatment offered in Australia for these infants mirrors the UK, however, health care systems do differ and therefore the individual responses from this parent were also considered separately during the analysis, however, they echoed the responses from other parents.

There was a variation in the sample in terms of age range, employment status, family income; distance from the specialist hospital, timing of diagnosis in terms of antenatal or postnatal and age of their infant at the time of completing the questionnaire (see table 4.1). However, most parents who completed the questionnaire were living with their

partners (n=18, 81.8%) and most stated their ethnicity was white British (n=17, 80.9% mothers; n=18, 90% fathers). Over two thirds of mothers (n=15, 68.2%) had a Bachelor's degree or higher. Half of the fathers (n= 11, 50%) had a Bachelor's degree or higher. 75% of the fathers were employed and 20% were self-employed whereas 40.9% of mothers were employed and 40.9% were either on maternity leave or a homemaker. Almost half of the families (42.8%) were in the higher total household income bracket [over £50,000] (see table 4.1).

### 4.3 The Family's Medical Information

The family's medical information is presented in table 4.2. The age of the infants at discharge (T0) varied from 3 days to 70 days; the mean age of infants at discharge was 28.95 days (SD 17.38, median 26.5 days). Additionally, T1 (at the time of completing the questionnaire) was not a standard time point for all the families that participated; the mean infant age at T1 was 15.68 months (SD 7.59, median 16 months).

Two thirds of respondents had been given an antenatal diagnosis that their infant had congenital heart disease at the 20-week scan. The infants' diagnoses were hypoplastic left heart (and variants) in 14 infants (64%) and hypoplastic right heart in 8 infants (36%). The latter group included tricuspid atresia, pulmonary atresia with intact septum and unbalanced forms of transposition with small right ventricle. Almost half (45.5%) of the infants spent longer than three weeks in the specialist heart hospital.

Most parents were fit and healthy (mothers n=19, 86.4%; fathers n=20, 90.9%). None of the parents had congenital heart disease; two mothers and one father had chronic illness and one mother reported mental health problems. Those responding (n=15) stated that the other siblings were fit and healthy (n=12, 54.4%), whilst two siblings had other congenital heart disease. The age of the infants at discharge (T0) varied from 3 days to 70 days; the mean age of infants at discharge was 28.95 days (SD 17.38, median 26.5 days).



**Table 4.1 Phase one demographic data**

<b>Infant's Age (at time of survey)</b> 0-1 year 1 year 2 years	Infant/child (n=22) 7 (31.8%) 14 (63.6%) 1 (4.5%)	
<b>Number of Siblings</b> 0 1 2 3	7 (31.8%) 8 (36.4%) 6 (27.3%) 1 (4.5%)	
<b>Primipara</b> <b>Multipara</b>	7 (31.8%) 15 (68.2%)	
<b>Parent's Age</b>  22-25 26-30 31-40 41-50 51-60	<b>Mother (n=22 responses)</b> 2 (9.1%) 4 (18.2%) 12 (54.5%) 4 (18.2%) 0	<b>Father (n=21 responses)</b> 0 1 (4.5%) 16 (72.7%) 3 (13.6%) 1 (4.5%)
<b>Employment</b>  Employed for wages Self-employed Out of work and looking for work Out of work but not currently looking for work A homemaker Maternity/paternity leave	<b>Mother (n=22 responses)</b> 9 (40.9%) 0 1 (4.5%) 3 (13.6%) 7 (31.8%) 2 (9.1%)	<b>Father (n=20 responses)</b> 15 (68.2%) 4 (18.2%) 1 (4.5%) 0 0 0
<b>Education</b>  Secondary school to 16 – (GCSE or equivalent) Sixth Form/College (A levels, BTEC, IB, or equivalent) Bachelor's degree (BA, BSc) Master's degree or Professional Degree Doctorate degree (e.g. PhD, EdD) No qualifications	<b>Mother (n=22 responses)</b> 3 (13.6%) 4 (18.2%) 6 (27.3%) 9 (40.9%) 0 0	<b>Father (n=20 responses)</b> 5 (22.7%) 3 (13.6%) 6 (27.3%) 4 (18.2%) 1 (4.5%) 1 (4.5%)
<b>Ethnicity</b>  White – British White - Irish White, any other Black or Black British	<b>Mother (n=21 responses)</b> 17 (77.3%) 1 (4.5%) 2 (9.1%) 1 (4.5%)	<b>Father (n=20 responses)</b> 18 (81.8%) 0 2 (9.1%) 0
<b>Distance from home to the specialist heart hospital</b>  Less than 20 miles 20-30 miles 30-40 miles 50-100 miles over 100 miles	<b>Number of responses (n=22)</b> 4 (18.2%) 2 (9.1%) 4 (18.2%) 8 (36.4%) 4 (18.2%)	
<b>Living Arrangements</b>  Living with partner (married or unmarried) Living alone (with children) Not stated	<b>Number of response (n=21)</b> 18 (81.8%) 3 (13.6%) 1 (4.5%)	
<b>Total Household income</b>  Less than £10,000 £10,000-£19,999 £20,000-£29,999 £30,000-£39,999 £40,000-£49,999 Over £50,000	<b>Number of responses (n=21)</b> 1 (4.8%) 3 (14.3%) 4 (19%) 1 (4.8%) 3 (14.3%) 9 (42.8%)	
<b>Benefits received</b>  None Child benefit Working Tax credit DLA Employment Support Allowance Carer's Allowance Income support with carers premium	<b>Number of responses (n=19)</b> 6 (27.2%) 8 (36.4%) 5 (22.7%) 7 (31.8%) 1 (4.5%) 3 (13.6%) 1 (4.5%)	

**Table 4.2 Phase One Family's Medical Information**

<b>Parent's Health</b>	<b>Mother</b> (n=22 responses)	<b>Father</b> (n=21 responses)
Fit and healthy	19 (86.4%)	20 (90.9%)
Congenital Heart Disease	0	0
Chronic illness	2 (9.1%)	1 (4.5%)
Mental Health problems	1 (4.5%)	0
<b>Siblings Health</b>	<b>Number of responses (n=15)</b>	
Fit and Healthy	12 (54.5%)	
Other Congenital Heart Disease	1 (4.5%)	
Chronic illness	1 (4.5%)	
CHD, Chronic and Mental Health problems	1 (4.5%)	
<b>Time of Infant's CHD Diagnosis</b>	<b>Number of responses (n=22)</b>	
Antenatal	17 (77.3%)	
Postnatal	5 (22.7%)	
<b>Infant's Diagnosis (in parents' words)</b>	<b>Number of responses (n=22)</b>	
Hypoplastic Left Heart Syndrome, including: <ul style="list-style-type: none"> <li>Mitral atresia and Coarctation of Aorta</li> <li>Coarctation and 2 x VSD</li> </ul>	14 (63.6%)	
Hypoplastic Right Heart, including: <ul style="list-style-type: none"> <li>Pulmonary atresia</li> <li>Tricuspid Atresia</li> <li>Tricuspid atresia with ventricular septal defect</li> <li>Transposition of the Great Arteries (TGA, with double inlet left ventricle, pulmonary stenosis and dextrocardia)</li> <li>TGA and pulmonary atresia, VSD, ASD</li> </ul>	8 (36.4%)	
<b>Length of infant's first hospital admission</b>	<b>Number of responses n=22</b>	
1-3 days	1. (9.1%)	
4-10 days	1 (4.5%)	
11-14 days	3(13.6%)	
15-21 days	6 (27.3%)	
22-28 days	4 (18.2%)	
29-31 days	2 (9.1%)	
5 weeks	2 (9.1%)	
1-2months	1 (4.5%)	
Greater than 2 months	1 (4.5%)	

## 4.4 Qualitative and Quantitative Findings

Four key themes emerged from thematic analysis of the qualitative data (Braun & Clarke 2006; section 3.2.8), which was the detailed parental responses regarding their experiences; however, there was some overlap across the themes. The descriptive statistics arising from the categorical survey data are included to support the themes, which were:

1. Mixed emotions about going home: fear versus excitement
2. Knowledge and preparedness
3. Support systems
4. Gaining control: The need to return to or commence family functioning

### 4.4.1. Mixed emotions about going home: fear versus excitement

Parents described a range of both positive and negative experiences of discharge and these mixed emotions were evident in all parents' descriptions regarding their experiences of going home, as these examples show: *"I was very happy, but very sad. I could not accept the fact that other children are healthy and mine is sick"* (M8). *"A little scared but really excited"* (M22). *"Delighted that we were finally going home. Somewhat anxious about everything I had to look out for"* (M5).

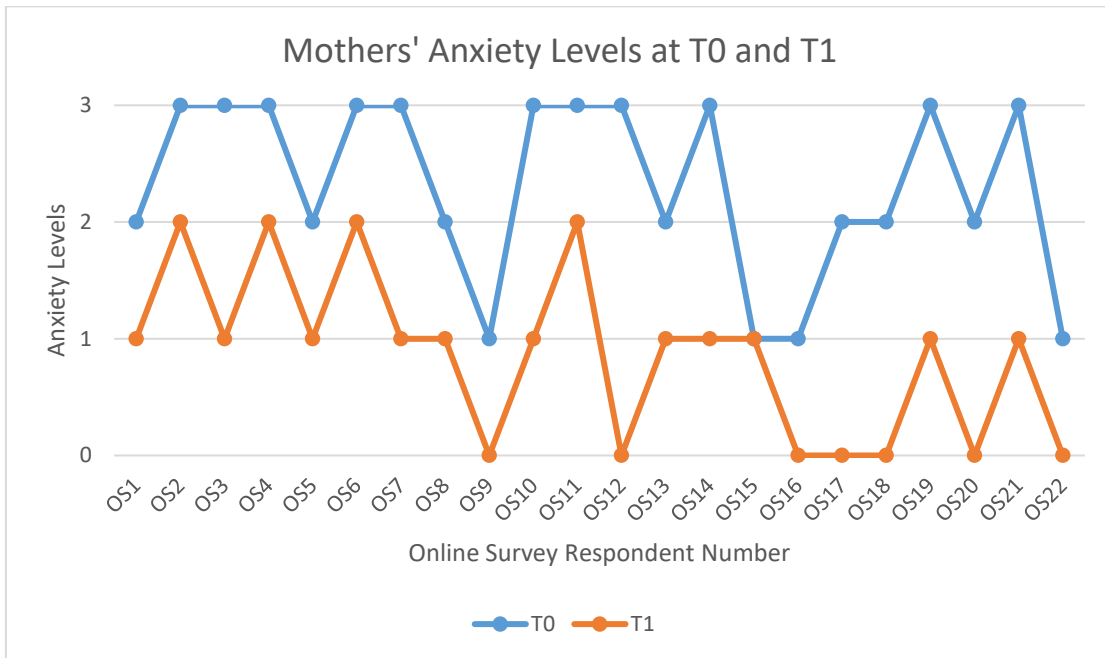
A constructivist subtheme emerged within the parents' descriptions of their emotions, which related to whether the parent was a first-time parent or already had other children. For first time parents, their excitement related to *'getting home to be a mum'*; bonding with their infant, getting to know their baby and adopting the parenting role. These parents were fearful of the responsibility of being a first-time parent, as this example demonstrates: *"I was very frightened just because I was a first time mum so felt the huge responsibility of being a mum for the first time and not really knowing what I was doing"* (M7).

In addition, their fears related to being a parent of a baby with a cardiac problem, for example: *“I was terrified at how I was going to manage, I was relieved to be leaving the local hospital after a month of being in hospital (two weeks in the specialist hospital, two weeks in the local hospital) and utterly elated to be taking my baby home. Again, it was a very mixed bag of emotions”* (M7) as well as the associated problems of going home with their fragile baby, as this mother described: *“I don't remember being particularly worried about her heart condition as she had had her surgery. I was, however, stressed about her weight gain as she hadn't gained much in hospital and I felt very responsible for making sure she got enough breastmilk. She was a sleepy baby, I felt because of her heart condition, and therefore didn't think other mums would be able to relate to my issues”* (M9). Conversely parents with other children described their excitement of going home to their family, and seeing their other children, for example: *“Absolutely terrified but we longed to be a family for so long so it was good that we were able to do that”* (M4).

The fears described by parents related to the fear of: being alone; not having monitors at home; night times; recognising deterioration; that the baby would stop breathing; the unknown; not knowing what to do; not knowing who to contact; the fear of something happening and the huge responsibility of going home for the first time. These fears about going home were also reflected in the heightened levels of anxiety that both mothers and fathers perceived they had experienced before discharge home for the first time from the specialist heart hospital [at T0] (blue lines in figure 4.1, 4.2); compared to their perceived levels of anxiety in relation to how they were feeling at the time that they completed the online questionnaire [at T1] (orange line in figure 4.1, 4.2).

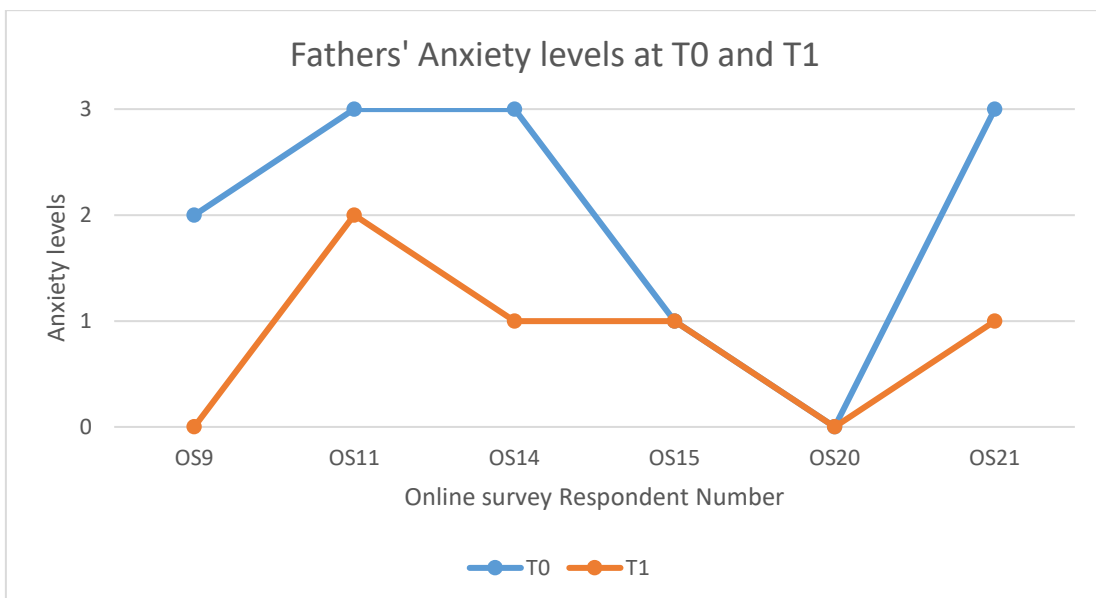
From the qualitative data, it was difficult to separate out the fears described by parents in terms of their infant's diagnosis, because every parent that commented described being fearful in some way. However, another constructivist subtheme arising from the qualitative data, related to the distance of the specialist hospital from home. Some parents commented on their fear of being so far away from the specialist hospital, for example one mother described that they were: *‘terrified and underprepared especially as we lived so far from the hospital and had to rely on the small local hospital that were not equipped to deal with the condition’* (M11). Given that some parents clearly described their fear of being so far away from the specialist hospital, these were real and socially constructed fears.

**Figure 4.1 Mothers' Anxiety Levels at T0 and T1**



Where anxiety was rated as: Not at all =0, Slightly = 1, Moderately =2, Extremely =3  
 Respondents 1, 2, 10, 11 and 17 received a post-natal diagnosis.

**Figure 4.2 Fathers' Anxiety levels at T0 and T1**



In summary, this theme 'mixed emotions: fear versus excitement', considered factors that parents were excited about. Some of these linked into the fourth theme about 'gaining control' and returning to what some parents described as 'normal' family functioning, whereas for the first-time parents it was the excitement of getting home to become a parent that was more apparent. The fears and anxieties that parents experienced upon discharge home also related closely to the next theme that emerged in terms of parents' and Health Care Professionals' (HCP) knowledge and preparedness, and hence the effectiveness of discharge preparation through teaching and provision of information. The findings relating to parents perceived levels of confidence at T0 and T1 are also explored within this theme, due to the close relationship between knowledge, understanding, preparedness and competence.

#### 4.4.2 Knowledge and Preparedness

This theme was subdivided into 'knowledge and preparedness of parents' and 'knowledge and preparedness of the community and local hospital teams' because parents separated out their perceived knowledge and preparedness from that of those supporting them at home.

##### 4.4.2.1 Knowledge and preparedness of parents

Parents' comments about their knowledge and understanding demonstrated different levels of competence at the point of discharge (T0). Some parents were consciously competent, as this example demonstrates: *'I had written everything down in a special book and kept a diary for 6 months of her meds/sats etc. We had had CPR training, so that was scary but it was good and supportive'* (M13). However, most parents recognised limitations in their knowledge (they were consciously incompetent) and reflected on their preparation before being discharged, as one mother explained: *'The info given to us from the specialist heart hospital was excellent but it was a scary and bewildering time so it probably didn't all go in - only over time as my understanding in the condition grew and my confidence in being able to be a good mum grew'* (M7).

At this post discharge stage some parents classed themselves as novice in terms of their knowledge and preparedness, as going home with their fragile infant was a new

experience for them. Some parents wanted to know more and felt unprepared for going home, as these comments demonstrate: *[I would have liked] "to be better prepared for the signs of going into heart failure or becoming ill"* and *"to be prepared that it can be hard work and tiring"* and *"I think parents need to be better prepared for home and how hard it can be"* (M1).

*"We received some very vague statements when leaving, along the lines of "you are the parents you will know when there is a problem"* (M2).

*"I did want to know more about life support and what signs to look out for. I think we got these from our own internet research"* (M9).

*"I would have like more definite information about who to contact if I needed advice. I would have liked her local hospital to have known about her, as she was sent in a couple of times with colds, just to check her O2 sats"* (M9).

As demonstrated in the comments above, parents could retrospectively identify elements that would have made their discharge preparation more effective, including: understanding feeding and weight problems; understanding how to administer medications; learning signs of heart failure and what to look out for; understanding the risks of normal childhood illnesses and knowing who to contact. Additionally, parents recognised that at the time of discharge they thought that they had knowledge and understanding, but they were unaware of their limitations (they were unconsciously incompetent). For example, one mother explained that she had been taught about the signs to look out for but despite thinking that she knew what they were, she missed them when they occurred: *'It was certainly a crisis management situation taking each day as it came and constantly being vigilant for the signs that I had been told to look out for. Even when they were there I didn't see them, but fortunately we had a follow up appointment [at the specialist centre] 2 weeks after discharge and we were then readmitted'* (M6).

It is possible that other factors impacted upon parents' ability to recognise deterioration in their infant once they were at home, such as normalising the signs and fear of another separation from the family unit, as this mother reflected: *'It was such a relief to be home and out of [the] hospital environment and to see my daughter that in fact I may have unconsciously ignored some signs that he wasn't managing as well as he should have been. I desperately didn't want to go back into hospital and leave my daughter again. I*

*think this is key information because not many people would admit to this being a barrier to them seeking help for their baby' (M6).*

Furthermore, social factors, such as their own expectations of their role, further added to the pressure of going home: *'I was a first-time mom so felt a huge responsibility of being a mom for the first time and not really knowing what I was doing' (M7).* Psychosocial functioning and previous experiences of parenting were also impacting factors, for one mother it was more about survival: *'I had already been a mother to a young baby but this time around all other concerns were over ridden by a need to make sure that the baby survived. There was no time at that stage for feelings in terms of satisfaction etc. it was frightening' (M6).*

Some parents also recognised that despite being informed of what to expect they were still unprepared for going home and stated that nothing can prepare you for the level of responsibility. These findings would suggest that there is a need to clarify before discharge, parents' knowledge, understanding, skills and levels of competence in relation to recognition of deterioration; to ensure that they have understood the teaching and preparation that they have been given.

The information that parents received about their infants was variable. Parents were asked whether they received teaching that was 'general to all cardiac babies'; 'specific to their own baby' or 'no teaching at all' (see Figures 4.3-4.11). Approximately a third perceived that they had received *no teaching* at all regarding essential care such as: wound care; breathing; skin colour; activity level and feeding and over half of those responding received no teaching regarding heart rate, body temperature and measuring oxygen saturations. However, as detailed above only 5 infants received oxygen saturation monitoring at home. Almost half of the respondents felt that they were taught signs '*general to all cardiac babies*' regarding wound care; feeding and weight. Whereas the number that were taught signs '*specific to their baby*' was generally less, with approximately a third being taught specifically about breathing; measuring oxygen saturations; skin colour; heart rate; activity level; feeding and weight for their infant.



Figure 4.3 Teaching regarding breathing Figure 4.4 Teaching about wound care  
 Blue = no teaching; Orange = generic teaching; grey = specific teaching

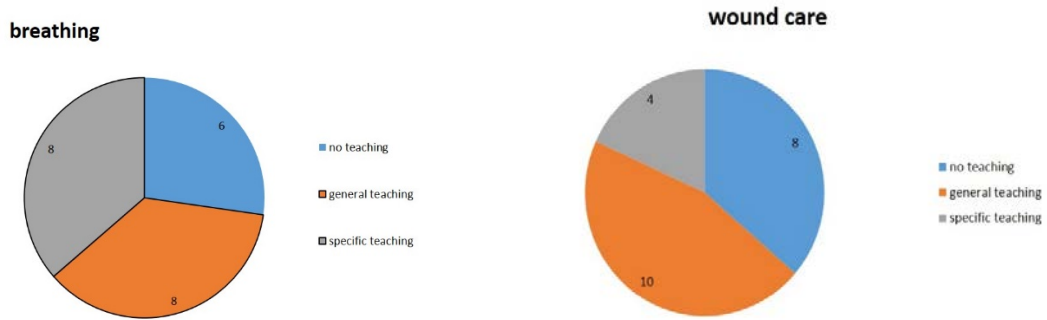


Figure 4.5 and 4.6 Teaching about measuring oxygen saturations and skin colour

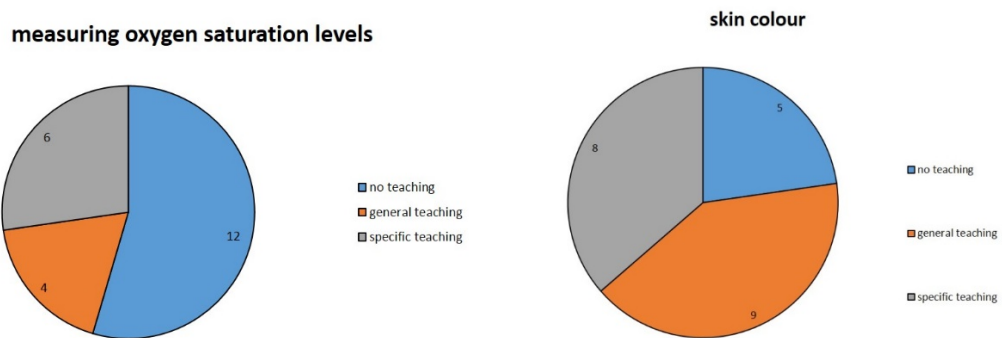


Figure 4.7 and 4.8 Teaching about heart rate and body temperature

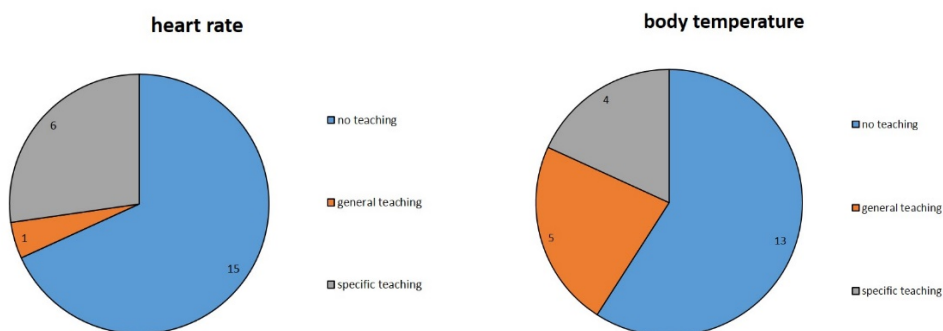


Figure 4.9 and 4.10 Teaching about activity level and feeding

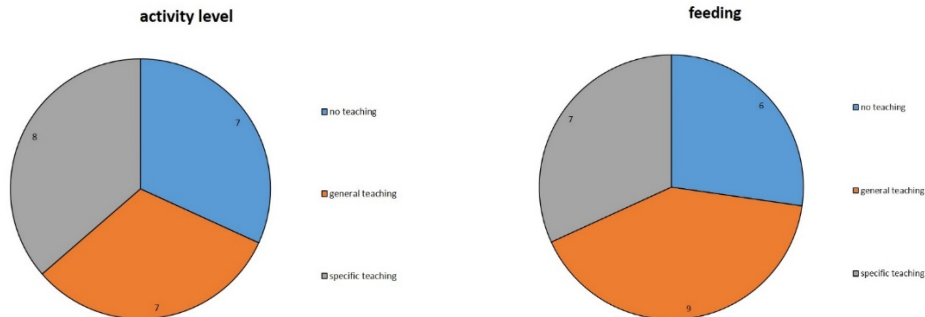
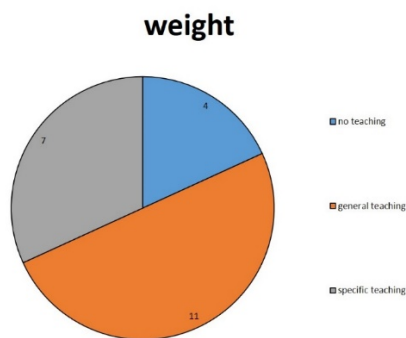


Figure 4.11 Teaching about weight



In terms of confidence, parents generally reported being anxious about going home in their explanations and none of them described feeling confident. However, they were also asked to score their perceived levels of confidence before being discharged from the specialist hospital for the first time [T0] and at the time of completing the questionnaire [T1]. This confidence score is rated based on items around knowledge, tasks and feelings about parenting their infant with the highest score being 70 (Parker, Zahr and Cole 1992). The mean maternal confidence score at T0 was 54.2 (SD=11.24, range 29-70); the mean paternal confidence score at T0 was 53 (SD= 12.14, range 41-70). Whereas, the mean maternal confidence score at T1 was 65 (SD= 3.74, range 58-70) and the mean paternal score at T1 was 61.3 (SD=8.89, range 49-70) indicating higher levels of confidence in both mothers and fathers at T1 than T0, albeit slightly lower

confidence scores for fathers at T1 than mothers. There were however, smaller standard deviations to the overall scores at T1 for both mothers and fathers than at T0.

These findings would suggest that parents' confidence grew over time, although fathers' confidence levels at T1 were slightly lower than mothers. This may have been related to the contact time that the mothers had with their infants compared to fathers; as all but one of the fathers were working at T1, whereas only 9 (41%) of mothers were working.

In summary, this subtheme has considered parents' knowledge and understanding of the essential signs of deterioration and has highlighted variations in terms of levels of competence. It has also considered how prepared parents felt at discharge in terms of the perceived teaching that they had received and their perceived confidence in parenting their infant. The next subtheme relates to parents' perceptions of the knowledge and preparedness of community and local hospital teams.

#### *4.4.2.2 Knowledge and preparedness of community and local hospital teams*

A key finding, that emerged from thematic analysis of the data, was that the parents perceived that community HCPs had expectations in relation to their knowledge and understanding of their infant's condition, for example this mother described: *"I found going to our local hospital difficult in some ways and good in others. However, [name] did not seem quite as well when we got there and I felt that staff were mostly relying on my knowledge of [name] and how he should be and that felt like a lot of responsibility"* and *"It did turn out that he had started to take a downward turn and this was not picked up locally even when I took him to A and E a few days after we got home"* (M4).

Parents stated that they lacked confidence in these professionals as well as staff in local hospitals, for example this mother described that *"The information from the local hospital was not as excellent simply because they don't have the same experience of the condition as our specialist hospital, so we didn't feel so confident in their ability to help us and look after us except for one outreach nurse who had experience of the condition. She was great but everybody else at the local hospital didn't seem to grasp what we were going through"* (M7). One reason for this was because parents felt as though they were being relied upon to know what was normal for their infant; when in fact their own lack of understanding was one of their greatest fears. Parents highlighted the need for

the specialist hospital to prepare community and local hospital teams effectively so that they understand the care required and can identify signs of deterioration without relying on parents' knowledge. Parents felt that there was no one locally that understood their infant's condition, for example: *"Although the health visitor checked on us very regularly regarding weight and normal baby development she was not familiar with any specifics of the heart condition. Generally, we felt that there was no one locally who understood the condition"* (M15).

In terms of parents' perceptions of the HCP's knowledge and preparedness, all the parents said that their Cardiac Liaison Nurse fully understood their infant's heart condition, whereas 87.5% of parents said that the ward nurses at the specialist heart hospital fully understood their infant's heart condition. Just over half (55.6%) of the parents said that the doctor at the local hospital had full understanding and just over a third (35.7%) said that their Community Children's Nurse had full understanding of their infant's heart condition. Less than a third said that their General Practitioner (26.7%), Health Visitor (25%) and local ward nurses (22.2%) had full understanding of their infant's heart condition. Parents generally felt that they would rather contact the specialist heart centre than their local teams due to the lack of knowledge that these professionals had of congenital heart disease and specifically about their infant's condition.

In summary, theme two explored the findings around 'knowledge and preparedness of parents and HCPs'. This highlighted some pertinent points for future consideration around adequate preparation for parents and a need to clarify their understanding. In addition, the findings indicated a need to prepare local and community staff and to encourage them to consider the impact of their expectations of parents. The following theme links to this as it identifies the support mechanisms acknowledged by parents, both institutionally and socially constructed.

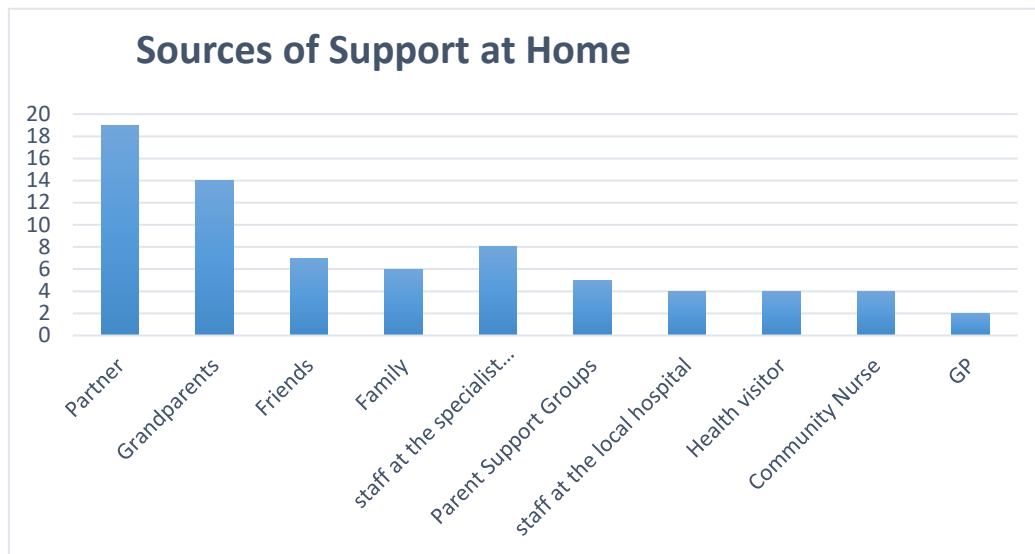
#### 4.4.3 Support Systems

Parents' responses regarding support systems were mainly categorical rather than qualitative. However, some parents did reflect on the benefit of having their partner at home and their need for support. This theme has therefore been separated into three sub themes that consider: social support; institutional support and care required by the infant at home.

#### 4.4.3.1 Social Support

Parents were asked to rate the top three sources of support at home (see figure 4.12). Partners were indicated as the main source of support at home (86.3%); followed by grandparents (63.6%); friends (31.8%) and family (27.2%).

Figure 4.12 Parents sources of support at home

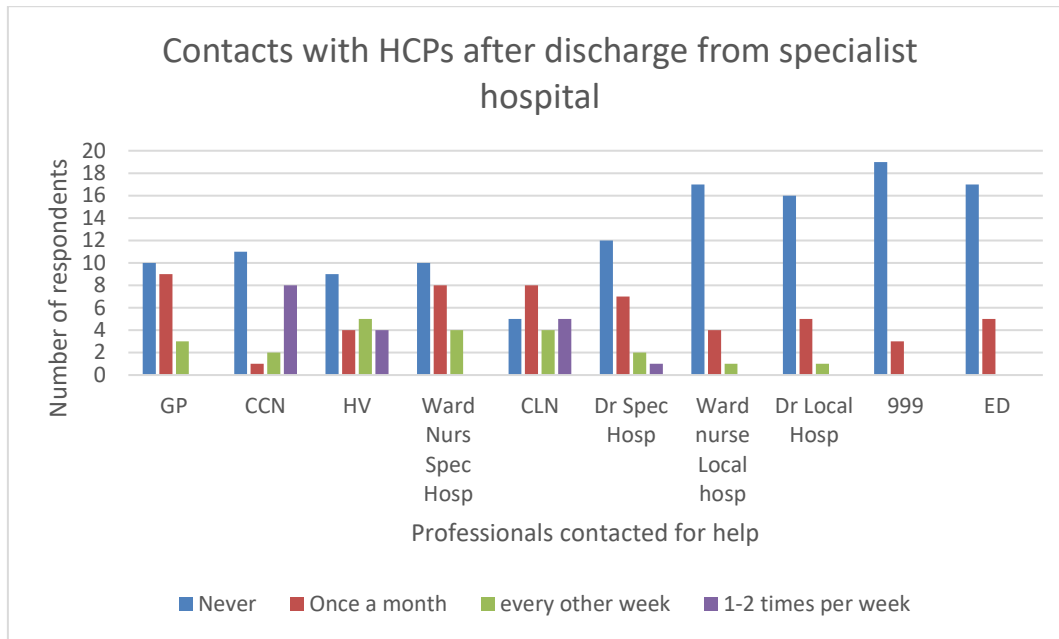


#### 4.4.3.2 Institutional Support

As discussed in 4.4.2.2, parents' detailed comments about their experiences revealed that they were not confident in the advice and support that some of the local and community professionals gave in relation to their infant's cardiac condition. Institutional support at home was rated lower but was provided (in order of prevalence) by staff at the specialist heart hospital (36.3%), parent support groups (22.7%); staff at local hospital, health visitors and community nurses (18.2%) and the GP (9%). Parents were asked which professionals they contacted for support after discharge from the specialist hospital and how often (see figure 4.13). Community children's nurses (CCN) were contacted most frequently, followed by Health Visitors and Cardiac Liaison Nurses (CLNs). From the parents' comments the advice obtained from community professionals related more to general parenting and childhood issues, whereas parents felt more

confident contacting the CLNs at the specialist hospital for specialist advice. Emergency services, local doctors and nurses were contacted less frequently.

Figure 4.13 Number of times respondents contacted HCPs for advice after discharge from specialist hospital



#### 4.4.3.3 Care required by their infant at home

Parents' responses identified the key elements of care needed by their infants at home in terms of normal baby care (feeding) but also the medicalised elements of care such as administering medications and monitoring through measurement of weight and oxygen saturations, which required support from HCPs. At discharge, most infants were fed orally either bottle or breast fed or a mix of both (n=17, 77.2%) with feeding regimes that were predominantly 3-4 hourly (n=15, 68.2%) (Table 4.3). Most of the infants went home with medications (n=20, 90.9%) that were mainly given orally (n=17, 77.2%), 2-3 times a day for half of the infants. Half of the infants had no other treatments or measurements at home. The other half had their weight and/or oxygen saturation levels monitored either daily, twice a week or weekly. Five infants received oxygen saturation

monitoring at home either daily or weekly; of these five, three parents received teaching general to all cardiac babies and two received teaching specific to their infant.

**Table 4.3 Infants' care needs at discharge**

<b>Feeding Method</b>	<b>Number of responses (n=22)</b>
Bottle fed	7(31.8%)
Breast fed	3 (13.6%)
Mixed breast and bottle	7 (31.8%)
Nasogastric	1 (4.5%)
Mixed NG, Breast, Bottle	4 (18.2%)
<b>Frequency of Feeds</b>	
On demand	5 (22.7%)
2 hourly	1 (4.5%)
3 hourly	13 (59.1%)
4 hourly	0 (9.1%)
Continuous NG	1 (4.5%)
<b>Number of Medications</b>	<b>Number of responses (n=22)</b>
0	2 (9.1%)
1	4 (18.2%)
2	1 (4.5%)
3	5 (22.7%)
4	4 (18.2%)
5	5 (22.7%)
6	1 (4.5%)
<b>Frequency of Medications (times per day)</b>	<b>Number of responses (n=19)</b>
1	3 (13.6%)
2	6 (27.3%)
3	5 (22.7%)
4	2 (9.1%)
5	3 (13.6%)
6	1 (13.6%)
<b>Administration Route of Medications</b>	<b>Number of responses (n=20)</b>
Oral	17 (77.2%)
Nasogastric	3 (13.6%)
<b>Other Treatments/Measurements at home</b>	<b>Number of responses (n=22)</b>
None	11 (50%)
Daily weights	1 (4.5%)
Daily oxygen saturations	1 (4.5%)
Both daily weight and oxygen saturations	1 (4.5%)
Both twice weekly weight and oxygen sats	1 (4.5%)
Weekly weight	4 (18.2%)
Weekly oxygen saturations	1 (4.5%)
Both weekly weight and oxygen saturations	1 (4.5%)
INR	1 (4.5%)

#### 4.4.3.4 Written information

Parents' support systems also included the written information that they were given, for example: *"We were given a folder with lots of information which really helped in the early days and knowing that I could phone the cardiac liaison nurse during working hours or the ward outside of these hours was really helpful - being able to phone for advice any time we were worried about anything was invaluable"* (M3). Parents' needs focused on having adequate verbal and written information at the point of discharge but also once they were home, as this extract demonstrates: *"I knew I would be able to ring the cardiac liaison sister and she did actually ring me every week for the first six months so that really helped me"* (M5).

Some parents also wished they had known who they should contact for advice about their infant's cardiac condition. Conversely, some parents described how being given written information to take home and knowing that they could call the cardiac liaison nurse or ward at any time was helpful and supportive, for example: *"When we first left the specialist unit we would receive frequent calls from the cardiac liaison nurses to check everything was ok. This was really reassuring, these calls don't come anymore, but they are always at the end of the phone if we need any advice about anything"* (M8).

Parents were asked about the type of discharge information that they received relating to specific signs of deterioration (Table 4.4).

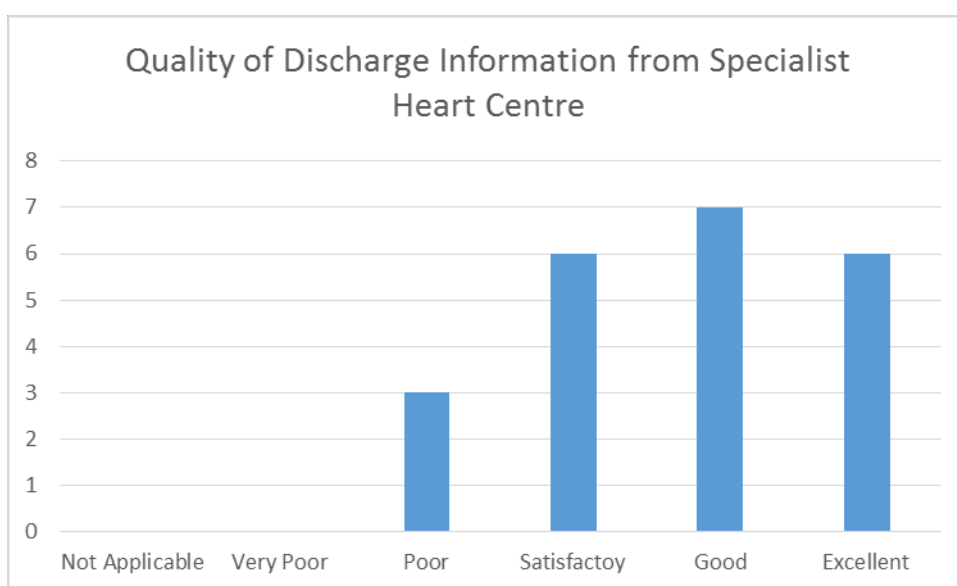
Parents were also asked to rate the quality of discharge information from the specialist hospital (See figure 4.14); approximately half of the responses rated the quality of discharge information from their specialist hospital as good or excellent.



**Table 4.4 Written Information Received Prior to Discharge**

	No written instructions given n (%)	Given general cardiac written instruction n (%)	Given specific written instructions for my baby n (%)	Given written information e.g. LHM Book n (%)	Other n (%)	Given all 3 forms of info n (%)
Wound care	11 (50)	8 (36.4)	1 (4.5)	1 (4.5)		1 (4.5)
Breathing (shortness of breath, grunting)	8 (36.4)	8 (36.4)	2 (9.1)	1 (4.5)		3 (13.6)
Measuring oxygen levels (saturation)	13 (59.1)	1 (4.5)	5 (22.7)	2 (9.1)		1 (4.5)
Skin colour (blueness)	7 (31.8)	6 (27.3)	4 (18.2)	2 (9.1)		3 (13.6)
Heart rate (fast/slow)	13 (59.1)	3 (13.6)	3 (13.6)	2 (9.1)		1 (4.5)
Body temperature (fever)	14 (63.6)	4 (18.2)	1 (4.5)	2 (9.1)		1 (4.5)
Activity level (lethargy/not responding)	8 (36.4)	6 (27.3)	4 (18.2)	2 (9.1)		2 (9.1)
Feeding (off feeds/wet nappies)	11 (50)	4 (18.2)	3 (9.1)	3 (13.6)		2 (9.1)
Weight (increase or decrease)	10 (45.5)	5 (22.7)	3 (13.6)	2 (9.1)		2 (9.1)

**Figure 4.14 Quality of Discharge Information from Specialist Heart Centre**



In summary, this theme has highlighted that the support mechanisms parents accessed, once they were at home, included social and institutional systems. Parents preferred to seek specialist advice from the staff at the specialist centre and general parenting advice from their local teams. There was a variation in the type and amount of written information provided to parents and this did not necessarily equate with their infants' needs. However, despite this approximately half of the parents rated the quality of information as good or excellent. The final theme that emerged related to parents gaining a sense of control and their need to become or return to being a family.

#### 4.4.4 Gaining control: parents' well-being needs

Parents, both new and existing parents, described how being in hospital had impacted upon their ability to control their rudimentary needs (sleep, home comforts and food); they described how they were looking forward to going home and the benefits of home comforts, for example: *"Just to be able to make a cup of tea in our home was a luxury"* (M3).

They described how being in hospital had created a loss of control and loss of role function, as this quote demonstrates: *"Being in hospital sends you completely mad, you have no control over anything including your child"* (M3); impacting on their safety and wellbeing (home, health and the stability of family functioning) and how a break-up of the family unit and parent-child separation had impacted on their social needs, including love and support (their parenting role, intimacy, connections with family and friends), for example: *"It was such a relief to be home and out of hospital environment and to see my daughter [that in fact I may have unconsciously ignored some signs that he wasn't managing as well as he should have been]. I desperately didn't want to go back into hospital and leave my daughter again"* (M6).

Feelings about going home also focused on the paradoxical 'fear and excitement' of becoming de-medicalised; *"I (mother) was nervous about spending my first night with just me and my husband but we were lucky to be able to sleep in a room on the ward with our baby so that if we had any problems, the nurses were just outside"* (M9); beginning to reduce their reliance on monitors, for example: *"and having no monitors going off all night (he didn't need them post op but the wards are so scared of the*

*condition they leave them on with the oxygen sats set too high so they alarm continuously)" (M3) and hospital routines, "In hospital you can see how your child is doing and can grow reliant on the monitoring machines. It was very scary to be coming home without a SATs monitor etc." (M15) and getting used to being alone without a nurse nearby to call for help: "I felt nervous initially - my biggest concern was 'losing' the sats / heart rate monitor. I very quickly became used to the absence of the 'beeping' noises and settled well. I purchased a sensor mat/alarm which has been very useful and reassuring" (M17).*

Parents also described regaining their parenting role, or developing their parenting role as first time parents and developing confidence over time, for example: *"Utterly elated to be taking my baby home" and "[Only] over time as my understanding in the condition grew and my confidence in being able to be a good mum grew" (M7).* They also described the excitement of taking their baby home, for example: *"Delighted that we were finally going home, that I was actually going to be able to take my baby home" (M5) getting to know their baby and bonding with them "I felt so very relieved to be home and to have brought my baby home and in some ways, to have a little space to get to know him because I knew that this was vital" and "I had already been a mother to a young baby but this time round all the other concerns were overridden by a need to make sure that the baby survived" (M6).*

In summary, this final theme 'gaining control' represented the transition from hospital to home in terms of the physical, environmental, financial and social constructs that impacted upon family functioning whilst they were in hospital and how these changed when they got home.

#### 4.6 Chapter summary

This chapter has presented the dominant qualitative findings from phase one of this study, which have been supported by the quantitative findings, focusing on four main themes: mixed emotions about going home; knowledge and preparedness; support systems and gaining control. The next chapter presents the results for phase two of this study.

# Chapter 5 Phase Two Findings

## 5.1 Introduction

This chapter presents the findings from phase two of this study. The themes arising from the qualitative data analysis are used to structure the presentation of findings, as this was the dominant aspect of the study; the descriptive data and the categorical data are presented concurrently to support these themes. The main aim of phase two was to prospectively obtain a greater understanding of the experiences of a group of parents whose infants were being discharged home following first stage treatment for complex congenital heart disease.

In phase two 13 families were recruited to the study. One mother (BZ8) consented however, did not take part in the interviews. Additionally, one infant (MZ6) did not go home following recruitment to the study and therefore whilst an interview was undertaken with the mother at T0 and T3, the data from T3 was removed from the analysis because it did not relate to the overarching research question for this study.

## 5.2 Parental demographics

The qualitative data set included 38 interviews with 12 mothers and 4 fathers. There was a variation in the sample in terms of age range for mothers; fathers' age was not documented; parity, distance from home to the specialist surgical centre, postcode deprivation index, employment status, education, and fathers' ethnicity (see table 5.1). However, two thirds of mothers were White British (n=9, 75%); most mothers were living with their partner (n=11, 91.7) and were either a homemaker or were taking maternity leave (n= 11, 91.7%); whereas most fathers were either employed or self-employed (n=8, 66.6%) and their ethnicity varied.

Table 5.1 Parents' demographics data

<b>Parent's Age</b>	<b>Mother (n=12)</b>	<b>Father (not recorded)</b>
<ul style="list-style-type: none"> <li>• 20-25</li> <li>• 26-30</li> <li>• 31-40</li> </ul>	3 (25%) 4 (33.3%) 5 (41.7%)	
<b>Primipara</b>	5 (41.7%)	
<b>Multipara</b>	7 (58.3%)	
<b>Parent's Health</b>	<b>Mother (n=12)</b>	<b>Father (n=4)</b>
<ul style="list-style-type: none"> <li>• Fit and healthy</li> <li>• Congenital Heart Disease</li> <li>• Chronic illness (e.g. Diabetes, Asthma, Adult Heart Disease e.g. high BP)</li> <li>• Mental Health problems (e.g. Depression, Schizophrenia)</li> </ul>	10 (83.3%) 0 1 (8.3%) 1 (8.3%)	2 (50%) 0 1 (25%) 1 (25%)
<b>Living Arrangements</b>	<b>(n=12)</b>	
<ul style="list-style-type: none"> <li>• Living with partner (married or unmarried)</li> <li>• Living alone (with children)</li> <li>• Not stated</li> </ul>	11 (91.6%) 1 (8.3%)	
<b>Distance from home to the specialist heart hospital</b>	<b>Number of responses (n=12)</b>	
<ul style="list-style-type: none"> <li>• Less than 20 miles</li> <li>• 20-30 miles</li> <li>• 30-40 miles</li> <li>• 50-100 miles</li> </ul>	6 (50%) 2 (16.7%) 2 (16.7%) 2 (16.7%)	
<b>Deprivation Score</b>	<b>Number of responses (n=12)</b>	
0-5,000 5,000 – 10,000 10,000-15,000 15,000-20,000 20,000-25,000	6 2 3 0 1	
<b>Employment</b>	<b>Mother (n=12)</b>	<b>Father (n=12)</b>
<ul style="list-style-type: none"> <li>• Employed for wages</li> <li>• Self-employed</li> <li>• Out of work and looking for work</li> <li>• Out of work but not currently looking</li> <li>• A homemaker</li> <li>• Maternity/paternity leave</li> <li>• Sick leave</li> </ul>	0 1 (8.3%) 0 0 8 (66.7%) 3 (25%) 0	6 (50%) 2 (16.6%) 0 1 (8.3%) 0 0 3 (25%)
<b>Education</b>	<b>Mother (n=12)</b>	<b>Father (n=8)</b>
<ul style="list-style-type: none"> <li>• Secondary school to 16 (GCSE equivalent)</li> <li>• Sixth Form/College (A levels, BTEC, IB)</li> <li>• Bachelor's degree (BA, BSc)</li> </ul>	4 (33.3%) 5 (41.6%) 3 (25%)	3 (25%) 4 (33.6%) 1 (8.3%)
<b>Ethnicity</b>	<b>Mother (n=12)</b>	<b>Father (n=12)</b>
<ul style="list-style-type: none"> <li>• White – British</li> <li>• White - Irish</li> <li>• White - European</li> <li>• Black British</li> <li>• Black Caribbean</li> <li>• British Asian</li> <li>• Kurdish</li> </ul>	9 (75%) 1 (8.3%) 0 1 (8.3%) 1 (8.3%) 0 0	7 (58.3%) 0 1 (8.3%) 1 (8.3%) 1 (8.3%) 1 (8.3%) 1 (8.3%)

### 5.3 Infant's birth and medical demographics

Eleven couples had received an antenatal diagnosis for their infant of complex CHD. The diagnoses were pragmatically grouped into hypoplastic left heart syndrome (HLHS) (n=10), functionally univentricular heart (right) (n=1) and a systemic shunt dependent lesion, tetralogy of Fallot (TOF) (n=1) (see table 5.2). All infants had survived the first two stages of surgery; the time between surgery ranged from 62-228 days (median = 151; mean = 145.6; S.D. = 61.6).

There were seven female infants and five males; ten infants were born after 38 weeks' gestation. All the infants were admitted to the specialist hospital having been retrieved from the maternity unit in which they were born. All the infants had an intravenous prostaglandin infusion running to maintain arterial duct patency, at the time of admission to the specialist hospital; thereby maintaining life. Six of the infants were mechanically ventilated prior to their surgery; eight infants showed signs of acidosis and five infants required intravenous inotropic support prior to surgery. These were all indicators of the infant's clinical condition prior to the first stage of surgery.

One infant (JT8) was born early (35<sup>+2</sup> weeks' gestation), had the lowest birth weight (2.18Kg), had the most restricted (narrowest) aorta and was the sickest infant pre, peri and post stage 1 surgery; this infant had the second stage of surgery only a month after stage 1. The range of time between stage 1 and stage 2 surgeries for all infants was between 32- 214 days (1-7 months).

**Table 5.2 Infant's Birth and Medical Information**

<b>Time of Diagnosis</b>	<b>Number of responses (n=12)</b>
Antenatal	11 (91.6%)
Postnatal	1 (8.3%)
<b>Female</b>	7 (58.3%)
<b>Male</b>	5 (41.6%)
<b>Gestation</b>	
35+	1 (8.3%)
36+	1 (8.3%)
38+	4 (33.3%)
39+	3 (25%)
40+	2 (16.6%)
42+	1 (8.3%)
<b>Birth weight</b>	
2-2.5Kg	4 (33.3%)
2.6-3Kg	2 (16.6%)
3.1-3.5Kg	4 (33.3%)
4.1-4.5Kg	2 (16.6%)
<b>Diagnosis</b>	
Hypoplastic Left Heart Syndrome	10 (83.3%)
Hypoplastic Right Heart	1 (8.3%)
Tetralogy of Fallot	1 (8.3%)
<b>Other non-cardiac defects</b>	5 (41.6%)
<b>Genetic abnormality</b>	3 (25%)
<b>Specialist Hospital Admission Route</b>	
Retrieval team	12 (100%)
<b>Pre-operative management</b>	
Mechanical ventilation	6 (50%)
Prostaglandin infusion	12 (100%)
Inotropic support	5 (41.6%)
Acidosis	8 (66.6%)

#### 5.4 Qualitative and Quantitative Findings

In this section the themes (patterns of experience) arising from thematic analysis of the qualitative data are used to structure the presentation of findings, as this was the dominant aspect of the study; the descriptive statistics arising from the categorical data are presented concurrently to support these themes.

Dynamic constructivist and constructionist social processes occurred for all the families, which involved physical, physiological, psychological and cognitive elements within four key patterns of their experience:

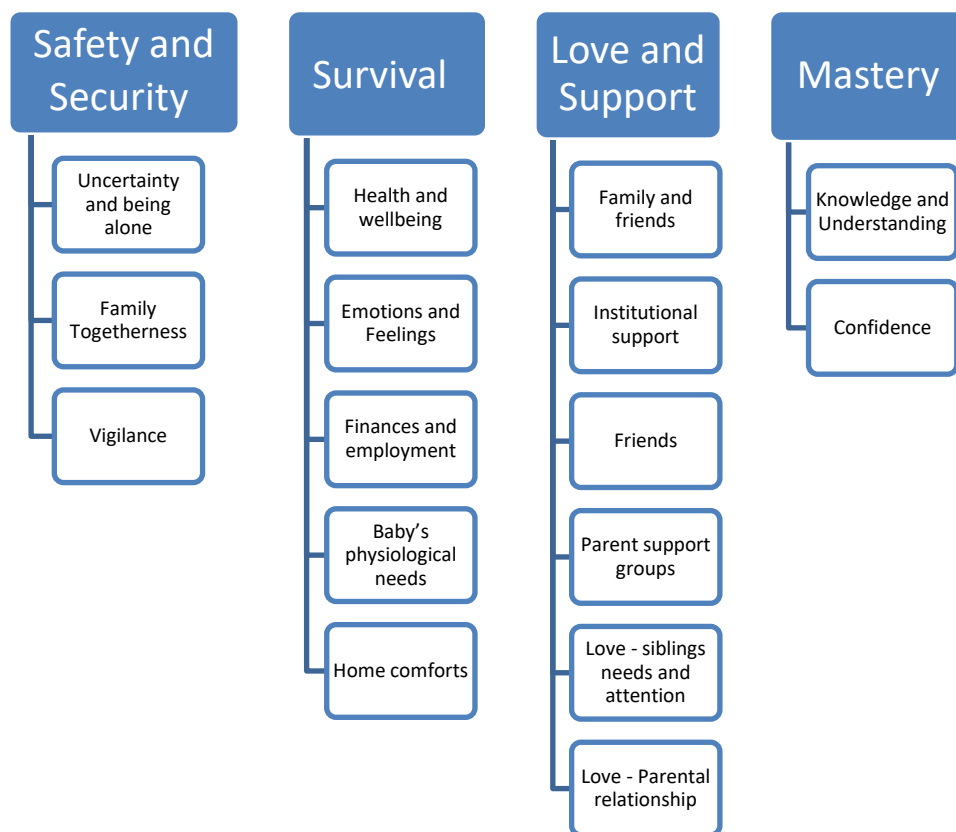
- i. safety and security
- ii. survival
- iii. love and support

iv. mastery

The parents' experiences overlapped and transformation occurred for each pattern (theme) over the four time frames from:

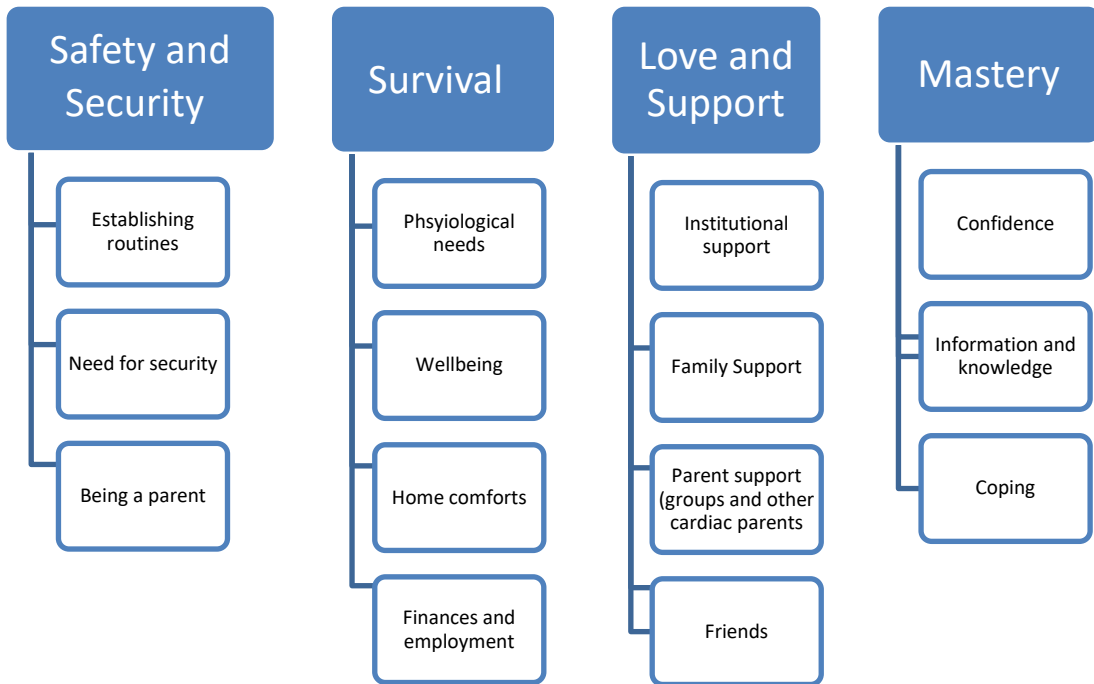
- T0 preparation for discharge home (themes in figure 5.1)
- T1 being at home (themes in figure 5.2)
- T2 preparation for second stage of surgery (themes in figure 5.3)
- T3 going home again after stage two surgery (themes in figure 5.4)

**Figure 5.1 Themes arising at T0 prior to discharge home**

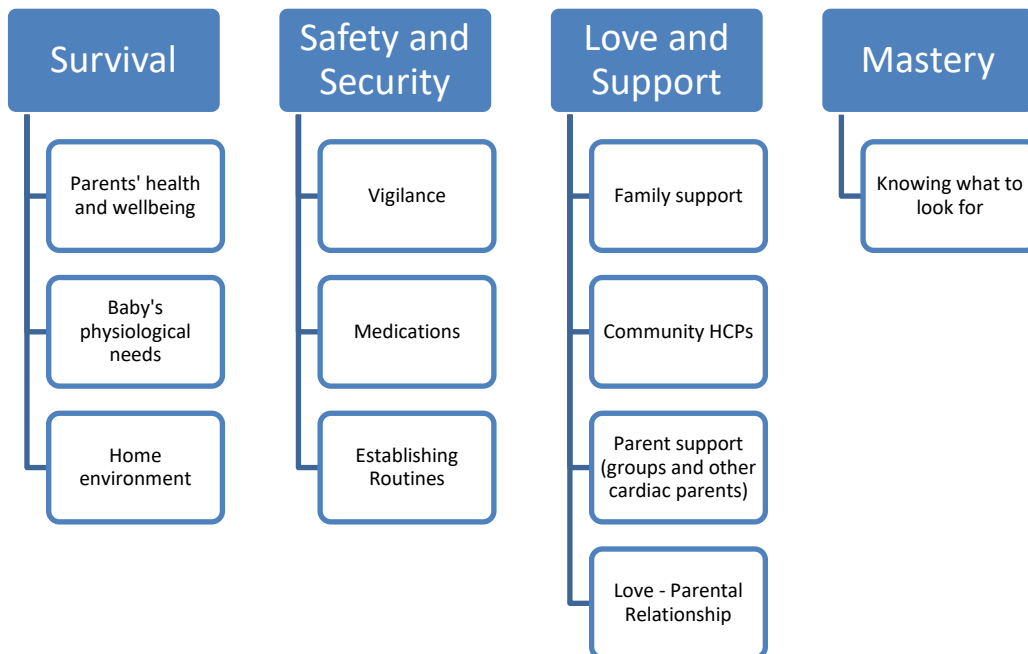




**Figure 5.2 Themes arising at T1 two weeks after discharge**



**Figure 5.3 Themes arising at T2 eight weeks after discharge**



**Figure 5.4 Themes arising at T3 After stage two of surgery**

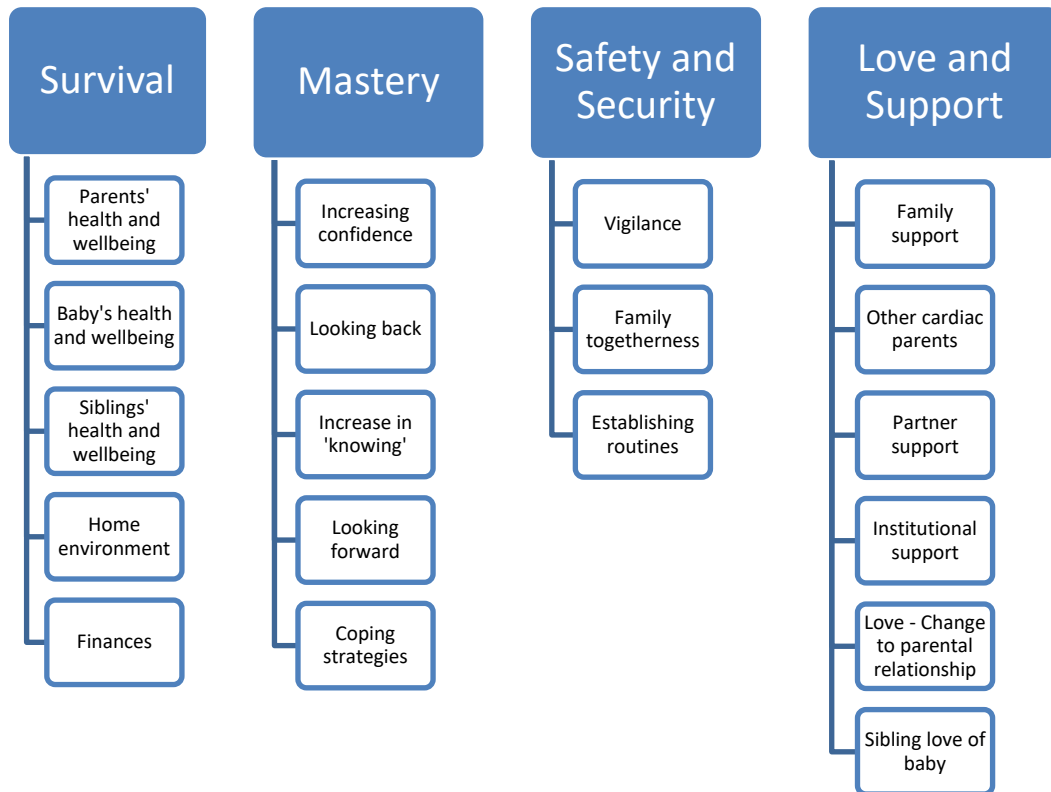


Table 5.3 compares the patterns of experience identified throughout the parents' experiences at the four time points: before discharge (T0); two weeks after discharge (T1); eight weeks after discharge (T2) and after stage two cardiac surgery (T3).

**Table 5.3 Key patterns of parents' experiences arising at the four time points**

T0 (n= 12 interviews)	T1 (n= 9 interviews)	T2 (n= 7 interviews)	T3 (n= 9 interviews)
<p><b>Safety and Security</b></p> <ul style="list-style-type: none"> <li>• Uncertainty and being alone</li> <li>• Family togetherness</li> <li>• Vigilance</li> </ul> <p><b>Survival</b></p> <ul style="list-style-type: none"> <li>• Health and wellbeing / Emotions and feelings</li> <li>• Finances and employment</li> <li>• Baby's physiological needs</li> <li>• Home comforts</li> </ul> <p><b>Love and Support</b></p> <ul style="list-style-type: none"> <li>• Family and friends</li> <li>• Institutional support</li> <li>• Friends</li> <li>• Parent Support groups</li> </ul> <p><i>Love</i></p> <ul style="list-style-type: none"> <li>• Siblings' attention needs</li> <li>• Parental relationship</li> </ul> <p><b>Mastery</b></p> <ul style="list-style-type: none"> <li>• Knowledge and understanding</li> <li>• Confidence</li> </ul>	<p><b>Safety and Security</b></p> <ul style="list-style-type: none"> <li>• Establishing routines</li> <li>• Vigilance</li> <li>• Need for Security</li> <li>• Being a parent</li> </ul> <p><b>Survival</b></p> <ul style="list-style-type: none"> <li>• Physiological needs</li> <li>• Wellbeing</li> <li>• Home comforts</li> <li>• Finances/employment</li> </ul> <p><b>Love and Support</b></p> <ul style="list-style-type: none"> <li>• Institutional support</li> <li>• Family support</li> <li>• Parent Support (Groups and other cardiac parents)</li> <li>• Friends</li> </ul> <p><i>Love</i></p> <ul style="list-style-type: none"> <li>• Sibling love</li> <li>• Parental relationship</li> </ul> <p><b>Mastery</b></p> <ul style="list-style-type: none"> <li>• Confidence</li> <li>• Information/knowledge</li> <li>• Coping</li> </ul>	<p><b>Survival</b></p> <ul style="list-style-type: none"> <li>• Parents' health and well being</li> <li>• Baby's physiological needs</li> <li>• Home environment</li> </ul> <p><b>Safety and Security</b></p> <ul style="list-style-type: none"> <li>• Vigilance</li> <li>• Medications</li> <li>• Establishing routines</li> </ul> <p><b>Love and Support Support</b></p> <ul style="list-style-type: none"> <li>• Family support</li> <li>• Community HCPs</li> <li>• Parent Support (Groups and other cardiac parents)</li> </ul> <p><i>Love</i></p> <ul style="list-style-type: none"> <li>• Parental relationship</li> </ul> <p><b>Mastery</b></p> <ul style="list-style-type: none"> <li>• Knowing what to look for</li> </ul>	<p><b>Survival</b></p> <ul style="list-style-type: none"> <li>• Parents' health and wellbeing</li> <li>• Baby's health and wellbeing</li> <li>• Siblings health and wellbeing</li> <li>• Home environment</li> <li>• Finances</li> </ul> <p><b>Mastery</b></p> <ul style="list-style-type: none"> <li>• Increasing confidence</li> <li>• Looking back</li> <li>• Increase in 'knowing'</li> <li>• Looking forward</li> <li>• Coping strategies</li> </ul> <p><b>Safety and Security</b></p> <ul style="list-style-type: none"> <li>• Vigilance</li> <li>• Family togetherness</li> <li>• Establishing routines</li> </ul> <p><b>Love and Support Support:</b></p> <ul style="list-style-type: none"> <li>• Family support</li> <li>• Other cardiac parents</li> <li>• Partner support</li> <li>• Institutional support</li> </ul> <p><i>Love:</i></p> <ul style="list-style-type: none"> <li>• Change to parental relationship</li> <li>• Sibling love of baby</li> </ul>

### 5.4.1 Safety and Security

Safety and security over the four time frames related to several sub experiences: vigilance; family togetherness; uncertainty; being alone and establishing routines. Behaviours were illustrated that aimed to protect the survival of their infant from the point of diagnosis through to going home after the second stage of surgery. This protection originated in the decision to continue with the pregnancy following an antenatal diagnosis, despite being informed that their unborn infant had a life-limiting condition that would require life-saving surgery in the first few days of life. Parents who received an antenatal diagnosis demonstrated awareness of the survival rates, the palliative nature of the surgery and the need for several operations, and had obtained information from a variety of sources to prepare themselves for the events that lay ahead.

However, one mother (QH5, T0) believed that she had given birth to a *'perfectly healthy baby'*, for her the *bombshell* occurred after birth. She explained how she sat for the first 24 hours in intensive care watching over him, feeling *devastated* and *crushed*. This 'watching' links to the sub experience of parents' vigilance.

#### 5.4.1.1 Vigilance

Parents demonstrated safeguarding of their infant through constant vigilance during the hospital stay as well as vigilant behaviours once at home. It was mainly the mothers that expressed their need to constantly watch over their baby whilst in hospital, although one father also explained *"I've sat in there and I've watched and watched"* (QU5 father, T0). Whilst another father had spotted how his wife easily became fixated on specific aspects of their daughter's condition and care, both whilst they were in intensive care and on the ward: *"because you can get, I've seen [mum] fixates on various stages of [baby]'s recovery it like initially it was the lactic acid levels, sort of like fixating on that for two weeks"* and *"but [mum] really does have a tendency to sort of fixate on various little stages of her recovery"* (RR8 father, T0).

In hospital, vigilance for some parents related to looking out for changes in their baby's condition and notifying staff of those changes. One mother (QH5, T0) talked about watching her baby's colour and how she knew that he needed a blood transfusion: *"I've sat and I've watched and I've watched his colours, I knew when he needed a blood transfusion when he was on intensive care, although the numbers weren't adding up. I was adamant he needed a blood transfusion because of his colour and I fetched the doctor and I said you know [name] and she says 'yeah' and I said 'can you come and look at him please'. She come over she took one look at him she went 'he needs a blood transfusion'".*

Another mother's vigilance (EU4, T0) had also enabled identification of signs of deterioration and communication with the doctor: *"when she first got here she was fine and they thought she was doing well and then she dropped and I'd noticed her colour changing all day and I had the doctors up to look at her, because I noticed her nail colour changing"*

In addition to constantly looking for changes from a safety perspective, parents used this vigilance to develop their ability to spot signs of deterioration in preparation for going home, for example: *"so she went and got the blood, so erm, you know erm, it's kind of 'cos I've sat and looked at it for hours and hours and hours, I know his kind of respiratory rate, I know if he's in distress, I know if he's got wind, I know if he's got a dirty nappy, erm, you know, I've monitored him so closely to try and get to know his colour for when we do go home"* (QH5 mother, T0).

Another mother (JT8, T0) also explained why she was being so vigilant in hospital: *"...so erm, this is why I stay close beside her to see all the little different changes that she's making, if she is poorly I'm gonna know"*. Most mothers talked about wanting to keep their baby close to them at home, especially at night time: *"she'll be in my room for a long time I think [laughs], when she's about 5 she might be in her own room!"* (EU4, T0). One mother (NK4, T0) said *"I won't want to let him out of my sight"* and demonstrated a reluctance to leave him whilst she did other things, such as: [whilst working] *"I'll have him in one arm"*.

Only one mother talked about the future, such as attending baby classes but when asked about leaving her baby with others she said *"I find it more comforting to be close to her"* (CQ9, T0). Vigilance continued over time, however, became less evident in parents' accounts, as they became more experienced in knowing what they were looking for, what

to do and where to obtain support.

#### 5.4.1.2 Uncertainty and Being Alone

The major worry and uncertainty for parents prior to going home was the fear of the unknown and related to being on their own at home; without the institutionalised safety and security of the monitors and the lack of immediately available HCPs if anything happened. Parents had grown used to the security of the hospital environment, they were worried that they would not know what to look out for, what to do or who to call for help, as these accounts demonstrate, for example: *“it’s just scary, you wanna get her home because you wanna just be normal but then you don’t wanna; because here this is more constant, you watch her, you’ve got monitors on her and stuff and then when you get home you’ve got none of that it’s just you”* (EU4, T0).

Another mother explained: *“they’re not there at the touch of a button so yeah if anything was to happen, like his temperature was to go up, I couldn’t just say ‘nurse his temperature has gone up’ I’d have to ring other people and watch him slowly so it’s just reassuring having the nurses there”* (NK4, T0).

However, there was evidence that the fear of being alone without the security of the hospital changed over time as parents adjusted to being on their own, as this mother reflects: *“but then after a few days I kind of calmed down regarding like there’s no support there when, you know, like by your side and just concentrating on (baby) himself and on his colour and stuff like that”* (mother QH5, T1).

For some mothers, the fear of being alone also related to the recognition that their partner would need to return to work. Both mothers and fathers talked about establishing routines before the fathers needed to return to work and that those routines might change once that happened: *“it’s just to get support and get a routine going before he does go back to work, which when he does go back it’s gonna be part time, so that the help is still there for me you know, when I need him”* (mother QH5, T1).

Another mother explained: *“we’ve got a fab rota at the moment but he’s going back to work”* (mother RR8, T1), whilst the father recognised: *“it will be all change next week because I’m back in work”* (father RR8, T1). The initial uncertainties, fears and anxieties

about being alone were superseded over time by happiness and positivity, as parents adjusted to being back in the comfort of their home environment, adjusting to new routines and relaxing into family life.

#### 5.4.1.3 Family togetherness

Family togetherness at T0 was connected to parenting (first time parents and parenting roles); bonding with the baby and the other siblings; separation of the mother and baby, separation of the family and longing to be a family and have 'normality'.

Parents of infants who were diagnosed antenatally gave explanations about how they had been not to be able to engage in the 'normal' bonding process at birth because of the immediacy of the situation and the lack of time with their infant before they were rushed off to the specialist centre. One mother and father described this 'awful' time and how it felt as though they 'had lost her': "... I had a normal delivery but she was literally. I held her for 2 ... 2 ... 2 ...5 minutes" (RR8 mother). "It was probably about 10 minutes when you look back, but at the time it was like ... gone" (RR8 father). "It didn't feel like it, she was taken away and I didn't see her for 5 hours and then when I did get to see her the children's hospital van was there and she was taken immediately. So, I wasn't discharged and then they discharged me from the [maternity hospital] at 9 o'clock at night, bearing in mind I'd given birth at 6 in the morning. So, I got here to see her in [ward] and I was, it was in the process she was moved again, so I didn't see her again" (RR8 mother, T0) "They were moving her to PICU?" (Interviewer) "Yeah" (RR8 father). "Then we went down to intensive and we didn't get there until ... midnight?" (RR8 mother). "Yeah about midnight yeah so" (RR8 father). "So I just hadn't seen her and of course, I couldn't cuddle her then because she was all wired up" (RR8 mother). "How did that feel?" (Interviewer) "It was awful, it was like I'd given birth to a baby and given her away [pause] but we knew it was for the right reasons, I'd rather do that, than her be in my arms and then I've lost her" (RR8 mother, T0).

Despite the pressure of knowing that they could not physically hold their infant, one mother explained her fears and how she needed to be constantly present: "It was the fear of losing her...it was just going through my head I want to be there, I want to be there, it's like I said, if anything did happen and I wasn't there I would never ever, and I know they say don't ever say unless you've ever done it, but I'd never forgive myself because at the end of the day she needed her mom or her dad there, do you know where I'm coming from?" (AZ7 mother, T0).

Whilst emotional bonding took place through constant watching, physical bonding was put on hold until after the surgery and once the baby was back on the ward, this mother further explained: *“that’s why I’ve constantly got her in my arms”* (RR8 mother, T0). There was also evidence of a desire to get home so that physical bonding could commence, as one father explained: *“... deep down I’m really looking forward to going home because then we can bond properly”* (QU5 father, T0). However, for some the ‘bonding’ at this time point was more than physical bonding with the infant, it was family bonding and a desire for ‘normality’: *“I want to take her home and be a normal family”* (EU4 mother, T0).

The first-time parents talked about the dichotomy between longing to get home to be a ‘normal’ parent, but also the benefit of learning and being taught how to parent whilst in hospital: *“...personally at the minute I find it more comforting to be closer to her ... but I don’t know if that’s more a case of, I’ve not got her at home so I need to be able to bond with, bond a bit better and by being closer.... I think that’s helped. I don’t know if that’s more about me, just wanting to be like a normal mum or whether it’s a case of ... oh she’s crying and what does that mean. You know it’s case of go and pick her [up], breathe, breathe, breathe ...and well if she went blue I’d be a bit concerned .... but pink’s ok ... so I think from being here I’ve picked up some of the tools ...* (CQ9 mother). Another mother explained: [being in hospital] *“it’s been good because erm as a first time mum I didn’t have a clue about a lot of things, so I suppose being here they’ve showed me quite a lot ...”* (BM6 mother, T0).

The transformation of ‘family togetherness’ over time was a move towards what parents described as the ‘normality’ of family life despite having an infant with complex congenital heart disease, for example: *“But we just try to make time for them and individually like take it in turns playing, you know, and doing things as a family. Doing things altogether. Especially at weekends, we tend to like all get on the settee, get [baby] on the settee and we watch X Factor. So, it’s like, just trying to get back to normal, normality and being just a family in the situation we’re in”* (QH5 mother, T1).

Parents also recognised that over time they had adopted specific roles; some had become ‘medical parents’, learning about everything medical and technical whilst in hospital and adopting a *nursing role* at home. However, in some cases whilst one parent had adopted the medical role, the other parent had become the *comforter*. One mother’s perception was: *“... it just seems to be the mums who hold the child while they’re*



*screaming and stuff like that and the dads just kind of are the ones to comfort them after, it's like the good cop, bad cop (laughs)*" (HH0 mother, T1). Adopting different roles was associated with 'establishing routines'.

#### 5.4.1.4 Establishing routines

'Establishing routines' and getting organised was considered an important element of the preparation for going home, as this father explains: *"Just making sure we're organised I think, make sure we've got everything that we need and that it's all there waiting for us, that's my biggest thing making sure that we've got everything we need and that we're fairly organised"* (NS7 father, T0).

An integral part of establishing routines was identifying individual roles and responsibilities, as this father reveals: *"She's already put me on two weeks of night duties [laughs]"* (QH5 father, T1). Additionally, adjustment to being at home with their infant was related to establishing routines: *"... get into some sort of routine and get comfortable at home"* (RR8 father, T0).

For some of the first-time parents, having an infant with a heart problem did not influence their development of routines once at home, because they had nothing to compare to. This mother was asked whether there was anything that made it difficult at home, such as the feeding or medications, she explained: *"I guess, I don't know, I guess for other people it would have been difficult, but I know it kind of goes back on what I've said; but because it was my first it was kind of like routine, it was just incorporated into what I was doing anyway so it didn't really seem different"* (HH0 mother, T1).

By the time the infants were going home after their second stage of surgery (T3) most parents acknowledged that their home routines had made 'being alone' easier. One mother reflected on her first experience of going home and said: *"... once we got him home and we got into the routine it was perfectly fine, [I] just took to it [motherhood] quite quickly"* (NS7 mother, T3).

Some parents also experienced a faster transition to their home routines after the second stage of surgery, demonstrating adjustment and adaptation: *"It was just, yeah, it took a couple of days to get erm, you know, transitioned into a routine again"* (BM6 mother, T3).

An integral part of 'establishing routines' during the transition from hospital to home was the nature of the home environment and the simultaneous development of survival strategies.

#### 5.4.2 Survival

A second dynamic theme 'survival' was associated with meeting the family's physiological needs; a recognition of factors impacting upon health and wellbeing, the influence of home comforts and finances (employment).

##### 5.4.2.1 Health and wellbeing

Health and wellbeing was associated with the physical and psychological health of the parents and the siblings. Parents vividly described the 'shock' and 'devastation' experienced at the time of diagnosis as well as the 'shock' they experienced at the time of the birth, which they were not prepared for. Whereas a postnatal diagnosis allowed an enjoyable pregnancy; albeit experiencing later self-blame for the diagnosis, for example: *"what did I do wrong in my pregnancy. I took all the vitamins, I ate healthy, I did exercise and everything to the book with this pregnancy and ... I was just ... I was crushed ... I think that's what it was"* (QH5, mother, T0).

Parents reflected upon the time spent in the paediatric intensive care unit (PICU) and described feelings of 'helplessness'; detachment and dissociation, for example: *"it's like a standstill, you're like 'where am I?' you're on like a standstill, I was just focused on that one cot I wasn't even daring to look around me. Oh, god no, all I seen was these big machines and I thought I'm not even looking, I was like I'm not looking nowhere, my eyes, it was horrible"* (AZ7 mother, T0); 'parenting from afar'; blame; guilt; fear of loss and for one mother (who received the postnatal diagnosis) the trauma associated with the lasting images: *"I think I sat for 24 hrs with him downstairs in intensive care and .... the images ... won't leave my head ... and that's what's like torture, that is"* (QH5 mother, T0).

There was little evidence in the parents' accounts of the mothers' focusing on their physical health following childbirth, rather their focus was related to survival of their

infant, as this mother explains: “... and then the sickness and stuff which, that’s positive on its own that I can walk in and not ... not feel like I’m drunk, I was swaying side to side and I couldn’t focus on anything ...cos I was just... I was just really feeling really poorly me self ... but in that situation you kind of think, no ... forget me, your baby’s like ...severely poorly, I’m sitting here and aint moving and then as I say I ended up on the floor and ...I was dehydrated and everything, so ... you know I’ve been giving other moms advice you know, drink plenty eat your food, cos you’re no good if you end up on the floor” (QH5 mother, T0).

On reflection, there was recognition that the parent’s health and physiological needs are important during the stressful events immediately after the infant’s birth.

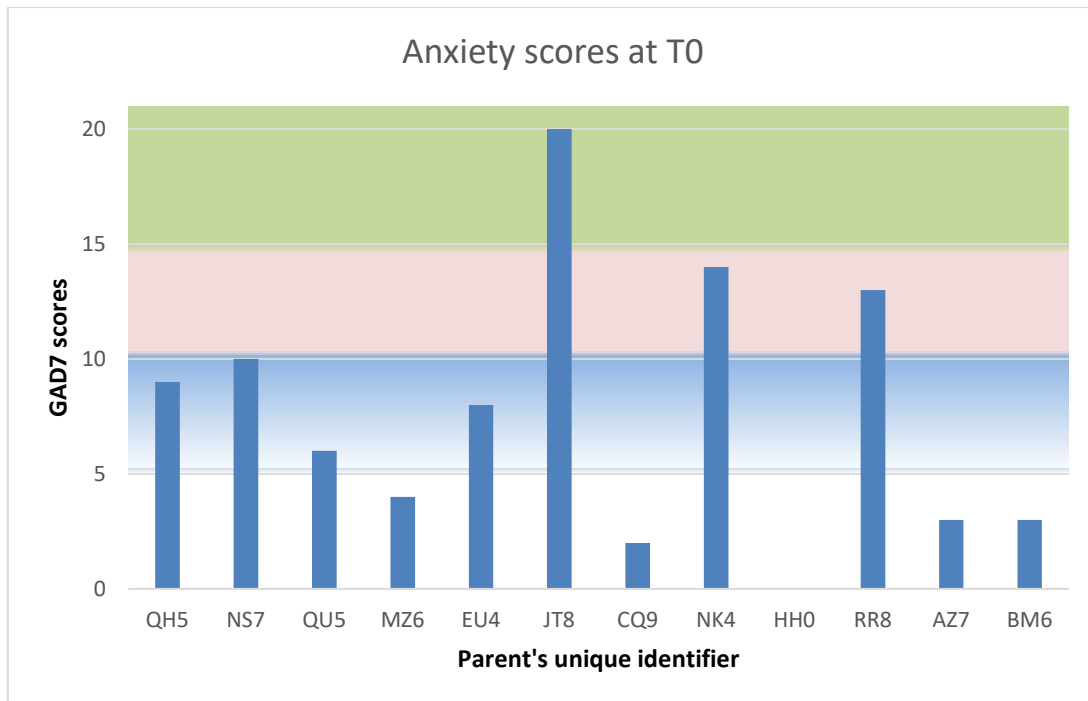
Siblings’ health and wellbeing was associated with the psychological impact of the situation: “well I brought one of my daughters here and the first time she came here she saw him she fell down, she came out and something said go and follow her and I followed her and she was like getting tissues from a nurse and I had to be there for her you know but it was very depressing” (NK4 father, T0) as well as the impact of having other children, with health problems, on the transition home with their fragile infant and the long term impact on the sibling’s behaviour: “...me one twin is under a Psychologist at school with it because his behaviour had just spiralled out of control and he was getting to the point where he was picking his fist up to hit me and I know it’s all down to the situation and what they’ve seen and what they’ve been through. So, I had a word with the school and the school have set that up for me so we’re working together and.... it seems to be working” (QH5 mother, T1).

At the time of discharge all parents were experiencing mixed emotions: ‘fear and uncertainty’, as described earlier, as well as ‘happiness and excitement’ about going home: “I can’t express, it’s a good place, feels good, I can’t wait” (NK4 father, T0). However, by the time that the infants had undergone stage 2 surgery parents described their feeling and emotions as positive, relieved and relaxed. Parents reflected on their anxieties about going home the first time and the reduction in stress as recognised by this mother: “less stressed being back at home” (JT8 mother, T3).

5.4.2.2 Anxiety and depression scores

Parents were asked to rate their anxiety, depression and confidence at the four interview time points (T0, T1, T2, T3) using GAD7, PHQ9 and MCS. The CUDAS tool (Furze, 2013) was used to calculate scores for GAD7 and PHQ9, it also provided management recommendations, which were documented in the study notes and acted upon when referral to GP was recommended. Only one mother did not return the questionnaire at T0 (BZ8). One mother scored zero (HH0) and four other mothers scored under 5, denoting no anxiety (MZ6; CQ9; AZ7; BM6). Two mothers (QH5; EU4) scored between 5-9, denoting mild anxiety which required monitoring. Three mothers (NS7; NK4; RR8) scored moderate anxiety (10-14) denoting a possibly clinically significant condition and one mother (JT8) scored 20 at T0 (see figure 5.5) where active treatment is probably warranted. This mother gave the researchers permission to inform her GP and the cardiac team; infant JT8 was the most fragile pre, peri and post operatively.

**Figure 5.5 Mother’s anxiety scores (GAD7) at T0**



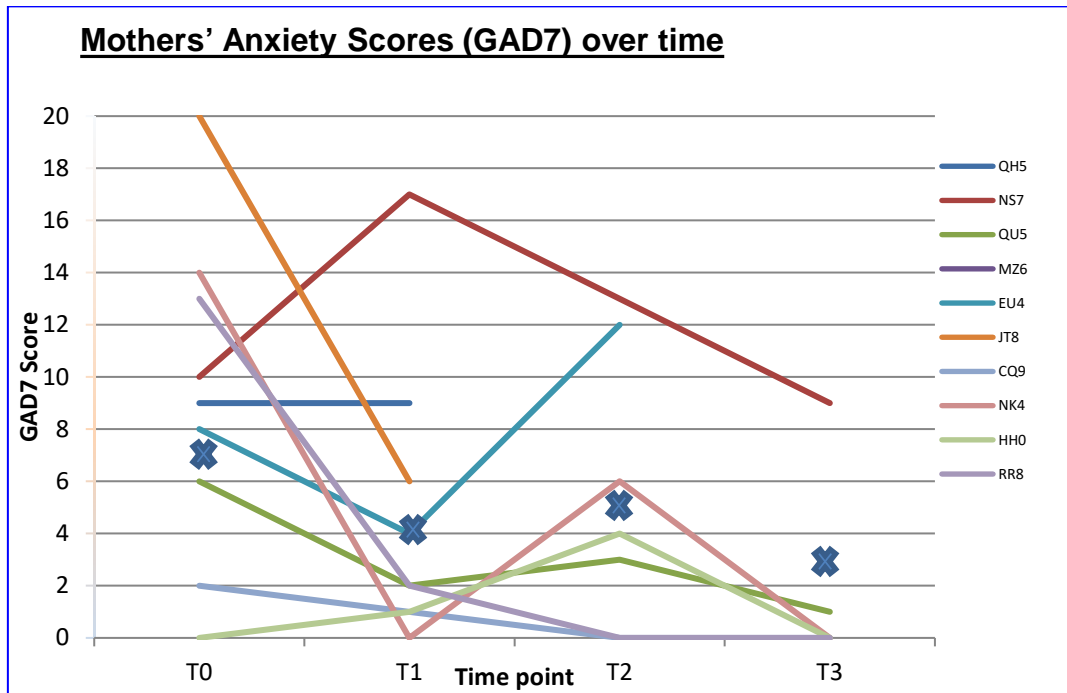
Scores: No anxiety 0-5; mild anxiety 5-9 (pale blue); moderate anxiety 10-14 (lilac); over 15 significant anxiety (green).

Several mothers did not complete the GAD 7 or PHQ9 at all four time points due to their infant being readmitted to the hospital before the scheduled time for the interview (JT8, QH5, MZ6). Some mothers chose not to take part in all four interviews (EU4, AZ7, BM6, BZ8) and therefore their data is incomplete and denoted by an X (see table 5.4 and table 5.5). Figure 5.6 graphically shows a general downward trend at T1 and an increase in GAD7 scores at T2 for some mothers, incomplete scores as described above are denoted on the graph as a discontinuation of the line and therefore these trends need to be viewed with caution. The GAD7 scores at T0 for mother JT8 were given to her GP by staff from the research team at the study site, with the mother's consent, as it triggered referral to GP on the CUDAS tool (Furze 2013).

**Table 5.4 Mother's GAD7 scores at T0, T1, T2, T3**

Unique Identifier code	T0		T1		T2		T3	
QH5	9	Mild	9	Mild	X		3	None
NS7	10	Moderate	17	High	13	Mod	9	Mild
QU5	6	Moderate	2	None	3	None	1	None
MZ6	4	None	X		X		2	None
EU4	8	Moderate	4	None	12	Moderate	X	
JT8	20	High	6	Mild	X		8	Mild
CQ9	2	None	1	None	0	None	0	None
NK4	14	Moderate	0	None	6	Mild	0	None
HH0	0	None	1	None	4	None	0	None
RR8	13	Moderate	2	None	0	None	0	None
AZ7	3	None	X		X		X	
BM6	3	None	X		X		X	
BZ8	X		X		X		X	

Figure 5.6 Mother's anxiety scores (GAD7) over time from T0 to T3



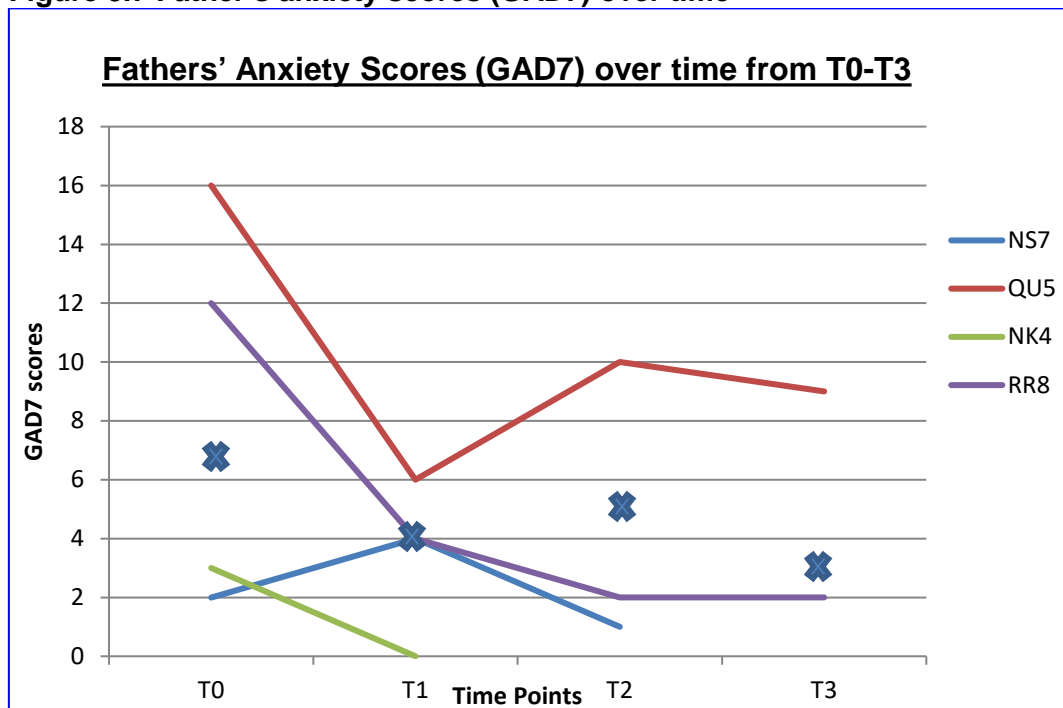
✕ Mean GAD7 scores at each time point

However, as can be seen in the visual representation (figure 5.6) two mothers' GAD7 scores at T1 increased (HH0 and NS7) whilst one stayed in the same mild anxiety range from T0 to T1 (QH5) and the others all decreased. However, whilst HH0 scores increased they remained in the 'no anxiety' range; NS7 increased from moderate at T0 to high at T1. This may indicate maladaptation for these three mothers because their anxiety levels increased or did not reduce after the first two weeks being back at home with their infant.

At T2 four of the mothers had an increase in their GAD7 scores compared to T1 (EU4, NK4, HH0, QU5). EU4 increased from 'no anxiety' at T1 to 'moderate anxiety' at T2; NK4 anxiety increased from none at T1 to mild at T2; HH0 and QU5 increased scores but still within the 'no anxiety' range (0-5). From T1 to T2 the other mothers' scores generally reduced, with NS7 going from high to moderate. Three of these mothers' scores (EU4, NK4, QU5) had dropped at T1 into the 'no anxiety' range, perhaps indicating adjustment and adaptation to being home and then increased at T2 (EU4 to moderate; NK4 to mild; QU5 still within the 'no anxiety' range) prior to being readmitted for stage 2 surgery; whereas one mother's scores (HH0) had increased at each interview, until after stage 2 (T3) when they returned to baseline, although all her scores were within the 'no anxiety' range (0-5).

Four fathers consented to take part in the interviews (QU5, NS7, NK4, RR8) and completed the GAD7, PHQ9 and MCS assessment. One father was not available for the interviews at T2 and T3 (NK4), this father did not live with the infant’s mother and was not particularly engaged with the research project, despite having consented to take part. One father was not available for the interview at T3 (NS7) as he had returned to work. These missing scores are denoted on the graph as a discontinuation of the line and therefore the trends need to be viewed with caution (see figure 5.7). Three fathers’ anxiety scores dropped at T1, QU5 dropped from high at T0 to mild at T1; RR8 dropped from moderate at T0 to none at T1 and NK4 score dropped within the ‘no anxiety’ range (0-5). NS7 score increased from T0 to T1 but both scores were within the ‘no anxiety’ range. There was a general downward trend over time for three of the fathers, except for QU5 who had an increased score at T2 from mild to moderate anxiety. This father had pre-existing post-traumatic stress disorder (PTSD) that was being managed by his GP, he was awaiting psychological therapy referral via Improved Access to Psychological Services (IAPT). The GAD7 scores at T0 and T2 for father QU5 were given to his GP by staff from the research team at the study site with the father’s consent as it triggered referral to GP on the CUDAS tool (Furze 2013). This father’s GAD7 score dropped back to within the ‘mild anxiety’ range at T3.

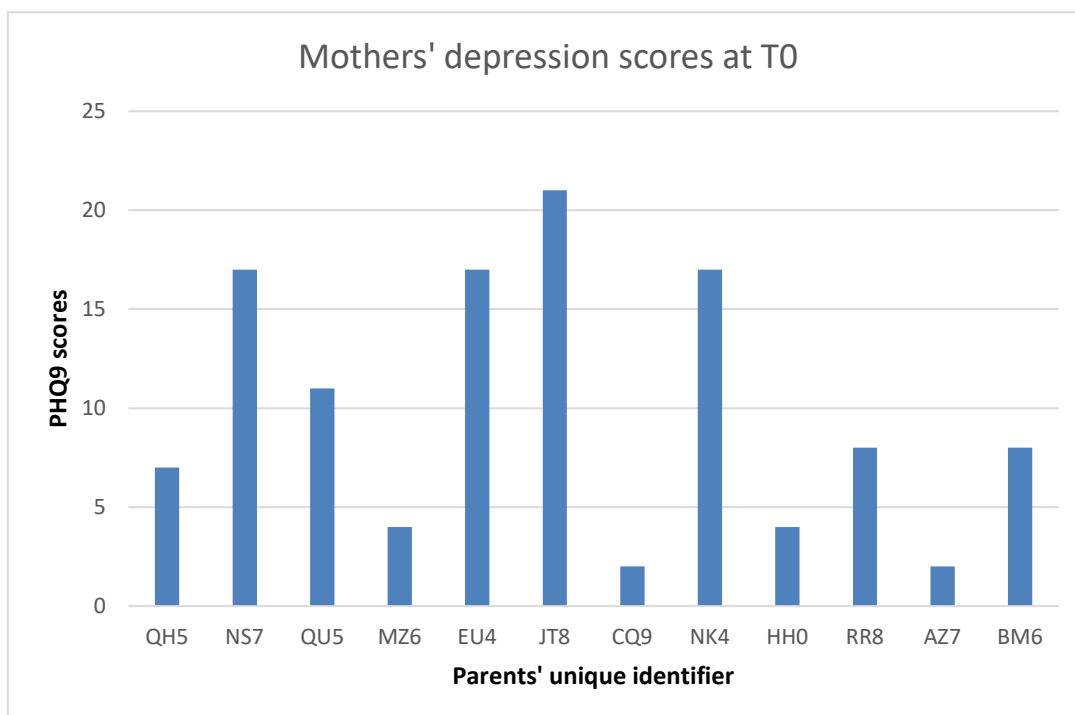
**Figure 5.7 Father’s anxiety scores (GAD7) over time**



✕ Mean GAD7 scores at each time point

None of the mothers scored zero for PHQ9 at T0 (see figure 5.8). One mother scored over 10 at T0 indicating minor depression requiring monitoring and watchful waiting and four mothers scored over 15 which indicated major depression, moderately severe indicating a referral to their GP. One of whom (JT8) scored over 20 indicating major depression, severe. Question 9 screens for the presence and duration of suicide ideation; this triggers a risk assessment, which was negative for all five mothers. The information was passed onto their GPs by staff from the research team at the study site, following verbal consent to do so from the parent.

**Figure 5.8 Mothers' depression scores (PHQ9) at T0**



Scores 5-9 minimal symptoms; 10-14 minor depression; 15-19 major depression, moderately severe; over 20 major depression, severe



**Table 5.5 Mothers' depression (PHQ9) scores over time T0, T1, T2, T3**

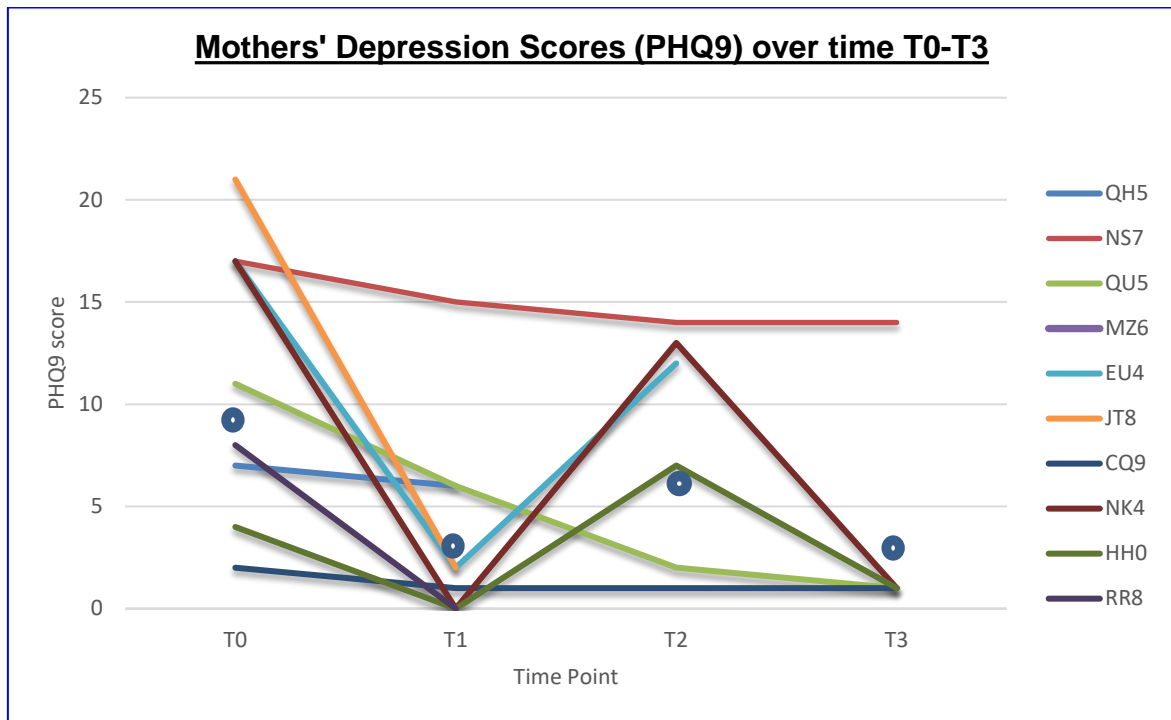
	T0		T1		T2		T3	
<b>QH5</b>	7	Minimal	6	Minimal	X		0	None
<b>NS7</b>	17	Major	15	Major	14	Minor	14	Minor
<b>QU5</b>	11	Minor	6	Minimal	2	None	1	None
<b>MZ6</b>	4	None	X		X		4	None
<b>EU4</b>	17	Major	2	None	12	Minor	X	
<b>JT8</b>	21	Major, severe	2	None	X		4	None
<b>CQ9</b>	2	None	1	None	1	None	1	None
<b>NK4</b>	17	Major	0	None	13	Minor	1	None
<b>HH0</b>	4	None	0	None	7	Minimal	1	None
<b>RR8</b>	8	Minimal	0	None	X		0	None
<b>AZ7</b>	2		X		X		X	
<b>BM6</b>	8		X		X		X	
<b>BZ8</b>	X		X		X		X	

There was a downward trend in depression scores at T1 and an upwards trend at T2 (see figure 5.9). One of the mothers (NS7) showed signs of major, moderately severe depression at T0 and minor depression at each subsequent time point, she was risk positive at T1 but risk negative at T2. This mother was already known to her GP and had a mental health worker who she was seeing due to pre-existing mental health issues. She was not at all surprised about her scores and gave consent readily for the information to be passed onto her GP by the research team each time the scores were obtained. She had been seen by her GP one week before T2 and was taking anti-depressant medication. At T3 she again scored risk positive and consented to her GP being notified. There was also a co-existing feud within the family and relationship problems with her husband, which had improved over time since first discharged. However, these additional stressors added to the transitional factors impacting upon her maladaptive psychosocial functioning.

Three of the fathers had PHQ9 scores of 10 and over at T0, indicating minor depression and triggering referral to their GP (see figure 5.10). Fathers NK4 and QU5 also triggered a risk assessment at T0, which was negative for both. Again, all fathers consented to their GP being informed of their scores. QU5 had known psychological problems, as previously discussed. Father NK4 had not disclosed any pre-existing psychological

issues at the initial interview, but he did discuss an issue that had occurred whilst they had been in hospital that was obviously causing him distress and impacted on his behaviour and comments during the pre-discharge interview T0. Likewise, father RR8 did not disclose any pre-existing psychological issues.

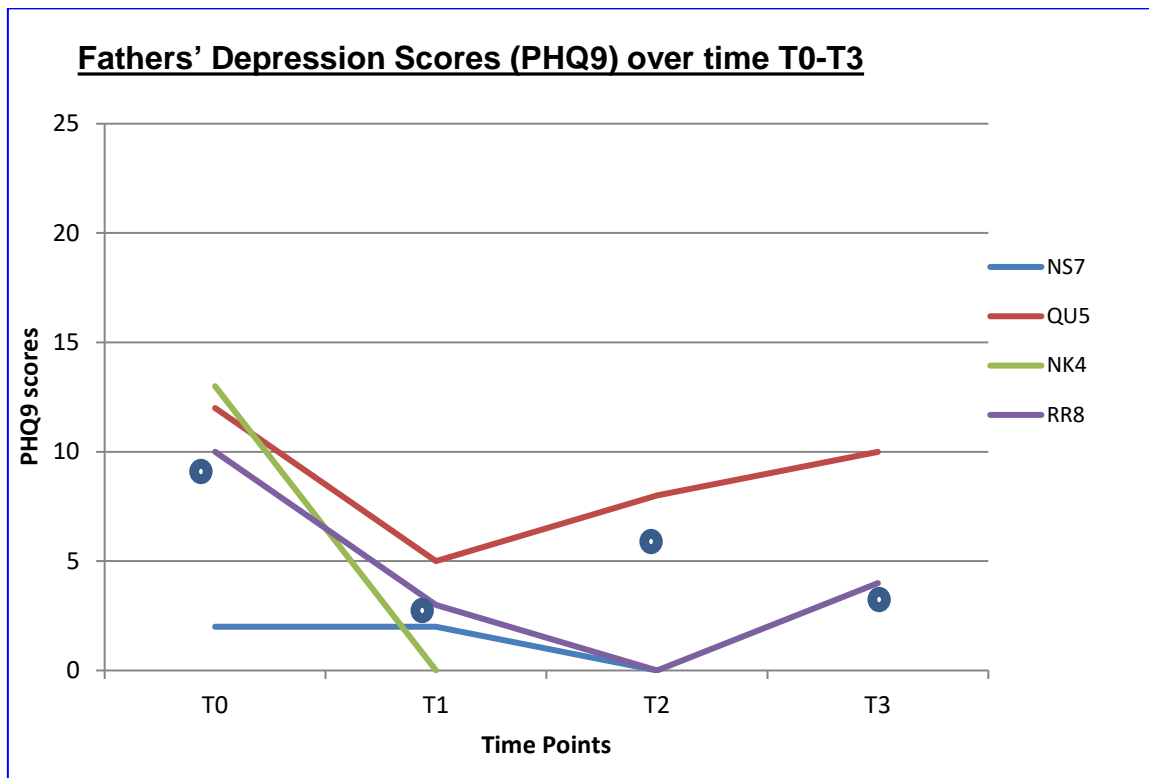
**Figure 5.9 Mothers' depression scores (PHQ9) over time**



● Mean PHQ9 score at each time point

There was a general downward trend at T1 for three of the four fathers. There was an increase in PHQ9 score at T2 for one father (QU5) and again at T3 for the same father; this father's score triggered the risk assessment at T3, which was negative. It also triggered referral to his GP, which was undertaken by the research team at the study site after he had consented to the information being shared. There was also a slight rise in PHQ9 score for father RR8 at T3 but the score was still in the classification range of 'no depression'. These findings support the qualitative findings and the descriptive statistics, indicating that parents' depression levels reduced following discharge home from hospital at T1, T2 and T3.

Figure 5.10 Fathers' depression scores (PHQ9) over time



- Mean PHQ9 scores at each time point

#### 5.4.2.3 Physiological needs

Adjusting to going home focused on the 'normal' physiological needs of their infants, for example: "I'm trying to keep being a normal mom the same you know, cuddles, lots of cuddles and just doing normal baby things with him, with bath time and routine and things like that" (QH5 mother T1). Some parents with other children felt that parenting was no different to before: "There's no difference really for me, just her medication .... 'cos at the end of the day she's just another little baby" (QU5 father). The mother reaffirmed the perceived 'normality': "She still does baby stuff doesn't she ... you couldn't really tell, unless you saw her ... saw the scar, I don't think you'd know any different would you really ...." (QU5 mother).

Another parent explained how looking after her baby's 'normal' physiological needs was relaxing for them both: "I'm sort of letting her dictate to me when she's ...hungry, when

*she wants to play and when she wants to sleep, erm and I think it's not only made her more relaxed and get on with things, it's also helped me out as well. I think at the end of the day I've come home and gone right we'll just treat her as we would have done with any normal baby or any normal child. You know she's still got the same sort of needs, still needs to be fed, changed, cuddled and everything like that so ... it's kind of been a case of we'll respond to what she wants, she'll tell us when she's tired, she'll tell us when she's hungry or whatever else, so we're letting her pretty much tell us what she wants and when, so it's been quite relaxed in that respect" (CQ9 mother, T1).*

Whilst normal parenting of infant's physiological needs was important, enhanced cautiousness regarding infection was evident; the home and sibling's hands were '*kept clean*'; associated with vigilance, health and wellbeing and the home environment.

#### 5.4.2.4 Home comforts

Parents' physiological needs, were affected during the hospitalisation resulting in a lack of sleep and not eating properly; generating a longing for their '*home comforts*'. Physical home comforts '*sleeping in your own bed*', *being able to make a cup of tea*', '*not having to share a shower*' facilitated an improvement of physiological functioning over time. There was also evidence of nesting as mothers described preparing the home for discharge; very few physical changes were made at this stage to the home environment, other than cleaning, heating and organising the space. Ongoing '*survival*' was evident over time, through establishing routines to meet the family's physiological needs, balanced with housekeeping and managing the family's finances.

#### 5.4.2.5 Finances

There was variation in the significance of finances and this linked in some cases with the parents' employment. One mother, who lived alone and had envisaged being able to continue managing her business, described the significant negative financial impact of not being able to work and the resultant additional stress of handling bailiffs. Several fathers returned to work having fully exhausted their holiday entitlement, whereas others were '*signed off sick*' to provide support at home.

For some sick leave was fully paid, whilst others received nothing, adding to their stress. Furthermore, one father recognised a link between returning to work and a decline in his health and wellbeing and an increase in anxiety. One of his colleagues has severe CHD and was empathetic and supportive regarding the situation: *“for me to actually make the decision that I needed to have some more time off ... well not just my health but it's (baby's) health as well because with her feeding regime, [it] effectively runs through the night, [it] started to get to the point where I was sleeping through alarms and obviously, I can't let that slip”* (RR8 father T2).

Parents' psychosocial functioning was inferentially explored with parental demographic information. However, no statistically significant relationships were found when comparing mean anxiety (GAD7) and mean depression scores (PHQ9) with postcode deprivation index, parity, education, employment and distance from home.

#### 5.4.3 Love and Support

Love (met or unmet) was associated with the love, intimacy, closeness and supportiveness of the parental relationship; and the relationship, love and closeness with their other children and between siblings. As would be expected parental relationships were affected by the demanding hospital experience; as well as the lack of home comforts and 'space', as these two parents' quotes demonstrate: *“We didn't communicate very much. I suppose because we were both very tired”* (NS7 father, T2), whilst the mother said: *“I think it had an effect on our relationship, I think it put a lot of strain on our relationship”* (NS7 mother, T2).

For other parents, hospitalisation had a more positive effect, for example: *“it's brought us closer together, I'd say, we're finding each other's weaknesses and erm I'd say, I've heard you say it's brought us closer together”* (QU5 mother, T2).

The transition home was associated with survival whilst establishing family togetherness through the development of routines; positively influencing the resilience of the parental relationship. For some couples this took longer than others and perceptions of the impact over time altered within relationships, for example at T1 NS7 father said: *“So now he's*

*[baby] home it's a bit easier, a bit more time to relax as well". And at T3 NS7 mother said: "...we're starting to create a routine that will work for both of us ...I think it's helped our relationship so we're not arguing so much now [laughs]"*.

Siblings received *love and attention* from other members of the family, especially grandparents, whilst the baby and parents were in hospital. However, there was evidence of an association with the sibling's and parents' psychological health and wellbeing (survival) and the impact of separation on family togetherness (safety and security). Re-establishing the 'family' prior to discharge was deemed important; several siblings stayed in the hospital for the last few days, for example: *"...all of us leaving as a family"* (RR8 mother) *"yes that was nice"* (RR8 father) *"something she [sibling] shared as well"* (RR8 mother, T1).

Once home parents' accounts included ensuring the availability of 'love and attention' for the sibling: *"... we're also conscious of making the time to just spend a little bit of quality time with her as well as sort of almost keeping (baby) out of the equation"* (RR8 father, T1).

Support was connected to the help received from family and friends, other cardiac parents; and HCPs; it encompassed care and compassion; information and guidance; sympathy and empathy. The pursuit and provision of support altered over time; in the initial transition phase from hospital to home, parents sought support mainly from family and friends. Grandparents were the greatest source of support, many of whom lived nearby and could help around the home, caring for siblings, assisting once the father returned to work and as their and parents' confidence increased providing short breaks by looking after the infant so that parents could get out to shop or attend appointments.

Parents also obtained support for cardiac related advice from the specialist nurses, for example: *"...that point of contact for peace of mind to say, she's doing this, based on that information I'm giving you, what do you suggest, does this sound about right, even if it's someone to sound off to and they go 'yeah that's fine'"* (CQ9 mother, T2) and were aware that community HCPs were less knowledgeable about the cardiac problem. Health visitors, community nurses and GPs were however, sources of support for 'normal' new baby advice and monitoring.

Institutional support became less needed as time progressed, whereas other cardiac parents became a major source of friendship and support. This strong 'cardiac parent

community' interacted predominantly via social networking sites and text messaging; sharing good and bad news stories between parents who had formed friendships in the hospital environment and who understood each other: One father explained how difficult previous friendships had become because of a lack of understanding: *"it's just a whole other level and trying to emphasise that it's a completely different ball game [to parenting a well-child] and it's not even in the same ball park it's quite – yes that can be a little bit frustrating I think"* (RR8 father, T3).

This increase in knowledge, understanding and confidence related to the final aspect of parents' experiences, mastery.

#### 5.4.4 Mastery

Mastery can be contextualised in terms of the parents' journeys of knowledge construction through listening, watching and learning; dissociation and detachment; explicit and tacit knowledge development; emerging coping strategies; gaining confidence and reflection.

Learning or gaining knowledge commenced from the time of their infant's diagnosis, both antenatally and postnatally. Parents' experiences of learning, knowing and understanding their infant's diagnosis were dependent upon when they received the diagnosis; the social situation; who was involved in providing the information, for example: *"I didn't know anything about it at all, but now yeah, especially when they referred me to the women's hospital and I saw the doctor there, [name], yeah and she was really really good, she went into a lot of detail and explained it really well"* (HH0 mother, T0); How the information was given and where, such as: *"I sort of deal with well what is it you know, what can they do, what can't they do and all that sort of side of it so. I don't, whether it helped or not I don't know, whether sometimes knowledge can be you know, too much"* (RR8 father, T0).

Knowledge acquisition was not only an explicit transfer of information but tacitly embodied through their emotions and feelings of shock and devastation: *"...it feels like I'm still in a nightmare that I'll wake up any minute and I'll still be pregnant"* (QH5 mother, T0). For many parents, there was evidence of dissociation of their thoughts from their

body's experiences; especially during the immediate post-operative intensive care of their infant, for example: *"...it's like a standstill, you're like 'where am I?' you're on like a standstill, I was just focused on that one cot. I wasn't even daring to look around me. Oh, God no, all I seen was these big machines and I thought I'm not even looking, I was like I'm not looking nowhere, my eyes, it was horrible"* (AZ7 mother, T0).

Experiential learning (both explicit and tacit) continued in the ward environment as parents asked questions: *"you know, to try and get into my brain exactly what is the matter with him, what they've done, what procedure was done... and what the surgical procedure was done and what the next one and so like from a medical point of view... I know what's going on with him.... I don't fully understand it because I'm not medical, but to try and get in my head so I know exactly what to look for when we are at home"* (QH5 mother T0) and eagerly watched and learned from the nursing and medical staff, for example: *"I think from being here I've picked up some of the tools and how to spot and doing simple things like putting a hand on her and checking her breathing"* (CQ9 mother T0); to ensure safety and security once they were discharged home and sourced information from the internet and leaflets.

Parents also learned from the experiences of other parents, the excitement of another infant being discharged or the distress of another infant's death, as well as through sharing their collective parenting experiences. Parents learned strategies for coping with their experiences, both physical ('crying'), such as: *"I don't say I don't cry, I cry a lot, I cry, sometimes I just, I have to just hideaway and cry, just feel better"* (JT8 mother T3) and psychological (disconnection). They learned the social and cultural norms of being in hospital; being a 'cardiac parent' and being part of a socially constructed community.

Once home further experiential learning occurred, establishing their own routines, learning to cope without the safety net of the monitors, alarms and readily available specialist knowledge in hospital. But knowing that specialist advice was available at the end of the phone. They learned to cope on their own, to source love and support from other places and to develop personal knowledge of their infant's individualised needs. This knowledge became cognitively more explicit, as they learned to understand the signs and symptoms they were observing and hearing. Parents already bound by the cardiac parent community, had to decide whether to integrate the explicit and tacit knowledge and information presented to them by different social constructs, such as individuals with only 'normal baby experience': *"no one else understands"* (RR8 mother T2) and other cultural and social environments (knowing the diversity of environments



and organising days out around giving medications and feeds): *“I find it easier to go to someone’s house rather than out to town or something, it’s more comfortable to give his meds and stuff”* (HH0 mother T2).

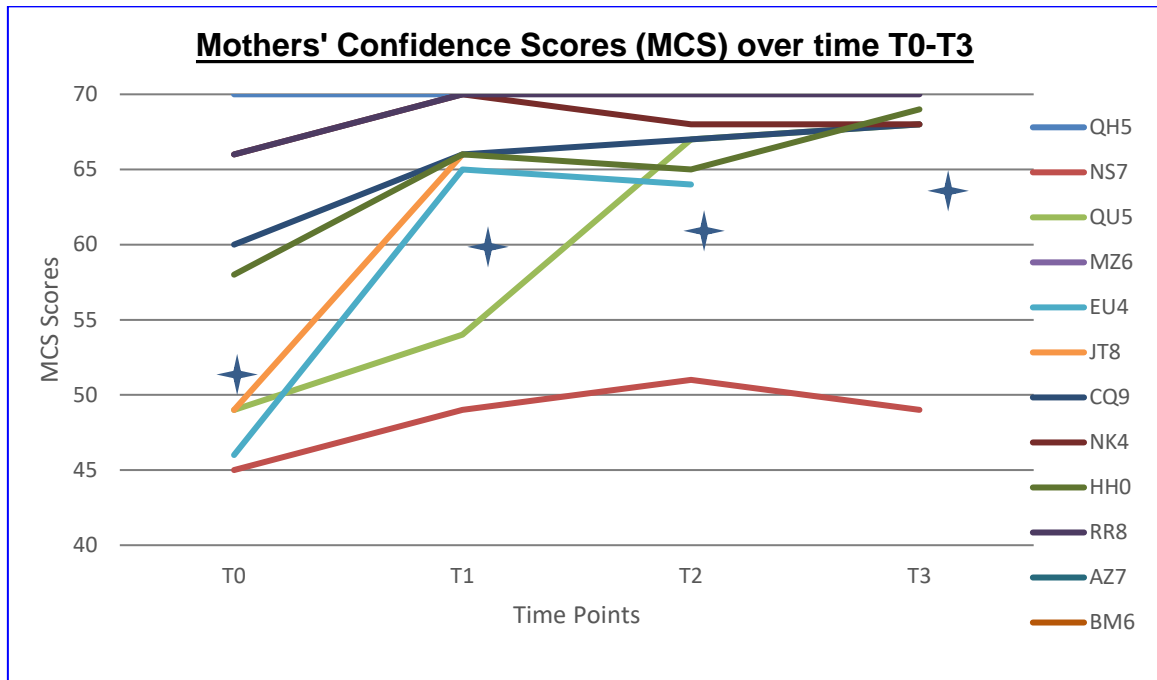
In the early interviews parents were immersed in the minutiae of learning holistically about their infants, surviving without time to pause and reflect. However, there was some evidence of learning from spiritual practice and faith was extremely important for one mother, for example: *“it’s rocky, sometimes you have to cry, cry if you wanna cry, [pause] but take one day slowly, one step at a time and keep your faith”* (JT8 mother T3).

#### 5.4.4.1 Confidence

Confidence (MCS) scores (Parker, Zahr and Cole 1992) range between 0-70, higher scores equate to higher levels of confidence. Figure 5.11 graphically shows a general upward trend at T1 and a decrease in scores at T2 for some mothers, incomplete scores as described above are denoted on the graph as a discontinuation of the line and, therefore, these trends need to be viewed with caution. There is an increase in MCS scores again at T3 for some mothers.

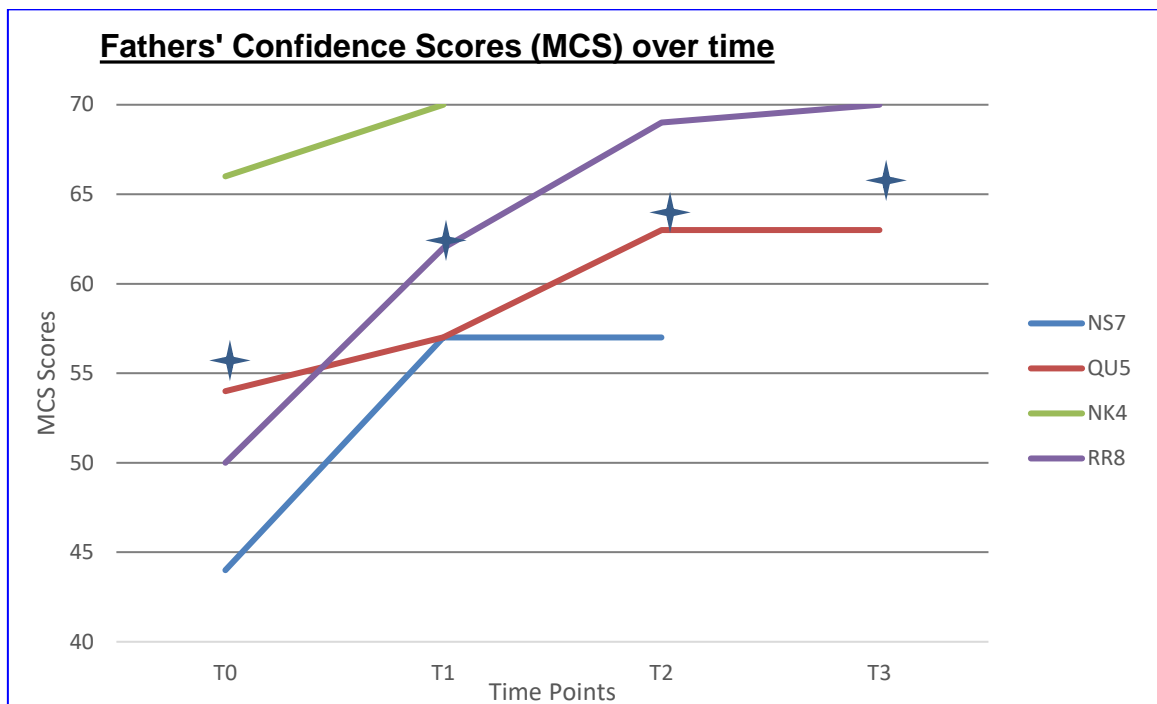
The fathers’ confidence scores increased at T1 (see figure 5.12), with a general upward trend over time stabilising at T3, except for NS7 who had the same score at T2.

Figure 5.11 Mothers' confidence scores over time



★ Mean MCS scores at each time point

Figure 5.12 Fathers' confidence scores over time



★ Mean MCS scores at each time point

#### 5.4.4.2 Reflection and looking to the future

In the accounts at T3 it became evident that emotional learning was taking place, parents could reflect on their feelings and emotions at T0 and recognise how they had moved on; knowing what they did now, they wondered why they had been so fearful about going home for the first time. Parents' accounts at T3 demonstrated positivity more than negativity and a shift in focus towards looking to the future, recognising that there was still some learning and uncertainties ahead: *"...a few days ago I started to look into erm child care and him going to school and things and obviously erm I went onto the LHM website and I kind of realised how daunting it can actually be having your child go to school and things like that and making sure that they're aware of the situation and they can cope when something happens and things like that so ... getting advice from parents that have gone through it you know it's very helpful"* (NK4 mother T3).

An important element of this learning was the shift in their sources of support and the integration of knowledge, as parents began sharing their experiences and listening to others in the wider 'cardiac parent community' via social networking sites: *"I don't know, like it's kind of support you see – just knowing that other people in common knowing exactly what you're going through because friends and family support you, but they can't fully understand it"* (HH0 mother, T3)

And: *"...we get a lot [support] on Facebook don't we really, you can see everyone going through what you're going through and if you're not sure on something you can ask them you know, they might have had it or ..."* (QU5 mother T3).

A process of integration was identified at T3, where parents could assimilate the emotional, experiential and cognitive learning that had taken place, resulting in the development of knowing and creation of knowledge.

However, for some families transition from hospital to home was a constraint, for example the betwixt and between space was clearly demonstrated in this couple's comments: *"I think because we left it so late going home even though we were discharged like mid-day but we didn't actually get home until like half past 8"* (RR8 father, T3). *"How do you mean you didn't manage to get home till 8? was that just because you didn't ..."* (interviewer) *".... clinging on to straws"* (RR8 mother, T3).

## 5.5 Chapter Summary

In summary, this chapter has explored the four key patterns of experience of parents transitioning from hospital to home with their infant following first stage of cardiac surgery: safety and security; survival; love and support and mastery. The key processes were dynamic and transformational overlapping over the four time points from T0-T3. The next chapter discusses the key findings from both phases of this study.

## Chapter 6 Discussion

### 6.1 Introduction

This chapter discusses the key findings arising from phase one and phase two of the study and considers how they relate to and further inform the extant literature. The discussion will include relevant concepts and theories based around transition, adaptation and adjustment, resilience, psychosocial functioning, parenting and family centred care, which will be summarised in relation to the patterns of the parenting experience emerging from the qualitative and quantitative analysis in this study. The key themes arising from the study were:

Phase one:

- Mixed emotions about going home: fear versus excitement
- Knowledge and preparedness
- Support systems
- Gaining control: The need to return to or commence family functioning

Phase two:

- Safety and security
- Survival
- Love and support
- Mastery

### 6.2 Phase One Discussion

One of the key findings of phase one was that the parents felt unprepared physically, emotionally and educationally for their discharge home with their infant following first stage of cardiac surgery for a univentricular heart. This lack of preparation reflects the findings of other studies that have specifically explored parents' understanding of their child's CHD and found that parents had knowledge gaps and needed effective educational programmes (Cheuk et al 2004, Staveski et al 2015).

The perceived advice reported by parents in phase one, in terms of the teaching and written information given to them before discharge varied amongst respondents and amongst centres. Furthermore, when asked about elements of the teaching and written information they received before discharge from the specialist hospital, some families reported that they did not receive any preparation at all. This would suggest that current parental educational programmes are inconsistent and do not meet parents' needs. Parental dissatisfaction with quantity and quality of information received has been identified (Kosta et al 2015). This dissatisfaction is supported in other research by Arya et al (2013) in a study comparing expectations of cardiologists and parents regarding education and counselling. Parents consistently ranked such topics as more important than cardiologists did; Arya et al (2013) concluded that parents [of older children with CHD] would prefer to receive more counselling and education both prenatally and in the neonatal period than is perceived necessary by cardiologists. These studies demonstrate a recognition by both parents and HCPs that parents are not well prepared; that they lack detailed knowledge and understanding of their child's CHD and that educational programmes are ineffective. The findings from phase one further support this claim.

The advice in terms of teaching and written information given to parents before discharge varied in this doctoral study. Approximately half of the responses rated the quality of discharge information from their specialist hospital as good or excellent. However, when asked about elements of the teaching and written information specific to infants with univentricular hearts, some families did not receive any preparation at all.

The need for effective preparation before discharge home with their fragile infant, was one of the main themes arising from the parents' comments about their discharge experiences. The uncertainty of '*not knowing what to do*', '*not knowing who to contact*', '*not being able to recognise deterioration*', fear that the '*baby would stop breathing*' and the fear of '*something happening*' was a major worry for many parents. However, awareness, through teaching regarding their infant's needs, was one of the main facets positively facilitating the transition of discharge for parents in this study, conversely lack of awareness inhibited the process for some parents. Furthermore, the professed lack of consistency of written discharge information and the variation in terms of the amount and type of teaching received by parents participating in the survey could have been influenced by other factors. For example, the length of their hospital stay could have impacted on the perceived quantity of information given at discharge, as some parents

may have been receiving on-going teaching during the post-surgery period. Normal daily conversations with nursing staff during a long hospital stay might have implicitly included guidance and advice without the parents considering it as discharge information; conversely the nursing staff may have believed that they had been preparing families throughout the admission, development of knowledge perhaps being presumed through repeated interaction. The implications of this finding for practice relate to the need for nursing staff to clarify parents' knowledge and understanding before they are discharged rather than assuming parents have absorbed everything that has been explained to them. Competency documents would measure parents' ability to conduct a specific skill; however, it may be more time and cost effective to implement a tool that enables early assessment by parents of signs of deterioration.

Parents may not have fully 'heard' what was being explained to them in the pre-discharge period due to their anxieties and the stressfulness of the situation. Furthermore, the findings demonstrated some difference in the fears of the first-time parents compared to the experienced parents; the 'world' around these parents varied in terms of their previous experiences and social constructs, and may have also been influenced by their educational and social backgrounds as well as support mechanisms. Therefore, the clinical implications again relate to nurses supporting parents by checking that the message delivered has been heard and understood by parents; key elements of involving parents using a family centred care framework (Smith, Swallow and Coyne 2015).

The main sources of support for parents during this transitional period was their spouse and the infants' grandparents. This reflects the findings of other studies (Rempel and Harrison 2007, Rempel et al 2009) where grandparents were recognised as playing an active role in the care of their grandchild and their 'child' as parents, and indicates the need for future work to consider interventions aimed at the wider family. Support from the specialist heart hospital and the local community's health care services was reported by parents. However, parents reported the need for more effective preparation of community staff and local hospital teams to enhance their knowledge and understanding of congenital heart disease and the specific needs of their infants following complex surgery. Parents stated that they did not have confidence in their local teams and, therefore, they relied more on access to advice from the specialist hospital via telephone. Parents also felt that the local and community teams had unrealistic expectations of their level of knowledge and understanding at this early stage in their infant's health care

journey. This was an important finding given that there has been an increasing focus on community care and 'care closer to home' within health policy over the last ten years (DH 2006a, Harvey and McMahon 2008). The NHS Confederation (2012) recognised that appropriate education and training is essential to ensure that staff have the necessary expertise to make out-of-hospital care a reality. A recent mixed methods study assessed the preparation required to ensure that nurses can provide high quality out-of-hospital services for children and young people (Whiting et al 2015). Whiting et al (2015) found that young people ranked being cared for by professionals with the requisite knowledge and skills, as one of the most important aspects of healthcare at home. The implications for practice refer to the need to ensure that specialist educational opportunities exist for HCPs working with these parents and caring for these fragile infants in the community.

Prior to this doctoral study commencing, the CHD charity had reported an increase in families needing individualised support prior to and during the transition from hospital to home, and this was a contributing factor to the collaboration with the charity in developing and distributing the questionnaire back in 2011-2012. Whilst phase one had limitations in terms of sample size and the demographic of the participants, the data began to confirm the experiences reported by parents to the charity. Subsequently the CHD charity conducted a membership survey in 2013 (LHM 2015) to seek members' views regarding the impact on the family of their child's diagnosis and to review the support services available to them both from the state and third sector. The overriding principle was to identify parents' support and information needs so that future service development of the charity could be structured to meet deficits in the existing service (LHM 2015:4). In total 2,179 questionnaires were distributed plus a further 30 for over 18s and 360 more sympathetically-focused questions for bereaved members. In all cases where two parent members shared the same address two copies of the questionnaire were circulated. 197 completed questionnaires were received from parents of children of all ages and resulting in a different sample to phase one, which only focused on the 0-2 age range. The response rate for this membership survey equated to an 8% response rate for members, and a 6% response rate for bereaved families. The findings from the membership survey have enabled the charity to review the current provision of support and information to further develop their service. Conclusions drawn include that the charity has a positive role in supporting families along the treatment and lifestyle path and that the support needed will vary with individual families and at different stages of their journey. Additionally, that members like the style of the charity's information and communication tools. However, members stated that they



would like strengthened online services, communication, support and information. Members also still have many written information requests (LHM 2015:42)

These survey findings (LHM 2015) support the findings from phase one, which looked specifically at the time of discharge from the specialist centre after first stage of surgery, in that what parents' want is standardised discharge information; they want to know what to look out for, what to do and who to contact. There was however, a contradiction emerging in phase one findings, as parents also wanted individualised information specific to their baby's needs. These findings contribute to the evidence base required to support the implementation of nationally recognised standardised discharge information, as recommended by the clinical reference group working alongside the congenital cardiac services review (NHS England 2015). Specifically, the findings from phase one relate to the lack of provision of pre-discharge teaching or written information, across the 11 centres, and demonstrates that parents are not being fully prepared about the key signs of clinical deterioration (Dedieu and Burch 2012) to look out for in this group of infants. This clearly has implications for practice in terms of the preparation of parents by specialist hospital staff and the implementation of education initiatives to enhance the knowledge and understanding of local hospital and community teams.

The second key finding from phase one of this study was that most parents adapted to the transition of being discharged from hospital to home following their infant's first stage surgery for complex CHD over time. This was shown by an improvement in their adjustment from discharge (T0) to T1 as there was a perceived reduction in anxiety for both mothers and fathers during this time. In addition, there was a perceived improvement in confidence levels for both mothers and fathers.

The age of the infants at discharge varied from 3 days to 70 days of age, perhaps reflecting the severity of some infants' conditions prior to discharge and at T1 the infants' ages ranged from 4 – 36 months. Confidence and anxiety levels may have been different for those families that had longer to come to terms with their situation, compared to those whose infants had only recently been discharged. One of the limitations of this study is that the timeframe T0 and T1 were not the same for each family, the responses may therefore have been influenced by the time passed since discharge and therefore reliability of recall over longer durations (Raphael 1987; Last 2000), as well as the fragility of the individual infants at discharge.

Of importance in this discussion are the findings of Thomas and Deiner (1990) relating to memory accuracy in the recall of emotions. In their study, subjects were found to overestimate the intensity of both positive and negative emotions due to the salience of emotional events in peoples' lives, and to recall negative events with greater frequency. They also found that the frequency of emotions became mixed up with the intensity of those emotions and elements of this may be evident in phase one of this study. However, also of note is that the vividness of the descriptions was considerable across all responses, suggesting that retrospective recall of feelings was indeed still fresh in the parents' minds, something noted by Messias et al (1995).

An improvement in adjustment patterns from the point of diagnosis to six months' post birth, was also identified by Fonseca, Nazare and Canavarro (2013) for parents of children with congenital anomalies. Whilst Brosig et al (2007) found an improvement in the emotional status of parents six months after diagnosis, albeit a significant difference between parents given a prenatal diagnosis compared to those whose infants were postnatally diagnosed. Comparisons in anxiety levels were not explored between pre-natal and post-natal groups in phase one, however, figure 5.5 shows that there were variations across the respondents and it was not only those parents that had received a post-natal diagnosis that rated their anxiety high at T0.

Nevertheless, Brosig et al (2007) also found higher anxiety levels at diagnosis in parents whose infants had more severe CHD. This finding is contradicted in studies of older children where the severity of lesion has not been significant in relation to levels of parental anxiety (Doherty et al 2009, Lawoko and Soares 2006, Morelius, Lundh and Nelson 2002, Wray and Sensky 2004, Jantien Vrijmoet-Wiersma et al 2009). Given that each of the studies examines parental anxiety at different times (arguably at different critical points of transition) and in different ways, inconsistent findings could be expected. However, what is consistent is the recommendation that parents are screened and interventions are put in place to support both mothers and fathers psychologically (Svavarsdottir and McCubbin 1996, David et al 1998, Pelchat et al 1999, Goldbeck and Melches 2006, Brosig et al 2007, Doherty et al 2009, Jantien Vrijmoet-Wiersma et al 2009, Spijkerboer et al 2007, Lawoko and Soares 2007, Lawoko and Soares 2002, Lawoko and Soares 2003, Lawoko and Soares 2006). Additionally, McCusker et al (2009) demonstrated a positive improvement for infants with complex CHD and their mothers following a programme of generalised psychosocial interventions.

The implications of phase one findings for practice are important, albeit from a small sample of predominantly white British families. The responses were not from one specialist cardiac centre, instead they were the experiences of families from across the UK and one parent responded regarding his experiences whilst living in Australia, confirming that the need for psychosocial support is not specific to one geographical region. The findings from this phase of the study have already been used to inform the updated role descriptor for the Children's Cardiac Nurse Specialist (CCNS) in the Royal College of Nursing core competencies document (Gaskin et al 2014), to ensure standardisation of the role across the UK in relation to psychosocially supporting parents and families at the time of discharge. These role descriptions contributed to the development of the draft standards and service specifications (NHS England 2014) supporting the need for the CCNS role and supporting the role of the CCNS in 'providing psychological support to promote parental adaptation and adjustment' (standard H15, L1). Additionally, the draft standards and service specifications (NHS England 2014, standard B31, L1) recognised the need for psychological support and recommended that 'each specialist children's surgical centre should employ at least one full time psychologist with an experience of working with CHD per 400 children and young people (CYP) undergoing cardiac surgery each year'. Furthermore, the draft standards recommended that each Congenital Heart Network must have one full time psychologist per 5000 CYP with CHD (standard B31, L1). The standards have since been ratified and published (NHS England 2016) and are currently being implemented across centres in England.

What has been recognised in the national documentation arising from the congenital cardiac services review (Gaskin et al 2014; NHS England 2015) is that transitions are complex and multidimensional; however, several properties and conditions have been identified in phase one as being facilitative or linked to inhibiting a transition (Meleis et al 2000). The distance from home to the specialist heart centre was one such inhibitor in this study; mothers living further away from the specialist heart centre reported being more anxious at discharge than those living closer. This inhibiting factor was significant given that the review of congenital cardiac services initially considered moving towards fewer larger specialist surgical centres, meaning that the services would have been further away from home for more families (NSCG 2010).

Additionally, in the open-ended questions some parents commented that being so far away from home was one of their main fears about being discharged. The final Health

Impact Assessment (Mott MacDonald 2012:15) commissioned by the National Specialist Commissioning Group at the time of the Safe and Sustainable Review of children's cardiac services (see chapter 1), recognised that longer travelling times for children and families would impact on their '*level of access to networks of psychological and emotional support from the wider family, or from their religious or cultural community*' as well as *having financial implications*'. Based on the proposed changes in the original review, very long journey times would have been experienced by a small number of patients and their families; however, the considerable effect on family well-being was identified in this report (Mott MacDonald 2012:16).

Whilst distance from home was a major inhibitor for parents in phase one, the excitement of going home engaged parents with the transition process of discharge. So, whilst parents commented that they were *frightened, scared, bewildered* and *nervous* they were also *thrilled, elated* and *excited* to be going home. Parents were looking forward to '*getting home to be a mum*', '*adopting the parenting role*', '*bonding with baby*', '*seeing their other children*', '*longing to be a family*' and having their '*home comforts*'. These are factors that could be considered normal parenting aspirations and transitions, but superimposed on the transition of going home with an infant with complex CHD.

The personal transition conditions (Meleis et al 2000) were different for mothers and fathers in phase one in terms of employment. Fathers' confidence scores at T1 were slightly lower than mothers' confidence scores, which may have reflected the limited care-giving role of fathers in this sample compared to mothers, as most fathers (86%) were employed, whereas 60% of mothers were not. Furthermore, the self-report tool (Parker, Zahr and Cole 1992) used to assess confidence was originally designed for mothers; there is currently no available evidence regarding validity of the tool with fathers. It may, however, be that other factors affected parenting confidence in mothers compared to fathers, such as the time spent with their infant in hospital.

Mothers confidence scores were lower at T0 compared to T1, demonstrating patterns of recovery as mothers became used to the situation of parenting an infant with complex CHD at home. When asked how they felt now (at T1) about being at home with their infant, parents' positive comments included that they were getting to know their baby, had increased confidence, they were regaining their parenting role and developing their parenting role as a new parent.

### 6.3 Phase Two Discussion

Parents' experiences of the transition from hospital to home in phase two also reflected the findings of Messias et al (1995) in that the transition process was multi-faceted, with complex unanticipated transitional experiences becoming superimposed on those that were expected; resulting in a roller coaster of emotions. The multiple types and dimensions of transition (Meleis et al 2000) for these parents included: *developmental* (new baby, parenthood, sibling relationships, becoming a medical parent); *health/illness* (baby's cardiac diagnosis and surgery, fragility of their baby, mother's health and wellbeing following labour, psychological functioning of father, siblings and wider family); *situational* (maternity unit, ward and intensive care unit, discharge to home or local hospital) and *organisational* (hospital culture, ward culture, intensive care culture, culture of being a hospitalised cardiac parent, community/local hospital culture). A variety of social constructs impacted upon their transition and became either facilitating or inhibiting factors (Meleis et al 2000). These related to the 'world' in which they lived; such as the cardiac parent community within the hospital; the social world outside the hospital and the experiences of those parents that were new to parenthood (novice) versus the parents with other children (experienced). The family's personal situations (home and support), ethnicity, (cultural beliefs and attitudes), socioeconomic status (postcode deprivation index), education (preparation and knowledge) also differed and, therefore, influenced the individual transitional experiences of going home. There was no independent variable (demographic) that functioned within all the social processes involved in the transition.

Parents' experiences before discharge and within the first few weeks of being back at home related primarily to ensuring 'safety and security' and 'survival' of their infant, themselves, and the family unit. However, these patterns of experience overlapped and were transformational and dynamic. Therefore, the discussion, whilst split into the four patterns, will demonstrate some of the multiple crossovers that occurred.

### 6.3.1 Safety and Security

The pattern 'safety and security' resonates with the findings of Rempel and Harrison (2007), Rempel et al (2009, 2012a, 2012b, 2012c), Lee and Rempel (2011), Meakins et al (2015) and Pridham et al (2010), who described safeguarding as protecting, safety, vigilance, monitoring and survival; as well as uncertainty and vulnerability.

Parents' major worry and uncertainty about going home was the fear of being alone, the fear of not knowing what to do if something happened and the fear of not knowing who to contact for advice. Parents were used to the safety of the hospital environment and the security of knowing that there was always someone there to help them when required. This reflects the view that parental uncertainty is managed by parents through information management; where parents intensively pursue information about their child's illness (Stewart and Mishel 2000). However, in phase two parents were concerned that they did not have enough information, knowledge or skill to guide them once at home and on their own with their infant. The implications of this for practice focus on the need for standardised discharge information (LHM 2015).

Safety and security, also related to safeguarding their infant through vigilance; where parents described 'constantly watching' their infant, both in the hospital and once they were home. Linking vigilance to uncertainty, Carey, Nicholson and Fox, in another early study (2002) hypothesised that mothers responded to the persistent uncertainty by sustained vigilance through monitoring their infant's ongoing health status. Furthermore, this vigilance is supported in Stewart and Mishel's (2000) definition of parental uncertainty through parents' fervently observing HCPs for cues about their child's condition. This aspect of maintaining safety or 'safeguarding precarious survival' as described by Rempel and Harrison (2007) was also evident in phase two parents' accounts of their experiences and was evident throughout the time line from discharge (T0) through to going home post stage two surgery (T3).

Whilst the parents did discuss uncertainty about their infant's clinical outcomes, this uncertainty was more situational and related more to the physical transition of going home, which would be expected given the nature of the questioning in terms of the research question. However, there are similarities here to the third dimension of uncertainty proposed by Mishel (1981) regarding the complexity in what information is known (parents' knowledge and preparation), the system of care (family centred) and the

relationship with health care providers (becoming more distant as they transition to home). Furthermore, Mishel (1981, 1988) suggested that uncertainty is influenced by the individual (their mental health and personal beliefs), the illness (perceived severity and intensity of treatment) and environmental factors (such as social support, relationships with HCPs and sociocultural aspects). These influencing factors also reflect the properties of transition and facilitating or inhibiting transition conditions (Meleis et al 2000); so, one might conclude that successful adjustment and adaptation to transition could also be related to the management of uncertainty.

Uncertainty has featured in the research evidence regarding mothers of children with CHD since the 1960s (Glaser, Harrison and Lynn 1964, Linde et al 1966, Gudermuth 1975, Carey, Nicholson and Fox 2002) as well as more recently (Rempel et al 2009, 2012a) and, therefore, is not a new phenomenon. However, the definition of uncertainty for phase two parents was different to that identified in the work of Rempel et al (2009), where uncertainty related to the uncertain outcomes for their infants. The Rempel et al (2009) study took place 15 years ago; at that time the clinical outcomes were perhaps more uncertain for this group of infants with complex CHD because the surgical procedures were relatively new and there was little available evidence about short or long term outcomes. Whereas for the parents in phase two, there is more contemporary information available about the expected outcomes, benefits and risks of surgery for infants with complex CHD (Brown et al 2015), that both parents and HCPs can refer to. However, a recent survey of surgeons in major European centres, to identify their attitudes regarding management of HLHS and how they counsel parents; demonstrated a wide variation in survival and quality of life following surgical palliation and a wide variation in the estimated rates of termination of pregnancy (Murtaza and Elliott 2011). Furthermore, despite the availability and accessibility of information in the current surgical era and the availability in the UK of parental support groups (LHM 2009), Murtaza and Elliott (2011) found that there was marked inconsistency in the information given to parents as part of the process of counselling across Europe. Parents' expectations and, therefore, uncertainty regarding the clinical outcomes for infants with complex CHD, are likely to depend on the beliefs of HCPs in the centre in which they receive the diagnosis and treatment.

Therefore, despite improved outcomes in CHD in the UK (DH 2006) these inconsistencies remain to be resolved if parents are to make fully informed decisions for their child. Consequently, the implications for practice focus on the importance of

developing services based on the individual needs of the infant and family; through the development of collaborative processes and effective parent-professional relationships, as highlighted by Smith, Swallow and Coyne (2015).

### 6.3.2. Survival

Uncertainty has also been associated with parental psychological distress, measured by anxiety, depression and helplessness (Stewart and Mishel 2000) as well as post-traumatic stress disorder (PTSD) (Santacroce 2003). In this study 'survival' included the sub-pattern 'health and wellbeing', which was associated with the physical and psychological health of the parents and siblings. Mean parental anxiety (GAD7) scores for both mothers and fathers were higher before discharge (T0) compared to the mean GAD7 scores at T1, T2 and after their infant's stage two surgery (T3), suggesting that parents' anxiety decreased over time; perhaps due to adjustment and adaptation as they got used to their situation.

However, during the period that parents were at home with their infant between the first and second surgery (from T0 until T2), there was a drop in mean GAD7 scores at T1 and an increase in the mean GAD7 scores at T2. This could have been related to the ongoing parental uncertainty, relating to their infant's clinical condition and the unpredictability of their prognosis, quality of life and ability to function (Mishel 1981) as well as a fear of the second stage of surgery as it got closer. This uncertainty may alter after the infant has undergone the second cardiac operation and the infant is perhaps perceived as being more stable by the parents. Mean GAD7 scores at T3 were lower than the previous three timepoints (T0, T1 and T2).

Furthermore, mean parental depression scores (PHQ9) were also higher before discharge from hospital (T0), than at each of the following measurement time points (T1, T2, T3); although PHQ9 scores increased at T2 before dropping again at T3. Anxiety, depression, agitation, shock and dissociation are symptoms of acute stress disorder in the immediate aftermath of a potentially traumatic event (Shalev 2002). Shalev (2002) indicated that within a few days these symptoms can be replaced with those indicating PTSD. PTSD can only be diagnosed following exposure to a traumatic event, which is defined as one that results in a threat of death or physical integrity and in a subjective



response of fear, helplessness, or horror (American Psychiatry Association [APA] 1994). In 1994 the APA quantified that being given the diagnosis of a life-threatening illness for your child is a traumatic event that can cause PTSD (Santacroce 2003). Furthermore, an essential component of the response to an overwhelming, life-threatening event is fear (Yehuda, McFarlane and Shalev 1998). This fear response was evident in all parents' accounts of their experiences of having an infant with complex CHD, especially when they talked about the diagnosis, birth and first stage of surgery. However, not everyone experiencing a traumatic event or fear will subsequently experience PTSD (Santacroce 2003), reflected in this study as not all parents demonstrated characteristics of PTSD. Depression, acute emotional distress, lack of social support (Bisson 2002) and a history of chronic exposure to interpersonal trauma (Kessler 2000) are risk factors for the development of PTSD (Santacroce 2003).

In phase two, one father explained how he already had a diagnosis and was being treated for PTSD from a previous traumatic experience; he had high anxiety and depression scores before discharge (T0), which both reduced slightly after discharge (T1) but remained high throughout his participation in the study. Three mothers (QH5, RR8, AZ7) demonstrated characteristic signs of PTSD (re-experiencing, avoidance, numbing of emotions and hyperarousal, APA 1994) within their accounts of the shock and devastation that they experienced at the time of diagnosis; the time of the birth and during their infant's stay in the intensive care environment. These parents described feelings of helplessness, detachment and dissociation, parenting from afar, and the trauma of the lasting images '*the images won't leave my head*' (QH5 mother); all associated with the horror, helplessness and fear evoked by the traumatic event (Santacroce 2003:46) and characteristic of PTSD (Shalev 2002). It has been proposed that the overwhelming nature of traumatic experiences prevents individuals from fully processing them at the time (Halligan, Clarke & Ehlers 2002; Brewin, Dalgleish & Joseph 1996; Ehlers & Clark 2000; Foa & Hearst-Ikeda 1996; Horowitz 1976; Siegel 1995; van der Kolk & Ducey 1989). The memory pattern in PTSD may in part be related to the data-driven processing, which involves processing of sensory impressions and perceptual characteristics rather than processing what was meant by the event, otherwise known as conceptual processing (Ehlers & Clark 2000). Individuals engaging in data-driven processing are thought to be at higher risk of PTSD than those who elaborate on the meaning of the traumatic event (Halligan, Clarke & Ehlers 2002), perhaps reflecting those parents that benefitted from the therapeutic relationship developed with the

researcher (conceptual processing) (further discussed on p.196) versus those that did not (data driven processing).

These acute stress symptoms are consistent with Franich-Ray et al (2013) who found that approximately one-third of parents' who completed the Acute Stress Disorder Scale one month after their infant had been discharged from hospital following cardiac surgery, experienced trauma symptoms consistent with a diagnosis of acute stress disorder. Whilst the time of assessment differed in Franich-Ray et al (2013) study compared to the parents in phase two who initially demonstrated these symptoms before discharge (T0), the vividness of parents' recall about the traumatic event articulated the strength of the feelings experienced. The risk of recall bias or memory inaccuracy again needs to be considered (Raphael 1987; Last 2000) although it is less likely to be prevalent in the prospective design of phase two of this study (Hassan 2005). Furthermore, the findings from the prospective phase two were similar to those from the retrospective phase one and, therefore, this adds credence to the findings of phase one and reduces the likelihood of significant recall bias, although this was not statistically tested.

Acute stress symptoms in these three mothers included high anxiety (GAD7) and depression (PHQ9) scores as well as their expressions of shock and dissociation during the pre-discharge interviews (T0). Shalev (2002) suggested that early responses (anxiety, depression, agitation, shock, and conversion and dissociation) are socially acceptable (in this case it would be acceptable to assume parents are anxious given the severity of the situation) and that they can communicate a need for help. Parents scoring high on either score (GAD7 or PHQ9) were referred to the specialist cardiac nursing team for support and their GP was contacted with the parent's consent and informed of their scores. In accordance, Bruce, Lilja and Sundin (2014) found that mothers receiving person-centred and family centred care felt more supported and were more likely to adapt to the stress of parenting a child with CHD. However, despite attempting to provide multi-professional person-centred care, one of the mothers did not want her GP to be informed as she was worried about being labelled as an anxious mother and, therefore, support was provided by the specialist nursing team instead.

The father (QU5) who was diagnosed with PTSD was already receiving support, however, at T1 he said that whilst the anxiety had not gone he was learning to cope with it and was trying not to think about things that would worry him. Nevertheless, his GAD7 (anxiety) and PHQ9 (depression) scores had decreased at T1 (two weeks after discharge) showing some improvement; yet at T2 and T3 the scores had both increased

again, perhaps related to the second stage of surgery and additional traumatic experiences. Two of the mothers presenting with PTSD symptoms before discharge, demonstrated a reduction in both GAD7 and PHQ9 scores over time, perhaps indicating adjustment and adaptation; however, their depression scores were lower before discharge than some of the other mothers, indicating the importance of triangulating methods of assessment. By the time the mothers (QH5 and RR8) were interviewed at T3 their anxiety scores were 3 and 0 respectively and depression scores were both zero (AZ7 only took part in the interview at T0) further indicating adjustment and adaptation over time.

The demographic of these three mothers was homogenous in that they were all white British, had higher postcode deprivation index scores (indicating lower deprivation), all had other children (indicating parenting knowledge), lived with their partners (intimacy and support) and had good social support networks (friends and family), all recognised as facilitators of transition (Meleis et al 2002). Furthermore, Tak and McCubbin (2002) recognised social support as a resilience factor between family stress and parental and family coping.

Whilst the aim of this study was not to specifically identify parents at risk of PTSD, the implications for practice of these findings refer to the need for early recognition of symptoms as potential predictors of parental PTSD, so that appropriate support can be offered for both parents, to modulate the responses and assist in adaptive processes where there is a high risk of psychological maladaptation. Numerous other studies, have identified the need for early interventions (Davis et al 1998, Pelchat et al 1999, Tak and McCubbin 2002, Fischer et al 2012, Fonseca, Nazare and Canavarro 2013). Furthermore, Helfricht et al (2008) found that acute symptoms of PTSD shortly after discharge, in parents of children aged 0-16 years undergoing cardiopulmonary bypass, were a major risk factor for the development of chronic PTSD. Whilst Helfricht et al (2008) studied parents of older children and, therefore, whilst their findings cannot be directly compared to the findings of phase two, the authors suggested that clinicians need to identify at risk parents early in order that they can be provided with appropriate support, which reflects the implications for practice recommended here. Conversely, only one study evaluated the effectiveness of psychological interventions (McCusker et al 2009). The implications for practice of this finding have already been recognised within the updated RCN role descriptor for children's cardiac nurse specialists (Gaskin et al 2014).

However, the role of clinical psychologists within the speciality needs further support, as has been recognised in the congenital cardiac service standards (NHS England 2016).

It has been suggested that having an opportunity to talk about and reflect upon one's experience may influence both early and long-term responses to traumatic events (Lazarus and Folkman 1984, Loftus 1993, Pennebaker and Susman 1988). Interestingly, the therapeutic nature of interviews with mothers of two-month-old infants who had recently undergone cardiac surgery was identified by Re, Dean and Menahem (2013). Mothers discussed how the interview had helped them to think about what had happened and that saying things out loud was part of the process of integration and had helped them to put things into perspective. Almost half of the mothers described how sharing their story with someone else had helped to relieve the burden that they felt (Re, Dean and Menahem 2013).

Whilst parents in phase two were not asked specifically about their experience of participating in the interviews, one mother (JT8) reflected upon taking part in the interviews and described the therapeutic benefit of enabling her to talk about her experiences and being grateful that someone had listened. Likewise, Re, Dean and Menahem (2013) concluded that in-depth interviews with an experienced and skilled professional who could listen whilst parents tell their story, without being shocked or overwhelmed, may well be therapeutic especially for those mothers who were highly stressed. They also recognised that the researcher could have been perceived by the mothers as an independent person, without any role within the clinical team treating the infant. By listening to the mothers' distress the researcher could provide an active thinking mechanism for the mothers, outside of the turmoil, to transform the raw emotion into a coherent narrative that assisted in mending the mother's own 'broken heart' (Re, Dean and Menahem 2013:283). Conversely, a therapeutic benefit may not be experienced by parents who demonstrate signs of PTSD, as the over-whelming nature of the traumatic event may prevent those parents from fully processing their experiences at that time (Halligan, Clarke & Ehlers 2002; Brewin, Dalgleish & Joseph 1996; Ehlers & Clark 2000; Foa & Hearst-Ikeda 1996; Horowitz 1976; Siegel 1995; van der Kolk & Ducey 1989). Moreover, Re, Dean and Menahem (2013) suggested that unresolved maternal trauma could be linked to insecure infant attachment, therefore, indicating the importance of psychological support for parents with PTSD.

Interestingly, recent attendance at Cardiology 2016 (19<sup>th</sup> Annual Update on Pediatric and Congenital Cardiovascular Disease, Orlando, February 2016) highlighted the growing

concerns amongst health care professionals working within the speciality regarding the impact of maternal stress on the developing foetus and subsequently on the growing infant. In some specialist cardiac centres in the USA, psychological monitoring is conducted and support is available for parents, from the point of diagnosis and throughout the pregnancy (Donaghue 2016) because the impact of maternal stress on the developing foetus has been recognised (Rychik et al 2013, Titapant and Chuenwattana 2015). Increased maternal awakening cortisol levels have been identified as a bio-marker for stress, anxiety and depression in pregnant women in the third trimester (Donaghue 2016). Troublesome features include the impact of maternal stress on fetal growth and neurocognitive development, as well as an increased risk of premature labour; there is also growing evidence of long lasting physiological sequelae for the infant (Thornburg 2016, Donaghue 2016).

Whilst the focus of the current study was not on prenatal maternal stress, the findings need to be considered more broadly in relation to the impact of maternal and paternal stress experienced in the postnatal and transition to home time frame, superimposed upon the stress experienced during the prenatal period. The effect of early and ongoing parental stress on the infant therefore needs further research.

### 6.3.3 Love and Support

In this study, parental attachment, or bonding with their infant was connected to 'family togetherness' within the 'safety and security' pattern of parental experience, however, this overlapped with family support and the parent-child relationship within 'love and support'.

Mothers (RR8, AZ7, QH5) talked about the fear of losing their infant and the associated trauma of being separated from their infant at birth and during the infant's stay in the intensive care unit (ICU). An association emerged during analysis of the interviews between the mothers who talked about difficulties bonding with their infant whilst in hospital; those with higher anxiety and depression scores and those displaying signs of acute stress (RR8, AZ7, QH5). Jordan et al (2014) explored mothers' subjective experience of their relationship with their infant, four weeks after discharge from hospital following cardiac surgery and found that, as a group, mothers' attachment feelings did

not differ from community norms. However, almost a quarter of the mothers indicated difficulty bonding with their infant and this was associated with prenatal diagnosis, high Edinburgh Postnatal Depression Scale (EDPS) score and low Maternal Postnatal Attachment Scale (MPAS) scores.

Two of the three mothers in phase two (AZ7, RR8) had received an antenatal diagnosis; whereas QH5 had received a postnatal diagnosis. Furthermore, whilst their depression scores decreased over time, they were not the highest depression scores recorded amongst the parents in phase two (figure 5.8-5.10) and, therefore, the findings do not corroborate with Jordan et al (2014).

Jordan et al (2014) suggested that their findings may have related to the differing impacts of cardiac surgery on the mother-infant relationship, where the crisis of the diagnosis either mobilised adaptive coping or was associated with ongoing difficulties. Unfortunately, Jordan et al (2014) study was not longitudinal and, hence, there was no indication as to how many of these mothers had ongoing difficulties as time passed. Whereas in this study, the mothers (RR8, QH5 and AZ7) described in later interviews how despite the initial delay to physical bonding, adaptive processes were mobilised; emotional bonding took place through watching their infant constantly, whilst physical bonding was delayed until the baby was back on the ward, or they were back at home. The other parents in phase two reported heightened vigilance, responsive caregiving and an increase in protective behaviours, such as always keeping the baby with them when they went home. These behaviours were also identified by Jordan et al (2014) for almost half of the mothers in their sample and were suggested as demonstrating that attachment was working well.

Physical and emotional barriers to parent-child interactions were also identified by Rempel et al (2012a); who found that parents had a desire to nurture their child, whilst wanting to protect themselves in case their baby did not survive. These tensions were not evident in the phase two accounts; instead parents (RR8, AZ7, QH5) talked altruistically about putting their infants' survival ahead of their own needs or health and wellbeing. One mother (RR8) described knowing that despite the physical barriers of the technology, wires and tubes, they were '*giving their baby away*' for the right reasons; whilst another mother described how her health began to suffer because she was determined to always be with her baby (QH5).

These findings have implications for HCPs in relation to the implementation of family centred care and assisting parents to bond with their infant in the early days of life. This is particularly the case in the intensive care unit (ICU) environment, where the infant's physical and social environment is disrupted by numerous factors. Providing family centred care within the ICU may pose a challenge, nevertheless Butler, Copnell and Willetts (2013) propose that nurses are uniquely positioned to build partnerships with families, whilst advocating for parents to be present when they choose to be. However, one of the findings arising from their literature review was that whilst many paediatric ICUs purport to have a family centred care policy, in reality, practice does not meet the ideal (Butler, Copnell and Willetts 2013). A finding echoed by Smith, Swallow and Coyne (2015) in a concept synthesis of family centred care and partnership in care. The emerging recommendation from this study is the need to further explore children's cardiac nursing practice in the UK to ascertain the degree to which patient and family centred care is promoted and achieved.

In addition to bonding with their infant, 'family togetherness' related to a desire for normalcy. In the pre-discharge interview this desire related to wanting to go home to start family life for the novice parents and a desire to return to 'normal' family functioning for the experienced parents. Thereby, normalisation emerged as a social construct that related to either developing normal parenting behaviours or maintaining normal family dynamics by engaging in activities that the family had engaged in before. Lee and Rempel (2011) recognised this normalisation as a behavioural process that was aimed at ensuring a normal upbringing for their child; whilst facilitating acceptance of their child outside the family unit. Parents in this study did not disclose feelings of needing acceptance from outsiders, this may have been due to the stage of treatment compared to the parents in the Lee and Rempel (2011) study, some of whom had children who were five years of age and had undergone the third stage of surgery.

The concept of family togetherness contained multiple realities especially for the experienced parents. These parents talked about the conflicting emotions whilst in hospital, relating to the more urgent care needs of their fragile infant and balancing these with the needs of the other siblings. There was evidence of guilt that they could not be with their other child or children and separation anxiety. However, the siblings were being cared for at home by other family members, mainly grandparents; who lived close by and were a great source of support for these families. Grandparents 'stepping in as needed' was also identified as a core category of grandparenting siblings of children with CHD

by Ravindran and Rempel (2010); where they would adopt the parent role to attend to the child's daily needs whilst the parents were preoccupied with their fragile and hospitalised infant. This was referred to by Ravindran and Rempel (2010) as 'triple concern', where not only did the grandparents have a concern for their adult children and the sick infant; they also had concern for the siblings, providing relief and reducing the stress for the parents whilst in hospital (Ravindran and Rempel 2010).

In contrast the first-time grandparents of first born infants with CHD (NS7, CQ9, EU4, HH0) had a different supportive role, which was mainly to emotionally support their adult children whilst the sick infant was in hospital. This was referred to by Ravindran and Rempel (2010) as 'double concern', arising from the conceptualisations of Hall (2004a, 2004b). In subsequent phase two interviews (T1, T2 and T3) the role of these grandparents changed as they began to gain confidence looking after their fragile grandchild, and could relieve the caretaking duties for their adult children; allowing the couple to have time alone, thereby enhancing their relationship and enabling them to regain intimacy.

The health and wellbeing of the sibling was discussed by parents in relation to the psychosocial impact of the situation. Several parents discussed the manifestation of behavioural changes in their other child (QH5, JT8, NK4, RR8, QU5), which they believed were related to factors such as anxiety, anger, jealousy, lack of understanding, feeling left out and resentment, especially whilst they were in hospital with their sick infant. These changes reflected parents' perceptions of the impact on healthy siblings, identified in a study conducted by Wray and Maynard (2005). The results of Wray and Maynard's (2005) study cannot be directly compared for several reasons: the participants were parents of children less than 19 years of age, with a variety of CHD, who had been inpatients between 1995-1999. Given the age of the study other influencing factors may have been involved. However, no other papers specifically focusing on siblings of infants with CHD were identified. Parents in the Wray and Maynard study (2005) also identified that: extra attention was given to the sick child; they were prevented from doing things as a family; the fear of getting too close to the sick sibling; feeling that the sick child did not have same rules to adhere to; intolerance and insecurity; some of which may have related to longer term impacts and outcomes. In contrast in phase two, improvements to sibling behaviour were identified after the family had been discharged home and this was perceived to be the positive effect of love and the support of being together as a family.



Positive emotions expressed by parents within the 'health and wellbeing' pattern and relating to 'love' were evident before they were discharged (T0) in the sense of their excitement to be going home to regain family functioning or to become a parent. In contrast, Lee and Rempel (2011) who also recognised parental positivity, referred to it as 'optimistic appraisal' of their infants' disability and their family circumstances; suggesting that it enabled return to a more positive view of the parents' life experiences, balancing out the perceived vulnerability of their infants' condition. As highlighted earlier, the research question for phase two directed parents to consider broader circumstances relating to their transition from hospital to home. Therefore, whilst parents were positive about their infant being well enough to go home; the developmental (parenthood), situational (going home) and health (infant and parental wellbeing) nature of their transition (Meleis et al 2000) were also prevalent within the meanings and interpretations of their positivity.

Whilst the findings of Lee and Rempel (2011) indicated that parents sought a balance between acknowledging their child's vulnerability and celebrating their child's resilience, within the desired backdrop of a normal life (p. 186); the balance in this study was different. For parents in phase two 'positivism' referred to their knowledge and preparation for discharge and confidence looking after their fragile infant at home on their own; balanced with their excitement about the situational change from the institutionalised hospital environment to the physical and psychological comforts of their own home. In contrast, within this study the 'false optimism' discussed by Lee and Rempel (2011), could be suggested as a time of 'liminality' when parents are moving through a liminal space (Van Gennep 1960, Turner 1956, 1969). This betwixt and between time enabled the parents to develop, maintain and restore a sense of self and control such that they were ready to face the hurdle of the transition from hospital to home.

Liminality as a concept originated from the work of (Van Gennep 1960, Turner 1967, 1969) on ritual and rites of passage; where ritual refers to a realm of transitions that define passage within society, such as birth, marriage and death (Van Gennep 1960). Van Gennep (1960) developed a three-way arrangement comprising rites of separation, threshold rites and rites of aggregation. The first phase relating to passage out of a previous phase or social status (first stage of surgery and hospitalisation); secondly, an ambiguous time and space betwixt and between fixed positions (preparing for discharge and going home); and thirdly re-entry into a new social position or period (settling into

home comforts or returning to family functioning). The central phase represents the liminal space (Hockey 2002).

Blows et al (2012) explain how Turner (1967) was particularly interested in the sociocultural properties of the liminal (transition) period, which reflects the interest for this study. Liminality is described as an 'inter-structural' situation where roles that are culturally accepted such as being married, single, or an infant, no longer apply (Turner 1967:93 cited in Blows et al 2012:2156). Hence an individual in a liminal space is structurally 'invisible' they are 'no longer classified and not yet classified' (Turner 1967:96 cited in Blows et al 2012:2156), and, therefore, are 'betwixt and between' structural classification (Turner 1967:97 cited in Blows et al 2012:2156).

Transition across the liminal space was a constraint for some, for example the betwixt and between space was clearly demonstrated in this couple's comments: *"I think because we left it so late going home even though we were discharged like mid-day but we didn't actually get home until like half past 8"* (RR8 father, T3). *"How do you mean you didn't manage to get home till 8? was that just because you didn't ..."* (interviewer) *"... clinging on to straws"* (RR8 mother, T3).

Whilst processes of parents moving 'from one place to another' had been identified by Rempel et al (2012a, 2012b) in the models 'Parenting Under Pressure' and 'Facets of Parenting' and perhaps as motivational categories (Pridham et al 2010); none of the extant evidence identified liminality as a concept or as a means of contextualising the transitional parenting experience. Indeed, a subsequent search using 'liminal\*' and 'rite of passage' as additional search terms to support the original search; yielded no results either. However, liminality has been used as a concept to explore the illness experience, specifically in adult cancer survivorship (Blows et al 2012).

However, transition through the liminal space was enabling for others. Furthermore, the nature of parents' positive emotions changed over time as parents became relaxed, relieved and happy (at T3). It was evident that 'home comforts' had enhanced parents physical and psychological wellbeing, as they described the benefit of having '*time out*' and '*getting enough sleep*'. Parents also described how they had adjusted to the changes at home by adopting different roles and establishing routines. For one couple (NS7) regaining home comforts and establishing routines rescued the precariousness of the parental relationship, that had deteriorated whilst the infant was in hospital (NS7). This family did not have the close (emotionally or geographically) support of grandparents or

friends; however, the transition from hospital to home relieved other stressors. For example, the father worked and travelled daily to the hospital resulting in them having very little time together; causing feelings of guilt for the father and resentment, anger and isolation for the mother. Going home reduced the daily commute for the father and gave them more time together as a family; this enabled the father to take part in caring activities, giving the mother time to herself and reducing the guilt and resentment. Establishing routines enabled the parental support to be restored within their relationship as they adjusted and adapted to the situation and developed their knowledge, confidence and mastery of the situation.

#### 6.3.4 Mastery

In phase two, the concept of knowledge construction resulting in mastery for these parents, was one building block in the theory of transition from hospital to home. Other elements, or building blocks, of each parent's multi-faceted transitions needed to be considered due to the various layers and nuances of the parents' experiences. Thus, whilst the transition condition within the overarching research question related to the physical transition from hospital to home, here transition was a journey through the construction of knowledge, commencing from the point of diagnosis. Knowledge construction varied depending upon the individual characteristics of the parents and, therefore, learning was not a simple case of transfer of information.

It must not be assumed that in the doctor-parent or nurse-parent relationships, transmission of the professional's knowledge at diagnosis (or indeed at any time during their health care journey) (Giordan, Jacquemet and Golay 1999) is sufficient for parents to fully understand the implications of having an infant with complex CHD. As previously discussed, Ayra et al (2013) explored the expectations of parents and cardiologists regarding education and counselling and found that parents would have preferred more than was perceived by the cardiologists. Parents came to the situation with their own ideas and experiences that influenced their knowledge construction (Giordan, Jacquemet and Golay 1999), perhaps reflecting constructivist models of learning. However, parents' educational needs and learning processes when faced with having an infant with life limiting and life threatening cardiac defects, are much more complex than

these theories (such as Piaget and Barbel 1969) allow, given that they were developed within specific fields of learning.

For example, it would be rare to find that parents have existing knowledge of the complexities of HLHS for example and indeed many HCPs do not understand the intricacies either as demonstrated through the parents' comments in phase one; therefore, simplifying the learning to assimilation and accommodation (Piaget and Barbel 1969) is impractical in this situation. It was not only the scientific concepts impacting on their infant's survival that parents needed to learn, they needed to learn to be parents of an infant with complex CHD and the minutiae of detail that accompanied that responsibility throughout the multi-faceted transitions that they experienced. Knowledge construction was, therefore, influenced by various contemporaneous, social, environmental and psychological factors. Here, parents vividly described their experiences of shock, devastation, protection, dissociation, disconnection, survival, dependency, acceptance, adaptation, resilience, grief, separation reaction, anticipatory grief; to name but a few of the complex elements of learning and knowledge construction identified throughout their transition from birth to surgery to ward to hospital to home.

For these parents learning was dynamic and transformational, learning opportunities overlapped transitional phases of their infant's journey, but successful learning and acquisition of knowledge was also dependent upon the parents' ability to absorb, integrate and adjust at any given time. Learning also involved the complexities of genetics, benefits and risks of surgery, and attitudes and values about survival, based on the beliefs of health care professional and other cardiac parents (Giordan, Jacquemet and Golay 1999). Therefore, the implications for practice of these findings are that the individual needs of parents of infants with complex CHD need to be assessed by HCPs at each stage of their healthcare journey, to ensure that appropriate information is provided to support their knowledge construction.

The information needs of parents of infants with life threatening conditions was explored in a recent PhD study that used data from a prospective longitudinal, case based, mixed-method research study (Twaddell 2013). Twaddell (2013) explored the parents' information needs and compared them with information given by health care providers to the parents during their infant's hospitalisation and after their infant's discharge. Six cases, three from extremely premature infant and three from complex CHD categories, were drawn from the surviving infants from the original study. Knowles' Theory of Adult Learning (Knowles, Holton, and Swanson 2011) was used as a conceptual framework to

review the information that parents received and the provider's method of instruction during hospitalisation. These were compared with the parent's information needs and their preferred method of instruction after the infant was discharged.

Twaddell (2013) found that parents looked for information relating to their infant's changing needs and condition, asking 'What is going on with my infant's care?', Furthermore, most parents displayed readiness to learn by asking the provider questions and adopting parenting roles that were not taught during the infant's hospitalisation and were found to be a topic that parents needed to seek information about (Twaddell 2013:184). Twaddell related this finding to Knowles' fourth principle of adult learning, which indicates that adults become ready to learn when a life situation presents a need to learn (Knowles, Holton and Swanson 2011). Twaddell (2013) also found that the parents' learning was influenced by their past experiences and concluded that as adults learn by linking new material to past experiences (Knowles, Holton and Swanson 2011) making both providers and learners aware of this fact could help parents build their new learning more quickly (p.197). An additional finding was that parents wanted consistent information in terms that they could understand and related to the status or condition of their infant. There are some similarities here with the findings of phase two; moreover, Twaddell (2013) recommended that further research regarding the consistency of information given to parents about their infant by HCPs is necessary.

A more recent study (Tregay et al 2015b), which ran in parallel to this doctoral study, qualitatively assessed the discharge processes and post-discharge care in the community, for infants discharged after surgery or interventions for CHD in the first year of life. Tregay et al (2015b) found that written documentation from tertiary centres frequently lacked crucial information and contained too many specialist terms, supporting the findings of this doctoral study and Twaddell (2013) and further demonstrating that parents of infants with complex CHD want consistent and individualised information. The implications for practice arising from phase two indicate that a standardised discharge package and educational programme is necessary to ensure that parents are adequately prepared for their infant's discharge. This supports Twaddell's (2013) recommendation that a more central communication record or standardised, consistent, scripted tool may increase the provider's ability to offer information to parents in a more consistent and thorough manner (2013:198) and supports the conclusion that service improvements are required in the UK to enhance mechanisms for effective transfer of information outside the tertiary centre (Tregay et al 2015b).

Education and training of local hospital nursing staff is referred to within the congenital cardiac services standards (NHS England 2016). These standards recognise that specialist children's surgical centres must provide sufficient cardiac clinical nurse educators to deliver standardised training and competency based education programmes across the congenital heart network (E6, L1); according to the '*RCN guidance on roles, career pathways and competence development*' (Gaskin et al 2014). The 'congenital heart network' includes level 1 specialist children's surgical centres; level 2 specialist children's cardiology centres and tier 3 local children's cardiology centres. The recommendation is that tier 3 services will be available in some local hospitals where there is a consultant paediatrician with expertise in cardiology and locally designated registered children's nurses with a special interest, training and education in children's cardiology (NHS England 2016). Therefore, implementation of these standards should ensure that the future local nursing workforce is better equipped to care for infants with cardiac problems. However, the standards do not refer to the education needs of HCPs providing out-of-hospital or primary care for these fragile infants and hence there is a need to identify effective modes of education and future research and evaluation of services within the community.

The findings this doctoral study indicate that parents of infants with complex CHD need to be effectively prepared, before their infant is discharged, to identify signs of clinical deterioration. Standard discharge advice for parents of infants with CHD is required nationally, in written and digital formats. In addition to standard information, parents of infants with complex CHD require information that has been individualised to the needs of their infant, with expected clinical parameters included such as oxygen saturation levels. For discharge preparation to be successful, it is necessary for nurses working within the congenital heart network to have the knowledge and skills required to teach parents about their infant's condition and how to spot signs of clinical deterioration in their infant. Assessment of parents' and siblings' psychosocial functioning is essential, including an exploration of family resilience and factors that may impact upon adjustment and adaptation. Furthermore, nurses need to know when and who to refer parents and siblings to for psychosocial support. However, to do this effectively, HCPs may need training that reflects a more person-centred and therapeutic communication style with respect to the assessment and treatment of patients and families. To ensure that nurses in the network have the right knowledge and skills to provide infants and their families with the highly specialised care that they need, every congenital heart network needs a team of clinical educators. This role of this team has been outlined in the RCN guidance

(Gaskin et al, 2014) and includes supporting local and community teams by providing cardiac study days and individualised educational support; and working in collaboration with local higher education institutes to develop and deliver educational packages and undertake research projects. Senior staff and clinical educators within the congenital heart network need to encourage nurses to become research active; to ensure that their nursing care is contemporary, evidence based and best practice.

In phase two of this study, mastery also related to 'reflection and looking to the future'. Parents' accounts at T3, which occurred at varying times after the initial interview, demonstrated that the space or distance from their infant's hospitalisation had afforded them the opportunity to undergo a process of rational analysis of their earlier experiences (Jordi 2011). It was evident that this reflective process was not merely cognitive in nature but included the richness and complexity of their emotions and feelings induced before and during the traumatic events experienced by themselves and their infant. Jordi (2011) argues that the individuality of our experiences provides us with tacit knowledge that enables us to have awareness of who we are; and that this implicit knowledge also materialises explicitly, resulting in cognitive construction of its meaning. Jordi (2011:195) suggests that invariably emergence of what was tacit becomes evident in language, which reflects the findings in phase two.

Parents in phase two also learnt cognitively and emotionally from other cardiac parents whilst they were in hospital. Furthermore, there was a shift in the sources of advice and support that parents utilised over time, where external engagement with other cardiac parents and parent support groups increased as the parents became more confident. In addition, the mechanism of obtaining advice and support became more virtual, with parents choosing to communicate with other cardiac parents via online social networking sites. Some parents actively sought electronic resources and Apps that they could utilise to support the constant monitoring of their infant.

Innovations in technology have been recognised as making it increasingly possible for people to be diagnosed and treated at home or in local primary and community facilities (DH 2003b). More recently, the Department of Health (DH 2012:8) has recognised that technology and the internet are transforming society in the way we communicate, work and organise our lives and that technology enables patients to control their health and care information; and, therefore, 'digital first' will become the primary method of delivering healthcare in the future. Online systems are also being explored as a method of providing support post-treatment. Moody et al (2015) recently investigated the self-

management support needs of teenagers and young adult cancer survivors, and whether these needs could be met via an online resource. They found that whilst a web based self-management resource could be utilised to provide support; face to face support was also deemed important by stakeholders. Nevertheless, the complementary nature of an online resource was recognised as beneficial given young people's engagement with technology. In addition, accessibility, usability, inclusivity and potential barriers were identified that could inform the development of future web-based resources in the UK (Moody et al 2015).

The findings from phase two suggest that parents want accessible and flexible modes of monitoring, advice and support; reflecting the findings of LHM (2015) and the digital proposals of the DH (2003a, 2012). Two centres in the USA have already developed online applications for parents of infants with CHD. The cardiac high acuity monitoring programme (CHAMP) (Erickson et al 2016) and the Smart Hearts App (Kight et al 2016) were presented at the 19<sup>th</sup> Annual Update on Pediatric and Congenital Cardiovascular Disease Conference in February 2016; data is currently being collected to explore the effectiveness of these online applications and to assess parents' preferences using smartphone discharge instructions versus paper instructions. These will inform future development of digital home monitoring of fragile infants in the UK.

## 6.4 Development of a conceptual framework

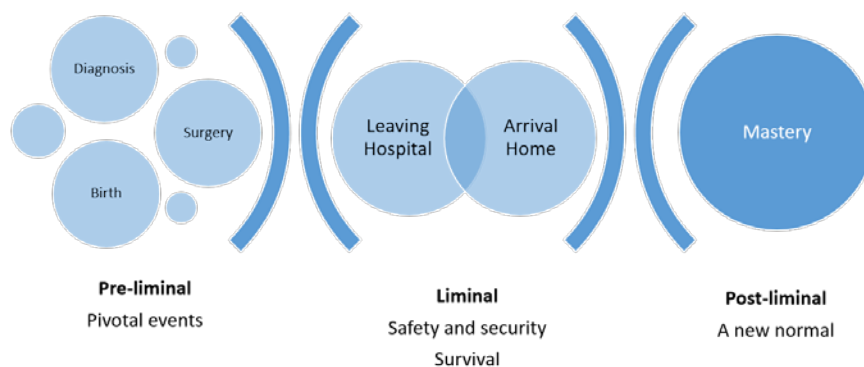
Theorisation of the empirical findings of this doctoral study led to the development of a conceptual framework, which related to the rite of passage for parents transitioning from hospital to home. Whilst some aspects of the original concept map and parental early assessment framework (appendix 5) are evident within this concluding framework, its development was based on the empirical findings arising from this study rather than the map of my initial perceptions and concepts that were useful at the beginning of my doctoral journey to identify my epistemological and ontological beliefs. As conceptual frameworks possess epistemological, ontological and methodological assumptions, each concept within the framework presents an epistemological and ontological role (Jabareen 2009). For example, ontologically the framework represents 'the way things are', and 'the nature of reality'; whereas epistemologically, the framework represents 'how things really are' and 'how things really work' in an assumed reality (Guba & Lincoln



1994:180). The conceptual framework ‘The Rite of Passage of Transition from Hospital to Home’ (figure 6.1) attempts to represent (with the acknowledged limitations of a 2-dimensional diagram) a dynamic model of transition from hospital to home for parents of infants with complex CHD; incorporating the phenomenon of liminality and the parental experiences of transition through a pre-liminal phase, liminal phase and post-liminal phase. The framework provides an interpretative approach to help in understanding the phenomenon of liminality for these parents, rather than to predict the phenomenon; and each concept plays an integral role (Jabareen 2009).

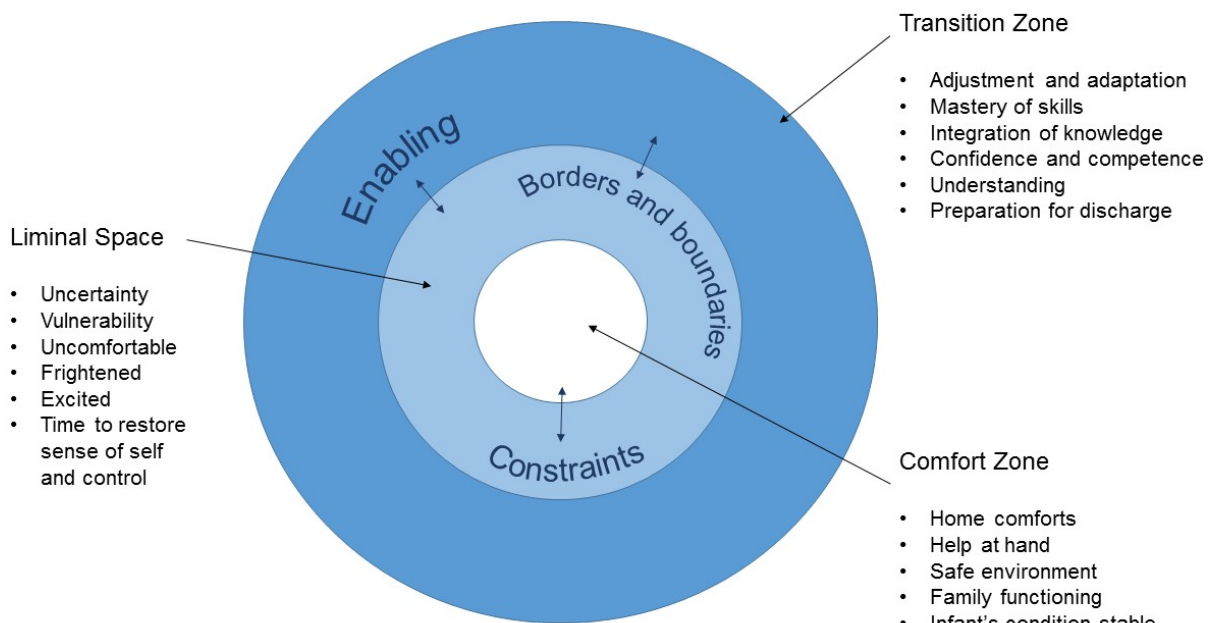
For parents transitioning home with their infant, during the ‘pre-liminal phase’ there were physical boundaries to cross during discharge, such as crossing the threshold of the ward into the outside world, possibly for the very first time with their fragile baby. These parents and their infants had already transitioned across several physical and situational boundaries since their infant’s birth: retrieval and transfer from the maternity unit, either directly into the intensive care unit (ICU) or via the ward; into theatres and then back to the ICU; and then the transition back to the ward. Parents had faced a roller coaster of emotionally traumatic events. So, the transition from hospital to home and traversing the physical boundary of leaving the hospital for the first time with their infant, was loaded with emotionally traumatic experiences that could not be separated from the specific physical transition that was being explored within this study.

**Figure 6.1 The rite of passage of transition from hospital to home**



Liminality occurred for parents at the point of being told that they could go home with their baby; this was not accounted for in the middle range transition theory (Meleis et al 2000). For a while some parents were in an uncertain place where they could not visualise what was ahead and how it would feel and this created anxiety and fear, at the same time as excitement. This was demonstrated in the phase one theme 'mixed emotions' and in the 'safety and security' and 'survival' themes in phase two. For these parents the transition from hospital to home was a crossing point from a place of safety and security, which had become a comfort zone into the unknown, uncertain place. The borders, boundaries and liminality during the transition from hospital to home is depicted 2 -dimensionally in figure 6.2.

**Figure 6.2 Border, boundaries and liminality during the transition from hospital to home**



In the current study, transition across the liminal space was a constraint for some, but it was also enabling. Parents were also bounded by the physical, emotional and social constraints in terms of their preparedness to go home, the fragility of their infant, the distance between the hospital and home, their home environment and the availability of support. Those parents that did not want to go home, were not ready or comfortable

enough to cross the physical boundary into the liminal space. Parents in this study were also bounded by a common ground, the social community that they had developed whilst in the ward environment of being a parent, but more importantly the boundary of being a parent of an infant with CHD. Exiting into a world where those boundaries were different, where other parents did not have the same experiences as theirs was frightening, irritating and isolating. Adjusting to the new situation, developing confidence over time, and becoming comfortable as they mastered new skills demonstrated that some of these parents could pass through that liminal space; it was their rite of passage (Van Gennep 1960, Turner 1967, 1969) and their threshold concept (Myers and Land 2006) to mastery of a new normal, which encompassed competence, integration and comfort.

A variety of other demographic, social, environmental, economic, relational, physical, psychological, resilience and support factors impacted upon the transition from hospital to home and the achievement of the new-normal, to progress into the post-liminal phase. This mastery of the new-normal could be compared with the theory of family resilience emerging from family stress and coping theory (McCubbin and Patterson 1982, 1983 and Patterson 1988, 1989); which highlighted that families participate in dynamic practice to balance their family demands, capabilities and meaning resulting in family adjustment and adaptation (Patterson 1988, 1989, 1993). In this study the family demands would have been the normative (having a new baby) and non-normative stressors (traumatic events before, during and after birth); the ongoing family strains (financial demands; other siblings; resentment, guilt) and daily hassles (such as lack of home comforts whilst in hospital). The family capabilities would have related to what the families had demonstrated through the 'safety and security' theme (psychosocial resources; vigilance; support from spouse and family) and what the families did (their coping behaviours, such as dissociation, anger, emotional outbursts); demonstrated in phase two through the 'survival' and 'love and support themes'. Patterson (2002) proposed that crises occur when the demands outweigh the capabilities (safety and security and survival) and that balance is restored (mastery of the new normal) through regeneration (survival) and resilience (safety and security and love and support).

The time frame in achieving this post liminal, new-normal was different and dynamic for each family, but so was the length of time that they were at home with their fragile infant between the first and second stages of surgery. Whilst there were some similarities identified through the inductive qualitative analysis of phase two, the key message was the diversity of each family's experience. They had different ways of coping; different

demographics, different family resilience strategies, different support mechanisms and different values and beliefs. Therefore, as explained previously, HCPs need to engage and negotiate with parents to ensure that the discharge preparation that they receive takes account of their individual differences and preferences and is family centred (Smith, Swallow and Coyne 2015).

## 6.5 Chapter summary

This discussion chapter has considered the key findings from both phase one and phase two in relation to other evidence and has considered the significance of the findings for clinical practice in relation to the current organisational context of congenital cardiac services and third sector support. A conceptual framework arose from the findings, which related to the rite of passage for parents transitioning from hospital to home. The next chapter concludes this study by summarising the findings arising from both phases of the study in relation to the overarching research aim and the secondary research questions.

## Chapter 7. Conclusion

### 7.1 Introduction

This concluding chapter provides the key conclusions emerging from the study, the implications for clinical practice, recommendations for future research and the strengths and weaknesses of the study. The aim of this study was achieved through addressing the following research questions:

- Do parental demographics and psychosocial functioning have an impact on the transition from hospital to home?
- Do parents perceive that the discharge strategy in their infant's cardiac centre met their needs?
- How confident or anxious did parents' feel about taking their infant home and how do they feel now about looking after their infant at home? (phase one)
- How confident, anxious or depressed are parents before and after taking their infant home (at T0, T1, T2 and T3)? (phase two)

### 7.2 Key conclusions

The conclusions from this mixed methods study emerged from parents' accounts of their experiences of going home with their infant as well as the data collected from a questionnaire and self-report tools; the key messages arising are:

1. Transition from hospital to home was complex and multi-faceted, with unanticipated physical and emotional transitions superimposed upon those that were expected. Numerous physical, emotional and social boundaries and borders were evident, such as the physical and emotional barriers to bonding in the early days of their infant's life.
2. Parents described intense and mixed emotions prior to their infants' discharge home, portraying the turbulence of the pre-transition condition, including 'numbness', feeling 'disconnected from life' and feeling 'too distressed and emotional to really listen'.

These reflected symptoms of potentially traumatic events and for some parents, feelings described were predictive of subsequent PTSD symptoms

3. Parents' adapted to their transition over time; adaptation was demonstrated through an overall improvement in mean anxiety and depression scores. However, individual scores provided a different picture and suggested that maladaptation had occurred for some parents
4. Several demographic variables were influencing factors for parents' psychosocial functioning, including: previous medical history (pre-existing psychological conditions), distance from home, finances and employment, number of siblings (novice versus experienced parents), knowledge (education), the parental relationship and support mechanisms. The reported levels of fear experienced by parents, at the point of discharge, was evident for all parents in both phases of the study and therefore it is fair to conclude that all parents were worried about going home despite their individual demographics.
5. Parents felt unprepared physically, emotionally and educationally for their discharge home. Parental educational programmes were inconsistent and ineffective at the time of undertaking the study and parents described a need for standardised discharge information that would tell them what to look out for, what to do and who to contact; as well as individualised information, specific to their infant's condition.
6. Parents perceived that community and local hospital teams had a lack of knowledge relating to the specific cardiac care that their infant required.

### 7.3 Implications for practice

The conceptual frameworks (fig 6.1 and 6.2) could be further developed to simplify their relevance for practice; thereby creating a model of assessment to enable HCPs to carefully measure each individual family's needs. The borders and boundaries (fig 6.2) during the pre-liminal phase, and liminality that parents may experience during their transition from hospital to home, could be considered alongside the 'rite of passage' (fig. 6.1) as an integral part of such a tool. This would necessitate consideration of the pivotal pre-liminal events that have occurred and factors that may impact biopsychosocially on the transition from hospital to home, so that an integrated care approach can be implemented to support parents during the liminal and post-liminal phases.

Parental support is necessary, alongside the medical support required for their infant, to ensure that discharge care is truly patient and family centred. Parents need to be engaged in the discharge planning process and given the opportunity to express their needs, so that care for them and their infant can be individualised. Involving grandparents in the pre-discharge planning may support the implementation of patient and family centred care.

Whilst the availability of a dedicated psychology service in every specialist cardiac centre would be preferable these recommendations have implications in terms of the cost-effectiveness of such a service; identifying and employing enough appropriately trained psychologists; considering the future academic preparation of clinical health psychologists; and the need for careful succession planning. The waiting lists may, therefore, be long. Instead a stepped care approach could be implemented initially, with peer support interventions as the primary objective; followed by professional psychological support interventions for those parents with 'clinical caseness'. Parents in this study described the benefit of online communication with other cardiac parents at T3 and therefore wider availability of online peer support would be beneficial. Additionally, education is needed to increase allied HCPs knowledge of the impact of transition on parental psychosocial functioning (the *what* and *why*); but it also needs to educate HCPs about *how* and *when* to engage with families. Furthermore, there is also a need for local and community health care professionals to be better prepared in order that they can effectively support these infants and their parents once they are back at home.

The impact of having an infant with complex congenital heart disease on parents' psychosocial functioning and the influence of this on the infant's clinical and neurodevelopmental outcomes, should not be underestimated. We need to be monitoring psychometric parameters and providing support for both mothers and fathers from the point of diagnosis, throughout their infant's health care journey. We also need to be aware of the impact on siblings and the wider family and provide appropriate support for them too.

## 7.4 Recommendations for future research

The current study has taken place during a time of uncertainty within congenital cardiac services in the UK; however, during this time the experiences of the public and patients have become increasingly more important within research (NIHR 2014). Additionally, during this era of service redesign there remain opportunities to influence the future of children's cardiac nursing and ultimately the patient and family centred care that children and their parents receive.

The findings from the current study have generated several opportunities for future research, investigating:

- the potential utility of liminality as a framework for understanding the experiences of parents of infants with CHD during the transition from hospital to home
- exploration of the effectiveness of conceptual frameworks (fig 6.1 and 6.2) in practice to enable practitioners to assess the needs of individual families
- the provision of patient and family centred care within the congenital heart network, such that improvements can be implemented acknowledging family differences and preferences
- the effectiveness of professional psychological interventions and peer support interventions
- the therapeutic nature of interviews and the associated psychosocial benefit of talking about their experiences
- the impact of enhancing nursing education and research opportunities, on parents' perceptions of the discharge care they receive
- the transitional experiences of non-English speaking families; such that discharge advice and support can be tailored to all parent and family needs
- the effectiveness of a standardised discharge package and educational programme designed to adequately prepare parents for their infant's discharge.
- the ongoing effectiveness of a parental early assessment tool, which enables parents to identify deterioration of their infant and empowers them to articulate their concerns promptly and to the right professional



## 7.5 Strengths and limitations of the study

### 7.5.1 Study strengths

One of the most advantageous characteristics of using a mixed methods methodological approach was the exploration of transition as a phenomenon from various vantage points, using different designs and methods. The dominant qualitative focus gave participants a voice in an environment that would otherwise have been clinically oriented. This facilitated therapeutic relationships that were beneficial to participants and demonstrated the value of such approaches to health care. The survey design in phase one enabled a faster, easier and cheaper method of collecting data; whereas, the longitudinal nature of phase two enabled exploration of the dynamic transformative nature of parenting over time. Exploring parents' experiences retrospectively in phase one informed the second prospective exploration of parents' experiences, identifying key themes to discuss about their experience of going home.

In phase two, meeting the parents before they went home helped to establish a rapport. Conducting subsequent interviews over the telephone reduced travel time and costs and reduced invasion on family time. Also, not visiting the family home was less intrusive for the family. Some parents requested to meet at the study centre for subsequent interviews and tied these in with scheduled out patient's appointments, effectively utilising their time. From an ethical perspective, gaining consent from parents who had scored high on GAD7 (anxiety) and PHQ9 (depression) scores to contact their GP, meant that they could be followed up by an appropriate health care professional.

### 7.5.2 Study limitations

The relatively small sample sizes in both phases, could be a limitation in terms of the quantitative data collection and analysis (de Winter 2013). However, as this study was dominantly qualitative the sample sizes in each phase were appropriate for this dominant methodology within a mixed methods study (Creswell & Plano Clarke 2011).

Using an online medium to collect data in phase one may have limited the number of parents that were able or willing to participate (Evans and Mathur 2005, Duffy et al 2005).

Additionally, only sending the survey invite to members of a charity, potentially limited the sample, sample size and demographic (Chesney and Chesler 1993).

Being available to conduct the first interview before parents and their infant were discharged was not always easy to anticipate or plan. For this reason, some of the interviews at T0 were conducted by the research nurse, potentially reducing consistency in the interviewing approach. However, the research nurse observed several interviews conducted by me, the Principal Investigator, to ascertain what was required and how to conduct the interview; and an interview schedule was used for consistency. Being a novice interviewer meant that the first few interviews were a learning curve. This led to improvement of the interview schedule based on what was learnt during the first two interviews, to engage in deeper probing of points raised by the parents.

Telephone interviews were more difficult with some parents, in terms of keeping the conversation going. This may have been related to being a novice interviewer as well as recognising that the parents may have had other better things that they wanted or needed to do and therefore not wanting to impose or take up too much of their time.

Including only English speaking families in phase two was a limitation both in terms of not being able to find out about the experiences of parents from other cultures but also as it limited the number of parents that could be approached to take part in the study.

Only one measure was used for each construct (e.g. anxiety, depression and confidence). Using self-report tools has several limitations in terms of the accuracy of the parents' reporting. Parents may answer in terms of what they think the researcher wants to hear rather than how they are feeling (Hawthorn effect, Thomas 2013). One mother did not want to be labelled as being an anxious mother and therefore social desirability bias may have been at play (Edwards 1953).

Not all parents participated in all four interviews, there were a variety of reasons for this, although these were not all verbalised. For example, the infant had been readmitted to the hospital or was not discharged at all; parents may have felt too overwhelmed once they were at home to take part in the study; parents may have been too busy with 'life' to take part; parents may have wanted to forget about the hospital experience and did not want to talk about it. One parent was very nervous about being 'interviewed' before discharge and therefore her interpretation of the word 'interview' may have impacted upon her lack of participation with the other three interviews.

## 7.6 Publications and conference presentations

Publications and conference presentations arising from this thesis are presented in table 7.1 and 7.2.

**Table 7.1 Publications and reports arising from this study.**

Publications and reports
Gaskin KL (2016) 77. Traversing the Boundaries and Borders of Discharge from Hospital Following First Stage Surgery for Complex Congenital Heart Disease: The Parents' Experience, <i>World Journal for Pediatric and Congenital Heart Surgery</i> , Vol. 7(2) 245-289
Gaskin KL, Barron D, Rooney M, Cooper L, Mohammed N (2016) 76. Psychosocial Adjustment and Adaptation in Parents of Infants with Complex Congenital Heart Disease Going Home for the First Time Following First Stage Cardiac Surgery: A Prospective Review, <i>World Journal for Pediatric and Congenital Heart Surgery</i> , Vol. 7(2) 245-289
Gaskin KL, Barron D, Rooney M, Cooper L, Mohammed N (2016) P12 Acceptability of a parental early warning tool: outcomes from a feasibility study of parental home monitoring and assessment, <i>Heart</i> , 102: A6-A7
Gaskin K, Barron D, Cooper L, Mohammed N, Rooney M, Daniels A, Hutchinson S (2015) A Feasibility Study of Parental Home Monitoring and Assessment of Babies with Complex Congenital Heart Disease, <i>Heart Research UK Interim report</i> , 27/05/15
Gaskin KL, Hutchinson S (2015) Transition from hospital to home: psychosocial adaptation and adjustment in parents of infants with single ventricle heart conditions, <i>Archives of Disease in Childhood</i> , 100 (Suppl. 3): A5
Gaskin KL, Barron D, Rooney M, Cooper L, Mohammed N (2015) A prospective review of psychosocial functioning in parents of infants with complex congenital heart disease going home for the first time following first stage cardiac surgery, <i>Archives of Disease in Childhood</i> , 100 (Suppl. 3): A6
Gaskin KL; Hutchinson S (2015) Parents' experiences of going home with their infant following first stage cardiac surgery for single ventricle heart, <i>Archives of Disease in Childhood</i> , 100(suppl3): A9
Gaskin K, Smith F, Broomfield R, Cochran C, Daniels A, Harte G, Hill R, Leaver LK, Robertshaw D, Smith L. (2014) Children's and young people's cardiac nursing: RCN guidance on roles, career pathways and competence development. Second Edition. London. Royal College of Nursing. Available at: <a href="http://www.rcn.org.uk/data/assets/pdf_file/0010/594658/004_121_web.pdf">http://www.rcn.org.uk/data/assets/pdf_file/0010/594658/004_121_web.pdf</a>

**Table 7.2 Conferences and presentations**

<b>Conferences and Presentations:</b>		
<b>Date</b>	<b>Conference</b>	<b>Contribution (if appropriate)</b>
24-28 <sup>th</sup> February 2016	Cardiology 2016 19th Annual Update on Pediatric and Congenital Cardiovascular Disease, At Loews Royal Pacific Resort at Universal Orlando Florida	3 x poster presentation  1 x oral presentation - shortlisted for Nurse Scientist Award
17 <sup>th</sup> -18 <sup>th</sup> November 2015	Cardiff International Cardiovascular Conference, City Hall, Cardiff	1 x poster presentation  Gaskin K, Cooper L, Mohammed R, Rooney M, Barron D (2015) Acceptability of a Parental Early Warning Tool: Outcomes from a Feasibility Study of Parental Home Monitoring and Assessment
28 <sup>th</sup> April 2015	Royal College of Paediatrics and Child Health Annual Conference and Children and Young People's Nursing Conference, 28 <sup>th</sup> April, ICC, Birmingham	2 x presentations  1 x poster presentation, co-author  Rooney M, Mohammed N, Gaskin K (2015) A prospective review of psychosocial functioning in parents of infants with complex congenital heart disease going home for the first time following first stage cardiac surgery  Gaskin KL; Hutchinson S (2015) Parents experiences of going home with their infant following first stage cardiac surgery for single ventricle heart  Gaskin K (2015) Transition from hospital to home: psychosocial adaptation and adjustment in parents of infants with single ventricle heart conditions
5 <sup>th</sup> March 2015	Congenital Heart Disease Nurses Networking Day, Royal College of Nursing, London.	Invited Speaker  Gaskin K (2015) Parent's experiences of going home with

		their infant following first stage cardiac surgery for complex congenital heart disease: Implications for discharge planning
25 <sup>th</sup> February 2015	Research Lecture Series, University of Worcester	Parent's experiences of going home with their infant following first stage cardiac surgery for complex congenital heart disease: Implications for discharge planning
18 <sup>th</sup> November 2014	British Congenital Cardiac Association Annual Meeting, Old Trafford Conference Centre, Manchester	Poster, presented by co-author  Gaskin K, Barron D, Daniels A (2014) Preliminary Evaluation of a Congenital Heart Assessment Tool (CHAT) for Parental Early Assessment and Home Monitoring of Infants with Complex Congenital Heart Disease
September 2014	UK Association of Chief Children's Nurses (ACCN) Children's and Young People's Nursing International Conference "Building the evidence base for practice", Jersey (Channel Islands) Sept 4-5th	Poster Presentation x 2 (1 relevant for this thesis)  Chair of session  Gaskin K, Barron D, Daniels A (2014) Preliminary Evaluation of a Congenital Heart Assessment Tool (CHAT) for Parental Early Assessment and Home Monitoring of Infants with Complex Congenital Heart Disease
June 2014	Royal College of General Practitioners, Midlands Faculty Annual Research Meeting, University of Worcester, 26 <sup>th</sup> June 2014	Poster Presentation x1  Gaskin K, Barron D, Hutchinson S (2014) A Feasibility Study of Parental Home Monitoring and Assessment of Infants with Complex Congenital Heart Disease
November 2013	British Congenital Cardiac Association Annual Meeting, 20-21 <sup>st</sup> November, Royal College of Physicians, Edinburgh	Poster Presentation x1  Gaskin K, Daniels A, Hutchinson S (2013) The Suitability of discharge information for parents of infants with single functioning ventricle heart condition: evolution of a

		congenital heart assessment tool (CHAT)
June 2013	Paediatric Nursing Associations of Europe Congress, Scottish Conference and Congress Centre, Glasgow, 6th-8th June 2013	Poster Presentations x 2 (1 relevant for this thesis)  Gaskin K (2013) How do parental demographics and psychosocial functioning impact on the transition from hospital to home for parents of infants that have undergone surgery for complex congenital heart disease? A review of the literature Poster Presentation

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**Appendix 1 Assessment Form 1**  
**(adapted from Hawker et al 2002)**

Author(s):

Date of Publication:

Abbreviated Title:

Reviewer:

**Relevance to Research Questions**

Is the focus on parents' experiences of going home? [ ]

Does the study explore psychosocial implications? [ ]

Does the study focus on parenting infants with CHD? [ ]

Is the 'discharge from hospital to home' time period explored? [ ]

Are the infants under 1 year of age? [ ]

**Congenital Heart Disease**

Focus or major part of study [ ]

Minor part of study [ ]

Mentioned in discussion/results [ ]

**Discharge**

To home [ ]

To local hospital [ ]

**Source of Data**

Mothers [ ]

Fathers [ ]

**Study Type: - (ring)**

[1] Empirical study—Peer reviewed

[2] Theoretical paper—Peer reviewed

[3] Research paper—Non-peer reviewed

[4] Theoretical paper—Non-peer reviewed

[5] Professional document

[6] Case study

[7] Other Comment:

**Appendix 2 Standardised Assessment Form**

(Hawker et al 2002)

Author(s):

Date of Publication:

Abbreviated Title:

Assessor:

Date Assessed:

---

Study Design

Quantitative

Qualitative

Combination

Aim:

Location of Study:

Sample—Size:

Sample—Description:

Research Questions/Hypothesis (If Any):

Method and Analysis:

Intervention (If Applicable):

Results:

Conclusions, Comments, and Issues Raised:

## Appendix 3 Critical Appraisal Tool

Protocol (Hawker et al 2002)

### 1. Abstract and title: Did they provide a clear description of the study?

*Good* Structured abstract with full information and clear title.

*Fair* Abstract with most of the information.

*Poor* Inadequate abstract.

*Very Poor* No abstract.

### 2. Introduction and aims: Was there a good background and clear statement of the aims of the research?

*Good* Full but concise background to discussion/study containing up-to date literature review and highlighting gaps in knowledge. Clear statement of aim AND objectives including research questions.

*Fair* Some background and literature review. Research questions outlined.

*Poor* Some background but no aim/objectives/questions, OR  
Aims/objectives but inadequate background.

*Very Poor* No mention of aims/objectives. No background or literature review.

### 3. Method and data: Is the method appropriate and clearly explained?

*Good* Method is appropriate and described clearly (e.g., questionnaires included). Clear details of the data collection and recording.

*Fair* Method appropriate, description could be better. Data described.

*Poor* Questionable whether method is appropriate. Method described inadequately. Little description of data.

*Very Poor* No mention of method, AND/OR Method inappropriate, AND/OR No details of data.

### 4. Sampling: Was the sampling strategy appropriate to address the aims?

*Good* Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.

*Fair* Sample size justified. Most information given, but some missing.

*Poor* Sampling mentioned but few descriptive details.

*Very Poor* No details of sample.

### 5. Data analysis: Was the description of the data analysis sufficiently rigorous?

*Good* Clear description of how analysis was done.

Qualitative studies: Description of how themes derived/ respondent validation or triangulation.

Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up/statistical significance discussed.

*Fair* Qualitative: Descriptive discussion of analysis.

Quantitative.

*Poor* Minimal details about analysis.

*Very Poor* No discussion of analysis.

### 6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

*Good* Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed.

Bias: Researcher was reflexive and/or aware of own bias.

*Fair* Lip service was paid to above (i.e., these issues were acknowledged).

*Poor* Brief mention of issues.

*Very Poor* No mention of issues.

### 7. Results: Is there a clear statement of the findings?

<i>Good</i>	Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
<i>Fair</i>	Findings mentioned but more explanation could be given. Data presented relate directly to results.
<i>Poor</i>	Findings presented haphazardly, not explained, and do not progress logically from results.
<i>Very Poor</i>	Findings not mentioned or do not relate to aims.

**8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?**

<i>Good</i>	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
<i>Fair</i>	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
<i>Poor</i>	Minimal description of context/setting.
<i>Very Poor</i>	No description of context/setting.

**9. Implications and usefulness: How important are these findings to policy and practice?**

<i>Good</i>	Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.
<i>Fair</i>	Two of the above (state what is missing in comments).
<i>Poor</i>	Only one of the above.
<i>Very Poor</i>	None of the above.

**Appendix 4 Scoring System**

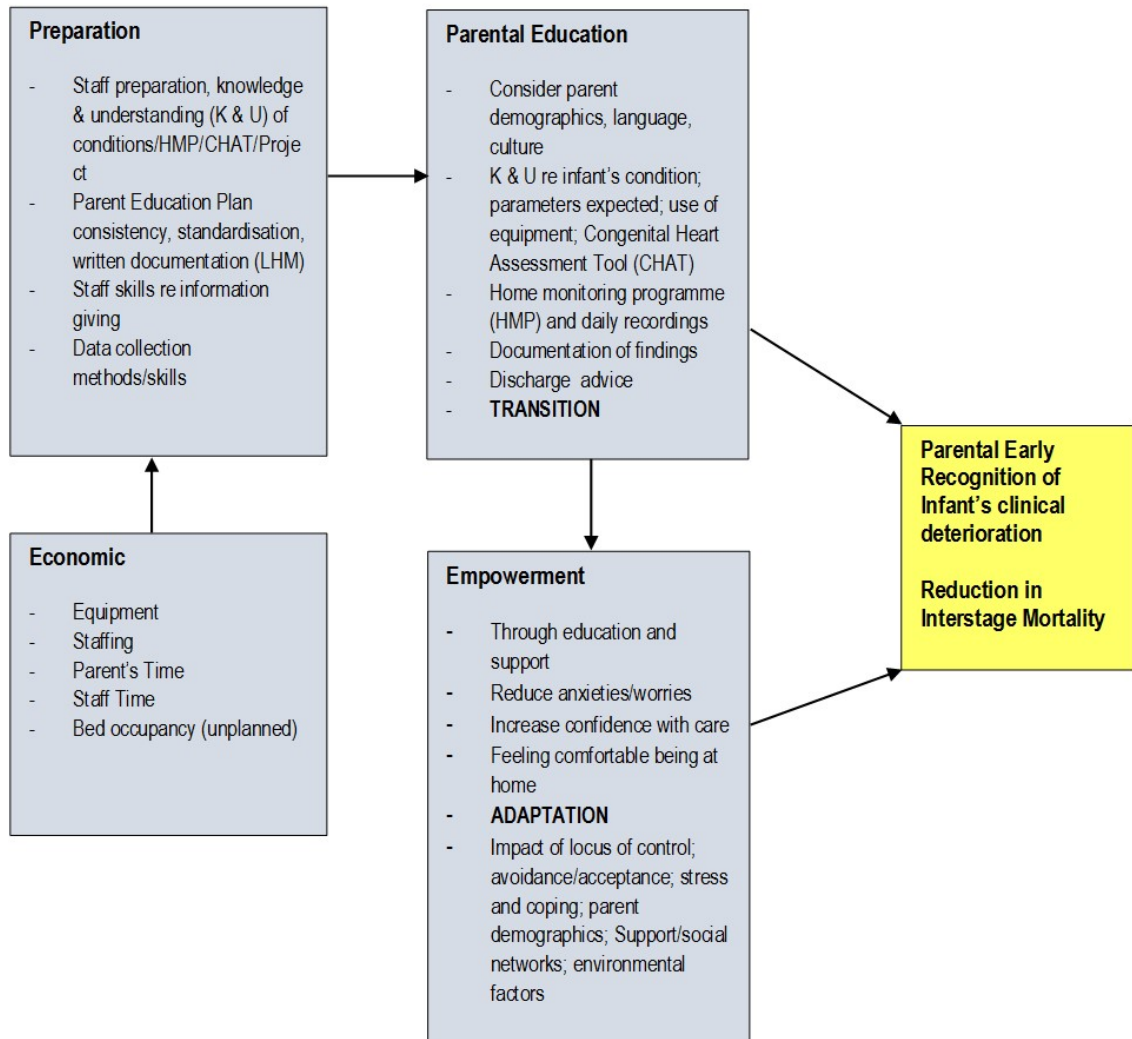
(Hawker et al 2002)

Author and title: \_\_\_\_\_

Date: \_\_\_\_\_

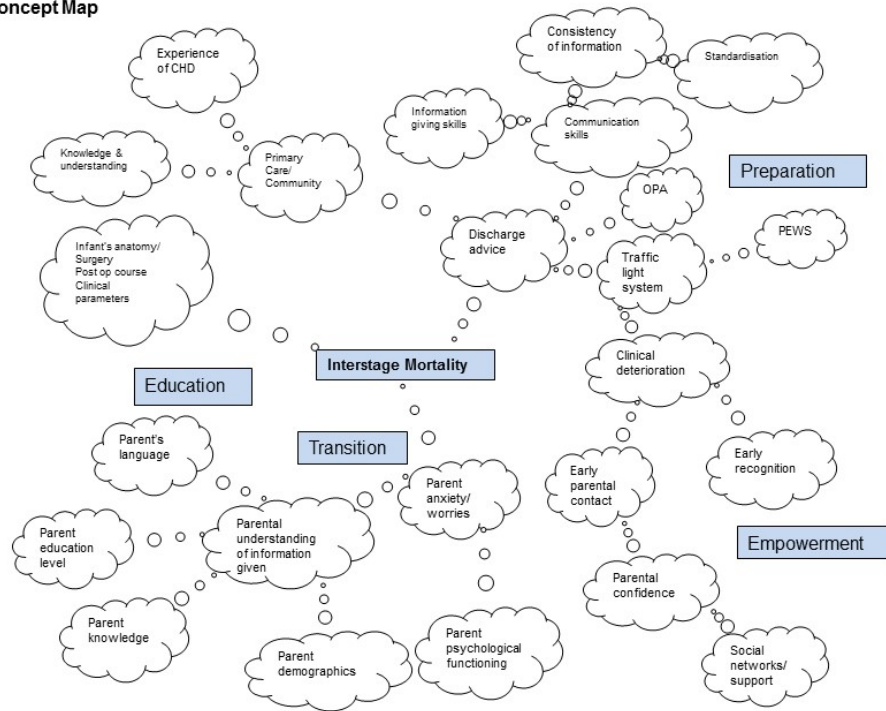
	<b>Score per item</b>	<b>Good (40)</b>	<b>Fair (30)</b>	<b>Poor (20)</b>	<b>Very Poor (10)</b>	<b>Comment</b>
1.	Abstract and title					
2.	Introduction and aims					
3.	Method and data					
4.	Sampling					
5.	Data analysis					
6.	Ethics and bias					
7.	Findings/results					
8.	Transferability/generalisability					
9.	Implications and usefulness					
	Total					

Appendix 5 Parental Early Assessment Conceptual Framework (designed 2011)



Appendix 5 (continued) Concept Map (designed 2011)

Map 2 Concept Map



Appendix 6 Phase One Ethics Approval

The screenshot shows the Coventry University ETHICS web application interface. The main content area displays the approval history for a 'Medium to High Risk Project'. The interface includes a navigation menu on the left with sections for 'Projects', 'Support', and 'Useful Links'. The central table tracks the project's progress through five steps, from submission to finalization.

Step	Status	Actioned by	Actioned on
Project	Submitted	<a href="#">Kerry Gaslin</a>	Tue, 24 Apr 2012 10:44 AM
Supervisor	Approved (minor conditions)	<a href="#">Gill Furtze</a>	Thu, 26 Jul 2012 07:03 PM
Referrer	Referred to Reviewer	<a href="#">Elaine Carmill</a>	Mon, 30 Jul 2012 02:52 PM
Reviewer	Approved (minor conditions)	<a href="#">Reviewer</a>	Tue, 21 Aug 2012 12:55 PM
Finalizer	Approved (minor conditions)	<a href="#">Elaine Carmill</a>	Tue, 21 Aug 2012 02:07 PM

5 Steps



## Appendix 7 Phase Two Ethics Approval



# Health Research Authority

## NRES Committee West Midlands - Solihull

East Midlands REC Centre  
The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839440

Facsimile: 0115 8839294

06 December 2012

Ms Kerry L. Gaskin  
Faculty of Health & Life Sciences  
Coventry University  
Coventry  
CV15FB

Dear Ms Gaskin

**Study title:** A Feasibility Study of Parental Home Monitoring and Early Assessment of Infants with Complex Congenital Heart Disease  
**REC reference:** 12/WM/0375  
**IRAS project ID:** 92184

Thank you for your letter of 04 December 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Laura Hewitt, [laura.hewitt1@nhs.net](mailto:laura.hewitt1@nhs.net).

### Confirmation of ethical opinion

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

### Ethical review of research sites

#### NHS sites

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

## Non-NHS sites

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

## Conditions of the favourable opinion

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

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

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

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

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

## Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		18 October 2012
Covering Letter		03 December 2012
Evidence of insurance or indemnity		01 August 2012
Interview Schedules/Topic Guides	Telephone Interview Schedule Group A and B version 1	06 November 2012
Interview Schedules/Topic Guides	Interview Schedule	06 November 2012

	Telephone Interview Group C version 1	
Interview Schedules/Topic Guides	Interview Schedule Pre Discharge Group A and B version 1	06 November 2012
Interview Schedules/Topic Guides	Interview Schedule Pre Discharge Group C version 1	06 November 2012
Investigator CV	Kerry Gaskin	
Investigator CV	David Barron	
Investigator CV	Gill Furze	
Investigator CV	Tim Kilner	
Letter from Sponsor		11 October 2012
Other: Baseline data to be collected	version 1	01 November 2012
Other: Theoretical Approach	1	16 July 2012
Other: Letter from David Barron - Consultant Cardiac Surgeon		29 November 2012
Participant Consent Form	4	03 December 2012
Participant Information Sheet: PIS Staff	3	05 October 2012
Participant Information Sheet: Participant Information Sheet	4	03 December 2012
Participant Information Sheet: Information for GP and other Health Care Professionals	4	03 December 2012
Protocol	4	17 October 2012
Questionnaire: PHQ-9 Depression		
Questionnaire: GAD-7 Anxiety		
Questionnaire: Maternal Confidence Questionnaire		
Questionnaire: Staff Online Survey Schedule/Half Way	1	06 November 2012
Questionnaire: Staff Online Survey Schedule/End of Study	1	06 November 2012
Questionnaire: Staff Online Survey Schedule/Pre Project	1	06 November 2012
REC application	92184/37552 6/1/13	18 October 2012
Response to Request for Further Information		04 December 2012
Sample Diary/Patient Card	Daily Diary Group A version 2	05 October 2012
Sample Diary/Patient Card	Daily Diary Group B version 2	05 October 2012

### 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.

#### **After ethical review**

##### Reporting requirements

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

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

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

##### Feedback

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

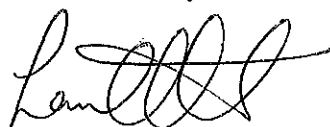
Further information is available at National Research Ethics Service website > After Review

<b>12/WM/0375</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

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/>

With the Committee's best wishes for the success of this project.

Yours sincerely



**Dr Rex J Polson**  
Chair

Email: [nrescommittee.westmidlands-solihull@nhs.net](mailto:nrescommittee.westmidlands-solihull@nhs.net)

Copy to:

*Professor Neil Forbes*  
*Dr Carole Cummins, Birmingham Children's Hospital NHS Foundation Trust*

fp

DIRECTORATE OF RESEARCH AND DEVELOPMENT  
Research and Development Office

Direct line: 0121 333 8707

Steelhouse Lane  
Birmingham  
B4 6NH

Tel: 0121 333 9999  
Fax: 0121 333 9998

Our Ref: KR/SS/R&D Approval

10<sup>th</sup> June 2013

Mr David Barron  
Consultant Lead for Cardiac Services  
Birmingham Childrens Hospital  
Steelhouse Lane  
Birmingham  
B4 7NH

Dear Mr Barron

**Re: Birmingham Children's Hospital NHS Foundation Trust R&D Approval**

**Project Title: A Feasibility Study of Parental Home Monitoring and Early Assessment of Infants with Complex Congenital Heart Disease**  
**REC Ref: 12/WM/0375**  
**IRAS ID: 92184**

Thank you for complying with the Birmingham Children's Hospital NHS Foundation Trust's R&D approval process.

I am now happy to approve the above study, however please note that recruitment cannot commence until Mr Barron and Kim Jones provide copies of their current GCP certificates to the R&D office.

You will note from the Research Ethics Committee (REC) approval letter dated 6 December 2012 that the favourable opinion is subject to obtaining management permission or approval at each host organisation prior to the start of the study. This letter constitutes that approval.

Approval of the study is subject to the following conditions:

1. That you inform the R&D Office and the REC of any significant protocol amendments, sending copies of correspondence with the REC and also sending us copies of your REC annual progress and safety reports
2. That you notify the R&D Office and the Governance Support Unit of any adverse events arising from this piece of research
3. That you provide the R&D Office with interim reports as requested by the R&D Office and a final report of your research
4. That you conduct the research in conformity with the Research Governance Framework and with clinical trials legislation where applicable.

Yours sincerely



Miss Katie Roebuck  
R&D Business Innovations Manager

**Coventry University**  
Priority Street  
Coventry CV1 5FB  
Telephone 024 7688 7688

**Professor Ian M Marshall**  
Pro-Vice-Chancellor (Research)



**TO WHOM IT MAY CONCERN**

RRU/Ethics/Sponsorlet

11 October 2012

Dear Sir/Madam

**Researcher's name: Kerry Gaskin**  
**Project Title: Parental Home Monitoring and Assessment of Infants with Complex CHD**

The above named researcher has successfully completed the Coventry University Ethical Approval process for her project to proceed (ref: 5680).

I should like to confirm that Coventry University is happy to act as the sole sponsor for this researcher and attach details of our Public Liability Insurance documentation.

With kind regards

Yours faithfully

**Professor Ian Marshall**  
**Deputy Vice-Chancellor, Academic**

Enc

**Pro-Vice-Chancellor's Office**  
Direct Line 024 7679 5293  
Fax 024 7688 8030

[www.coventry.ac.uk](http://www.coventry.ac.uk)



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## **Appendix 8 Good Clinical Practice Certificate**



# Certificate of Completion

**Kerry Gaskin**

has completed

## **Introduction to Good Clinical Practice (GCP) e-learning course**

A practical guide to ethical and scientific quality  
standards in clinical research

on 16 March 2013

### **Modules completed**

Introduction to Research in the NHS  
Good Clinical Practice and Standards in Research  
Study Set-up and Responsibilities  
The Process of Informed Consent  
Data Collection and Documentation  
Safety Reporting  
Summary



**National Institute for  
Health Research**  
Clinical Research Network

## Appendix 9 Phase One Participant Information Leaflet



### **The suitability of discharge information for parents of babies with single functioning ventricle heart condition**

#### Invitation

As a parent/s of a baby with a single functioning ventricle heart condition (half a working heart) we would like to invite you to take part in this online survey. The aim of the survey is to find out your views and experiences relating to the discharge information that you received when your baby was discharged home from the specialist heart hospital after the first stage of treatment. Before you decide whether or not to take part, we would like you to understand why the survey is being undertaken and what it will involve. Please take time to read the following information carefully.

#### *What is the purpose of the survey?*

The aim of this survey is to find out parents' views and experiences relating to the discharge information that they received when their baby was discharged home from the specialist heart hospital after the first stage of treatment. We would also like to find out more about you as a family to help us to understand how you dealt with the transition (going home with your baby), how you adapted to the new situation that you found yourselves in and whether the information that you were given helped in that transition.

We hope that the results of this survey will give health care professionals a better understanding of parents' ability to deal with the transition from hospital to home and adapt to the changes associated with going home after the first stage of treatment. We also hope that the results will enable us to standardise the current discharge strategies that are in place for parents across the UK before they take their baby home.

Your views will be collected through an anonymous online survey. The link to the online survey will be emailed to parents at the beginning of November 2012 by Little Hearts Matter. Parents who wish to take part will have 2 weeks to complete the survey online.

#### *Why have I been invited to take part?*

You are being invited to take part in the survey because you have a baby with a single functioning ventricle heart condition, who is aged between 0-3 years and we would like to hear about your views and experiences of going home with your baby, so that we can aim to improve discharge information and the transition for future parents.

#### *Do I have to take part?*

It is up to you to decide whether or not to take part. If you do decide to take part, you will be able to access the survey via the online link provided in the email. The first question of the survey will ask you to confirm that you have read this information sheet and that you consent to take part in the study. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

Taking part or not taking part in the survey will have no impact at all on your baby's care or on the support you can have from Little Hearts Matter.

*What will happen to me if I take part?*

**If you decide to take part, you will need to complete the online survey, which will take about 25-30 minutes of your time to answer.**

The survey may make you feel upset or emotional as you think back to you and your baby's first hospital experiences. If this is the case and you would like to talk to someone about your experiences, please contact Little Hearts Matter as they are able to offer support to parents.

If any potentially serious problems are reported through the survey, it will be the professional responsibility of the research team to refer the problem to the appropriate professional, so that something can be done about it. Your comments will however, remain anonymous in our communication with clinical teams.

*What are the possible benefits of taking part?*

The direct benefits for you are that you can share the experiences you had of the transition to going home, whether they were good or bad.

*Other beneficial outcomes of the survey include:*

Furthering our understanding of the situation

The information you give us will help us to inform staff of the current situation across the UK, so that changes can be made to standardise the information that is given out to all parents.

The information you give us about your views will also help us to develop an assessment tool (congenital heart assessment tool) to help families when they go home.

The results of the questionnaire will also help with the development of a home monitoring programme that will be used alongside the tool, in a larger project exploring 'Parental Home Monitoring and Assessment of Infants with Complex CHD'.

*Will what I say in this survey be kept confidential?*

All information collected from you will be anonymous

Confidentiality, privacy and anonymity will be ensured in the collection, storage and publication of research material. The survey will remain anonymous to the researcher who will be analysing the results. Cookies and personal data stored by your Web browser are not used in this survey. Only staff at Little Hearts Matter will have access to parent's personal information, email addresses and other details on the Little Hearts Matter database, data protection will be maintained as this information will not be available to the principal researcher.

All completed online surveys will only be accessed by the research team. The information collected from the online survey will be analysed by the research team to draw conclusions.

Data generated by the survey will be retained in accordance with Coventry University's policy on Academic Integrity. Data generated in the course of the research will be kept securely in paper or electronic form for a period of five years after the completion of a research project.

*What will happen to the results of the survey?*

Student number: 2030494

The results of the survey will be used in the Principal Researcher's thesis for the Professional Doctorate in Health and Social Care being undertaken at Coventry University

The results of the survey will remain anonymous at all times; they may be published by the Research Team and may be presented at a National or International Conference.

*Who is organising and funding the survey?*

The Principal Researcher, will be conducting the survey in her role as a Professional Doctorate student at Coventry University. The distribution of the Participant Information is kindly being funded by Little Hearts Matter

*Who has reviewed the survey?*

The survey has been approved by the University Research Ethics Committee, Coventry University.

Research Team Contacts for Further Information

*Principal Researcher:*

Ms Kerry Gaskin

Professional Doctorate Student

Senior Lecturer, Children and Young People's Nursing Team

Faculty of Health and Life Sciences

Coventry University

02476 795854

[Cookk2@coventry.ac.uk](mailto:Cookk2@coventry.ac.uk)

*Supervisor:*

Professor Gill Furze

Faculty of Health and Life Sciences

Coventry University

[Gill.Furze@coventry.ac.uk](mailto:Gill.Furze@coventry.ac.uk)

If you have any concerns about the way in which the study has been conducted, you should contact the Chair of the University Applied Research Committee on [i.marshall@coventry.ac.uk](mailto:i.marshall@coventry.ac.uk)

You can also get more information from:

Little Hearts Matter:

Suzie Hutchinson, CEO

Isabel Baumber, Trustee

[Suzie@lhm.org.uk](mailto:Suzie@lhm.org.uk)

[isabelbaumber@btinternet.com](mailto:isabelbaumber@btinternet.com)

Finally, we would like to thank you for taking time to read this information sheet.

Date 24/10/2012

## Appendix 10 Phase Two Participant Information Leaflet



### Participant Information Leaflet A Feasibility Study Parental Home Monitoring and Assessment of Infants with Complex Congenital Heart Disease



## Research Project Aim

The aim of this research project is to test the feasibility of parents using a Congenital Heart Assessment Tool (CHAT) as part of a home monitoring programme (HMP) for infants with complex congenital heart disease (single functioning ventricle [half a working heart] and shunt dependent heart conditions).

## Invitation paragraph

As a parent of an infant with a complex heart condition you are being invited to take part in this research project. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully.

## What is the purpose of the study?

The **principal** purpose of the feasibility study is to inform the development of a future research application for a large multicentre randomised controlled trial, by assessing:

- Rates of recruitment to the study and recruitment strategies
- Follow up rates and questionnaire completion rates
- Proportion of eligible parents entering the study and reasons for nonparticipation

The secondary objectives include:

- To record the number of times parents make urgent contact with health care professionals
- To investigate the acceptability of the Congenital Heart Assessment Tool (CHAT)/Home Monitoring Programme (HMP) from the perspective of parents of infants with complex congenital heart disease.
- To gain estimates or trends of effectiveness of the Congenital Heart Assessment Tool/Home Monitoring Programme (Group A)

compared with the CHAT alone (Group B) and with usual discharge care (Group C) in alleviating anxiety and depression in parents, increasing confidence and in reducing hospitalisation and/or mortality among the infants.

- To explore whether parental demographics and psychosocial functioning have an impact on the transition from hospital to home and whether there is any comparison amongst groups of parents (A, B and C)

### **Ethical Basis of the Study**

At the beginning of the study the research team have no significant evidence that one intervention (group A, B or C) is superior to the others or effective at all. Therefore, there is no known benefit at this stage of parents being randomised to any of the groups.

The principal aim of this study is to ascertain recruitment rates and strategies for a future larger multi-centred study that will provide more data. Therefore, as this is a feasibility study aiming to recruit a relatively small number of participants it is unlikely that enough evidence will be generated to convince the researchers that one intervention is more effective than another. However, if enough data is collected from a larger study to provide evidence for the most effective intervention, there is then an ethical imperative for the most superior intervention to be provided to all parents of infants with complex congenital heart disease.

### **The Home Monitoring Programme**

The HMP includes daily measurements by parents of their infant's oxygen levels and weight, after they have been discharged home following the first stage of treatment. Additionally, the CHAT uses a colour coded (traffic light) system to give an early indication of deterioration of the infant's condition, helping to inform parents and subsequently medical teams promptly about problems that may be occurring so that the infant can be assessed, managed and treated as soon as possible.

Parents will also be invited to take part in a face to face interview before they are discharged home and telephone interviews at 2 weeks, 8 weeks and 4 months post discharge. The aim of the interviews is to identify factors that may impact upon parents' transition from hospital to home, such as anxiety levels, depression and confidence in caring for their infant as well as parental demographics. These will be compared across the 3 groups.

The Research Team will contact the parent's GP and the Cardiac Liaison Team at Birmingham Children's Hospital (BCH) to alert them of any parents demonstrating increased levels of anxiety and depression so that support can be provided through Birmingham Children's Hospital and in the community.

### **Usual Discharge Care**

All parents have a named Cardiac Liaison Nurse and a direct line phone contact with them. Parents are also given the direct line contact number for the neonatal ward (where their infant would have been an inpatient) that can be used at any time (24/7). The liaison service includes a dedicated family support worker and together they can involve social services and the GP as appropriate. The standard out-patient follow up is for these infants to be seen within 2 weeks of discharge and then once every 4 weeks as minimum. Parents are given clear instructions to contact their named Liaison Nurse or the ward if there are any problems. The local GP and Paediatrician will be sent copies of all correspondence so that they are aware of any ongoing concerns. Local care from community teams will depend on where the family live and therefore will be the normal care in their geographical area.

Standardised discharge information specific to the medical or surgical treatment that the infant has had and therefore what signs of deterioration to look for in the infant will be given by the nurses before discharge. Parents will be taught about feeding and medications and any other care issues as necessary and again depending upon their infant's needs.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide not to take part, you will receive usual discharge advice and care as above and the same as Group C. If you decide to take part, you are still free to withdraw at any time and without giving a reason. Taking part or not taking part in the study will have no impact at all on your infant's care or on the support you can have from the clinical team or parent support groups.

### **What will happen to me if I take part?**

Parents will have a minimum of 24 hours, maximum 7 days to consent to taking part in the study. Once they have agreed to take part in the study they will be randomised (selected in no identifiable pattern) to one of the three groups. The Research Nurse will then ensure that they are fully prepared and to go home (see appendix 1, 2, 3) depending upon the group that they have been randomised to.

The Research Nurse (RN) at the study centre will also notify their GP, Community Children's Nurse (CCN), Local Paediatrician, Local Cardiologist, Dietician and any other relevant health care professional of their involvement in the study (Group A, B and C) and about the HMP and CHAT (for Group A and B).

### **What are the possible benefits of taking part?**

By taking part in this study parents will be helping us to obtain recruitment data for a larger multi-centre randomised controlled study. Additionally, the information will subsequently assist us to identify whether a home monitoring programme alongside an early assessment tool (CHAT) is beneficial in terms of identifying infants at home whose clinical condition is deteriorating; or whether the early assessment tool (CHAT) is beneficial on its own to initiate appropriate assessment, management and treatment more quickly for their infant.

Taking part in the interviews will enable us to identify the psychosocial impact of transition from hospital to home for parents, such that in the future appropriate mechanisms of support can be implemented before and after discharge for all parents.

### **What are the risks of taking part?**

- Being involved in the study may elicit an emotional response in parents (not the infant) such as anxiety and distress. However, the level of emotional response is difficult to predict as parents are likely to be anxious taking their infant home for the first time despite the project.
- Some parents may be more anxious than others and some may feel depressed about the whole situation and having an infant with a complex congenital heart defect.
- We will therefore be measuring anxiety (using GAD7) and depression (using PHQ9) in all parents taking part in the study (Groups A, B and C) to ensure that they get the appropriate psychological support as soon as possible.
- Those parents randomised to Group A may feel more confident taking their infant home with the Home Monitoring Programme/Congenital Heart Assessment Tool
- However, some parents may feel more anxious due to using the equipment (Oxygen saturation monitor and scales) and completing a daily diary.
- Daily weighing could increase the anxiety that most parents feel around weight gain/loss anyway with a new infant (the rationale for doing this on a daily basis will be explained to parents in Group A before they go home)
- Parents will be advised that if they would like to talk to someone about their experiences, they should contact the Research Nurse, Cardiac Liaison Nurse, GP or Little Hearts Matter who are able to offer support to parents.
- Parental anxiety and depression will be measured in all three groups of parents, before discharge, 2 weeks after discharge, 8 weeks after discharge and at 4 months post discharge.

- Parents who screen positive for heightened anxiety or depression will be referred by the research team to the appropriate professional, such as the Cardiac Liaison Team at BCH or their GP for further advice and support. These parents may be advised to withdraw from the study.

Will what I say in this study be kept confidential?

- All information collected from parents will be kept strictly confidential
- Whilst we will maintain confidentiality, if any potentially serious problems are reported throughout the study, it will be the professional and legal responsibility of the research team to refer the problem to the appropriate professional, so that something can be done about it.
- Confidentiality, privacy and anonymity will be ensured in the collection, storage and publication of research material.
- All completed baseline questionnaires will only be accessed by the research team. The information collected from the telephone interviews will be analysed by the research team to draw conclusions.
- Only staff at the study centre will have access to any other personal data not collected in the baseline information, data protection will be maintained as this information will not be available to the principal researcher. The principal researcher will have access to the parent's telephone number in order to undertake the telephone interviews.
- Data generated by the study will be retained in accordance with Coventry University's policy on Academic Integrity.
- Data generated in the course of the research will be kept securely in paper or electronic form for a period of five years after the completion of a research project.

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

- The results of the research will be used in the Principal Researcher's thesis for the PhD in Health & Social Care being undertaken at Coventry University.

- The results of the study will remain anonymous at all times; they may be published by the Research Team and may be presented at a National or International Conference.

**Who is organising and funding the research?**

- The Principal Researcher, will be conducting the research in her role as a PhD student at Coventry University.
- The research is kindly being funded by Heart Research UK who are funding the equipment and the Research Nurse and Little Hearts Matter, who are funding the CHAT and standard discharge information leaflets.

**Who has reviewed the study?**

The research has been approved by the University Research Ethics Committee, Coventry University; the NHS Research Ethics Committee and R & D Team at Birmingham Children's Hospital.

**Research Team Contacts for Further Information**

***Principal Researcher:***

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If you have any concerns about the way in which the study has been conducted, you should contact the Chair of the University Applied Research Committee on [i.marshall@coventry.ac.uk](mailto:i.marshall@coventry.ac.uk)

You can also get more information from:

**Research Nurses:**

Lucy Cooper, [lucy.cooper@bch.nhs.uk](mailto:lucy.cooper@bch.nhs.uk)

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Wellcome Trust Clinical Research Facility (WTCRF),  
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Dr Chickermane, Consultant Paediatric Cardiologist

Birmingham Children's Hospital **0121 333 9999**

Patient Advisory Liaison Service (PALS)

Birmingham Children's Hospital **0121 333 8403**

Little Hearts Matter

Office Team/Support Line

**0121 455 8982**

Suzie Hutchinson, Chief Executive

[Suzie@lhm.org.uk](mailto:Suzie@lhm.org.uk)

Finally, we would like to thank you for taking time to read this information sheet. Date 10/04/14

**A1 Information for Parents/Carers in Group A**

- All necessary information regarding the study & usual discharge education will be provided by the Research Nurse.
- You will be asked to follow the Home Monitoring Programme (HMP) by weighing your infant daily and taking daily oxygen saturation levels. You will be asked to record the information collected in a daily diary.
- You will be taught how to use the equipment and paperwork before you go home.
- It is important that this information is recorded daily so that comparisons can be made and a trend of data collected in order to be able to identify clinical deterioration in your infant (worsening of condition)
- You will be asked to bring the diary with you to routine outpatient's appointments, as the information will be reviewed by the Research Nurse, Consultant Cardiologist, Registrar, Cardiac Liaison Nurse or Advanced Nurse Practitioner.
- You will also be taught to use the congenital heart assessment tool (CHAT) alongside the HMP. This is a colour coded Traffic Light System used to identify any signs of clinical deterioration displayed by your infant, based on the information that you have collected on a daily basis and other signs such as poor feeding.
- You will be encouraged to contact the Research Nurse, Cardiac Liaison Nurse, Neonatal Ward or other health care professional when the CHAT demonstrates a change in your infant's condition that requires attention, so that appropriate interventions can be initiated.
- The diary will be collected from you by the Research Nurse when you return for heart treatment in hospital (or at 4 months) at which point your involvement in the study will end.
- Before you are discharged home, you will be asked to participate in a face to face interview with the Principal Researcher. The aim of this interview is to identify factors influencing your transition from hospital to home.
- During the interview you will be asked to complete 3 inventories called the PHQ9 which measures depression; the GAD7 which

measures anxiety and also the Maternal Confidence scale, which measures how confident you feel looking after your infant.

- If the results of these inventories denote high levels of anxiety or depression the Principal Researcher will refer you to the appropriate professional in order for you to access support. This may be your GP, the Cardiac Liaison Nurse or a Parent Support Group such as Little Heart Matter.
- The Principal Researcher will then talk to you to find out how you feel about the HMP/CHAT, including questions about how you feel about the transition of going home with your infant for the first time and how you feel about being involved in the project
- This will be an opportunity to discuss any issues or concerns that you have
- This part of the interview will be recorded, with your consent, so that the information can be analysed and fed back into the management of the project.
- There will also be 3 telephone interviews, the first will be two weeks after discharge, the second half way through your involvement in the project at 8 weeks and the last one just before readmission for any further heart treatment in hospital (or at 4 months).
- These telephone interviews will follow the same format as the pre-discharge interview as explained above.

## **A2 Information for Parents/Carers in Group B**

- All necessary information regarding the study and usual discharge education will be provided by the Research Nurse (RN).
- You will be taught to use the congenital heart assessment tool (CHAT) which uses a colour coded (traffic light) system to identify any signs of clinical deterioration (worsening of condition) displayed by your infant and to record this in a daily diary.
- This assessment will be based on your own observations of clinical signs such as poor feeding, shortness of breath and urine output.

- It is important that this information is recorded daily so that comparisons can be made and a trend of data collected in order to be able to identify clinical deterioration in your infant.
- You will be encouraged to contact the RN, study centre or other health care professional when the CHAT demonstrates a change in your infant's condition that requires attention, so that appropriate interventions can be initiated.
- You will be asked to bring the diary with you to routine Outpatients appointments, as the information will be reviewed by the RN, Consultant Cardiologist, Registrar, Cardiac Liaison Nurse or Advanced Nurse Practitioner.
- The diary will be collected from you by the RN when you return for stage 2 treatment (or at 4 months) at which point your involvement in the study will end.
- Before you are discharged home, you will be asked to participate in a face to face interview with the Principal Researcher. The aim of this interview is to identify factors influencing your transition from hospital to home.
- During the interview you will be asked to complete 3 inventories called the PHQ9 which measures depression; the GAD7 which measures anxiety and also the Maternal Confidence scale, which measures how confident you feel looking after your infant.
- If the results of these inventories denote high levels of anxiety or depression the Principal Researcher will refer you to the appropriate professional in order for you to access support. This may be your GP, the Cardiac Liaison Nurse or a Parent Support Group such as Little Hearts Matter.
- The Principal Researcher will then talk to you to find out how you feel about the HMP/CHAT, including questions such as how you feel about the transition of going home with your infant for the first time and how you feel about being involved in the project
- This will be an opportunity to discuss any issues or concerns that you have
- This part of the interview will be recorded, with your consent, so that the information can be analysed and fed back into the management of the project.

- There will also be 3 telephone interviews, the first will be two weeks after discharge, the second half way through your involvement in the project at 8 weeks and the last one just before readmission for any further heart treatment in hospital (or at 4 months).
- These telephone interviews will follow the same format as the pre discharge interview as explained above.

- There will also be 3 telephone interviews, the first will be two weeks after discharge, the second half way through your involvement in the project at 8 weeks and the last one just before readmission for any further heart treatment in hospital (or at 4 months).
- These telephone interviews will follow the same format as the pre-discharge interview as explained above

### **A3 Information for Parents/Carers in Group C**

- You will be thanked by the Research Nurse (RN) & reminded that you will receive the standard discharge advice and care from ward staff. This will include what signs to look out for in your infant and how to perform specific cares.
- Before you are discharged home, you will be asked to participate in a face to face interview with the Principal Researcher. The aim of this interview is to identify factors influencing your transition from hospital to home.
- During the interview you will be asked to complete 3 inventories called the PHQ9 which measures depression; the GAD7 which measures anxiety and also the Maternal Confidence scale, which measures how confident you feel looking after your infant.
- If the results of these inventories denote high levels of anxiety or depression the Principal Researcher will refer you to the appropriate professional in order for you to access support. This may be your GP, the Cardiac Liaison Nurse or a Parent Support Group such as Little Heart Matter.
- The Principal Researcher will then talk to you to find out how you feel about going home, including questions such as how you feel about the transition of going home with your infant for the first time and how you feel about being randomised to group C
- This will be an opportunity to discuss any issues or concerns that you have
- This part of the interview will be recorded, with your consent, so that the information can be analysed and fed back into the management of the project.

## Appendix 11 Phase Two Consent Form

Centre Number:  
Study Number:  
Patient Identification Number for this trial:  
Version 6 21/08/14

### CONSENT FORM

Title of Project: A Feasibility Study of Parental Home Monitoring and Assessment of Infants with Complex Congenital Heart Disease

Name of Principal Researcher: Kerry Gaskin

Parents Please initial box

1. I confirm that I have read and understand the information sheet dated.....(version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my infant's medical care or legal rights being affected.
3. I understand that relevant sections of my infant's medical notes and data collected during the study, may be looked at by individuals from the research team at Coventry University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my infant's records.
4. I agree to take part in the face to face and telephone interviews and for these to be audio recorded.
5. I agree to my GP being informed of my participation in the study
6. I agree to take part in the above study.

\_\_\_\_\_  
Name of Patient and Parent Date Parent's Signature

\_\_\_\_\_  
Name of Research Nurse taking consent (if different from Principal Researcher) Date Signature

\_\_\_\_\_  
Principal Researcher Date Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes

## Appendix 12 Phase One Questionnaire

### Section 1

#### Initial Classification Data

- 1) Are you the baby's mother or father?  
Mother  
Father  
Or are both parents answering the questionnaire?
  
- 2) What is your age? (mother and father)  
18-21  
22-25  
26-30  
31-40  
41-50  
51-60
  
- 3) What is your total household income?  
Less than £10,000  
£10,000-£19,999  
£20,000-£29,999  
£30,000-£39,999  
£40,000-£49,999  
£50,000-£59,000  
£60,000-£69,000  
£70,000-£79,000  
£80,000-£89,999  
£90,000-£99,000  
£99,000-£150,000  
Over £150,000
  
- 4) What is your current marital status?  
Single, never married  
Married  
Separated  
Divorced  
Widowed
  
- 5) How is your health? (mother and father)  
Fit and healthy  
Congenital Heart Disease  
Chronic illness (e.g. Diabetes, Asthma, Adult Heart Disease e.g. high blood pressure)

Mental Health problems (e.g. Depression, Schizophrenia)

Other (please state)

6) How many children do you have?

1

2

3

4

5

7) In which position in the family is your infant with single heart ventricle? (e.g. first child, second child)

8) Are your other children all fit and healthy?

Yes

No

Other children with congenital heart disease

9) What is your ethnicity? (mother and father)

White – British

White - Irish

White, any other

Mixed

- White and black Caribbean
- White and black African
- White and Asian
- Any other mixed background

Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background

Black or Black British

- Caribbean
- African
- Any other

Chinese or other ethnic group

- Chinese

- Any other ethnic group

Not Stated

10) What is the highest level of education that you have completed?

Mother

Father

No schooling completed

High school to year 11

High school graduate - high school diploma or the equivalent (for example: GCSE)

Some college credit, but less than 1 year

1 or more years of college, no qualification

Sixth Form/College (A levels, BTEC, or equivalent)

Bachelor's degree (for example: BA, BSc)

Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)

Professional degree (for example: MD, DDS, DVM, LLB, JD)

Doctorate degree (for example: PhD, EdD)

11) Employment Status (mother and father)

Are you currently...?

Employed for wages

Self-employed

Out of work and looking for work

Out of work but not currently looking for work

A homemaker

Maternity/paternity leave

A student

Retired

Unable to work

12) Employer Type, please describe your work. (mother and father)

Employee of a for-profit company or business or of an individual, for wages, salary, or commissions

Employee of a not-for-profit, tax-exempt, or charitable organization

Self-employed in own not-incorporated business, professional practice, or farm

Self-employed in own incorporated business, professional practice, or farm

Working without pay in family business or farm

13) Housing, Is your house, apartment, or mobile home –

- Owned by you or someone in this household with a mortgage or loan?
- Owned by you or someone in this household free and clear (without a mortgage or loan)?
- Rented? (private/local authority)
- Occupied without payment of cash rent?

## Section 2 Going Home

This section will focus on what happened when you were planning to go home for the first time, from the Paediatric Cardiac Unit (PCU).

- 1) How old (in days) was your baby when you went home for the first time from hospital?
- 2) When your baby was ready to go home from the first hospital admission, how was your baby feeding?
  - a. Breast fed
  - b. Bottle fed
  - c. Nasogastric tube feeds
  - d. Gastrostomy tube feeds
  - e. Other
- 3) When your baby was ready to go home from the first hospital admission, did your baby need to take regular medications?
  - a. Yes
  - b. No
- 4) When your baby was ready to go home from the first hospital admission, did your baby need any other treatments to continue at home?
  - a. Oxygen therapy
  - b. Daily Oxygen saturation (pulse oximetry) monitoring
  - c. Daily Weight measurement
  - d. Other (please state)
- 5) Who taught you how to care for your baby at home?
  - a. Ward nurse
  - b. Liaison nurse
  - c. Dietician
  - d. Doctor
  - e. Other



- 6) Were you taught specific signs to look out for in your baby? (for example about the wound/your baby's breathing/your baby's colour/your baby's feeding)
- Yes signs that related specifically to my baby
  - Only told about general signs to look out for
  - No
  - Other (please state)
- 7) Were you given written instructions about all of your baby's care needs?
- Yes, general information
  - Yes, information specifically relating to my baby's needs
  - No written information given
  - Other (please state)
- 8) Before you went home with your baby, who were you told to contact with any worries about your baby's cardiac condition?
- GP
  - Health Visitor
  - Community children's nurse
  - Cardiac Ward Nurses
  - Cardiac Liaison Nurses
  - Doctor at local hospital
  - Doctor at paediatric cardiac unit
  - 999 ambulance
  - A & E
- 9) How often did you seek advice after you went home for the first time?
- 1-2 times a week
  - 3-4 times week
  - 5-7 times a week
  - Every other week
  - Once a month
  - Other (please state)
- 10) Where did you mainly get your advice from?  
Please state:
- 11) Before going home for the first time, how anxious did you feel? (Likert scale)
- 12) Before going home for the first time, how confident did you feel in your parenting role? (Check appropriate box)

Please state who is completing this mother/father or both (if both please use the letters M or F next to your responses in the appropriate box)					
	Never	Seldom	Sometimes	Often	Always

a)	I knew when my baby wanted me to play with him/her				
b)	I knew how to take care of my baby better than anyone else				
c)	When my baby was cranky, I knew the reason				
d)	I could tell when my baby was tired and needed to sleep				
e)	I knew what made my baby happy				
f)	I could give my baby a bath				
g)	I could feed my baby adequately				
h)	I could hold my baby properly				
i)	I could tell when my baby was sick				
j)	I felt frustrated taking care of my baby				
k)	I would have been good at helping other mothers learn how to take care of their infants				
l)	Being a parent was demanding and unrewarding				
m)	I had all the skills needed to be a good parent				
n)	I was satisfied with my role as a parent				

The Maternal Confidence Scale (adapted from The Maternal Confidence Scale developed by Parker and Zahr [Badr] in 1985)

### Section 3 At home

This section will focus on how you feel now.

- a) Where do you get the most support from now?
  - b) Partner
  - c) Baby's grandparents
  - d) Extended family
  - e) Friends
  - f) GP
  - g) Midwife
  - h) Health Visitor
  - i) The hospital staff (nurses/doctors) local hospital
  - j) The hospital staff (nurse/doctors) paediatric cardiac unit
  - k) Parent support group
  - l) Other (please state)
  
- 2) Is there anything else that would have been helpful to know before you were discharged home?

- 3) How anxious do you feel now about being at home with your baby? Likert scale
- 4) How confident do you feel now in your parenting role? (Check appropriate box)

Please state who is completing this mother/father or both (If both please state M or F next to your responses in appropriate box)					
	Never	Seldom	Sometimes	Often	Always
a) I know when my baby wants me to play with him/her.					
b) I know how to take care of my baby better than anyone else					
c) When my baby is cranky, I know the reason					
d) I can tell when my baby is tired and needs to sleep					
e) I know what makes my baby happy					
f) I can give my baby a bath					
g) I can feed my baby adequately					
h) I can hold my baby properly					
i) I can tell when my baby is sick					
j) I feel frustrated taking care of my baby					
k) I would be good at helping other mothers learn how to take care of their infants					
l) Being a parent is demanding and unrewarding					
m) I have all the skills needed to be a good parent					
n) I am satisfied with my role as a parent					

The Maternal Confidence Scale (adapted from The Maternal Confidence Scale developed by Parker and Zahr [Badr] in 1985)

- 5) If there is anything else that you would like to add about your experience of going home for the first time, please leave comments below

**Appendix 13 Phase Two Baseline Questionnaire**

**Baseline data to be collected in the Parental Home Monitoring Study.  
Research study ref: 12/wm/0375**

**Table 1 Baseline data**

- Name, age, sex, ethnicity, hospital ID of patient, postcode derived deprivation index
- Work status of parents
- Siblings - age, sex, any significant medical history
- Gestational age of infant
- Weight of infant at birth and at surgical stage 1
- Ante natal or post-natal diagnosis of CHD
- Genetic abnormalities and non-cardiac system disorders
- Method of admission to paediatric cardiac centre (PCU)
- SpO2 at admission to PCU (?shocked baby)
- Paediatric Index of Mortality Score
- Retrieval or transfer to PCU?
- Pre-existing knowledge/Information/support obtained and where from

**Table 2 Confounding Variables**

<ul style="list-style-type: none"> <li>• Cardiac anatomy/defects                             <ul style="list-style-type: none"> <li>○ Diagnosis</li> <li>○ Ascending aortic size</li> <li>○ Aortic arch diameter</li> <li>○ Any aortic coarctation/interruption?</li> <li>○ Pulmonary artery sizes</li> <li>○ Intact septum?</li> <li>○ Valve Stenosis/Atresia?</li> <li>○ Ventricular hypertrophy</li> <li>○ Any other relevant anatomy/defect information</li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• Cardiac physiology                             <ul style="list-style-type: none"> <li>○ Pre-operative ventricular function</li> <li>○ Pre-operative AV valve regurgitation</li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• Preoperative mechanical ventilation requirements</li> </ul>
<ul style="list-style-type: none"> <li>• Pre-operative acidosis?</li> </ul>
<ul style="list-style-type: none"> <li>• Preoperative Inotrope requirements</li> </ul>

<ul style="list-style-type: none"> <li>• Surgical technique/procedure (Stage 1) <ul style="list-style-type: none"> <li>○ shunt size</li> <li>○ RV-PA conduit or BT shunt?</li> <li>○ Shunt clipped at end of procedure?</li> <li>○ Use of antegrade cerebral perfusion</li> <li>○ Cardiopulmonary bypass time</li> <li>○ Deep hypothermic circulatory arrest time</li> <li>○ Total support time (CPB time + DHCA time)</li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• Haemodynamic Stability/laboratory data during first 48hrs post operatively Stage 1 <ul style="list-style-type: none"> <li>○ Mixed venous saturation on return from theatre, at 24 hrs, 48 hrs</li> <li>○ Arterial and venous oxygen saturations</li> <li>○ Arteriovenous oxygen content difference</li> <li>○ Qp/Qs ratios</li> <li>○ Lactate on return from theatre, at 24hrs, 48hrs</li> <li>○ Inotrope requirement on return from theatre, 34hrs and 48hrs</li> <li>○ Haemoglobin</li> <li>○ Mean blood pressure</li> <li>○ Central venous pressure</li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• Other post-operative information <ul style="list-style-type: none"> <li>○ Length of time chest left open</li> <li>○ Length of time ventilated</li> <li>○ Length of time on PICU</li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• Ward Discharge information <ul style="list-style-type: none"> <li>○ Weight at discharge</li> <li>○ Nutritional status <ul style="list-style-type: none"> <li>▪ Feeding method</li> <li>▪ Presence of reflux?</li> </ul> </li> <li>○ Wound status</li> <li>○ Medication</li> <li>○ Recurrent Laryngeal Nerve (RLN) palsy?</li> <li>○ Neurological status</li> <li>○ Ventricular function</li> <li>○ AV valve regurgitation</li> <li>○ Prognostic factors – e.g. degree of existing cardiac failure</li> </ul> </li> </ul>

**Table 3 Data to be collected regarding parental contact for advice or upon hospital admission**

<p>Study group</p> <ul style="list-style-type: none"> <li>• Intervention group?</li> <li>• Control group?</li> </ul>
<p>Number of Emergency Health Visits in Primary Care</p> <ul style="list-style-type: none"> <li>• GP</li> <li>• Health Visitor</li> <li>• Community Children's Nurse</li> <li>• 999 ambulance</li> <li>• Walk in centre</li> <li>• A &amp; E</li> </ul>
<p>Number of calls/contact with health care professionals for advice</p> <ul style="list-style-type: none"> <li>• Who did the parent contact?</li> <li>• What for?</li> <li>• What information was obtained/given?</li> <li>• Any records in patient notes?</li> </ul>
<p>Number of hospital admissions</p> <ul style="list-style-type: none"> <li>• Where admitted</li> <li>• How long in hospital</li> </ul>
<p>Length of Time to Stage 2 Admission?</p>
<p>Interstage Death?</p> <ul style="list-style-type: none"> <li>• When?</li> <li>• Preceding events?</li> </ul>

**Appendix 14 Maternal Confidence Questionnaire** (Parker, Zahr and Cole 1992)

How confident do you feel in your parenting role? (Mark an **(X)** in the appropriate box.)

	<b>Question</b>	<b>Never</b> <b>1</b>	<b>Seldom</b> <b>2</b>	<b>Some</b> <b>3</b>	<b>Often</b> <b>4</b>	<b>A great deal</b> <b>5</b>
1	I know when my baby wants me to play with him/her.					
2	I know how to take care of my baby better than anyone else.					
3	When my baby is cranky, I know the reason.					
4	I can tell when my baby is tired and needs to sleep.					
5	I know what makes my baby happy.					
6	I can give my baby a bath.					
7	I can feed my baby adequately.					
8	I can hold my baby properly.					
9	I can tell when my baby is sick.					
10	I feel frustrated taking care of my baby.					
11	I would be good at helping other mothers learn how to take care of their infants.					
12	Being a parent is demanding and unrewarding.					
13	I have all the skills needed to be a good parent.					
14	I am satisfied with my role as a parent.					

Total score = /70

## Appendix 15 Phase Two Interview Schedules

### Interview Schedule - Face to face Interviews with parents participating in the study before discharge from hospital (T0)

Introduction

Obtain Consent

Interview Schedule:

Explain how the interview will progress and how long it will take

#### *Part 1 Quantitative Data Collection*

1. How anxious, depressed and confident do you feel looking after your infant at home?
  - a. Parents will be asked to complete the following questionnaires (explanation will be given)
    - i. GAD7
    - ii. PHQ9
    - iii. Maternal Confidence Questionnaire

#### *Part 2 Qualitative*

2. How do you feel about the transition of going home with your infant for the first time?
  - a. Perception of the transition (change in role, affect, source, timing, onset, duration, degree of stress)
  - b. What support systems do they have (intimate, family, friends, institutional, physical environment)
  - c. Individual characteristics (parent demographics, previous experiences, knowledge and understanding)  
(
3. Please can you tell me how you feel about being involved in the project?
  - a. Have they any anxieties related to being part of the project?
  - b. Is there anything else they need before going home in relation to the project?

Terminate the interview

Arrange date and time for the telephone interviews (at T1, T2, T3)

Thank the parents for their time, ensure they have contact details for Principal Researcher



## **Telephone Interviews with parents participating in the study after discharge from hospital (T1, T2, T3)**

Introduction

Obtain Consent

Interview Schedule:

Explain how the interview will progress and how long it will take

### *Part 1 Quantitative Data Collection*

1. How anxious, depressed and confident do you feel about looking after your infant now [at T1, T2, T3]?
  - a. Parents will be asked to complete the following questionnaires (explanation will be given)
    - i. GAD7
    - ii. PHQ9
    - iii. Maternal Confidence Questionnaire

### *Part 2 Qualitative*

2. How do you feel about the transition and adaptation to being at home with your infant now [at T1, T2, T3]?
  - a. Balance of resources and deficits
  - b. Differences in pre- and post-transition environment
    - i. Perceptions (change in role, affect, source, timing, onset, duration, degree of stress)
    - ii. What support systems do they have (intimate, family, friends, institutional, physical environment)
    - iii. Individual characteristics (parent demographics, previous experiences, knowledge and understanding)
3. Please can you tell me how you feel now [at T1, T2, T3] about being involved in the project?
  - a. Identify which group the parents have been randomised to
  - b. Have they any ongoing anxieties related to being part of the project?
  - c. Do they feel that they were fully prepared in relation to going home? Is there anything they now [at T1, T2, T3] know they weren't told about?
  - d. How do they feel about recognising clinical deterioration in their infant now [at T1, T2, T3]?
  - e. Is there anything else they need now [at T1, T2, T3] in relation to the project?

Terminate the interview

Confirm date and time for subsequent telephone interviews

Thank the parents for their time, ensure they have contact details for Principal Researcher

**Open Ended Question for Interviews FINAL Interview (T3) Differences – Perceptions**

1. How do you feel now about the transition of going home from hospital with your infant for the first time?
  - a. Return to normal family functioning
  - b. How did it differ from what you might have been expecting?
  - c. What impacted on the way in which you dealt with the transition?
  - d. Previous experiences of healthcare
  - e. Relationship with partner
  - f. What about social, cultural, ethnicity, religion
  - g. Education, jobs/employment – roles – values, beliefs arising from that
  - h. Finances – expectations, preparation
  - i. how have finances affected the transition – any change, would things have been different if ...
  
2. How has this experience changed your role as a mother/father?
  - a. What were your expectations as a first-time mother of parenthood and going home with your baby for the first time?
  - b. How had you planned for this before your baby was born?
  - c. What about your beliefs, values around becoming a mother?
  - d. Did anything change?
  
3. How has being in hospital affected you/the family?
  - a. How do you feel being in hospital has impacted on your stress?
  - b. What about coping strategies, what type of person are you
  - c. What about your partner?
  - d. Do you have similar coping strategies or do you cope differently?
  - e. How would you describe these?
  - f. Has the experience changed the way that you approach stressful situations?
  - g. Have you learnt anything about yourself or about you as a couple/family unit
  
4. How do your other children feel?
  - a. How has the experience changed the relationships/bonds between you and the other children or the children and their siblings?

**Differences – support systems**

5. What part have your support systems played in the transition?
  - a. How will your physical environment (home) support the transition/adaptation?
  - b. Family/friends
  - c. Health care professionals
  - d. Parent support groups
  - e. Other

**Differences – parent demographics (as above)**

6. What changes have there been to your family demographics?
  - a. Family structure (marital status)
  - b. Finances/jobs
  - c. Home environment/living arrangements

7. How has your education/employment helped in your understanding of your baby's condition?
8. How has your knowledge/understanding changed during the time that you have been at home?
9. What other healthcare experiences have you had?

**Appendix 16 GAD 7 Anxiety (Spitzer et al 2006)**

Over the <u>last 2 weeks</u> , how often have you been bothered by the following problems? <i>(Use "✓" to indicate your answer"</i>	Not at all	Several days	More than half the days	Nearly every day
Score	1	2	3	4
1. Feeling nervous, anxious or on edge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Not being able to stop or control worrying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Worrying too much about different things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Trouble relaxing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Being so restless that it is hard to sit still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Becoming easily annoyed or irritable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Feeling afraid as if something awful might happen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Column Totals	___ +	___ +	___ +	___

= **Total Score** \_\_\_\_\_

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Appendix 17 PHQ-9 Depression** (Kroenke, Spitzer and Williams 2001)

<b>Over the <u>last 2 weeks</u>, how often have you been bothered by any of the following problems?</b> <i>(Use "✓" to indicate your answer"</i>	Not at all	Several days	More than half the days	Nearly every day
<b>Score</b>	1	2	3	4
1. Little interest or pleasure in doing things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Feeling down, depressed, or hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Trouble falling or staying asleep, or sleeping too much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Feeling tired or having little energy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Poor appetite or overeating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Trouble concentrating on things, such as reading the newspaper or watching television	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Thoughts that you would be better off dead or of hurting yourself in some way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Column Totals	___ +	___ +	___ +	___

= **Total Score** \_\_\_\_\_

## Appendix 18 Positionality and Reflexivity

My position as the researcher was central in the exploration and interpretation of the knowledge that arose from the associations between the people involved in the study (Thomas 2013). Positionality represents a space between objectivity and subjectivity; however, achieving complete objectivity is unattainable, as we are unable to totally separate ourselves from subjectivity and this is what represents positionality (Bourke 2014). The research, particularly in phase two, represented a shared space that was shaped by the parents as participants and by me as the researcher (England 1994). Therefore, to explore the influence of parents' demographics, values and beliefs on their experience of going home, it was also necessary to recognise that my position in terms of my beliefs, political stance and cultural background (ethnicity, gender, age, employment, educational background, marital status) could impact on the research process (Thomas 2013).

I am a White British, mother of two children, and have lived in the West Midlands for most my life; with seven years living in Oxford and nearly three years living in London in my 20s and early 30s. I am mid-40s; my employment status is a full time academic; education status - currently undertaking a PhD; marital status – divorced, with experience of living for several years as a single mother with two young children. Therefore, I recognise that my beliefs and values have been created and moulded by my personal and professional experiences of transition, some of which have been highly stressful and in difficult circumstances.

Prior to the study commencing I felt that having insider knowledge through my professional experiences would be beneficial in terms of understanding the language and the nuances of the clinical environment (Maltby et al 2010). I also felt that having worked with children with Congenital Heart Disease (CHD) and their families since 1994 as a paediatric student nurse and subsequently as a staff nurse, senior staff nurse and nurse practice educator in three specialist children's cardiac units (Oxford, London and Birmingham), my experience and understanding would assist in establishing a rapport with the parents. However, this professional knowledge and understanding may have introduced a certain professional bias to the data collection and subsequent analysis. I also recognised that in my role as a PhD student and academic I might be viewed as an outsider, which also could have been either advantageous or disadvantageous. I felt that not being part of the clinical team might encourage some parents to open-up as there

was no threat to the care that they were receiving, conversely I recognised that some parents might be less inclined to talk openly with a stranger.

It was necessary, therefore, to accept my subjectivity and to recognise how this might influence the way I collected data and interpreted the results. There were two ways that this subjectivity could impact on the interpretation: firstly, the way that I as researcher interpreted the experiences of the parents and those of myself; and secondly, the way parents made meaning of their own experiences (Bourke 2014). An additional component was recognising the way in which my voice would be evident within the reporting of the research findings. This would be the way in which I left my own signature on the project; resulting from the use of 'self' or subjectivity. The strength of the qualitative strand of the research process would develop from the relationship between myself as the instrument and the parents as participants (Bourke 2014).

For example, as a parent of two healthy children, I had to be careful that I did not speak for parents in terms of what it is to be a first-time parent of a healthy newborn baby, or what it is to be an experienced parent having their second healthy baby; instead my work had to reflect the voices of the parents in the study. Parents of healthy infants do not experience what it is to be a parent of an infant with a life limiting or life threatening condition; parents of healthy infants are the norm within society, unlike the parents participating in this study who had infants with complex CHD, which is a relatively rare condition.

There was possibly less impact of my professional self on data collection in phase one as the invitation to participate was sent out to parents from the charity. The participant information only gave details of my academic role. I was not an insider as I had no place in the social group being studied (Moore 2012). Being an outsider might have been a disadvantage in terms of the parents' decision to take part, as they may have felt it was less relevant than if the survey had been undertaken by the charity (perhaps shown in the response rate to the charity survey undertaken the following year, LHM 2015). Conversely, the anonymity for parents in terms of my academic role and, therefore, being an outsider, may have been advantageous to those that participated.

One could question whether my educational background and the fact that I was conducting the study for my PhD encouraged responses from parents with a higher educational level, given that 68% of mothers and 55% of fathers responding to the survey

invitation had a Bachelor's Degree or higher. Providing information about my academic background may have discouraged those with lower education levels from taking part, as they might have thought that the questionnaire would be too difficult to understand. Additionally, parents may not have realised that it had been written and piloted in collaboration with parent members of the charity. Conversely the difference in educational backgrounds may have been a consequence of the survey being conducted online; where it was recognised that online surveys can attract responses from individuals with a more knowledgeable viewpoint (Duffy et al 2005). Furthermore, broadband availability and the cost of using the internet may have been an influencing factor.

In terms of the data analysis the descriptive and inferential data interpretation was less influenced by my values and more by my lack of experience of analysis of this type of data. During the qualitative data analysis, I experienced a light bulb moment where having read and re-read the parents' responses numerous times without seeing any key themes, it all suddenly became clear. This may have been due to my lack of experience of thematic analysis, additionally I had been reading about interpretative phenomenological analysis, which had made me question my approach to the analysis resulting in further exploration of the method of thematic analysis. My analysis was, therefore, influenced by what I was reading, which also included reading research around acute stress disorder and post-traumatic stress disorder. I also recognised that by using a deductive approach, the themes that emerged may have reflected my voice in terms of the themes I expected to be identified. However, my interpretation may also have been based on my previous 'insider' knowledge, understanding and experience from working with families in clinical practice. I wondered, therefore, whether I was initially looking for what I expected to see, rather than what was there. Conversely as an 'outsider' (in terms of not having worked at some of the specialist cardiac centres mentioned by the parents) I wondered whether I was surprised by what parents had experienced at those centres and less surprised about the centres in which I had worked.

In phase two I had direct contact with the participants and therefore in comparison to phase one, my position could have had more influence on the outcomes of the study. Whilst I was not involved in recruitment of the parents, the research nurses spoke to them about the interviews and had explained my position before I had met them. The parents may therefore have developed their own pre-conceived ideas about me as an



'insider' or 'outsider' based on the information that they had been given and the way in which it had been presented by the research nurse. The briefing with parents would have been dependent upon the research nurse's positionality, beliefs about the study and pre-conceived ideas about me as the researcher. This may have changed during the study due to the first research nurse being embedded within the ward environment and having clinical experience within the cardiac environment. The subsequent research nurses were embedded within the Wellcome Trust and had no experience within the cardiac unit.

My academic background and PhD student status was described within the participant information sheet, positioning me as an 'outsider' once again. However, I was aware that whilst I was not an 'insider' as I was not based at the study site, once I began talking to parents an 'insider' status as a children's cardiac nurse became apparent.

The reflective process was particularly important during the semi-structured interviews in phase two, as I reflected at the end of each contact with parents to think about how the situation may have impacted on my interpretation of the discussions that took place and the subsequent analysis of data. I also used the process of reflection as a learning tool to look back retrospectively on the experiences of interviewing families as well as looking forward prospectively on how the experiences would change or influence subsequent interviews. At the beginning of phase two I started the interviewing process as a novice researcher and in addition the first research nurse (RN) had no experience of research, but was an experienced ward nurse, and, therefore, I was supporting her too. I had put together a guide of topics for the interviews based on transition theory, however, it became apparent through the transcriptions of the first two interviews (one that I had done and one that the RN had done in my absence) that it was not an easy process and that we both needed to develop our skills. The key issues arising in the initial interviews were using closed ended questions (me) and deviation from the role of interviewer (RN) to become the giver of information, presenting her own ideas and engaging in counselling activities. A common pitfall of many novice nurse-researchers is recognised as the struggle to move from the clinical role to that of a non-clinical researcher (Tod 2006), however, it was important to be aware of the impact that this had on the quality of the interview and of subsequent interviews if it was not addressed. The RN and I discussed how to avoid counselling during the interview and agreed that if anything arose during the interview that needed counselling the RN would offer to provide more information and support once the interview had ended.

As I was struggling to think of open ended questions whilst the interview was taking place I decided to write a list of example questions based on the theory. By doing this the interviews moved from being more 'unstructured' to semi-structured. The same questions were then asked in all subsequent interviews, which provided consistency, especially when the RN needed to undertake the pre-discharge interview at short notice. This was due to the parents going home with their infant earlier than expected; me being based at the University over 30 miles away and having other role commitments. Despite having a list of questions, there was still freedom to explore some of the answers allowing deeper probing of an issue. The sequence of delivery of the questions could also be amended as guided by the parents' responses. Having a set of questions helped to provide some structure such that the interview remained an interview rather than becoming a counselling session. Additionally, articulation by the RN improved as she did not need to 'find the words' to explain what she was trying to ask and, therefore, using example questions for subsequent interviews made the questioning clearer.

The very first interview was difficult, predominantly because the mother seemed very subdued and waited for the father to respond before she did; meaning it was very difficult to engage her in conversation. I particularly felt out of my depth when, having scored the PHQ9 for the mother it triggered a risk assessment, I was not sure what to say or how to approach it, as the risk assessment questions were difficult to ask. I was very aware that I was not a psychologist and had no experience of administering these self-report tools previously, or of how to manage the results and this made me lack confidence in my interviewing ability. I discussed my feelings with my supervisory team and was given advice about using the CUDAS by its creator (Furze 2013). However, this mother did not seem at all surprised about her scores being high. It became apparent at the subsequent interview that she was already seeing a specialist for psychology support, yet, I had not been aware of that at the time of the first interview.

On reflection, this first interview reminded me that despite the parents consenting to be interviewed together I needed to openly and transparently discuss before administering the self-report tools, how they wished me to inform them of their scores; whether they were happy for me to do that whilst both parents were present or whether they wished me to tell them individually. In the next interview with parents new to the study I began by explaining exactly that. Using the online CUDAS (Furze 2013) meant that I could score the GAD7 and PHQ9 on a mobile device and show them individually; in

subsequent face to face interviews I gave the device to the parents so that they could complete it online and receive an immediate score, rather than using paper copies. Another learning point related to the order in which the tools were administered. In the first interview with RR8 the mother appeared to think that completing the tools would result in her being labelled an anxious mother and perhaps worried that this would impact on their planned discharge home; therefore, she answered 'no' to every question. This fear of being labelled also became a barrier within the subsequent interview and negatively impacted on my ability to develop a rapport with the mother; however, the father was very talkative. It was decided after reflecting upon the situation, to use the tools after the interview for future interviews with all parents.

There were a few interviews in the phase two data set (at T0) that I did not conduct and, therefore, it was important for me to familiarise myself not only with the data captured in the interview based on the interview schedule, but also to familiarise myself with the family. Having not met some of the families face to face for the first interview my perceptions of them as a family were based on what I had been told about them by the research nurse (RN) (and, hence, her perceptions); through conversations with the advanced nurse practitioner (ANP) who had met them at nurse clinics after discharge and based on the judgements I had made by listening to the audio recordings. It was important for me to be aware that the beliefs, values and perceptions may not have represented the reality and instead may have related to the RN and ANPs perceptions, beliefs and values too. So, for some of the families I came to the analysis stage with some initial analytic interests or thoughts as well as my personal assumptions of them as a family unit.

Sometimes we forget that parents might have their own agenda for inviting us to interview them; it may not always be an altruistic action to help other parents. It may be a way of venting frustration and knowing that as the interviewer you are there to listen and that the interview is being recorded. I felt that this was certainly the case for the father of NK4 who had made a complaint during their infant's hospitalisation; the first interview with these parents was clouded by his experiences during that time.

I immersed myself with the data (both phase one and phase two) through repeated reading, reading in an active way, searching for meaning and patterns and making notes as mind maps. I found transcription a good way to familiarise myself with the data especially for the interviews at T0 that I did not conduct. This is recognised as an

interpretative action where meanings are created whilst writing rather than just the mechanical act of typing the words (Braun and Clark 2006). As I progressed through the six stages of thematic analysis I kept an audit trail. Whilst I aimed to inductively analyse that data I found that I was unable to separate my knowledge of theories and results of other studies, hence perhaps why there are some similarities in the terms used in the discussion. However, the themes did emerge from the data; furthermore, I decided not to review any further extant literature until I had completed the inductive analysis to prevent additional preconceptions.

In retrospect, the parents that were more open and able to talk to me during the interviews were those with a higher level of education; whereas those with lower education levels did not complete the four interviews. One example was AZ7 who interpreted the word 'interview' as a scary meeting, such as a job interview. Whilst the initial interview was very open and I felt that I could establish a rapport with her, this mother avoided further meetings by not answering phone calls. This highlighted the importance of 'symbolic interactionism' (Blumer 1986) and demonstrated that researcher language is not always recognised or interpreted in the same way by lay people.

A key finding from my reflections has been the way in which conducting longitudinal interviews created therapeutic relationships. The benefit of someone listening, enabling parents to say out loud their intense emotions, was clearly therapeutic for some parents. For example, once the interviews and participation in the study had ended one mother (JT8), wanted to keep me informed of her infant's progress and each time I was on the ward after her participation had ended, she would come over to talk to me about how they were getting on.

Allowing these parents to talk openly may have implicitly provided spiritual care, allowing them to have hope, feel love, trust and faith. As I reflected upon this unexpected therapeutic aspect of the researcher role, I considered whether this was because the ward nurses were perceived not to have the time to listen (extrinsic) or perhaps were using avoidance mechanisms (intrinsic) to elude the challenge of parents opening-up and expressing their feelings. This may have been particularly so for younger or junior nurses with little experience of managing difficult conversations. I recognised that as an experienced children's cardiac nurse I understood, cared and showed compassion; as a researcher, I was unable to leave these traits outside the interview. This therapeutic relationship may well have impacted on the data analysis from a constructionist and

constructivist perspective, as the therapeutic relationship developed with some of the mothers informed what happened in subsequent interviews. I was aware that for these mothers the process for me (interviews as a method of data collection) meant something different for them and, therefore, I was aware that I needed to consider the outcome, in terms of them being able to let go after the final stage 2 interview. The impact for these mothers was that although I was interviewing them as a researcher, for them it had perhaps implicitly become a counselling relationship.

Perhaps I was intrinsically more aware of the benefits of a therapeutic relationship, given that I have espoused the theory of therapeutic nursing since I was a BA student and have endorsed the virtues of 'nursing as therapy' (McMahon & Pearson, 1998) with my undergraduate children's nursing students since becoming an academic in 2005. However, whilst practitioners may recognise the value of a therapeutic relationship and subscribe theoretically to a person-centred approach; the pressures and constraints on their time in a busy ward or clinical environment may result in a more instructive approach to communication being adopted. The implications of this for practice link to the need to provide appropriate training and education for HCPs; in terms of *how* to engage therapeutically with parents and families.

One of the questions that I have asked myself during the process of this study is 'Why did I not choose a grounded theory approach at the beginning?', especially as other researchers in the field had used this approach. However, incorporating inductive analysis into phase two was perhaps reflective of a grounded theory approach. The interviews were participant led and the study responded to an issue in practice. I was also aware that whilst I had not chosen a grounded theory approach, elements of this approach were embedded into the process. For example, I decided not to read the new extant literature that I had found before analysing phase two; as I did not want my analysis to be influenced by what I was reading.

In addition, working full time, whilst undertaking the PhD, has meant 'dipping in and out of the study'; this had its advantages and disadvantages. At times, not having time to work on the thesis has been advantageous as it has given me the space to think about the study; my experiences and my interpretations of the parents' experiences. However, a disadvantage of this has been the time it has taken me to pick back up from where I had last paused my writing; these gaps have negatively impacted the creative flow of writing and have resulted in what have felt like many wasted hours re-reading large chunks to get back up to speed.