‘Sometimes You Don’t Get To Just Go To Hospital And Get Fixed, Sometimes You Have To Spend Your Entire Life Fighting’.
Fathers’ Experiences When Their Child Is Born With Congenital Heart Disease

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Abstract

The aim of this study was to explore the experiences of fathers, when their child was born with congenital heart disease (CHD). CHD is the most common congenital condition in children, affecting 8:1000 live births in the UK. CHD relates to a range of heart defects, which vary in severity and therefore the treatment required. Children born with more severe forms of CHD will require a range of surgical and medical treatments across their early years, adolescent period and for some, into adulthood. Family centred care has been described as the foundation of children's nursing practice, however within the available healthcare literature fathers are much less visible than mothers and within the CHD literature, very few studies have presented fathers' experiences across a range of clinical settings. Wider literature exploring the role of fathers and caring masculinities has helped to inform this study.

Following a narrative methodology, the study explored fathers' experiences through various turning points in their child's treatment. Data were collected through the use of semi-structured interviews at two separate points in the father's journey. Fathers' upbringing, planning for children and their hopes for fatherhood were explored in order to gain an appreciation of who the fathers were and their expectations of parenting. There was a sense here of the expectation of a routine pregnancy and birth without complications. The fathers experienced different journeys through the same landscape. Six fathers received an antenatal diagnosis, three fathers received a postnatal diagnosis soon after birth and one father, a late diagnosis due to their son's unrelated illness.

Fathers accessed surgery for their children at six out of the eleven children's cardiac surgical centres in the UK. All of the fathers had the treatment elements of their journey in common, clinical investigations, diagnosis, referral, transfer of care, surgery and aftercare. What was apparent was how fathers approached the disruption to the expected fatherhood narrative differently with some taking a strong lead, wanting to maintain an element of control even though this had to be given over to healthcare professionals. Other fathers, however, talked about burying their heads in the sand or being content to follow the expected treatment process.

Data from the interviews are presented across three chapters, journeys to fatherhood, disruption of the expected fatherhood narrative and finally an uncertain future. Some fathers' journeys have ended with successful surgical corrections of their child's CHD, accessing only routine annual reviews and some sense of normality in their lives. Other fathers, however, are still facing the prospect of uncertain futures, with their child's transition to adult services, potential heart transplantation or palliative care all possible outcomes.

The findings demonstrate the importance of the role of the father and the need for greater recognition of their needs by healthcare professionals. The findings illustrate the unique ways in which fathers made sense of their experiences to date and how their experiences could have been enhanced at various points in their journey.

Acknowledgements

Undertaking this research study has been a long and winding journey to get to the point of submitting this thesis. Firstly, I would like to thank the fathers who participated in this study as without them the research and findings would not have been possible. It has been a privilege to spend time with the fathers who shared their stories so openly.

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Finally, to my mother Kay (1928-2000), you always recognised the inherent value of education even though yours was cut short by the war. You always encouraged me to try my best and you were both mum and dad.

Contents

Appendices

Appendix 1 Florence Nightingale Scholarship award letter

Appendix 2 Overview of research articles within the review

Appendix 3 JBI Critical Appraisal checklist for qualitative research

Appendix 4 Online recruitment statement

Appendix 5 Participant information sheet

Appendix 6 Participant Consent

Appendix 7 School of Healthcare Sciences Ethical Approval letter

List of Figures

List of Tables

List of Key Abbreviations

ASD - Atrial Septal Defect
CHD - Congenital Heart Disease
DORV- Double Outlet Right Ventricle
HLHS - Hypoplastic Left Heart Syndrome
LCC - Local Children’s Cardiology Centre
LRH - Local Referring Hospital
NICU - Neonatal Intensive Care Unit
PIC - Paediatric Intensive Care
SCCC - Specialist Children’s Cardiology Centre
SCSC - Specialist Children’s Surgical Centre
TGA - Transposition of the greater Arteries
TOF – Tetralogy of Fallot
VSD - Ventricular Septal Defect

Transcription Symbols

... Indicates a pause

Double quotation marks **“ ”** in block quotations indicate quotations within the quotation

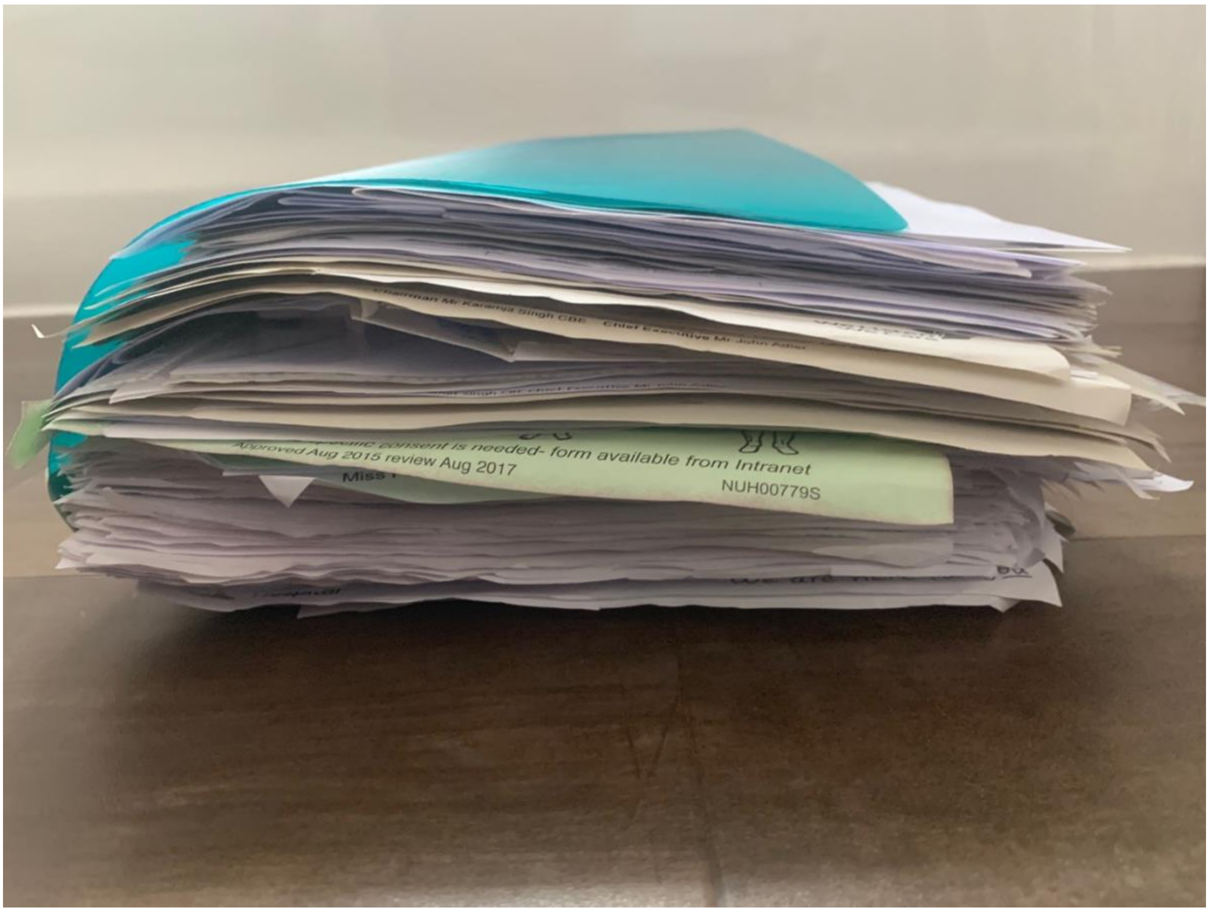
CHAPTER ONE - Introduction

1.1 Setting the scene

> *"Sometimes the smallest things take up the most room in your heart.*
> *Winnie the Pooh".*
> *The House at Pooh Corner* (A.A. Milne 1928)

When we talk about the heart, we tend to think of it not as a major organ responsible for pumping blood to the body and lungs but in emotive and spiritual terms. When we think of the heart we think of love, emotion and for some, the soul or spirit. We commonly use phrases such as 'they put their heart and soul into it', 'they wear their heart on their sleeve', 'they died of a broken heart' and 'my heart goes out to them'. All phrases giving more meaning to a bodily structure than the anatomical and physiological function it serves.

This thesis explores the experiences of ten fathers whose children had been diagnosed with congenital heart disease (CHD). The diagnosis of CHD, either in utero or postnatally, can be devastating for parents who are faced with unfamiliar terminology, invasive treatments and for some, uncertain outcomes. The fathers within this study all highlighted their lack of awareness or preparedness for having a child with CHD. The unexpected nature of the diagnosis led to a disruption in the expected narrative of relationships, children and a certain future. This chapter sets the scene for the thesis by defining CHD, exploring its incidence and the development of CHD interventions alongside causes, signs and symptoms, diagnosis and treatment. There is also a brief overview of policy and service organisation which has been a controversial political issue in recent years. The chapter concludes by providing an overview of the organisation of the thesis chapters, my personal narrative and theoretical position.



(Figure 1)

The above photograph in Figure 1 was provided by James, the father of a little girl born with CHD. At the end of the first interview, we talked about the way in which the families would be represented when I was teaching or presenting my research findings. We had already discussed confidentiality and anonymity. Eventually the conversation turned to a representation of James and his family in another way, which is where the idea for a photograph came from. Representation of the families was an area discussed with a number of fathers who also sent photographs with significant meaning for them. James explained the meaning behind his photograph:

> *There were quite a few images I considered sending but I feel this one hits home the hardest. Every time we open our baby box, we relive the ordeals she has faced; how precarious the situation has been and how things will never really be over. It demonstrates the relentless appointments, medical procedures, discharge letters, evaluations and clinical diagnosis evaluations. How the pile just keeps growing.*

> *Sometimes you don't get to just go to hospital and get fixed, sometimes you have to spend your entire life fighting.*

The sentiment expressed by James is reflective of the experience of a number of fathers within the study. The aim, objectives and research questions in this study were formulated to address the gap in the literature and contemporary research. These highlight a limited visibility for fathers when their child is diagnosed with CHD, or indeed in the wider literature around family centred care, which is a fundamental aspect of children's nursing (Hayes and Savage 2008; Swallow et al. 2011; Rempel et al. 2012). Although policy and clinical guidance focuses very much on a family centred care approach, in practice fathers are often overlooked and their needs unmet (Bennett et al. 2008). Policy drivers highlight inclusivity for the whole family, but this is sometimes challenging to achieve in practice (WAG 2005a; NHS 2010; Scottish Government 2016; Welsh Government 2019). This study explores the experiences of fathers when their child is diagnosed with CHD.

My personal motivation for undertaking the study was through my clinical background which was in paediatric intensive care (PIC). Around eight years ago I met a family who were on PIC as their baby had been diagnosed with CHD and required invasive ventilation prior to transfer to a CHD surgical centre. This was their first baby and the pregnancy had gone well. The baby was diagnosed with a complex heart defect soon after birth when their condition deteriorated. The couple talked of the whirlwind that had disrupted their lives moving from the joy of the birth, to the unknown environment of the PIC and the surgery and treatment that awaited them once transferred to a surgical unit. This encounter caused me to think about how services are organised, the range of treatments offered, the environments in which they are delivered and also the parental role. The father stood out as he was clearly bewildered and talked about not knowing what his role was and how he should deal with the circumstances that he found his family in. One comment stood out which was the need to be strong but not knowing how to be.

Exploring fathers' experiences when their child is born with CHD has given me an insight into the fathers' stories across a period of time. The stories have a temporal association as fathers describe their journeys to parenthood and the unexpected diagnosis of CHD. The stories evolve like a series of scenes which are linked to specific episodes and turning points that the fathers have identified as being significant for them. Diagnosis, investigations, treatment, relationships with healthcare staff and a view of their futures were all significant aspects of the fathers' narratives.

1.2 Definition and Incidence of CHD

CHD refers to a range of heart defects or conditions which develop whilst the baby is still in utero (Bedford and Lomax 2011; Batchelor and Dixon 2012). The incidence is variable across studies but is in the region of 5 and 10 per 1,000 live births, 8 per 1,000 live births is the mostly commonly quoted incidence in the United Kingdom (Billet at al. 2008; Bedford and Lomax 2011; NHS England 2017). According to NHS England (2017), between 5,500 and 6,300 babies are born with CHD each year. The difference in overall incidence figures is accounted for by a variation in definition and whether minor heart defects are included in the count. Regardless of the incidence, CHD remains the most common congenital defect in the new-born (Horrox 2002; Batchelor and Dixon 2012).

1.3 A Brief History of CHD Interventions

Congenital heart disease has been recognised since ancient times, often through the work of the anatomist or in more modern times, the pathologist (Richardson 2015). Various illustrations of heart defects have appeared through history with Leonardo Da Vinci drawing an atrial septal defect alongside other defects and the cardiac anatomy (Shoja et al. 2013). Over the last sixty years the outlook for children born with CHD has improved dramatically as surgical and interventional cardiology techniques have advanced (Baum 2006). In 1938, Robert Gross successfully undertook the first ligation of a patent ductus arteriosus (PDA), (Gross and Hubbard 1939). Work on the development of shunts advanced during the 1940's with the development of the Blalock-Taussig (BT) shunt in 1944. Helen Taussig was a paediatric cardiologist at Johns Hopkins University Hospital and recognised that children born with Tetralogy of Fallot presented with cyanosis, apart from those with an open PDA who experienced cyanosis when it closed (Baum 2006). Taussig realised that if a surgical equivalent of a PDA could be created to increase pulmonary blood flow, the degree of cyanosis could be reduced. The surgeon who undertook the procedure was Alfred Blalock who had developed a similar operation in dogs. The first patient was a 15-month-old girl who survived the first operation but subsequently died following a second procedure six months later. This ground-breaking procedure was discussed in Time magazine (1945), describing the operation on a blue baby with a beating heart. Further operations were performed and the BT – shunt became one of the few available CHD operations. Shunt development continued in the 1950's with the Glenn shunt and then in 1962 David Waterston who worked at Great Ormond Street hospital developed the Waterston shunt to increase pulmonary blood flow (Waterston et al. 1972). Mortality was initially high at around 43% in infants and 26% in all age groups in hospital. As surgical techniques and patient management improved mortality rates fell (Baum 2006).

Alongside the development of shunts, the 1950's saw the development of cardiac catheters and angiography alongside the development of cardiopulmonary bypass which introduced the era of open-heart surgery (Noonan 2004). During the 1960's there was limited access to paediatric cardiologists with the majority of children being seen by adult cardiologists (Moodie and Coselli 2011). The 1960's and 70's saw an expansion in the range of operations available and the recognition of paediatric cardiology as a subspecialty (Richardson 2015). In 1971 Fontan and Beaudat, two surgeons working in Bordeaux, developed the Fontan operation to completely repair tricuspid atresia (Fontan and Beaudat 1971). Advances in treatment continued with the development of surgery for Transposition of the Greater Arteries (TGA) by Jatene in 1975 (Baum 2006) and the Norwood procedure for hypoplastic left heart syndrome (HLHS) in 1980 (Salim et al. 1995). As surgical techniques slowly improved cardiology interventions developed, two dimensional and colour doppler in the 1980's allowed for more accurate heart imaging and the expansion of interventional cardiac catheters which enabled the closure of ducts, small septal defects and device implantation (Richardson 2015).

Alongside open-heart surgery, heart transplantation was also developing. The first infant heart transplant was attempted by Adrian Kantrowitz in America in 1967 three days after Christiaan Barnard's first heart transplant (Bailey 2009). The recipient died a short time later. Professor Magdi Yacoub performed a heart transplant on a 10-day-old baby in 1984 in London, and the infant survived for 18 days. The first successful infant recipient was transplanted by Dr Denton Cooley in 1984 and this child survived 13 years (Chinnock and Bailey 2011).

CHD services have since developed worldwide. In the UK CHD surgery is concentrated in eleven centres with cardiology referral centres spread across the country. The majority of children born with CHD today will survive into adulthood and most will have full lives. Moodie and Coselli (2011) identified that in the West, there are now more adults with CHD than children. This has led to adult cardiac services developing grown up congenital heart services (GUCH). However, Alsoufi and Caldarone (2015) note that CHD remains a significant cause of mortality.

1.4 Causes

The causes of CHD are thought to be idiopathic, however they are also associated with wider environmental, chromosomal and other syndromes or congenital defects at birth (Veal and Bailey 2018). Various infections in the first few weeks of pregnancy can have a significant impact on the foetus. Rubella has been associated with pulmonary valve stenosis and an increase in PDA (Oster et al. 2010). Long term conditions in the mother and their treatment may give rise to increased risk of CHD. Liu et al. (2013) found that hypertension and diabetes mellitus are linked to CHD. Diabetes is specifically linked to an increased risk of TGA and ventricular septal defect (VSD), (Park 2010). Some anti-epileptic medication, alcohol, smoking and some illicit drugs also have an association with an increased risk of CHD (Dixon and Crawford 2012; Etemad et al. 2012). Chromosomal abnormalities are present in a number of babies born with CHD. Down's syndrome (Trisomy 21) is associated with; VSD, atrial septal defect (ASD), atrioventricular septal defect (AVSD), PDA and Edwards Syndrome (Trisomy 18) is associated with VSD, ASD and PDA. (Horrox 2002; Bedford and Lomax 2011; Batchelor and Dixon 2012). In terms of foetal cardiac development, it is important to highlight that the heart is fully formed with four chambers, two great vessels, is beating and has a blood flow by eight weeks gestation. This being the case some environmental factors such as prescribed or illicit drugs as well as alcohol may have been ingested before the mother was aware of the pregnancy meaning it is too late to make either lifestyle or medication adjustments in an unplanned pregnancy.

1.5 Classification of CHD

There are various classifications of CHD, which may be organised by morphology, whether cyanosis is present or in terms of altered blood flow (Horrox 2002). Most CHD will fall in to one of four categories based on alteration to blood flow. Firstly, those with increased pulmonary flow (left to right shunt) such as a VSD, Those with decreased pulmonary blood flow such as tetralogy of Fallot, TOF, those with decreased systemic blood flow such as HLHS and finally those with some mixing of pulmonary and systemic circulation such as TGA (Davies and McDougall 2019). Other classifications such as cyanotic, acyanotic and simple, complex are also used.

1.5.1 Diagnosis

The impact of diagnosis is significant and effectively life altering and in some cases life limiting. Although present at birth, not all children receive an immediate CHD diagnosis with Wren et al. (2008) stating that around a third of children will receive a diagnosis following a collapse at home or as a result of routine screening or medical examinations for other conditions. This will vary in nature from a GP detecting a heart murmur, to a baby collapsing and becoming acutely unwell as their PDA closes. The postnatal diagnosis is based on presentation and is usually confirmed following echocardiography in the first instance followed by cardiac catheter sometime later.

Many parents will receive the CHD diagnosis antenatally via 12 and 20 week scans, these are routine events during antenatal care National Health Service (NHS), (2018). The heart and greater vessels can be visualized, although a number of abnormalities may be missed. There is some variability in antenatal detection rates across the UK. In 2015 /16 the overall rate for the UK was 50.4 % with Scotland having the lowest at 43.1% and Wales the highest at 58.9% National Institute for Cardiovascular Outcomes Research (NICOR 2019).

Antenatal diagnosis can happen late on in the pregnancy, this limits the parents' options when considering the law on viability and abortion in the UK. Parents being given a suspected diagnosis of CHD may experience some delay in having this confirmed via a second scan. At the same time other investigations may have taken place and results awaited from genetic screening for syndromes associated with CHD e.g., Downs syndrome.

CHD is sometimes diagnosed immediately after birth when the baby develops signs such as cyanosis or a heart murmur is detected. All neonates born in hospital will be examined prior to discharge (Lomax 2011; Public Health England 2019). As well as clinical examination, pulse oximetry is also used to monitor oxygen saturations in order to detect potential CHD; however, it is unclear how effective oximetry is as a means of detection (Cuzzi and Bradshaw 2011; Ewer et al. 2011). Other clinical signs can be better indicators as babies with low oxygen saturations may have a range of non-cardiac conditions (Evans 2017). Some CHD will not present until a few days following the birth (Ewer et al. 2011) meaning that parents will have returned home with an apparently healthy baby before any signs and symptoms present (Cuzzi and Bradshaw 2011).

1.5.2 Signs and Symptoms of CHD

Babies born with CHD can present in a number of ways, with cyanosis that does not improve with supplementary oxygen, with a heart murmur, differences in blood pressure between the upper and lower limbs and differences in pre - ductal (right hand) and post ductal (either foot) oxygen saturations (Ruegger et al. 2010; Davies and McDougall 2019). The first signs in a baby that has not received an antenatal or a swift post-natal diagnosis could be poor feeding tolerance, lethargy, tachycardia and tachypnoea (Taylor and Eidem 2016). Once CHD is suspected a range of investigations will be undertaken including a full set of vital signs, chest X-ray, electrocardiogram and an echocardiogram. Colour Doppler ultrasound enables three-dimensional visualisations of the defect, its location, size and the degree of intracardiac shunting (Taylor and Eidem 2016). At this point a cardiologist would be able to confidently diagnose the type and severity of defect. At a later stage an invasive cardiac catheterisation procedure would be performed to confirm and add further detail to the diagnosis (Crawford 2020).

1.5.3 Treatment

Treatment will depend on the severity of the defect and the stability of the baby or child. Heart valve defects and coarctation of the aorta are examples of conditions which may become apparent as the child grows and therefore may not be detected until later in childhood. For premature babies and neonates, when CHD is detected their initial care and treatment would be managed within a Neonatal Intensive Care Unit (NICU). Neonates may be discharged home if they have less complex heart defects and are otherwise stable e.g., small VSD. Others will be kept within NICU until their surgery. For neonates discharged after birth and then readmitted, care will be managed either in a paediatric ward, high dependency unit or paediatric intensive care unit (PIC) depending on the severity of their condition.

In the UK, surgery is carried out in eleven paediatric cardiac surgical centres (Level 1). For children in Wales their surgery would be undertaken in Bristol or Alder Hey and for children in Northern Ireland they would receive surgery in Dublin. Scotland has one surgical centre in Glasgow. The organisation of services means that families may have to travel some distance for surgery although ongoing care is delivered in a range of level 2 and 3 centres across the UK. Once surgery has been undertaken, children will be cared for in a PIC and are usually placed on a ventilator to assist with breathing whilst they recover (Hazinski 2013). Once awake and stable, ventilation is removed and children will reduce their dependency on medical interventions, eventually transferring to a paediatric ward and after some time being discharged home. Some CHD children will require further surgery e.g., Hypo-plastic left heart syndrome (HLHS), while others will require regular reviews but no further planned surgery.

1.6 Service Organisation and Policy

The organisation of CHD services in the UK has been a controversial issue in recent years with various proposals to reduce the number of specialist children’s surgical centres. The controversy stems back to the Bristol public inquiry into the concerns around children undergoing complex cardiac surgery at Bristol Royal Infirmary (Kennedy 2001). The inquiry identified numerous failings in care as well as a lack of clinical governance and oversight of the services provided for children and young people requiring cardiac surgery.

In 2008, the Department of Health launched the safe and sustainable review to set out clinical standards for all CHD centres. The review was intended to improve the experience of CHD care for families and to raise standards by locating specialist care in fewer hospitals. The full recommendations of the review were controversial, and were never fully implemented, this has led to other reviews and commissioning reports over the last ten years (NHS 2011; NHS England 2016; NHS England 2017). In 2016, NHS England set out the Paediatric Congenital Heart Disease Specification, which covers both paediatric cardiac surgery and cardiology in all centres (NHS England 2016). There is a three-level approach, with Level 1 being a specialist children's surgical centre (SCSC), Level 2, a specialist children's cardiology centre (SCCC) and Level 3, a local children's cardiology centre (LCCC). All centres are expected to work towards achieving the standards set. There are multiple standards within the specification around service provision, the availability of wider medical support services at centres and the throughput of patients. In 2017, NHS England released proposals to implement standards for CHD services for children in England. These were again considered controversial, by accepting these proposals two Level 1 SCSC would close at the Royal Brompton Hospital in London and at Glenfield Hospital in Leicester. This would leave eight SCSC in England plus one SCSC in Glasgow. These latest proposals have not yet been implemented (2021) as various standards are still to be met by the SCSC that would remain.

There are three very specific standards that will need to be met by all of the remaining SCSC:

- There must be four surgeons in each SCSC by 2021 and each must operate on at least 125 children per year.
- All services that CHD patients rely on must be on the same hospital site.
- Interventional cardiologists must work in teams of four with the lead cardiologist performing a minimum of 100 procedures per year and the other cardiologists performing a minimum of 50 procedures.

NICOR (2019) reported that between 2015 -18 there were 11,412 procedures carried out in the UK SCSC. The number of procedures varied from 681 in Newcastle, 1361 in Birmingham and 1812 at Great Ormond Street hospital which houses the largest SCSC in the UK. Surgical survival at 30 days across all centres has some variation with 97.35 being the lowest and

99.4% the highest. Over the past thirty years survival rates across all SCSC have improved significantly with developments in both surgical techniques and pre and post-operative management. The majority of children who have CHD repaired today can expect to live a reasonably full life.

1.7 Organisation of the thesis

The thesis is comprised of ten chapters, this includes the introduction. In this opening chapter a brief overview of congenital heart disease (CHD) has been presented. Chapter Two explores the wider social influences on fathers' journeys to parenting. Gender, masculinity, role and identity are all discussed in providing a background to the influences that impact fathers' roles when their child is diagnosed with CHD. Chapter Three presents a review of the relevant literature. The review focuses on three main areas: family centred care, literature around fathers whose children have long term conditions and fathers whose children have CHD. Chapter Four discusses the methodological approaches to the study opening with a discussion of narrative before exploring the stages that were followed in the research process.

Chapter Five introduces the fathers, followed by chapters six to eight, which discuss the findings from the study. Chapter Six introduces the fathers, their background story around upbringing, planning for children and their role as a father. Chapter Seven explores the fathers' experiences when the expected fathering narrative is interrupted by virtue of their child's diagnosis and treatment for CHD. Chapter Eight then goes on to explore the aftermath of the diagnosis with the sense for some fathers of a restored narrative and for others an uncertain future. Chapter Nine provides a discussion of the findings in relation to the research questions and focus of the work, identifying the limitations of the study and areas for further research. Chapter Ten offers a conclusion to this thesis.

1.8 My Personal Narrative

In exploring the stories of the ten fathers within this thesis it was important to reflect on my own story, to consider my own background, upbringing and career and how this has influenced my approach to the study. One of my earliest memories was playing with a small car on the floor in the bedsit where I lived with my mother until I was four. My father had left soon after I was born, and I had intermittent contact with him in my early years but no real memory of his presence in my life. My mother ended up on her own bringing up a small child in the 1960's. As a catholic this was difficult, divorce was not an option at that time so she remained in limbo and officially could not attend church or accept communion. Her faith had always been a cornerstone in my mother’s life and happily as the years moved on and views changed, she found her place in the church again, later becoming a church housekeeper and minister of communion. I did not really notice my father’s absence whilst growing up as my mother had taken on both roles and I did not know any other life. In some ways I was fortunate, this was a time when parents did not tend to accompany children to school sports or other events, which is in sharp contrast to the way in which I have parented and is an area that a number of the fathers in the study did discuss.

I was brought up in Liverpool in a socially deprived inner-city area. At sixteen I had very few qualifications. At my last parents evening my mother attended as usual, and I can remember a teacher feeding back on my potential next steps and saying that I would probably not achieve very much. I can remember my mother being really angry and stating, ‘We’ll see!’. When I obtained my undergraduate degree, some five years later, she sought out the teacher to inform them of my achievement and to remind them that their role was to encourage pupils not put them down.

In my teenage years my mother and family had been heavily involved with the church, so I became an altar boy and consequently entered the seminary moving away from home at sixteen. This was quite a culture shock; the seminary was 100 years old and was housed in an historic Victorian building set in acres of its own grounds with numerous sports facilities, a golf course and a farm. It was privileged and remote from the people and environment that I knew. As time progressed, I knew that the priesthood was not for me. Once I left, I became a youth leader and then went on to study an undergraduate degree in social sciences; the church had provided the education that I lacked in my teenage years. Whilst undertaking the degree I volunteered in various youth projects, mainly related to sport. I then worked with the probation and education welfare services. At this time, I knew I wanted to work with people but was unsure in what capacity.

While at the seminary I had travelled to Lourdes, accompanying sick and terminally ill people from Liverpool on the annual diocesan pilgrimage. This meant that I gained an understanding of the role of the nurse and some limited experience in providing personal care. Following my degree, I commenced my Registered General Nurse training which I enjoyed immensely. At the end of the programme, I worked in various areas including adult critical care and care of the elderly. I then obtained a role in a newly established paediatric cardiac surgical unit. I cared for the first child to be operated on in the unit and the last child to undergo surgery before the surgical service closed. The experience really opened my eyes to the complexity of the surgery involved and the trauma that parents experience when a diagnosis is made.

Following this period, I continued to work in children’s critical care before moving into education where my role has continued. I am now a senior lecturer in children’s nursing and have the opportunity to pass on my enthusiasm for nursing to others. I have always appreciated the educational opportunities that I have been provided with and which have enabled me to progress in my career. I see my role as providing me with an opportunity to help my students to progress. A large part of my role is focused on undergraduate nurses and their development. It is extremely rewarding to watch someone, who thinks they are not academic, progress through their degree to qualification and beyond.

I became a father at thirty-one and now have two grown up children. Planning and expectations around children were an early focus in the first interviews of my study. Some fathers talked of not really planning ahead for their children, while others discussed a life plan which generally revolved around career development and some sense of economic security. I have a clear memory of when I knew I wanted to be a father. I remember being in a shopping area in the newly redeveloped Liverpool docks and seeing a father playing with his son whilst waiting for the child’s mother. Although I had worked with children and young people in various capacities, I had not thought about having my own children until that point. They kicked a small ball back and forth and were laughing, oblivious to those around them. I think it was the joy in both their faces that made me think about having my own children, once in the right relationship. Like a number of fathers in the study I also considered it important that my career had developed in order to be able to have a stable financial background and home. For me this stemmed from my own upbringing, growing up in an environment where money was limited, and it was sometimes difficult for my mother to provide for us. Like a large group of people in society she worked incredibly hard, with long hours for limited financial reward.

As my career has developed, I have been involved in various research studies both clinically and in higher education. This has predominantly involved me gathering data for medical research in practice or educational research in university. In both settings this has been for other researchers. In commencing this PhD, I wanted to undertake my own study in an area of interest to me as a novice researcher. In undertaking the study, I was grateful for the support of the University, Florence Nightingale Foundation and Menat Trust in providing me with a scholarship (Appendix 1).

In researching fathers, it was important to recognise my own role as a man, a husband, a father, a nurse and someone with knowledge of the care that the families had experienced. In interviewing fathers, I recognised that my own background could influence my approach and how the fathers responded to me. I did not explore this with the fathers but answered honestly when asked if I was a father and if I had children. The fathers all knew that I came from a nursing background but as interviews progressed this seemed to be forgotten with fathers taking the time to explain investigations, procedures and events in some detail to ensure that I understood their significance. In developing the research, it was important that I represented the fathers' experiences as clearly and accurately as possible, which is why I have chosen to use a narrative approach. In presenting my own narrative I have recognised the influence that my background has brought to the study.

1.9 Theoretical Perspective

In this section I offer an overview of my own theoretical perspective. I am a man, a father and a children's nurse. These are not roles or identities that can be ignored in the undertaking of research, and as my male identity is apparent, the participant information sheet identified my clinical background and as part of the general conversation with the fathers prior to the interview most asked if I had children to which I had replied honestly. In reflecting on my experiences interviewing the fathers, it was clear that I had shared a range of commonalities with most of the men. Career development, planning for children, having a need to provide for and protect the family were reflective of my own approach to fatherhood. There was a proximity here between my own and the participants' life experiences. What was different was that I had no personal experience of fathering a child with CHD or any other potentially life-threatening illness.

Role, gender, masculinity and identity have been the key theoretical perspectives which have informed the development of my work. Role theorists contend that social roles evolve into expected norms which are recognisable regardless of the social situation (Biddle 2013; Carter and Fuller 2016). Fatherhood is one such role. Fatherhood has evolved in recent years and is now more closely associated with terms such as being involved, caring and modern. By implication there appears to have been a change in societal views of what a father should be and how they contribute to the upbringing of their children (Banchefsky and park 2016). Reflecting on my own approach to fatherhood I would say that terms such as caring or being involved reflected my own approach to the parenting of my own children.

Although I accepted this perspective in terms of the current gender, role masculinity and identity theory, I was cognisant that this should not influence my approach within the interviews with fathers. I asked very few questions in the interview and those that I did ask tended to be broad in order that I limited my influence or perspective on how the fathers answered and constructed their narratives. Dwyer and Buckle (2009) discuss the potential influence of researcher membership in relation to the participants or area studied. Membership can vary with an insider sharing characteristics, roles or experiences with the participants within a study. The outsider will share few if any membership characteristics with participants within the study. Certain characteristics are difficult to avoid, such as gender. Angrosino (2005) identified that a critique of researcher roles and position developed in response to a greater awareness of situational identities and the perception of relative power. Postmodernism emphasises the importance of understanding the researcher's own context including gender, social class, and ethnicity, as part of narrative interpretation (Angrosino 2005). In response to this situation, researchers often identify their own membership in the areas that they study. The position of the researcher, including their membership status in relation to those participating in the research, is an essential and ever-present aspect of the investigation (Dwyer and Buckle 2009; Holloway and Wheeler 2013; Silverman 2014).

My own approach was to reflect on my own background and recognise that this would have some influence on my approach to the study. I accepted that I shared some characteristics with a number of fathers within the study, notably being male, a father and some aspects of social class and background. I recognised that this made me a partial insider, however, I had no experience of parenting a child with CHD, although I had observed other families in this position throughout my nursing career.

Theoretical perspectives on masculinities have developed to reflect the experience of modern fatherhood. Connell's (1987;2005) work on hegemonic masculinity informed my general understanding on the development of approaches to societal views on men as fathers. Hunter et al. (2017) also argued that hegemonic masculinity is still relevant when considering the role of fathers and how they present themselves. This is an area that Stryker and Serpe (1994) explored in terms of fatherhood being central to identity. The more a role is valued the more it will be displayed in social situations. Role and identity are, to my understanding, still key aspects of fathering behaviours (Adamsons and Pasley 2013).

Although the theory around men, masculinities and fatherhood is well developed within the social sciences literature it is less apparent within both nursing and healthcare research. Much of the nursing literature has instead been developed around the concept of family centred care. Family centred care is a fundamental principle within children's nursing and one that has guided my clinical practice and informed my teaching of students over the duration of my career. This has also evolved as a concept over a number of years and is strongly embedded in practice, but difficult to define and evaluate in terms of impact on the quality of care provided (Shields et al 2012; Al-Motlaq and Shields 2017). Importantly, fathers are not well represented in the literature on family centred care (Hayes and Savage 2008; Massoudi 2010). There is an understanding of parental role as being present, caring and involved but does not reflect fathers' experiences.

In considering fatherhood, masculinity and roles, it is apparent that although the theory in this area has evolved to represent aspects of involved or caring masculinities, the theory around family centred care is not reflective of this position; a situation which is highlighted within my study. These are two different and, I would argue, distinct developments in terms of theory. Family centred care has developed to improve families' experiences in a practice environment whereas the theory around gender, masculinities and fatherhood explains men's positions and roles within the wider societal context have been largely ignored. My own view is that family centred care does not fully, or even partially, recognise the needs of fathers or encompass the changing role and involvement of men in the care of their children. There is, in practice, an unrecognised form of discrimination with care provision more focussed on meeting mothers' needs, particularly in the provision of acute hospital care services that I will explore.

Within the study I will explore the experiences of fathers whose children were born with CHD. The study is informed by the nature of fatherhood, masculinities, role and gender alongside clinical practices and theory relating to family centred care in healthcare environments.
Part of the focus of my study is to explore whether fathers have any different or unrecognised needs which need to be accommodated within care practices and healthcare environments. Different needs may be identified from fathers' perceptions of their own role within the family, and wider societal contexts, and the change that occurs by virtue of their child's diagnosis of CHD.

CHAPTER TWO – Key Theoretical Concepts

2.1 Introduction

This chapter sets the scene for the study in presenting wider sociological approaches to understanding social role, identity, gender, masculinity and fatherhood. This is important as the men, who are the focus of this study, do not exist in isolation and should be viewed in terms of their own backgrounds and the influences that have shaped the transition into their fathering role. The exploration of these sociological approaches provides knowledge and understanding to inform the reader and position the study in relation to sociological, political and contemporary discourses that have been established within the literature. Exploring the sociological discourse provides a useful understanding of the role of fathers before exploring links with family centred care and everyday aspects of the father's journey within the literature review chapter.

2.2 Role theory and identity

Role theory describes individual and social behaviour in relation to the various social roles that a person displays. Biddle (1986; 2013) identified that social roles incorporate expectations that people are expected to conform to in demonstrating the behaviour related to their social identity. These expectations are developed through everyday interactions and socially accepted norms. Role theory is associated with symbolic interactionism, a perspective that maintains that social interaction is developed from person to person, recurring, significant interactions between people (Carter and Fuller 2016). Through this social interaction social roles evolve and are constructed into forms which are recognised as norms (Biddle 1986). Sheldon Stryker (1980) defined roles as sets of expectations linked to social positions or symbolic categories which inform expected behaviours. Two relevant aspects of role theory are role ambiguity and role conflict (Biddle 1986). Both concepts have relevance within my study as fathers appeared to experience each at various points in their narratives. Role ambiguity is a state where expectations around a specific role are lacking or inadequate to guide behaviour this leads to some unpredictability in the individual's behaviour. This is often evident at the point of diagnosis with fathers unprepared for the potential of fathering an unwell child and having had a diagnosis being unsure how to behave (Friedman et al. 2015). Role conflict occurs when the demands with one role hinder an individual's ability to fulfil the demands of another role or part of that role. McNeill (2007) found that this was evident in fathers addressing competing demands during their child's illness specifically around inpatient episodes. Some fathers talked of 'stepping up' to the perceived norms of the fathering role, in being strong and protective but at the same time being unsure on how to perform this role.

This was particularly challenging for fathers whose children had a long-term illness such as juvenile rheumatoid arthritis where there are repeated periods of hospitalisation and ongoing treatment (McNeill 2007).

Identity theory suggests that behaviours are socially constructed and revolve around individual status, societal expectations and the feedback or role reinforcement that we receive (Adamsons and Pasley 2013). Park and Banchefsky (2019), discuss the core of an individual's identity being their sense of self. This reflects work by Baumeister (1998) who referred to a 'reflexive consciousness' which asks questions of who the individual is, what is their place in the world and how does the individual value him or herself. Identity in this instance is shaped by individual self-concept but also the social groups that people belong to.

Stryker and Serpe (1994) described identity as being closely linked to gender and perceived societal roles. Two of the most important roles are seen as our occupation and our family life. Family researchers have used identity theory to explore individual parental behaviour, this has also been applied to fathers specifically (Dyer 2005; DeGarmo 2010). Park and Banchefsky (2019) identified that fathers' and mothers' roles are seen very differently. There is a closer category link between mothers and women than there is between fathers and men. In terms of gender identity expectations, women experience much greater role conflict than men when stepping outside of familial roles to pursue careers for instance. Following cultural scripts and expected norms, mothers put children first before careers and professional development. It is accepted that in contrast, a father will pursue career goals in order to be a good provider for his family (Parker and Stepler 2017). Identity guides behaviours and theorists such as Stryker (1968; 1980) propose that when an individual takes on a social role such as that of being a father, they will adopt the expected attributes of that role such as providing for and protecting the family and will forge an identity to fulfil that role. Stryker and Serpe (1994) discussed three concepts, salience, centrality and commitment in relation to roles. In essence the more important or central the role, the more likely it is that it will be performed across various social situations. Salience establishes that in any given situation the individual will enact a particular identity. The centrality of that role reflects the importance of the identity associated with it. Adamsons and Pasley (2013) use the example of fatherhood, if this is deemed an important identity, expected fathering behaviours and traits will be enacted across social situations regardless of the context of that situation or with whom the individual interacts. Stryker and Serpe (1994) identified that commitment was an important concept within the fathering identity with two components: extensiveness and intensiveness. Commitment extensiveness relates to the number of relationships that would support an identity and commitment intensiveness relates to the importance of those relationships to the individual. The more family and friends that a father has who support his fathering identity, the higher his commitment to that role becomes and the more likely he will be to enact fathering behaviours (Adamsons and Pasley 2013).

Updegraff et al. (2001) found that fathers' identity does evolve over time and gave the example that fathers adopt fewer care giving approaches with young people than they did when their children were younger. Adamsons and Pasley (2013) noted that childhood illness provoked a strong reaction in fathers which was likely to lead to changes in perception of role. The role of fathers being impacted when their child is ill has been identified in several studies (Peck and Lillibridge 2005; Bennett at al. 2008; Pelenstov et al. 2016). A number of fathers within these studies described traditional and gendered views around coping with their child's diagnosis and illness journey. Fathers' approaches included attempting to maintain some degree of control over the situation that they found themselves in, having more direct communication with healthcare professionals and identifying themselves as being more involved in delivering care to their children through different stages of their illness and treatment.

2.3 Theoretical perspectives on gender

Role theory identifies that an individual's social identity is developed and informed through a range of social roles, one such role is gender. The theoretical literature on gender is an evolving body of work. From an evolutionary process men and women are considered to be on separate ends of a continuum (Booth et al. 2000). Men are at the rational, aggressive and competitive end whilst women are at the more emotional, passive and relational end (McNeill 2007). Within this continuum distinct identities and behaviours are established, leading to men and women fulfilling distinct gender roles. West and Zimmerman (1987) explored the everyday interactional process of 'doing gender,' a term which first appeared in Garfinkel's (1967) work. The process of 'doing gender' is organised by societal expectations of masculinity and femininity. Gender is defined as a performance of everyday activities which demonstrate and express feminine and masculine traits (West and Zimmerman 1987).

Eagly (1987) examined social role theory identifying that the role behaviour of group members shapes group stereotypes. There are two primary ways in which gender has been characterised. Eagly and Wood (1999) identify that biological determinism takes an evolutionary view that men and women have distinct biological roles which have evolved over thousands of years into sex specific characteristics and traits. Booth et al. (2000) view this position as overly simplistic and advocate a move away from simplistic models to the more dynamic position where a variety of influences impact on gender including the biological but also environmental and behavioural factors. Essentialist notions of gender have been critiqued as having a perspective with a focus on the reductive. Men and women are in two distinct groups rather than exploring group and role differences (McNeill 2007). Focusing on reductive generalisations, on what is masculine and feminine, removes the influence of social class, race, environment, education, age and socioeconomic background. These are all socialising influences, which will aid in the development of future parenting roles. The social role of parents has changed over time with traits, which have been identified as male and female, becoming more blurred. As roles deviate from the accepted norm the ascribed traits become less identifiable to gender.

Gender is also apparent in key social structures within society and is marked by power struggles and inequalities e.g., the suffragette campaign, equal pay (Equality Act 2010). Gender hierarchies are maintained by belief systems and attributed meanings, which are generated by representations (Milestone and Meyer 2012). These representations have a symbolic dimension and include aspects of life such as language, image and accepted social practices.

Second wave Feminism emerged in the 1960's and identified gender inequality across a range of settings including education, the workplace and within wider societal opportunities. This oppression was due to the patriarchal society. Walby (1990) defined patriarchy as rule of the father or men. In advanced capitalist societies patriarchy exerts indirect control although there is an appearance of both equality and equal access. Key structures including household production, work, the state apparatus, social and cultural institutions and heterosexuality all serve to maintain the patriarchal status quo (Milestone and Meyer 2012). There were various strands to feminism including radical and liberal. All strands viewed gender inequality as being responsible for disparity and oppression. Postfeminism is based on views that equality has largely been achieved in developed societies. However, this approach had compelled women to pursue careers and lifestyles which many did not want in the pursuit of equality (Milestone and Meyer 2021). Early feminists devised the concept of gender in order to emphasise that maleness and femaleness are not just biology, they are a social construct (Faludi 1991). The social construction of gender is apparent in both categories, male and female, alongside social attributes and accepted behaviours which portray conventional images e.g., men are strong, decisive and protective while women are caring, nurturing and in need of protection.

Social constructionism views phenomena, objects, events; identities as societal rather than nature. Interactions between individuals and institutions shape the world we experience, and the meaning derived from them. Masculinity and femininity are the outcomes of social processes e.g., employment. Simone De Beauvoir (1972) stated that gender is what we do, men and women are not born but it is what we become. This reflected both Goffman (1959) and Butler (1990) who examine both performance, in the case of Goffman, and performativity in Butler's work. For both, gender is a construct that is not static. Gender portrayal follows sequenced practices in which characteristics that are deemed to be masculine or feminine are repeated, developed and solidified (Butler 1990).

Goffman (1959) viewed masculine and feminine gender roles, those that men and women perform as actors, constantly engaging in actions which reinforce these stereotypes. There are typical behaviours that are portrayed such as being caring for women and assertive for men. For Goffman (1959) gender is a display, a conventional presentation of culturally ideal male and female roles. For symbolic interactionists such as Goffman, gender roles become most evident when they are broken. Milestone and Meyer (2012) provide examples of broken roles relating to labelling. Lesbian women who present themselves with short hair and 'butch appearance' are denied femininity. Conversely roles can be learnt. Men who are transitioning to women learn the 'rules' of how to present as a woman; how to sit, dress and interact. This is particularly evident in the preoperative phase of transitioning (Milestone and Meyer 2012).

Goffman (1959) has been criticised for viewing gender as a performed role, which implies that aspects of that performance are optional, and can be undertaken when we choose to. West and Zimmerman (1987) argue that Goffman underestimates the social structure requirement to adhere to gender roles. 'Doing Gender' is a continuing everyday activity which is embedded into social roles, and which require little thought. Some of these criticisms have been addressed by Butler (1988; 1990; 2004) in her theory of performativity. Performativity she argues is a performative construct rather than a performance as in Goffman's work. Individuals present gender through a series of practices or performances. As a post structuralist, Butler (1990) did not see a performer or actor behind the performance. Performance pre-exists the performer with society and cultures determining which acts, characteristics and traits identify the masculine and feminine. Actions are not conscious decisions to play a part but are habit, re-enactments that create gender. Gender identity becomes the effect of performativity rather than the cause.

Butler (1990; 2004) identifies significant differences between masculinity and femininity in modern cultures. This is not due to essential differences which cause men and women to behave differently, rather the structural categories of gender produced scripts from which the feminine and masculine can be re-enacted. Performativity is not noticed within society; it has become so embedded that it becomes natural and invisible due to repetition and routine. Butler

(1990) uses the example of the drag artist to demonstrate that gender is a performative construct not linked to sex. Drag is seen as subversive; the artist exaggerates the feminine in order to fulfil their role. Men can perform the feminine as women can perform the masculine. For Butler there is a distinction between sex and gender and the relationship between the two. Sex is a biological construct while gender is a social construct; they are not related and are radically independent. Milestone and Meyer (2012) use the example of the middle-distance athlete Caster Semenya to illustrate these differences. At the 2008 Beijing Olympics, there was mass media coverage of Semenya's sporting prowess. She was and still is criticised within the media and sporting circles as being not entirely a woman due to her visual markers, sporting achievements and being born intersex. Her sexuality and gender and those of other athletes are regularly commented on by both sporting bodies and other female athletes. Butler (1990) categorises both sex and gender as powerful but unstable conditions, which is why they are continuously reaffirmed through performative actions. Butler (1988) argues that gender is observed as an imitation of an ideal and through performance the idea of gender is replicated and accepted. Gender has an impact on parenting roles in that mothers and fathers are perceived to engage with children differently and to carry differing roles and responsibilities (Palkovitz et al. 2014). Fathers are often perceived to be less involved in direct caring roles and more involved in wider activities such as play (Hofner et al. 2011). In part the difference in role is associated with masculinity and the perceived role of the father.

2.4 Masculinity

Fatherhood is wrapped up in the concept of masculinity. However, there have been changes in the composition of households, media representations of men, the workplace and the responsibilities, meanings and functions of fathers (Pleck and Masciadrelli 2004). Between 1965 and 2003, Bianchi et al. (2006) found that American men had doubled the time they attributed to both housework and childcare. This corresponds to a doubling of stay at home fathers in the US in most decades since the census in the US started collecting this data (Smith 2009; Craig et al. 2014).

The limited research into fathers' roles, despite changes in their contribution to childcare and household tasks, demonstrates that they still contribute less than mothers (Schoppe - Sullivan et al. 2013). As fathers take on more traditionally female roles, women are moving to become less feminine (Diekman et al. 2005). Possible resistance to change from specific social structures which value strong masculine embedded traits is evident (Bosson et al. 2006, Moss-Racusin, 2014). This is despite evidence that this has an impact on men's health and their close relationships. This limits the development of gender equality.

Ricciardelli et al. (2010) conducted a content analysis of eight different men's lifestyle magazines on general sale in Canada between 2004 and 2006. This examined the way in which masculinity and gender identity was being portrayed within the mainstream media. Conclusions drawn from the study were that although there are different portrayals of masculinity the hegemonic depiction was consistent across all publications reviewed. Benwell (2004) and Attwood (2005) had previously recognized these views in UK based research.

2.5 Hegemonic masculinity

Gramsci developed the theory of hegemony whilst incarcerated in an Italian prison due to his opposition to the then fascist Italian state (Bates 1975). Hegemony refers to a form of power characterised by leadership and the manufacturing of consent rather than the imposition of control. (Bates 1975; Connell 1987). In Gramsci's theory the ruling class challenges subordinate groups to develop an alliance for power. This is an ideological approach to achieve hegemony by convincing subordinate groups to agree. Hegemony in the Marxist view holds a fragile dominance over capitalist societies where people will knowingly compromise and consent for their own benefit.

Connell further developed the concept of hegemonic masculinity (1987; 2005). The view of men as providers and breadwinners is aligned with the fathering identity which values an established form of masculinity (Petroski and Edley 2006; Hanlon 2012). As there is a societal expectation of the father as being the main provider, this position can be viewed as hegemonic. (Hunter et al. 2017). Seidler (2006; 2013) relates this position to the Western traditional protestant view of men, as head of the household holding authority over the family. Within this position men must maintain a sense of detachment and exercise self-control particularly on an emotional level. This view of a detached, objective, male family figure head is apparent in various 'Abrahamic' traditions including Christianity, Judaism and Islam (Seidler 2006). Hegemonic masculinity encompasses the culturally normative and influential ideals of masculinity. The ideals are enshrined within a structure of social relations where some men are subordinated (Ricciardelli et al. 2010). Masculine hegemony is viewed as a role, status set, a perspective, and a set of behaviours or personal characteristics which Connell (1987) suggested was positioned at the top of the hierarchy of masculinities. Men might not embody all aspects of this at once although they may possess individual elements. Ricciardelli et al. (2010) recognised differences between certain roles e.g., professional athletes possess physical strength and stamina whilst the chief executive of a multi-national company possesses authority and prestige. In this way hegemonic masculinity is represented through discourses of appearance e.g., strength and size, work ethic and emotional strength, sexuality in terms of heterosexual and homosexual behaviours, violent or assertive, occupation in valuing career over housework and family. This has often led to the subordination of women and children (Pringle 2005).

Discourses and norms shift over time, when hegemonic masculinity is challenged it adapts and changes form becoming more powerful, it has the ability to adapt and resist change (Connell 2005). This is often seen as an ideal, it may not be realisable for most men although it is a benchmark with which relative success or failure is measured. Hegemonic masculinity, as well as subordinating women and children, subordinates other forms of masculinity. More perceived feminine traits are not valued, neither is being gay or effeminate. There is some debate around what hegemonic masculinity is and its wider role in society (Wetherell and Edley 1999; Speer 2001; Connell and Messerschmidt 2005). What is established within the debate is that not all representations of masculinities carry equal status. Connell (2003) defined the concept of hegemonic masculinity as being the most sought form of masculinity which determines the expectation of what it means to be a man. This form of masculinity dominates and subordinates other forms of masculine presentation and how womanhood is expressed (Connell 1987). Connell (2000) suggested that even if men do not attain the societal ideal of hegemonic masculinity, they recognise its existence and maintain it, as they are advantaged from the subordination of men who are outside of the ideal and women. Connell and Messerschmidt (2005) suggest that few men attain the masculine hegemonic architype, but all men are measured against it.

Hegemonic masculinity informs all facets of men's lives but has a relevance for fatherhood as it provides a societal understanding of the father's role and how good fathers present themselves (Hunter et al. 2017). Brandth and Kvande (1998) suggest that hegemonic masculinity presents the view that fathers construct their identities through work and income which confers a position of power on such men within the nuclear family with its traditional acceptance of fathers being associated with power, importance and authority. Individual men will take on some elements of the expected role but not all. However, there is a consensus across the literature that the ideal of the provider and protector father remains one of the core definitions of fatherhood (Miller 2011; Coper and Sparrow 2015; Medved 2016). Hanlon (2012) identified that the financial provider role can be understood as a form of caregiving as it is seen as a way of demonstrating care provision for the family. Gatrell et al. (2015) argue that it is incorrect to assume that the hegemonic view of fatherhood does not value caregiving or involvement in bringing up children rather it makes income a greater priority than other forms of provision for children.

Althusser (1971) further developed Marxist theory and identified the way in which ideologies become prevalent in societies. A key hypothesis of Althusser is interpellation or hailing. Through interpellation individuals are turned in to subjects which are always ideological. The example he uses is that of the police officer shouting ‘Hey you!' and the individual turning to answer the hail. Althusser states that once interpellated, the individual becomes a subject. This happens before we are born, most babies take their father’s surname and therefore have an immediate identity that is irreplaceable. The child once born becomes a subject in the specific familial ideological configuration, in the way that society expects from conception. Butler (1990) identifies interpellation in association with the social construction of gender identity. At birth, by identifying that the baby is a boy or a girl the baby is positioned as a subject. Althusser describes two forms of intervention to maintain the status quo. Repressive state apparatuses (RSA) such as the police and Ideological state apparatuses (ISA) such as the family. The repressive is designed to punish anyone who rejects the dominant ideology. Hegemony is less reliant on RSA than it is on ISA, as ideology is embedded in the individual subject. For Althusser the individual is interpellated as a free subject in order to accept their oppression.

Althusser (1971) develops Marx's concept of the relationship between base and superstructure by adding his concept of ISA. Marx distinguished various "levels" in a society, the infrastructure or economic base and the superstructure that includes institutions such as the law and government. Althusser identifies a range of ISA including the family, which serve to maintain the state ideology. ISA function by ideology and acceptance but can sometimes punish or repress those who deviate. He provides examples of punishment including school expulsion, and churches disciplining their congregations. Wider ISA would include the media and censorship. Although quite wide, ISA serve to protect the predominant ideology of the ruling class. This can be seen in terms of gender and masculinity norms and traits. ISA maintain the stability of the ruling class and ensure a degree of control over populations.

In recent years there has been a developing interest in what is deemed to be a new form of masculinity. This has developed as a result of the change in fathering roles, fathers are more engaged in childrearing and as primary caregivers (Hunter et al. 2017). This new form has been characterised as a new, involved or caring masculinity in contrast to past projections of the masculine (Hunter et al. 2017). Latshaw and Hale (2015) found that gender roles were becoming more blurred with women increasingly involved in developing their careers and men undertaking more housework and childcare. However, women in heterosexual relationships continue to take the greater share of these responsibilities. In Western societies there has been a shift in the expectations of the male role. Elliott (2015) suggests that this is a move towards a caring masculinity rather than the hegemonic as proposed by Connell (1987).

Primary caregiving fathers do not fit into the concept of hegemonic masculinity despite some aspects remaining apparent such as that of financial provider. The concept of caring masculinity proposes that men adopt various traditionally identified feminine traits e.g., care, sensitivity and emotional expression (Miller 2011). Such men are viewed as both new and modern, this is reflected in the literature with fathers now expected to be more caring and engaged with the family (Henwood and Proctor 2003; Stevens 2015). Fathers demonstrating a caring masculinity have not necessarily rejected traditional masculine characteristics but now have the opportunity to express a more nurturing approach with some expectation of involvement in caregiving (Wall and Arnold 2007; Habib 2012; Latshaw and Hale 2015).

2.6 Fatherhood

Traditional fatherhood is rooted in social, cultural and historic constraints of hegemonic masculinities with a male breadwinner and protector. Fatherhood is an evolving and changing socially constructed role. Social role theorists suggest that stereotypes of fathers are shifting and dynamic, there is a move from traditionally paternal roles such as providing the household income to more maternal roles e.g., childcare (Banchefsky and Park 2016). Various authors have identified the value of an approach to fathering that is attentive, engaged and involved rather than one which is remote and detached (Henwood and Proctor 2003; Stevens 2015).

Banchefsky and Park (2016) undertook a study which examined the role of the typical mother and father at three points in time, 1950, the present day and in 2050. They recruited 425 psychology students: 203 women, 211 men and 11 unidentified from a range of cultural and ethnic backgrounds including white American, Latino and Native American. The research presented two hypotheses. The first that mothers and fathers would be increasingly similar in roles and traits over time. The second that in reflecting social role theory, perceived changes in roles should mediate perceived changes in traits.

The participants wrote sentences concerning primary parenting roles related to the identified years. In identifying gender specific roles Banchefsky and Park (2016) suggested maternal roles such as babysitter and comforter for mothers and roles such as provider and household repair and maintenance for fathers. Key traits were also identified, kindness and understanding for mothers whilst fathers were considered as stern and authoritarian. The identified traits were taken from an earlier study by Williams and Best (1977). The findings noted that the participants viewed gender roles as similar between 1950 and the present, however traits were evolving as fathers discarded some paternal traits to acquire maternal ones such as childcare whilst mothers had adopted paternal traits such as bringing in an income. Parental stereotypes which were prevalent in the 1950's still persist.

New fathers are ideally seen as being more nurturing, developing closer emotional relationships, sharing joys and caregiving with mothers (Wall and Arnold 2007). Hearn and Pringle (2006) identified new possibilities in modern fatherhood with intentions and practices being different to preceding generations. Anticipating and then experiencing early fatherhood is set against changes in society. The change in the way fathers are expected to behave has been influenced by the move of mothers into the world of work throughout the 1980's (Ranson 2001) and a change in role as a result of the introduction of government initiatives such as paid paternity leave. Williams (2008) and Featherstone (2009) highlight the fact that involvement in fatherhood may be due to structural circumstances and changes in society's expectations rather than an explicit choice. Fathers are now seen more as co-parents (Craig 2006), rather than interested spectators. Thebaud (2010) discussed the need for new questions to be asked on gender, equality and family lives due to the slow process of change in the organisation of paid work. Domestic tasks and caring for children are now very much seen as part of the modern fatherhood role. Gender expectations and behaviour have evolved with the contemporary western portrayal of fathers, there is greater emphasis on emotional closeness in relationships with children, the sharing of joys and the work of caregiving (Wall and Arnold 2007).

Modern fatherhood involves a transition to a state where the masculine role changes to take on some aspects of what would traditionally have been considered as female responsibilities. Miller (2011) explored the transition and practices of gender through first time fatherhood. This was a qualitative longitudinal study which collected data around antenatal intentions and postnatal practices. The study replicated earlier research around motherhood (Miller 2005 2007). The fathers within the study were men taking normative positions within the male parenting role. The participants were in employment, middle to upper class, white, heterosexual and became fathers at a culturally appropriate stage of life. Their ages ranged between 24 and 39 with a mean age of 33.7 years. It would have been interesting to have had a contrasting group of men to assess how views differ across social, ethnic and cultural boundaries. The pregnancies were planned, and the men were eligible for paid paternity leave, therefore the circumstances around the pregnancy and subsequent birth would facilitate involvement in their child's care and disrupt traditional behaviours and perceived roles.

Miller (2011) interviewed 17 men on four occasions with interview schedules from 2005 to 2009. Semi-structured interviews were used to collect the data. Six key themes came out of the study, these were: exploring expectations, birth, fathering experiences, perceptions of self-caring, work intentions and practices. The antenatal interviews explored men's expectations of fatherhood and their changing role. They used language associated with motherhood referring to instincts, bonding and the primary care role (Miller 2011). One father discussed instincts 'kicking in', in comparison with mothers who it was deemed would instinctively know how to care. On the whole, involvement with their child's care would revolve around job commitments with their wives positioned by them as being the mother and therefore having primary caring responsibilities. One father expected to be both primary carer and breadwinner however this is unusual. Fathers generally talked of hands on caring and being supportive, this was expressed as 'doing my bit' (Miller 2011). In earlier studies examining motherhood it was deemed unthinkable to articulate partial episodic involvement and care (Miller 2007). This was due to role and gender-based expectations of mothers which involved primary caring responsibilities and sacrificing career aspirations for motherhood.

Several authors examine the concept of the 'good father' (Wall and Arnold 2007; Dermott 2008). In this literature there seems to be a balance between masculinity and the caring role, this is in contrast to the absent or non-caring, non-providing father. There is a prevailing view that fathers should be active, caring and involved. Good fathering starts early in the pregnancy with participation in all aspects of preparation e.g., attendance at scans (Gillies 2009). Draper (2002) identified good fathers as those who had been involved in preparation for the birth through parental and birth classes. None of the fathers within the study saw themselves as being solely responsible for caring for their child. This would be an interesting area to explore further as Doucet (2006) identified that men can feel marginalised when in a full time caring and fatherhood role.

There is also general social acceptance of 'fitting fatherhood in'. There appears to be more involvement following the birth, however portrayals of the modern father and their participation in care give way to longer-term practices of 'patriarchal habits' where normative behaviours re-emerge as the path of least resistance (Wall and Arnold 2007). Miller (2011) found that some fathers moved very quickly from intense shared involvement back to paid work. In early postnatal interviews (6-12 weeks) there was a rationalisation of involvement due to the need to return to work and have the financial input to support the family. The undoing of gender stereotypes following birth, when men were heavily involved in caring practices, quickly gave way to normative practices and the transference of full responsibility to the mother. Maternity leave was seen as the new world of work. Miller (2011) found that fathers anticipated what fatherhood would be like and held the view that their fathering practices would be different from their own fathers. There was a clear view of how a good father would parent, and this involved a sense of equality in both sharing roles and caring. Nine fathers were then interviewed around their child's second birthday. At this point it was highlighted that there was a return to normal life for most men, they had more input into their child's care than their fathers did but there was a falling back into gender stereotypes.

2.7 Summary

This chapter has explored the wider sociological literature around social role, identity, gender, masculinity and fatherhood. Descriptions of the fathering role and the influence of societal expectations around gender and how that gender is performed influences a range of interactions, including those in healthcare contexts. Fatherhood has evolved and developed into more involved practices such as direct childcare (Henwood and Proctor 2003; Featherstone 2009; Miller 2011). However, the male fathering role is still measured against the hegemonic ideal of a detached, head of the family who protects and provides for the family (Seidler 2006). Aspects of the fathering role, as provider and protector can be seen in most of the fathers within my study in planning for children and across their CHD journey with their children.

Although not explicit within the literature around family centred care, which will be explored in the next chapter, there are assumptions being made around fathers' involvement in care which relates to the theory discussed earlier. A small number of studies identify how fathers need to protect their family and keep some elements of control over their child's treatment and clinical care. They further described clinical situations where they felt there was some degree of exclusion and a feeling of not being wanted within the clinical area or being treated differently during consultations. It may be that within family centred care, embedded gender stereotypes of the role of men as fathers persist based on dated views and expectations of societal norms which have moved on. I would suggest that there needs to be a reframing of family centred care and wider approaches to supporting families in order to identify and meet the needs of fathers and more diverse families that sit outside the accepted stereotypes.

The theoretical perspectives around masculinity, fatherhood and gender could apply to all of the fathers within my study, as does the concept of family centred care as an underpinning theory of healthcare practice within child health services. However, these theories have developed from different perspectives and disciplines, and I would argue that family centred care has not been informed by the evolution of wider theoretical positions, rather it is rooted in a time when fathers were largely seen as provider and head of the household which is described by Seidler (2013) as being common in the Abrahamic tradition. Understanding the theoretical background has been informative in considering the experience of men in my study in a real-life context when they are in a vulnerable position, outside of the expected norm of parenting a well child. It can be argued that a father's masculinity can be impacted by their child's illness and the need to engage in caring activities across the illness trajectory.

In formulating the research questions for this study, I wanted to know how fathers experienced care across a range of settings from diagnosis to at least one inpatient treatment episode. These were likely to be emotive experiences for the fathers and ones in which role salience, centrality and commitment as described by Stryker and Serpe (1994) were evident. In developing the research questions, I wanted to examine how fathers perceived an alteration in their role due to their child's diagnosis and how those perceptions were influenced by their view of themselves within the family and wider societal context.

These theoretical perspectives have helped in my own recognition of the limitations of family centred care which I had not considered fully in my previous clinical experience, teaching or indeed my own assumptions of what this model of care actually is. I recognise my own use of language in describing family centred care with a default position of regularly discussing the needs and presence of mothers rather than parents equally. Following this newly acquired knowledge I can see that there is a need to integrate the theory around gender, masculinities and fatherhood more into family centred care and healthcare practice in order to recognise and meet fathers' needs.

CHAPTER THREE - Literature Review

3.1 Introduction

The aim of this chapter is to explore the specific context of the current study in relation to the existing literature around fathers' experiences when their child is born with congenital heart disease (CHD). Family-centred care (FCC) is a central concept that is pervasive within children's nursing and within the literature more broadly and as such it is explored in some depth within this chapter. Family centred care is promoted by children and young people's nurses as being the foundation of high-quality holistic care (Higham and Davies 2012). FCC is a multi-faceted concept that has evolved over time to become integral to modern healthcare practice and is a central tenet of children and young people's (CYP) nursing, Smith et al. (2010). Existing literature on fathers' experiences can be divided into three main categories:

1. Literature exploring family centred care in children's nursing
2. Literature exploring fathers' experience of their child's long-term condition
3. Literature exploring fathers' experiences when their child is born with CHD.

The chapter begins with a brief discussion of the search strategy (See appendix 2 for a breakdown of the main studies used within the discussion). A number of pertinent areas are discussed within the review. Firstly, the chapter explores the concept of family-centred care. The discussion critically examines FCC and its development and integration into nursing practice from the 1950's and the seminal Platt report (1959). FCC will be defined and policy drivers for the implementation of FCC in modern nursing practice will be discussed. The chapter then moves on to examine the relationship between fatherhood and FCC within healthcare practice. As the chapter develops, fatherhood is discussed in relation to caring for a child who is ill, drawing on wider studies and finally there is an exploration of the literature relating to fathers and congenital heart disease.

3.2 Search strategy

A broad search strategy was developed intentionally, as from previous knowledge and experience I knew that there was unlikely to be a wealth of research focusing specifically on fathers' experiences when their child is born with congenital heart disease. There is an abundance of research and broader professional literature exploring family centred care which is a well-embedded concept and approach within children and young people's nursing. Where this literature is limited, however, is in the evaluation of FCC and its outcomes in clinical practice and exploration of fathers' needs specifically.

For the initial search a number of electronic databases were accessed including Cumulative Index to Nursing and Allied Health Literature (CINAHL), British Nursing Index (BNI), SCOPUS, PubMed and Applied Social Sciences Index and Abstracts (ASSIA). Hewitt-Taylor (2017) identifies that the first stage in any robust search strategy is the identification of key terms. A range of keywords were used singularly and in combination including 'parents, 'fathers', 'congenital heart disease' 'congenital heart defect', 'paediatric', 'pediatric', and 'family centred care'. Boolean operators 'and', 'or' were also utilised as were American spellings including pediatric. Initially the search was focused on UK literature as a starting point, but this was then expanded to cover international studies, where the research was undertaken within high-income health care systems which follow a similar approach to the treatment and management of children born with CHD. Only papers written in the English language were retrieved; a number of these were published outside of the UK.

The initial search was undertaken in 2014 and accessed literature from the last five years, due to limited literature the search was expanded to capture a wider range of sources and to explore the literature which maps the development of family centred care as a concept. The literature review has been revisited at various points in the development of this work. I had set up ongoing database alerts in 2016 in order to be able to easily access new and relevant literature as the study and thesis developed. Between April 2019 and September 2021 there were a number of alerts but very few with relevance to my study. Two studies, Jaschinski et al. (2022) and Franklin et al. (2021) were new, both with a focus on the mental health and psychosocial impact of parenting children with CHD. As with previous studies with parents, fathers were less well represented. The study by Jacschinski et al. (2022) did not add any new perspectives, whereas the study by Franklin et al. (2021) did add further understanding of the need for parental support from healthcare professionals and therefore has been added to this literature review.

Initially 756 articles were retrieved. There were a variety of articles including original research using a range of qualitative and quantitative methods alongside professional development articles and reports. A number of articles mentioned 'parents' in the abstract, however on closer reading a large number discussed mothers specifically or had very few fathers included in the sample. These were then filtered for relevance in order to focus on research involving fathers specifically or those which had a reasonable mixed sample of both mothers and fathers. This resulted in 26 articles being considered for use in this literature review.

Two original studies were found which focussed solely on fathers' experiences and CHD, Bright et al. (2013) and Bruce et al. (2016). A further four studies did include a number of fathers within their sample (Doherty et al. 2009; Franck et al. 2010; Rempel et al. 2012; Kosta et al. 2015). The findings from these studies were informative in the discussion around fathers' experiences. Finally, the new study by Franklin et al. (2021) was added to the review, although it examines parents' perspectives of raising a child with CHD and their mental health needs there is a reasonable representation of fathers within the study.

To review the literature, I used the critical appraisal checklist (See appendix 3), which is a recognised approach from the Joanna Briggs Institute (JBI) (https://joannabriggs.org/critical-appraisal-tools 2017). JBI is an international collaboration, which focuses on the development, synthesis and utilisation of evidence in healthcare including nursing. JBI has developed a range of these checklists which can be used with literature of varying quality. I selected the critical appraisal checklist as it allows for a range of healthcare papers to be critically evaluated but is also appropriate in appraising literature from wider disciplines. The checklist has three main foci:

- Congruity between the stated philosophical perspective and the research methodology
- Influence of the researcher in terms of their belief, values and impact on the research and participants
- Representation of the participant voices and presentation of this in the findings

3.3 Family-Centred Care (FCC)

Various authors have highlighted the widespread commitment to the concept of FCC in children's nursing in both the acute and community settings (Kuo et al. 2012; Carter et al. 2014; Coyne 2015). Carter (2008) highlights that FCC in various forms is widely promoted across CYP areas but there is some question of how it is embedded in practice. Various social drivers have impacted upon the roles that families play in CYP healthcare delivery. Advances in health promotion, illness prevention via immunisation, treatments for long term conditions and technology dependent CYP with chronic conditions have shaped where and how CYP are cared for (Lowes 2007; Carter et al. 2014). Formerly fatal diseases, such as congenital heart defects and childhood cancers, are now treatable with many CYP expecting to have full lives or at the very least survive into adulthood (Stang and Joshi 2006).

FCC is, however, a socially constructed concept, which has moved from mere parental presence in health care environments to direct participation and involvement in care. Richman and Skidmore (2000) recognise the evolving theoretical underpinnings of FCC in response to nurses and parents understanding of the concept. They further note that the social construction of the FCC concept is part of a social world with multiple realities depending on the individual's experiences. Where FCC is fully integrated into practice, families may experience partnership and collaborative working leading to empowerment in order to ensure holistic care is provided across care settings (Smith and Coleman 2010). However, there is inconsistency in interpretation and operationalisation across CYP clinical areas.

There are various definitions of FCC, a succinct definition is provided by Shields et al. (2006, p.1318) who describe it as:

> A way of caring for children and families within health services which ensures that care is planned around the whole family, not just the individual child/ person and in which all family members are recognised as care recipients.

Shields et al. (2006) echo the focus of the children and young people's National Service Framework (NSF) (2004) in ensuring that care is planned and delivered around the needs of the whole family. However, they also note that there is some difficulty in implementing FCC in practice, with nurses and families having differing understanding of what the term actually means. Al-Motlaq and Shields (2017) highlight the challenges of finding an agreed definition of FCC when there has been an ongoing debate amongst researchers and practitioners on its meaning, implementation in practice and interpretation across cultures. A number of terms have been used to describe the components of FCC including parental involvement, participation, parental presence, family nursing and partnership (Smith et al. 2002; The American Academy of Pediatrics 2012; Coyne 2015; Institute for Patient and Family Centered Care 2018). CYP nurses strongly advocate the philosophy of FCC in practice as an ideal approach to care delivery which leads to effective parental involvement and collaboration, however this can be a challenge to achieve (Carter 2008). Shields et al. (2012) undertook a systematic review of qualitative studies on FCC. This demonstrated that there was a lack of evidence around FCC and its efficacy in practice. FCC was found to be problematic due to barriers such as relational and attitudinal issues which impacted on the effectiveness of FCC. This finding was supported by Mikkelsen and Freidriksen's (2011) concept analysis, they concluded that FCC was not yet a mature enough concept and that the ill child's perspective was not sufficiently prominent in the present conceptualisation. The shifting of care from the acute to the ambulatory and community settings also presents further challenges in the implementation of FCC (Margolan et al. 2004; Darvill et al. 2009; Royal College of Nursing 2020). Ford (2011) found that shorter bed stays limited the time available for CYP nurses to foster an FCC approach. In an attempt to develop a consensus of values towards a definition of FCC, Al-Motlaq et al. (2019) used a modified Delphi technique to obtain an agreement on the description of FCC and its component features. The study involved CYP nursing experts from eight countries who developed an agreed list of 27 descriptors which could be used in future study across countries and settings. Statements with approved consensus generally explored areas such as participation, involvement, interdisciplinary approaches and the need for nurses specifically to have a clear vision of what FCC is. The study concluded by highlighting the benefit of developing a tool developed from the consensus statements in order to measure the 'family centeredness' of healthcare professionals' clinical practice. The study was clear in identifying that even amongst experts in FCC, understanding of the concept varied (Al-Motlaq et al. 2019) Coyne (2015) noted that despite the limitations of FCC and the lack of a coherent accepted definition, there appears to be extensive agreement that FCC promotes the welfare of hospitalised children. For FCC to become fully embedded in practice, however, it seems that its underlying rationale, alongside its implications for practice, particularly in the acute setting, must be well defined (Uniacke et al. 2018).

A number of authors highlight the issues surrounding the definition, interpretation and operationalisation of FCC (Smith and Coleman 2010; Al-Motlaq and Shields 2017). Without this, it becomes challenging to measure the effectiveness of FCC in meeting the needs of families and in the case of my study, fathers specifically. This is important from an academic and research point of view but also from a family care viewpoint. If healthcare professionals and CYP nurses specifically are unclear on what FCC actually is, then families will be equally challenged in knowing whether the services, care and treatment that they receive is appropriate and meets the tenets of the concept in totality. The authors within this section are all clear on the challenges of FCC but less clear on how they may be resolved. There is a benefit in taking the approach of tool development as identified by Al-Motlaq et al. (2019) in that the descriptors could be used within practice areas to measure 'family centredness' of clinical practice however further research would be needed to measure the effectiveness of such a tool in practice.

3.4 The Development of FCC in the UK

FCC as a concept has developed and evolved over the last 70 years reflecting changes in society, this has led to greater involvement of families in care decisions. In the 19th, and for large parts of the 20th, century, parents were excluded from their hospitalised children.

Inclusivity is now key in caring for CYP in acute environments (Bradshaw and Coleman 2007). Street (1992) discussed hospital visiting rules from 1947, which focused more on the needs of the institutions rather than the children they cared for. Parents were allowed to visit their children on alternate Sundays for 1.5 hours, but this was still at the discretion of hospital staff. The rules were intended to safeguard the best interests of the CYP however such practice did not support the needs of families and led to children being isolated from their parents for long periods of time. Common practice prior to and including the 1950s was that care followed a behaviourist approach, which encouraged adherence to routines but lacked warmth or emotional engagement (Darbyshire 1994). Research by John Bowlby (1953) and James Robertson (1958) demonstrated the emotional need of children to be near their parents with a focus on mothers specifically. Bowlby (1953) examined maternal deprivation in childhood while Robertson researched the impact of separation from mothers on the hospitalised child. Findings from these early researchers heavily influenced the conclusions of the Platt report (Ministry of Health 1959), which recognised the austere nature of hospital environments and made the key recommendation of open visiting but at a reasonable time. Although Platt's recommendations are clear it took some time before there was recognition of the fact that CYP and their families' interests should be central to child health care practice. Darbyshire (1994) argued that Platt's recommendations were too simplistic and failed to recognise the sociological experiences of parents being with their child in hospital. Within the Platt report and the studies that influenced it, there is barely any reference to the contributions that fathers make towards parenting. The recommendations refer to 'parents' with mothers specifically identified as needing to participate in some aspects of care and to have the opportunity to be resident with children under 5 years of age if the hospital allows. There is one mention of fathers, in an earlier discussion of visiting which suggest that evening visiting should be allowed for fathers to attend after work (Platt 1959).

In 1961 The National Association for the Welfare of Children in Hospital was advocating for more open visiting for parents. This can be seen alongside Platt (1959), as a turning point in the development of FCC. However, progress was slow with the Court report (Department of Health 1976) recognising that more needed to be done to meet the needs of children and families. This report recognised that the type of care children required was different to that of adults and that a partnership approach with parents was the way forward. There was also recognition of resistance to change from both nurses and wider healthcare professionals. In 1989, the Children Act came into being, this included a legal definition of parental responsibility and had implications for the delivery of health, education and social services to families. The United Nations Convention on the Rights of the Child (UNCRC) was introduced in the same year with a broad range of articles, these included recognition of the fact that the best interests of the child should be paramount across a range of settings including health. There was a shift in emphasis under the law towards the rights of the child with their involvement in decisions relating to their own health and welfare.

In 1991, the Department of Health published a report entitled Welfare of Children and Young People in Hospital, this identified the need to provide quality and seamless care experience for CYP regardless of the care environment. In 1993, the Audit Commission report recognised FCC as an accepted concept in CYP healthcare, although improvements were needed in the way that this care was actually delivered to children and families. It was clear at this time that FCC was limited in practice. This was partially due to the way CYP services were organised and delivered. One example within the Audit Commission report (1993) highlighted the fact that some surgical teams operated predominantly on adults and were providing care for less than thirty children per year. This led to an expansion in paediatric surgical training with the appointment of specialist surgeons across a range of hospitals rather than being confined to the existing children's hospitals. By 1996, the NHS had developed a patient's charter for services to CYP and families. This required healthcare staff to involve families in care decisions but was on a somewhat superficial level, although it did signpost the way forward. Action for Sick Children (1999) developed millennium targets for CYP in an attempt to raise standards for the care of CYP in acute areas. They also sought to support, encourage and empower parents to be participants in their child's care.

By 2005, National Service Frameworks (NSF) were introduced into practice (Welsh Assembly Government 2005). The focus of these standards was to ensure that high quality service delivery was child-centred and met the needs of the whole family. There was also a requirement that healthcare staff should consider CYP's views on their own care and provision. The NSF was also a partial response to the Kennedy report (2001), this had examined failings in the surgical care of CYP who required surgery for congenital heart disease in Bristol. In 2010 the Department of Health report entitled 'Getting it Right for CYP' was released. The findings recognised that changes had occurred within healthcare and that these required the facilitation of FCC and CYP involvement and participation in care and treatment decisions. At the same time the report recognised that FCC was not fully embedded within the National Health Service and that there was more to do to enable this to happen. Current policy and strategy have built on previous reports and recommendations including Department of Health Northern Ireland (2016) A Strategy for Paediatric Healthcare Services Provided in Hospitals and in the Community – this will span 10 years from 2016–2026. Welsh Government (2018) A Healthier Wales: Our Plan for Health and Social Care, which also aims to provide seamless local health and social care closer to home, this approach also appears in the NHS long-term plan for England (NHS England 2019). All of these policies highlight the importance of holistic approaches to care provision and the needs of families and service users.

Although numerous reports, recommendations and legislation have highlighted the need for parents and CYP to be involved in care decisions and for parents, direct care delivery, there remains an issue about how fathers are viewed in care environments. It can be argued that this stems back to the Platt report (1959). Influential theorists such including Casey (1988) and Darbyshire (1994) both highlight Platt (1959) as a turning point in the recognition of FCC, but this was very much related to mothers' involvement in care. Key reports from the 1970's through to the present day continue to discuss FCC in broad terms without specifically addressing all component family member's needs.

I would suggest that there has been greater recognition of CYP needs which is evidenced in legislation including the Children Act (1989: 2004) and underpinning policy including Welsh Government, Rights of Children and Young Persons (Wales) Measure (2011) which has helped to embed the UN Convention on the Rights of the Child (1989) in all decision making. In practice this has meant that a Children's Rights Impact Assessment is undertaken when any proposed law, policy or budgetary decision is made. In Scotland there is a similar approach to embed CYP rights based on the UNCRC (Children and Young People (Scotland) Act 2014). In England the UNCRC (1989) is embedded within the legal system and has influenced wider legislation including the Human Rights Act (1998) and the Equality Act (2010). Although Government legislation, national reports, guidelines and policy support FCC, there remains a disconnect in relation to fathers needs specifically. It can be argued that CYP needs are well recognised but not always met. There is an implicit acceptance of mothers' roles within FCC, whereas fathers are somewhat invisible both in terms of policy and FCC in clinical care.

3.5 Models of FCC

Casey (1988) devised the partnership model of care, the main principle of this model being that nursing care in ward environments can best be delivered by parents with the support and education being provided by nurses. In this model parents take on the everyday care of the child with nurses taking a secondary role. Smith (1995) further developed the concept of negotiated care with two key concepts, negotiation and involvement. Both theorists were highly influential in the way nursing care was delivered to families, but this was not a fully family focussed approach. More recently, Smith et al. (2010) addressed this when they described FCC as a practice continuum which starts from the point of no involvement at all from parents, to care being fully parent and child led. Care being parent and child led appears to be the exception rather than the norm, with most care being negotiated to some extent whilst still being nurse led (Smith et al. 2010). Shields et al. (2006) undertook a systematic review, which included eleven qualitative studies around FCC. They found that although FCC had become embedded in paediatric practice, there was a lack of evidence around its effectiveness and contribution to outcomes. Three key themes were explored within the systematic review: negotiation, roles and cost. Negotiation was seen as being a good indicator of relationships between nurses and parents in the hospital setting. This was reflective of Darbyshire's (1994) earlier work in which he explored relationships between staff and parents during a period of hospitalisation. This was a phenomenological study involving 30 parents; 26 mothers and four fathers and 27 staff in general children's wards. Parents describe moving into a state of 'defensive parenting' as they felt that they were at risk of being an annoyance to the nurses. Parents also felt pressured to respond to offers of participation in care in the way that nurses expected of them, this was the perceived norm. Espezel and Canam (2011) undertook a thematic analysis with 8 parents of children over the age of eighteen months. They found that negotiation and partnership in care was not collaborative, but rather was nurse led. De Lima et al. (2001) also described nurses as gatekeepers who ensured that once mothers were socialised into the ward environment, a division of labour took place in which mothers were allocated more menial manual roles whilst nurses carried out the 'intellectual' work. There was no recognition of mothers' past experiences, skills or knowledge or indeed of the potential role of fathers.

Within the wider child health nursing research there has been a strong focus on family centred care and the needs of parents. The majority of available research has focused on mothers' experiences whilst fathers' experiences and contribution to care has been widely ignored (Higham and Davies 2012). When family centred care is examined, 'families' and parents are often referred to in the discussion with little consideration of the separate needs of the individual family members. Coyne et al. (2011) discussed what family centred care actually meant to nurses. Throughout this research 'parents and family' are used as interchangeable terms but the nurses within the sample failed to identify specific individual needs. Smith et al. (2015) developed a framework to help improve the collaboration between parents and healthcare professionals. This approach identified the need to develop services around the child's needs and that in order to do so their parents' views should be taken into account (Noyes et al. 2014; McNamara - Goodger 2017; NHS England 2019).

Although models and approaches to FCC have been developed, there remains a lack of consistency in their approach and implementation in practice. From Darbyshire (1994) through to Espezel and Canam (2011) there is a consistent finding that FCC is, to some extent, controlled by healthcare professionals with limited negotiation and partnership with parents. Where parents' views and experiences are explored within the literature there is a strong focus on mothers. Several authors do identify the challenges of recruiting fathers to participate in research although it is not made clear why this is the case. Without further studies exploring fathers' experiences across CYP care environments their voice will not be heard or practice changed to encompass the needs of all family members.

3.6 Failings in FCC

The health care and well-being of society has been the focus of increased governmental and public attention in the UK. This interest was partly driven by the visibility of several high-profile public enquiries involving the death or serious injury of children and young people. These reviews made transparent to the public some of the deficits of maintaining a consistently high quality and safe service within the current health care system. These safety risks and quality issues have been attributed to poor partnership working and ineffective communication networks between professional groups and agencies responsible for safeguarding and delivering services to children and young people, thereby leading to fragmentation and critical incidents. Other contributing factors include the inadequate supervision and monitoring of professional practice (Kennedy et al. 2001; Laming 2003; Laming 2009; Munro 2011), poor leadership, accountability and governance (Kennedy et al. 2001; Redfern et al. 2001; Laming 2009; Munro 2011; DOH UK 2012; Francis 2013), along with a lack of involvement of parents in the decision-making process. The outcomes from these reviews and, in light of them, mounting public pressure, has encouraged health care policies and recommendations for children and young people's services to be designed and delivered around their needs, and to safeguard them (NHS England 2019).

A number of these high-profile inquiries have involved families of CYP with CHD and demonstrate that the care delivered to CYP, and families has fallen far below the accepted standards. Parental concerns were dramatically highlighted in the Kennedy report (2001), this report investigated the care of CYP undergoing cardiac surgery at Bristol Royal infirmary between 1984 and 1995. One of the key findings was that 30 – 35 more children under the age of one died following open-heart surgery in Bristol than would have been expected at other units with a comparable throughput of patients. These issues may not have been made public if it were not for the role played by Dr Steve Bolsin, whose actions as a whistle-blower brought the issues at Bristol to public attention. Kennedy (2001) found that communication between staff and parents was poor, particularly in relation to consent to treatment but also in the way care was delivered. Although highly critical of medical staff Kennedy (2001) also established that nursing staff had let down children and families in their care. FCC does not appear to have been a fundamental principle in their approach to the delivery of nursing care at that time.

Another public scandal, which erupted around the same time, was that of organ retention. This came into the public domain in the autumn of 1999 (Leith 2007). Many families discovered that in consenting to a post-mortem on their child, they were deemed to have given permission for hospitals to retain tissue samples or even whole organs. Permission is not required from families for a coroner's post-mortem as this is part of the legal process, but it was required for hospital post–mortems that served to enhance medical knowledge (Department of Health 2001). In response to this, the Human Tissue Act (2004) aimed to ensure that full informed consent had to be given for both post-mortem and the retention of any tissue type. Parents raised two main concerns following this scandal, firstly that that they had not given informed consent for organ and tissue retention and secondly upset around the wholeness of their child's body (Royal Liverpool Children's Inquiry Report 2001). Both the Bristol and the Liverpool inquiries highlight the paternalistic nature of medical practice and a failure of nursing staff to raise issues of concern. Such approaches to care have a major impact on families' experiences with healthcare practice and add to the grief experienced by those who have lost children. One parent who gave evidence to the Royal Liverpool Children's Inquiry stated:

> "I am not deeply religious, but I do have certain beliefs. I believe that your heart is your soul. My daughter is not together, and she has not been laid to rest." (Parent, Chief Medical Officer Summit 2001).

More recently, an inquiry by NHS England (2014) was launched into the care delivered to children with congenital heart defects who had received surgical care at Leeds Teaching Hospitals NHS Trust. The review focused on the 35 children who died following surgery between 2009 and 2013. It concluded that the unit did not appear to have an excessive rate of post-surgery mortality. The report confirmed that the unit was safe however, serious problems were found with the care offered to sixteen families of very sick children. The report details that during the most stressful experiences of the families' lives they had encountered extraordinary stress, a lack of compassion, poor counselling and badly handled complaints. (Children's Congenital Cardiac Surgery Services at Leeds Teaching Hospitals NHS Trust 2014). Families felt let down by a range of healthcare professionals including nursing staff. In

March 2014 it was announced that there would be another inquiry led by Sir Ian Kennedy into the care and treatment of at least ten children who had either died or been left severely disabled following paediatric cardiac surgery at Bristol Children's Hospital. The Inquiry reported in 2016, and although it found that the mortality and complication rate was no worse than at other paediatric cardiac surgical centres, families had received less than optimal care and that was attributed to staffing and capacity issues (Grey and Kennedy 2016).

Although these high-profile inquiries have very much focussed on patient safety and outcomes, they do demonstrate that FCC is not the fundamental driver of healthcare professionals' approaches to families that the CYP nursing profession in particular considers it to be. The poor care, lack of support and compassion demonstrated across various CYP settings over the last 27 years highlight the lack of FCC provision and clinical cultures where poor care and outcomes are allowed to flourish. FCC is essentially viewed as the underpinning concept of care, yet at times this is missing, or is not sufficiently embedded in practice in order to address failures in care. What stands out in the various inquiries, is that they were undertaken following a whistle blower who was a doctor, coming forward in the case of Bristol (Kennedy 2001), parents in the Liverpool and Leeds inquiries (Royal Liverpool Children's Inquiry Report 2001; NHS England 2014) and both parents and coroners in the second Bristol inquiry (Grey and Kennedy 2016). If FCC had really been fully embedded in practice, it would be pertinent to expect CYP nurses to also lead the call for improved practice and to identify failings through whistle blowing.

3.7 The Different Needs of Mothers and Fathers

There is a general lack of research examining the respective experiences of fathers and mothers, either singly or within couples, when managing their child's long-term conditions. The diagnosis of a long-term condition is often a life changing event for families (Compas et al. 2011; Hockenberry et al. 2019; Christie & Khatun 2019). Moore et al. (2010), discuss the impact in terms of the change in parenting role as they move towards being primary carers for their child. The impact of this role change in parents can be significant in terms of the physical care required but also the social, psychological and environmental impact. Swallow et al. (2011) undertook a qualitative study with fourteen couples whose children had long-term kidney disease. Data were collected via semi-structured interviews with the couples. The study found that both mothers and fathers contributed to the care and management of their child's condition. A key finding of the study was the need to develop skills in the management of their child's condition. The development of these skills was negotiated between the couple over time, taking into consideration paid employment, caring for other children and the need to provide practical and emotional support to each other. Fathers developed a protective role and tended to focus on the long-term outcomes of the condition while mothers focused on their child's current needs and clinical condition. These approaches are aligned to traditional gender based approaches to parenting and the division of labour within a couple (Wall and Arnold 2007; Thebaud 2010). To ensure professional engagement with both mothers and fathers it was concluded that healthcare staff needed to express appreciation for both parents' skill development and ongoing contribution to care (Swallow et al. 2011). Carter et al. (2014) also highlighted the need for ongoing and open communication with all parents to ensure that services are able to meet the families' ongoing needs.

Hayes and Savage (2008) examined fathers' perspectives on the emotional impact of caring for their child with cystic fibrosis. They found that fathers were an under researched group. Specifically, in their findings they found that supportive interventions were not geared towards fathers who found themselves experiencing difficulties in communicating their concerns to others. Massoudi et al. (2010), in their study of Swedish nurses, found that almost all agreed that working with fathers was a positive experience although their participation in care was much lower than mothers. Nurses reported that it rarely came to their attention that fathers might be distressed or needing support. It was concluded from the research that fathers received less support from children's nurses than mothers and that many nurses were ambivalent towards fathers' capacity to care in comparison with mothers (Massoudi et al. 2010). When a child is ill, mothers and fathers may be expected to assume different roles and responsibilities. Both may provide care, but it is mothers who often provide most direct input to care and maintain on-going relationships with healthcare professionals. Fathers often assume the protector role and consider the long-term outcomes of their child's health and wellbeing (Swallow et al. 2011). This role separation may be due to the fact that mothers will often be more readily available for clinical consultations, particularly following the birth and during the longer-term care which inevitably involves periods of hospitalisation. This has impacted on both care and research involvement for fathers. Swallow et al. (2011) described mothers' views being used as 'proxy accounts' for fathers. Healthcare professionals may accept role separation based on society's views of fatherhood and masculinity, which will impact on involvement in care and engagement with healthcare professionals (Massoudi et al. 2010).

3.8 Fatherhood and Ill Health

Although some studies have focused on fathers' experiences of caring for children with long term illness this has been quite limited and requires further exploration (Hayes and Savage 2008; Garfield and Isacco 2012; Laws 2018). Peck and Lillibridge (2005) identified the ways in which fathers experience a broad range of emotions when facing their child's chronic illness. Exacerbations of the condition, unpredictability of outcomes and the child's on-going need for medical input are all stressors which fathers face. Hovey (2003) examined the daily concerns of 48 fathers of children with cystic fibrosis (CF) and other chronic illnesses compared to 51 fathers of healthy children. Fathers of children with a chronic illness suffered a much higher degree of concern in relation to their child's overall health and prognosis. Hayes and Savage (2005) researched the experiences of 8 fathers of children with cystic fibrosis. Data were collected via face-to-face interviews, the findings demonstrated that all fathers were heavily involved in all aspects of their child's care, although this was to a lesser extent than their partners. Care giving impacted most on the fathers' emotional well-being. One father described living with CF as a constant worry with the fear that missing a medication or essential calories would be a significant threat to their child's health.

Hayes and Savage (2005) also discussed the differing reactions of husbands and wives; it is clear from their findings that fathers react differently from mothers. Three fathers described being less emotionally involved than mothers and more pragmatic in their approach to the illness. This was also evident in the reaction of professionals to fathers, where there is a lack of recognition of fathers' needs based on societal expectations of the role. Healthcare professionals can interpret masculine supportive behaviours as coping, and this may lead to isolation from support services and available interventions (Hayes and Savage 2005). On a practical level, and in order to ensure involvement, it was suggested that CF clinics could be run later in the day and on weekends with an emphasis on involving fathers in on-going treatment discussions. This is an interesting viewpoint which relates to Platt (1959) in the suggestion that fathers should visit after work. The underlying assumption being that fathers will work and be unable to engage in ongoing care and treatment discussions.

Bennett at al. (2008), in their study on fathers of children with cancer, reported that treatment teams needed to be mindful of fathers' working patterns when organising clinics or updating families on their child's progress. It was noted that a number of fathers worked long hours, this was seen to reflect the need to have a stable income but also as a possible coping method and an indicator for treatment teams to offer support. Furthermore, it was identified that in order to foster the involvement of fathers, teams may need to actively pursue opportunities to engage them in conversations and direct care.

McNeill (2007) undertook a grounded theory approach to explore the ways in which fathers of children with Juvenile Rheumatoid Arthritis (JRA) interpreted their parenting role and identity. Twenty-two fathers participated in the study; they were recruited from an acute care paediatric environment where their children were cared for. The average age of the fathers was 43.7 years and the sample included fathers from a range of educational, cultural and ethnic backgrounds, as well as those from intact families and also divorced, separated and remarried. The average age of their children was 8.7 years and two-thirds were female. Data were collected using semi-structured interviews. Some fathers expressed traditional views of their roles highlighting discipline, being a provider and role model. This resonates with what May (1996) described as the three Ps in terms of the male role; to provide, protect and procreate. Chronic illness and repeated hospitalisation may help to ensure a father's involvement in their child's care is bound up with the need to protect. Social stereotypes were also re-enforced by one father who doubted his wife's ability to deal with technology (McNeill 2007). Mothers were perceived to have more emotional bonds with their children. This was the case even when fathers were primary caregivers and as one father said:

> "As far as bonding goes, I don't think a father can replace a mother because that's a bond only a mother and child can have. A father can provide and share as much as he can but there is still some kind of link between a mother and a child that is different from a father and a child".
> (McNeill 2007, p 416)

Later in the study some fathers rejected the accepted gender stereotypes by being more involved in their child's care and upbringing. In some ways, it seems as though their child's chronic illness allowed some fathers to gain closer emotional ties with their children. McNeill (2007) concluded by highlighting the need for clinicians to put aside gender stereotypes, which tend to assume a lack of hands-on involvement in care by fathers. These assumptions have earlier been described as a form of institutional discrimination by May (1991). Although many fathers in McNeill's (2007) study recognised gender-based role differences and took a biological viewpoint, their behaviours in terms of engagement and delivery of their child's care did not always reflect this position.

Friedman et al. (2015), undertook a study to compare mothers' and fathers' care roles when their child has asthma. The study explored several outcomes such as adherence to treatment, morbidity and parental quality of life. Mothers and fathers within 63 families of children aged 5 -9 were included in the study. The results showed that mothers were predominantly more involved in the day-to-day management of their child's asthma with stronger beliefs in the importance of medication management. It was found that mothers rated fathers' contribution to care much more highly than fathers did of their own input. They concluded that fathers tend to devalue both their level of knowledge of asthma and their input into their child's care. Further engagement with healthcare professionals would help fathers to take a more active role in their child's care. Pelentsov et al. (2016) undertook a study which examined the supportive care needs of parents who care for a child with a rare illness. They used an online survey with forty-five questions in six domains, this was designed to gather data from three-hundred and one participants, 91% of respondents were mothers. The domains looked at areas such as equity in care, practical care needs, relationships and emotional impact. As the fathers made up such a small part of the sample, results were reported within the domains for all parents rather than mothers and fathers specifically. Fathers were identified as providing some care and support, but with a focus on financially supporting the family which meant less engagement in direct care and communication with healthcare professionals. The study concluded by recognising that fathers are underrepresented within this and other studies, therefore their views and potential support needs are often not considered (Pelentsov et al. 2016).

There is a consistent theme running through these studies that fathers take on gender specific roles in being both the provider and protector (McNeill 2007; Bennett 2008; Pelenstov et al. 2018). This has a detrimental impact on how fathers are perceived when within CYP nursing areas, which is reflective of May's (1991) view of institutional discrimination being apparent in acute areas. Where fathers are represented in studies alongside mothers, it is clear that they can and do want to be involved in direct care delivery (Hayes and Savage 2005; Friedman et al. 2015). The limiting factor appears to be healthcare professionals' views of fathers' roles and ability to provide care. This is based on wider societal expectations but also supported by earlier reports, recommendations and literature around FCC. Fathers themselves, do see their role when their child is ill as being based on traditional gender division of labour (McNeill, 2007; Pelenstov et al. 2016), this is a position which is reinforced in clinical practice. To advance fathers participation in care, healthcare professionals need to adapt their approach in providing FCC with a focus beyond the mothers' perspective.

3.9 Fathers and CHD

There are a limited number of research studies which specifically examine fathers' experiences when their child is born with CHD. Some studies have explored parental experiences, stress and psychological functioning in parents of children with CHD (Doherty et al. 2009; Franck et al. 2010; Rempel et al 2012; Kosta et al. 2015). Most studies in this area looked at parents rather than fathers in isolation and none looked at fathers' experiences across the illness trajectory where key events, such as CHD diagnosis, and a change in the parenting role from having the perfect baby to one with a possible life limiting, or in some cases life threatening condition occur. The transfer of their child through a number of centres in order to receive appropriate and specialist care is common and has a significant impact on parents generally **(**Kosta et al. 2015**)**. There will also be escalations in care particularly when their child has surgery and requires Intensive Care or Neonatal Intensive Care following acute collapse at birth. Rempel et al. (2012) undertook a study examining parenting under pressure. The focus was around young children with life threatening CHD. Four key themes were established; realising and adjusting to the inconceivable, growing increasingly attached, watching for and accommodating the unexpected and encountering new challenges. Although the focus of the study was parents, grandparents were also included as participants. Within the sample more mothers were interviewed than fathers; 10 fathers and 25 mothers and more grandmothers (17), than grandfathers (11). This is a valuable study, as it explores fathers' views, but it very much focuses on the experiences of the participants at a set point in time, relating purely to surgery rather than the whole journey of the family and fathers specifically.

Doherty et al. (2009) examined psychological functioning in both mothers and fathers of infants born with CHD. The parents of 70 infants were included in the study which used questionnaires, such as the brief symptom inventory, to examine psychological functioning. Doherty et al. (2009) found that one third of mothers experienced clinically significant levels of psychological distress, while this impacted on only one fifth of fathers. In addressing differing levels of distress, Doherty et al. (2009) identified that this may be an underestimate of the prevalence amongst fathers, as they may wish to appear strong even when responding to questionnaires rather than direct discussion. This was also identified as an issue in an earlier study by Clarke and Miles (1999).

Doherty et al. (2009) also identified that fathers may adopt maladaptive coping mechanisms such as disengagement alongside alcohol use, however the evidence for this within the study is unclear. Kosta et al. (2015) examined parental experiences when their infants were hospitalised for cardiac surgery. The goals of the study were to explore what parents found difficult, how they would have liked their experience to have been different and what might improve the experience for future parents. The participants were parents who had babies requiring cardiac surgery either open heart or closed within the first three months of life. A total of 154 parents were included in the sample, 91 mothers and 63 fathers. Some families were single parent, in those cases only mothers were interviewed. The researchers noted that single fathers were approached but declined to participate in the research stating that they were ‘too busy’ and therefore a father was not available for interview. There is no further commentary on this within the paper. Data were collected using structured interviews, which were arranged for 1-month post discharge. This was in order for parents to have settled back into their regular lives and routines but also allowed for a period of reflection on their experience in hospital. To analyse the data a thematic analysis was undertaken using Braun and Clarke's (2006) approach.

Six themes were identified within the study: baby, context, relationships, information, waiting and individual coping strategies. More than half of the parents identified aspects of the experience that were directly related to their baby's illness, these included the diagnostic process and the uncertainty of surgery and ongoing treatment. When asked what they would have liked to be different, all parents not unsurprisingly, reported that they wished they had not gone through the experience at all. Structural and systemic issues of the context of the whole experience featured highly amongst a large number of parents. This was an area that parents wanted to be different. On a micro-environment level issues such as the environment of care and specifics such as ward policies, e.g., visiting hours to the macro-environment level, nearby accommodation, food and parking were all expressed as being of real concern. Parents reported difficulties in navigating their way through the stay in hospital and problems obtaining resources to meet their daily needs. The demands of home life, particularly when travelling to and from the hospital, balanced with the needs of caring for other children was also highlighted as an area to be addressed. This reflects the position within the UK where cardiac surgery is delivered in a small number of regional centres which may be many miles from the parents’ home environment and usual support structures. Families in Wales would need to travel to England for their child’s surgery with parents in Northern Ireland needing to access surgery in Dublin.

In terms of relationships and the information theme, Kosta et al. (2015), reported that 72% of participants found the hospital / family interface to be the most helpful relationship. Helpful actions as described by parents included providing information, answering questions and providing both emotional and practical support. Certain staff attributes were deemed helpful including updates during surgery, being nice, understanding and supportive. Challenges with relationships included unhelpful communication styles, issues with staff availability, consistency of information and feeling excluded from decision making. Differences in opinion between clinicians on approaches to treatment were particularly unhelpful. Parents also reported some difficulty in understanding the roles and responsibilities of the range of professionals that they encountered, this impacted on the level of emotional support that they experienced. It is apparent within the study that parents experienced a sense of 'living' in the hospital and waiting for something to happen both pre and post-surgery. The expression ‘taking it one tube at a time', is highlighted within the study and reflects the milestones that parent experience across their stay. These milestones contributed to individual coping strategies with some parents reporting that they looked for short term improvement in their child’s condition such as invasive line removal, whereas other parents looked further ahead to reduction in clinical dependency, discharge or some sort of return to family life. The majority of parents identified the need for accessible services, knowing who to contact, professional roles within the treatment pathway and the capacity of healthcare staff to meet with parents and respond to their needs (Kosta et al. 2015).

The findings of Kosta et al. (2015) study are consistent with wider studies examining the experiences of families within neonatal intensive care settings, particularly the need to be near their child (Wigert et al. 2006; Schenk and Kelly 2010; Harvey et al. 2013). The value of accurate and timely information as well as the importance of relationships with healthcare staff has been identified as both helpful and challenging (Cleveland 2008; Hollywood and Hollywood 2011). Parents want to understand their child's condition, the treatment options and where definitive care and treatment can be safely delivered (NHS England 2010; NHS England 2014).

Bratt et al. (2017) examined parental concern during transition to adult care for adolescents with CHD. On first reviewing the title and focus of this paper there seemed to be limited relevance to the current study. However, on reflection, there are elements of transition to adult services which may be delivered in another hospital or service which do mirror the journey of parents in my study. The parents may have journeyed through at least two, and in some cases four, different hospital settings with initial care being provided in a local district general hospital followed by transfer to a neonatal unit and then further transfer to CHD surgical centres. Bratt et al. (2017) conducted semi-structured interviews with eighteen parents of sixteen adolescents, aged 13 -18 years. They accessed care at four paediatric cardiology centres in Sweden and were on the pathway for transfer to adult services. The main themes identified included feeling secure with the importance of being well informed and prepared for change, alongside recognising when the right time is to hand over care. This is reflective of the position in my own study where certain aspects of care can be managed in local neonatal or acute paediatric settings, but definitive care and treatment needs to be accessed within the lead cardiac surgery settings. In contrast with transition to adult services, transfer to appropriate facilities may be both unexpected and immediate with lifesaving interventions being required in the first few days of life. Subcategories within Bratt et al. study (2017) included being kept informed and involved in decisions around care, understanding the process of transferring care and being prepared for the change in environment. For some families this process could be rapid, an example would be a baby born at home, collapsing, being rushed to a local hospital and then transferred on to a cardiac centre all in the space of a few hours.

When neonates and children are admitted to a CHD centre following diagnosis, care is provided in a range of settings, these include Neonatal Intensive Care, paediatric wards and Paediatric Intensive Care. The environment of care will depend on the severity of the defect and dependency of the child (Paediatric Intensive Care Society 2015). Hill et al. (2018) examined parents' perceptions of how the physical and cultural environment of the paediatric intensive care unit (PIC) impacted on the delivery of family centred care. A longitudinal qualitative descriptive design was utilised for the study. A series of interviews were undertaken over a period of one year with three mothers and three fathers whose infants were admitted to PIC with complex CHD. Interviews took place monthly ranging from soon after birth, up to one year, or up to the death of the child. The core concepts of family centred care were identified from interviews. These included information sharing, participation, respect and dignity. Parents identified that the nature of the PIC environment impacted their perceptions of how family centred care was implemented and how it impacted their experience. The importance of healthcare professionals engaging with parents, providing timely and accurate information and recognising parents' needs throughout the duration of their child's treatment were important factors in improving the parents' experience. The nature of the PIC environment and its impact on parents has also been recognised in various studies (Noyes 1999; Davies 2005; Oxley 2015). Without an antenatal diagnosis of CHD parents would have little or no preparation for entering into high care environments which is challenging for healthcare professionals who are trying to support parents and address their needs.

Govindaswamy et al. (2019) examined the stressors of parents of infants undergoing neonatal surgery for congenital anomalies. The study identified that parents of babies admitted to the neonatal intensive care unit experienced high levels of stress, but little is known of the added impact of surgery. A quantitative approach was used to gather the data from 111 parents admitted to the neonatal unit for surgery in a tertiary centre. Data were collected using a parental stressor scale, which is a 5-point Likert scale similar to that developed by Carter and

Carter (1989) in their seminal study on parental stress. Sights and sounds, infant appearance and alteration in the parental role were key features of the measure. From the results, 57% of mothers identified alteration in the parental role as the greatest stressor followed by the appearance of the infants, for fathers, this was 47%. A strength of the study was the number of fathers participating (48%). However, 17% also cited time constraints as limiting their involvement in the study (Govindaswamy et al. 2019).

Franklin et al. (2021) explored barriers and facilitators to discussing parental mental health with parents of children born with CHD. Seventy-nine parents were included within the sample, 30% of whom were fathers. Although there is an under representation here this is a reasonable response rate from fathers compared to other studies (Pelenstov et al. 2016). Data were collected via an online social media platform, with 37 open ended questions posted over a 6-month timeline. Participants could see and comment on each other anonymised posts which were then analysed using an inductive thematic approach (Braun and Clarke 2006), focusing on parents' subjective perceptions, feelings and experiences. The results are reported for 'parents' rather than mothers and fathers specifically although at times gender responses are evident or commented upon. Parents reported various barriers and facilitators to discussing mental health. Barriers included the expectation from healthcare staff that parents should stay strong, fear of negative judgement on disclosing mental health needs, negative reactions to past disclosures, the desire to maintain care resources on their child and the belief that mental health support was outside of the CHD healthcare team remit. Facilitators included confidence in the care team, intentional efforts by the care team to offer support and parents own personal connections with the healthcare team.

Franlkin et al. (2021) identified that participants who were fathers, or from racial and ethnic minorities, were difficult to recruit and were underrepresented. Where fathers' responses are evident, they tend to report barriers such as the expectation to stay strong and stifle emotions. One father noted that at times it was unacceptable for men to express emotions, particularly sadness or fear relating to their child's condition or outcomes. Another father stated that the care team were so focussed on their child's needs, that it was less important to discuss the stress that he and his partner were experiencing. One father in the study did state that they felt comfortable talking about their feelings and stress but related this to their extrovert personality. The study concluded that healthcare professionals working in CHD services need to be more aware and accommodating of parents' needs and be willing to signpost parents to resources for support, as well as engaging in discussion with parents to support their mental health needs.

Two specific studies were found that focused solely on fathers and CHD (Bright et al. 2013 and Bruce et al. 2016). Bright et al. (2013) undertook a mixed method study to examine the father infant relationship in infants with CHD. Sixty-three fathers participated in the study which explored their attachment to their babies within two months of hospital discharge. The fathers were recruited from one surgical centre in Australia. For the quantitative element of the study, fathers reported on their relationship with their infants on the Paternal Postnatal Attachment Scale. The scale uses descriptors related to potential thoughts and feelings about their child. Areas such as affection, pleasure and interaction, patience and tolerance were measured. Results from the quantitative data demonstrated that on the whole fathers reported high levels of attachment with their babies, with overall levels comparable to expected norms in fathers whose children do not have a CHD diagnosis. However, there were some concerning results. For affection, pride and pleasure for interactions with their babies 25% of fathers had lower scores than 85% of those in the wider community. The researchers theorised that this may be due to the fragility of the babies some of whom will have been cared for in a NICU and for some fathers it may also have been due to spending less time at home and having less contact.

Interviews were used to collect data in the qualitative element of the study. In these responses over a third of fathers reported a stronger connection with their baby due to both the diagnosis of CHD and hospitalisation. Other fathers reported some degree of strain within the relationship, particularly around attachment. Interestingly the majority of fathers identified treating their child the same as any other as being important. A sense of normalcy was an area that was apparent in some of my interviews with fathers being keen that their children engage in sports and access a range of activities as other children would. Bright et al. (2013) concluded by highlighting that the fathers in the study demonstrated similar levels of attachment quality but lower levels of pride, pleasure and affection when compared to fathers from the wider community. They also noted that as this study was one of the first to examine relationships between fathers and infants with CHD, more studies need to be undertaken and healthcare services should be aware of the issues described in order to provide support and encourage interaction, particularly during periods of early hospitalisation.

The study by Bruce et al. (2016) explored the lived experiences of support for fathers of children with CHD. A phenomenological hermeneutic method was used to interpret recorded interviews with five fathers. This was part of a larger study with the parents of twenty-five children recruited from a CHD outpatients' clinic, however, only five fathers participated. The reason that fewer fathers consented is not clear from the study. The findings were then grouped into a range of themes and subthemes. The results demonstrated that it was important for fathers to feel both safe and supported when there were opportunities for direct involvement in care. A reported sub-theme was a feeling of validation that their role as fathers was valued and understood to be important by healthcare professionals. Fathers also reported feeling more secure when healthcare professionals are highly qualified, have specialist knowledge and are experienced in the care, treatment and management of children with CHD. The specialist nature of knowledge and expertise was reflected in this study, some fathers whose children had rarer forms of CHD searched for experts in their care at other SCSC. This was also reflected in some fathers expressing more trust in the SCSC than their own level two or three centres.

Another theme was around connectedness with significant others. This theme was focused on fathers' feeling that there was a sense of normality in their role, sharing experiences with family and friends, just as those without a child with CHD would do. Conversely fathers also felt some benefit in sharing their experiences with other CHD families making them feel less isolated. This was an area reflected in my own study particularly when fathers discussed coping and the differences with mothers. Sone fathers talked of mothers supporting each other and engaging more together as they were more likely to be present, particularly during periods of hospitalisation. Some fathers felt that there was less support for them and recognition of their role. This is an area that is further reflected in Bruce et al. (2016) study where some fathers expressed a feeling of being confused and lonely when they were not involved in their child's care to the same extent as mothers. The study concludes by highlighting the need for fathers' support, in being in sharing relationships both with their family and wider healthcare professionals.

Although there are a lack of studies that explore fathers' experiences specifically, there has been limited research which has been successful in recruiting some (Docherty et al. 2009; Kosta et al. 2015; Govidaswamy et al. 2019). Findings from these studies demonstrate that fathers may experience some degree of psychological distress even when they appear to be strong and coping well with their child's condition (Docherty et al. 2009: Hill et al. 2018). This finding is supported by Massoudi et al. (2010) earlier study, which found that nurses may not recognise when fathers are in distress and in need of support. Kosta et al. (2015) found that ongoing support and regular updates on the available information, helped parents to navigate through the various healthcare services that they engaged with to manage their child's illness. Fathers do want to engage with healthcare professionals and be involved in caring for their children. However, it appears that fathers need specific support in order for them to feel confident and competent in the care that they give. Bruce et al. (2016) found that fathers need to feel safe and supported by healthcare professionals, which led fathers to feel validated in the caring role. There is a sense here that permission is needed by some fathers to actively participate in their own child's care and to take on the caring, and involved, fatherhood role.

3.9.1 Summary

Existing literature suggests that despite continuing policy, guidance and study on gender equality, it is apparent that the concept of FCC continues to take a traditional and uncritical approach, which fails to distinguish between the differing needs of mothers and fathers, with many fathers being positioned on the periphery of care (Uniacke et al. 2018). It is also evident that the delivery of FCC can be challenging for healthcare professionals to facilitate. Full participation and involvement of CYP and their families in the planning and delivery of care requires on-going commitment by a range of healthcare professionals, service commissioners and policy makers. At present, there is a lack of evidence of fathers' involvement in FCC and the extent to which their participation is normative (Massoudi et al. 2010; Bruce et al. 2016). There are well established policies and guidelines which recognise the value of FCC and highlight parental involvement but do so without any real consideration of how this is achieved in practice (Smith et al. 2015).

Parents whose children are born with CHD will experience care and treatment in a range of clinical settings, these include district general hospitals, neonatal units, paediatric wards and highly specialist PIC. For some parents, a diagnosis will be made only after the baby's birth with little warning of the complexity of the treatment and surgical interventions to follow. There is limited literature, however, that examines fathers' individual experiences either from the FCC viewpoint, or throughout the care journey. The literature reviewed within this chapter was limited in some ways. This was mainly due to the lack of current studies specifically focused on the experience of fathers whose children had a CHD diagnosis, and few studies detailing their subsequent journey across services. When CHD studies were identified, they tended to focus on the experiences of both parents with a stronger exploration of mothers, perhaps due to the lack of involvement of fathers in research. Whether this was lack of planning or design is unclear, however it is consistent across wider studies (McNeill 2007; Pelenstov et al. 2016; Franklin et al. 2021).

What the literature does suggest is a disconnect between the perceived goals and implementation of FCC and its operationalisation. This is evidenced in various studies which accept FCC uncritically as a CYP nursing cornerstone philosophy. Al-motlaq et al. (2019) identify the challenges in offering a definition of what FCC is and although criteria are developed it is not apparent how these will be evaluated in practice. Smith and Coleman

(2010) discuss the FCC in terms of a scale but again there is a lack of evaluation in everyday widespread CYP practice.

There is also a disconnect between the literature discussed in chapter 2 focussed on gender, masculinity and fatherhood and FCC as concept. The two literature streams stem from very different disciplines with the former being social science based and the latter developing out of nursing. There is very little congruity between the two with only occasional comments related to fatherhood in the FCC literature. FCC in the CYP literature tends to focus more on mothers with ‘parents’ being described as a homogenous group rather than individual mothers or fathers with different needs. There may be some links to the development of FCC as a concept with seminal work such as Casey (1988) and Darbyshire (1994) being produced at a time when mothers were the main care providers and fathers being less involved. As has been identified in this literature review, FCC is not a fully embedded concept but many of the foundations stem from earlier work and the range of key reports, recommendations and guidance that was produced from the 1950’s onwards. Just as it takes time for concepts such as FCC to mature, it also takes time to develop its influence in practice and to adopt a criticality that may change that influence to take account of father’s needs. Shields et al. (2006) stated that the goal of FCC was to meet the needs of all family members by viewing the whole family as recipients in care. I consider this to be partially met, with CYP and to a large extent mothers’ needs being visible within the literature, while fathers remain peripheral to care at best.

CHAPTER FOUR - Research Design and Methods

4.1 Introduction

This chapter will explore the planning, development, and subsequent implementation of the study. The study followed a narrative inquiry approach with the aim of exploring the experiences of fathers when their child is born with congenital heart disease (CHD). The chapter commences with a discussion of the nature of narrative research and highlights studies undertaken which use this approach in exploring illness contexts. The chapter will then address the research process including research design, data collection, data analysis and quality issues including ethical considerations.

The literature review revealed a gap in the current research exploring fathers' experiences when their children are born with CHD. Knowledge about how fathers experience care for their children and their interaction with healthcare professionals is also lacking, as is knowledge about how fathers make sense of their experiences and navigate their way through their child's healthcare journey. It was this experiential knowledge, with a key focus on how fathers view their experiences and understand them, that I wanted to explore within this study.

4.2 The nature of narrative research

There were several research designs that could have been used within this study. I selected a qualitative research design as I wanted to focus on the individual experience of the fathers caring for children with CHD. By choosing to utilise a qualitative design it allowed for an inductive approach to the research, allowing for in depth explorations of the contextual experiences and stories of the fathers to be captured (Holloway and Freshwater 2007; David and Sutton 2011). It is important when considering which qualitative research design to utilise, to ensure that the chosen approach will lead to the research questions being answered.

A narrative approach was used in order to achieve the aims of the study. Narrative encompasses a range of approaches which are used to explore how people make sense of their life experiences (Holloway and Freshwater 2007; Casey et al. 2016). Narratives can refer to the stories people tell about aspects of their lives and (Polkinghorne 1988). Joyce (2015) described narrative as the production of a spoken, written account or story. Denzin (1989) defined narrative as a formal, measurable framework, which adds context to the articulated story. It is an approach that aims to examine how people tell of and create meaning to their experiences (Rejno et al. 2014). Labov and Waletzky (1967;1997) describe narrative as speech events, although the spoken word is important, it is meaning that is of interest to Labov and Waletzky (1997). They identified the value of the form of narrative and how the story is told. Ricoeur (1984;1991) discussed the narrative process, with people integrating thoughts and actions into a coherent narrative linking past, present and future experiences.

Frank (1995) views the 'story' as being the tales that people tell, whereas the narrative is a larger 'general structure' that encompasses a number of particular stories. Stories are socially constructed and recounted from the viewpoint of the individuals' experiences, this allows for some degree of collaboration between the storyteller and listener (Polkinghorne 1988; Riessman 2003; 2008). Narrative includes a number of approaches including life history, storytelling, biography, autobiography and life incidents (Silverman 2014). More recently, blogs, individual websites, discussion forums, tweets and social media posts also fulfil the same role.

Jovchelovitch and Bauer (2000) describe narrative form and identify two dimensions of narrative and storytelling. The first is chronological which is clearly sequenced with a beginning, middle and end. The second is a non-chronological plot, constructed through a series of events combined into a larger story. Riessman (2008) argues that story and narrative are ambiguous terms. Paley and Eva (2005) found that the lines between narrative and storytelling can be somewhat blurred. They identified that story requires a plot and character to be present while narrative examined a sequence of events and the relationship between them. Paley and Eva (2005) identify the necessary conditions for a plot as a basis for the narrative. The plot must include a central character, the character encounters problem, a link is made between the character and explanation. The plot and arrangement of the narrative then provokes an emotive response in the listener. Within this study each narrative has a central character, in the father, with links to other key characters, including their partner, the child, wider family and healthcare professionals. The core 'problem' is the child's diagnosis of CHD and the decisions about treatment and care that follow, alongside the fathers' experience.

Listening to the fathers' narratives, there were various points where the emotional impact of their experiences is highlighted, which are clearly very powerful. Within this study, narratives demonstrated a clear beginning, middle and end which reflects the point in the treatment trajectory that these fathers were at. For some participants this was following initial treatment and for others it was at a point where the limits had been reached in what could be achieved surgically with the child's existing heart and they had moved on to the active transplant list.

Labov (1972) undertook early research using a narrative approach and considers narrative to be more specific than storytelling with narrative as the retelling of past events. Riessman (2008) differentiates narrative from other kinds of storytelling by highlighting the goal of answering the question of what happened next. Narrative provides insight into how humans experience the world and their own life journey. Within my study, fathers presented a series of turning points across their healthcare journeys with a constant look to the future and what events would happen next in their child’s treatment. Although the fathers looked to the future they were also influenced by their past, their own upbringing and approach to fatherhood.

Within healthcare, narrative allows the researcher to gain insight and understanding of the individual’s journey across their healthcare experience (Hall and Powell 2011). Narrative research is primarily a qualitative approach with meaning attributed to the experience of the individual. Within the narrative, it is possible for the individual to make sense of their own or others illness experience (Weingarten 2011). Lieblich et al. (1998:2) defined narrative research as ‘any study that uses or analyses narrative material’. For the purpose of this study, the stories were elicited from fathers with the subsequent interpretation of their experiences of coping with their child’s illness. Narrative and storytelling are terms that are often used interchangeably but both have the same goal to communicate a specific experience or sequence of events. Within the story, there is recognition of the importance of the experience (Hawkins and Lindsay 2006). Importantly, Denzin (1989) identified that the story is shaped by the narrator and will generally have an introduction, a middle or narration followed by a conclusion. In self-narrative approaches, there is no input from the listener, however with an interpretive approach the researcher enters the social world of the narrator in order to understand the phenomena described (Silverman 2014).

There are various reasons for using narrative and storytelling including providing meaning to life experiences, interpreting key events such as diagnosis and treatment and providing a holistic view of the narrator’s experience (Holloway and Freshwater 2007; Riessman 2008). Other elements included within narratives are shared group cultures, responsibility, adjustment and control over lives particularly when related to illness narratives. Healthcare has an oral narrative culture (Sandelowski 1994; Adamski et al. 2009) as healthcare professionals we are exposed to stories of our own and patient interaction. At the start of each clinical shift a handover takes place with a brief summary or story of each patient’s journey to the clinical setting. Although focused on clinical condition and presenting signs and symptoms in acute environments, other aspects of the patient’s life may be included in recounting their story, family relationships, treatments to date and the wider involvement of healthcare professionals may also be relayed.

Narrative in studies on illness

Narratives are increasingly evident in healthcare research literature, mostly in terms of data collection but also in analysis (Rejno et al. 2014). The use of a narrative approach in healthcare research can help improve care by enhancing knowledge and inform healthcare professionals of the patient's experience and the meaning they gain from it.
In illness narratives patients use narratives to tell of their experiences and share them with the researcher who in turn re-tells the story giving voice to the participants. Gareth Williams (1984) was an early exponent of using a narrative approach within his work. He developed narrative reconstruction as a concept when researching individuals with chronic illness. Williams undertook thirty interviews with participants who had been diagnosed with rheumatoid arthritis and asked a straightforward question about why each individual thought they had developed arthritis. This question elicited a range of stories, which Williams then reconstructed into three case studies to demonstrate how participants made sense of their disability.

Other researchers have also utilised the narrative approach to explore individuals' experiences of illness or disability (Kirmayer 2000; Carter 2004; Manning et al. 2017). Narrative approaches have also been used to examine encounters between healthcare professionals and those living with illness or their carers (Carter 2004; Mattingly 2010; Miconi et al. 2015). Carter (2004) used narrative in order to explore children's experiences of pain. The study was valuable to children's nurses and other healthcare professionals by hearing the stories of individual children and presenting new insights into their experiences. Brown and Addington - Hall (2008) undertook longitudinal narrative interviews over 18 months, with 13 individuals examining how they lived with motor neurone disease. Although individual experiences varied there were also common experiences. Storylines appear as organising strands to help healthcare professionals understand the patient experience and assist in care negotiation and provision.

Rejno et al. (2014) used narrative to gain insight into next of kin experience when a relative experienced sudden and unexpected death from stroke. Narrative inquiry is therefore valuable in gaining insight into participants' thoughts, feelings and experiences as they present them to the listener. Traditionally, healthcare research has focussed more on treatment options and patients' outcomes rather than individual experiences (Holloway and Wheeler 2013). Some authors have portrayed their own experiences of illness. Examples include Arthur Frank and Julius Roth. This approach is also echoed in autobiographical accounts of illness which are widely published in mainstream literature, examples include

Dodie Weir (2019), motor neurone disease, Linda Nolan (2018), cancer and Alistair Campbell (2020) depression.

Atkinson (1997) identified three major issues with narrative research. He highlighted that narratives of health and illness are a significant area of study within sociology and anthropology. There seems to be some degree of protection or ownership in this statement with a criticism of the expansion of the use of narrative to other fields. He further stated that some narratives are based on inapplicable assumptions and poorly applied methodological and theoretical assertions. Silverman (2014) acknowledges that this has been a criticism of other qualitative research approaches including narrative. Atkinson (1997) finally highlighted the importance of narrative analysis being systematic. He argues against the perceived simplicity of some narratives with researchers underestimating the complexity of the links between the narrative and the wider social and theoretical context. There is an importance here, in linking the focus of the research study to wider theoretical perspectives (Riessman 2008).

Frank (2000) stated that narrative and story are often used interchangeably but people actually tell stories not narratives. Narratives are structured and although a storyteller will use a structure to format, they are often unaware of this. In sharing their stories, the listener becomes part of a relationship in which the story is presented. Frank (2000) also notes that stories do have a restorative role as they create a distance between the storyteller and their experience. There is an affirmation here of the storyteller's experience, suggesting that the stories are not simply data for analysis but a reflection on the individual's life experience. Finally, Frank states that stories need to be heard and told, he views storytelling and narrative differently to Atkinson. Frank (2000 p355) states, 'Storytellers do not call for their narratives to be analysed; they call for other stories in which experiences are shared, commonalities discovered, and relationships built'. Atkinson and Delamont (2006) highlight that the overuse and uncritical acceptance of the story is an ongoing problem in narrative inquiry. What is needed is a balance, the narrative is heard in its entirety, but links are made in the analysis of narratives to wider social contexts and contributing factors which influence and shape the narrator's story. Other criticisms of narrative include the presentation of the narrative as memories that may fade, and content can be selective depending on who the narrator is presenting their story to (Riessman 2008). Polkinghorne (2007) identifies that for a narrative to be valid the knowledge gained needs to convince the reader that the support for any claim made by the researcher is sufficiently strong. Narrative research explores people's life events and, as such, needs to make clear how people understand their experiences and how those experiences impact themselves and others. Holloway and

Wheeler (2013) highlight that in presenting the narrative the reader needs to be convinced of the plausibility of the claims made in order to accept the research as valid.

In this study I felt it was important to explore the fathers' backgrounds, upbringing and wider influences on their decisions to plan for children as well as to consider how they felt they chose to present themselves, negotiate their healthcare journey and develop relationships with healthcare professionals. This aspect of the study links to the content in chapter 2, with the exploration of the literature around gender, masculinity, fatherhood and role theory. I have tried to present the narratives sequentially reflecting their journey from their own upbringing to their child's diagnosis and treatment in order to preserve the structure and flow of their life stories as this is how the fathers told their stories. When the fathers discussed their experiences following diagnosis, key plot lines or turning points, are identifiable where decisions or choices around treatment options are to be made. These options are often limited recognising the severity of their child's illness and a lack of alternatives to major surgery.

When developing a narrative, individuals recount stories of significance reflecting on their own and others feelings as they perceived events over time, and as part of this they offer some explanation and interpretation. In this study fathers have reflected on their experiences and why they have responded in certain ways or approached situations differently to their partners, particularly around the time of diagnosis but also in their approach to developing relationships with healthcare professionals. Some areas of their story offer more depth and focus than others. The narrator can choose to prioritise some aspects of their story over others and provide some context for this depending on who is hearing the story (Mattingly 2010). Some events come to the front and are focussed on, while others are neglected. My study does encourage the participants to present themselves as fathers and reflect on their experiences in this role and aspect of their lives as they have journeyed through their child's illness. In describing their experiences fathers have chosen to focus on aspects of their stories which are of most significance to them.

4.3 Study Aim, Objectives, Questions and Purpose

Aim

- To explore the views, experiences of treatment and care of fathers, whose child has been diagnosed with congenital heart disease.

Objectives:

- To explore fathers' perceptions of their role within the family and wider societal context.
- To examine how this role is altered by virtue of their child's diagnosis.
- To explore fathers' views and experiences of engaging with healthcare professionals during their child's illness in a range of clinical settings.
- To examine how fathers perceive they are viewed and supported by healthcare professionals in terms of the parenting role.

Questions

- What are the experiences of fathers when their child is diagnosed with CHD?
- How do fathers perceive their role within the family and wider societal context?
- How do fathers engage with healthcare professionals across their child's treatment journey?
- What are fathers' perceptions of support and engagement with healthcare professionals?

Purpose

- To disseminate the views and experiences of fathers whose children are born with CHD across the wider healthcare profession, in order to highlight the key issues in care and service delivery. I intend to present and publish the findings in order to raise awareness of father's needs, and by so doing, to develop practice.

- To influence policy, practice and research relating to fathers whose children are born with CHD but also fathers with CYP with a range of conditions who access healthcare in a variety of settings. This will be achieved by the publication of papers and following completion of the study presentation at appropriate conferences and dissemination through interest groups which are linked to the practice environment e.g., Congenital Cardiac Nurses Association.

4.4 Rationale

The aim, objectives and research questions in this study were formulated to address the gap in the literature and contemporary research which highlights a limited visibility for fathers when their child is diagnosed with CHD, or indeed in the wider literature around family centred care which is a fundamental aspect of children's nursing (Hayes and Savage 2008; Swallow et al. 2011; Rempel et al. 2012). Although policy and clinical guidance focuses very much on a family centred care approach, in practice fathers are often overlooked and their needs unmet (Bennett et al. 2008). Policy drivers highlight inclusivity for the whole family which is sometimes challenging to achieve in practice (WAG 2005; NHS 2010; Scottish Government 2016; Welsh Government 2019).

4.5 Sample and Recruitment

For the purposes of the study, I defined a 'father' in the broadest terms; biological, stepfather, adoptive father, carer or any adult who identifies themselves as having a fathering role or responsibility for children. Once recruited it transpired that all the participants were biological fathers, however, this was not deliberate in any way during the recruitment process. The goal of the study was to recruit a sample of eight to fourteen fathers. The final sample was comprised of ten fathers. In qualitative research the focus is on the quality of the data obtained rather than the quantity of the participants involved. Ensuring that an appropriate sample is identified is key to establishing rigour in any study (Silverman 2014). Denzin and Lincoln (2005) discussed the value of purposeful sampling in seeking out participants who belonged to groups or who had experiences which were relevant to the research question.

Potential participants had to meet the following inclusion criteria:

- Fathers of children born with a congenital heart disease
- Fathers who could speak English and provide written consent.
- Fathers whose children were at various stages of the treatment process e.g., antenatally, Neonatal Intensive Care, Paediatric Intensive Care, In-patient wards or at home awaiting treatment.

  or
- Fathers whose children had completed treatment.

In order to limit potential harm to participants, particularly those whose children had reached the limits of medical intervention the following exclusion criteria was applied:

- Fathers whose children were not able to access curative treatment
- Fathers whose children required palliative care.

Participants were recruited with the aim of obtaining rich data on the experience of fathers when their child is diagnosed with CHD. The final sample consisted of ten fathers who had accessed care for their child in a number of SCSC. Silverman (2014) discusses data saturation where data can be considered complete, when no further information is unearthed, due to the individuality of the fathers' stories, data saturation is not relevant to narrative, rather the quality of the stories told. Fathers in my study had similar, but also some different experiences, which were unique to the individual, demonstrating their distinctiveness. The uniqueness of the individual's experiences in narrative is recognised by several authors (Kleinman 1988; Frank1995; Riessman 2008 and Mattingly 2010). The recruitment was effectively complete when the stories being shared demonstrated the variety of experiences that fathers had encountered. A different sample of fathers could well present experiences in common but also in contrast to the fathers within my sample.

I wanted to gain a sample of fathers who accessed care in a range of CHD centres in order to capture the widest CHD journey possible. The stage of treatment was less important. However, it was relevant that fathers had been through at least one treatment episode at a SCSC; for example, this could have been cardiac catheterisation as part of the diagnostic process or invasive surgery. The fathers within the sample could have been experiencing care at different stages e.g., diagnosis, definitive surgery or follow up care and monitoring. I wanted to ensure that the sample represented this journey, which it did, with some fathers engaging in the first interview soon after surgery. At the point of the second interview three fathers had experienced further surgery for their children with the remainder being reviewed annually.

The two exclusion criteria were included in order to protect the families as I did not want to intrude if fathers were unable to access any ongoing treatment for their child. Some babies born with complex CHD may be unable to access surgery and will progress to palliative care services, this is also true of older children who may have reached a point with complex CHD, where further treatment would not be in their best interest. During the course of the study there was always the potential for change in the treatment options available for the child, at which point I would have discussed participants willingness to continue, however this was not the case.

Recruitment of the fathers mostly took place with the assistance of the Children's Heart Federation, a national children's heart charity which supports children and families with CHD. The charity has an active online presence and a regular newsletter. They were supportive of the research and actively promoted it over several months. Eight out of the ten fathers in the study were recruited in this way. The charity included details for my study on their website, in the newsletter and on their social media. For online recruitment a web information sheet was developed (see appendix 4) which the charity posted along with further contact details. The fathers contacted both me, and the charity directly. Once I had their details, I emailed the fathers to introduce myself and forwarded a copy of the participant information sheet for them to consider their participation (See appendix 5). This information included details on the scope and nature of the study as well as information around consent and anonymity. I gave the prospective participants a short cooling off period of around three days and then contacted the fathers again by email, asking if I could contact them by phone to introduce myself, discuss the study and to answer any questions. All fathers included in the study received the participant information sheet and a follow up call before taking part. Two fathers were recruited through conversations with staff within the university, they had friends or acquaintances with children diagnosed with CHD. The same process was followed in that they were contacted by the person who knew them to gain their permission for me to send out the participant information sheet. Once I had been granted permission, I forwarded the information again, left a cooling off period and then contacted them directly. I wanted to ensure that at no point did any father feel obliged to participate in the study.

In the original contacts from the charity there were a further six fathers who expressed an interest in the study. Of the six expressions of interest, three fathers were unable to participate due to international travel, repeated hospitalisations and a significant change in their child's condition. The final three fathers did not reply to my email following their initial expression of interest and receipt of the participant information sheet. I did send one further email to which one father replied, but again on follow up, he did not participate in the study.

In developing both the study and recruitment strategy I was grateful for the input of a CHD Nurse Specialist and other charities. I met with the nurse specialist who helped inform my thinking around the recruitment of fathers to the study and provided further insight into their experiences, including the complexity of the referral and care process as it is currently organised in the United Kingdom. When I met with the CNS, we discussed recruitment, at that point, I had considered recruiting solely at the local paediatric cardiology centre however it became apparent that the families would generally follow the same referral process with treatment in one CHD surgical centre. From this discussion, I came to the decision that wider recruitment was important so that fathers experiencing different care across CHD settings were included.

The CNS also identified a lack of research and wider professional literature which examines fathers' experiences when their child is diagnosed with CHD, therefore supporting my view of this being an under researched group. Other CHD charities were helpful in the development of my approach to recruitment. The charity, Contact a Family, regularly come into the university to teach undergraduate students. The discussion with them revolved around families' experiences and particularly the practicalities of care and medical management being delivered across centres, both in Wales and England. This helped in my consideration of wider recruitment that reflected referral patterns where a child could be diagnosed in one part of the country and have to travel some distance for treatment at the CHD surgical centre. For example, children in Scotland can only access CHD surgery in Glasgow, in Wales CHD surgery is undertaken either at Bristol Children's Hospital or Alder Hey in Liverpool. The representative from the charity also talked of the need for fathers to be supported more and their lack of visibility both in reports and recommendations but also in the hospital setting.

I also engaged with the Evelina Hospital charity (ECHO), Children's Heart Association and finally the Children's Heart Federation. All the CHD charities expressed an interest in the study; however, the Children's Heart Federation were the most engaged and had a very active social media presence and website on which to promote the study. The project manager engaged with the study and talked of the value of researching fathers to explore their experiences and needs, which they felt would be different to that of mothers. Overall, these were all positive steps in providing me with useful insights into the experiences of families and fathers in particular.

4.6 Data collection

Semi-structured interviews were used to explore fathers' experiences from diagnosis to definitive treatment. Open-ended questions guided the interview process in order to gain clarity (Streubert and Carpenter 2011). By using this approach, fathers were guided through their narrative in order to explore their experiences, tell their story and be heard. The focus here is on creating narratives based on the stories that were shared by the participants. These narratives create rich data in order to inform healthcare professionals of fathers' needs and experiences in an under-researched area.

Data were collected over a period of 2 years through the use of two semi-structured interviews. Eight of the ten fathers were interviewed face to face, with the remaining two fathers interviewed online. All participants had follow up discussions, these took place between the first and second interview and following the second interview. All but one of the participants were interviewed twice. One father was not contactable for second interview. The interviews lasted between forty minutes and an hour and a half with first interviews tending to be longer in duration than the second round. The average interview time was an hour. Following both sets of interviews a written transcript was produced from the recordings. The transcripts were returned to the fathers in order for them to review their content. The discussion between the first and second interviews, allowed fathers the chance to read their transcripts prior to the second interview. Transcripts were again returned after the second interview, for fathers to read and to voice any further views or possible amendments to their narratives.

4.6.1 The Interview

Most narrative studies within human sciences are based on using interviews to gather data (Riessman 2008). This is supported by Yeo et al. (2014) who highlight interviews as being the core qualitative research method in which to gain insight into the participants' social world. Mishler (1986) described interviewing as providing the opportunity to obtain an in-depth account of the participants' experiences. When utilising a narrative approach, the interview allows for meaningful collaboration in exploring lived experiences were the interviewee's become active participants in the research process. The interview has an interactional element that allows for interaction and clear communication to take place (Gubrium and Holstein 2011). Kvale and Brinkman (2009) identify that the interview is a form of conversation in which the objectives and role of the researcher differ to everyday talk. Kvale and Brinkman (2009) use two metaphors to describe the interview process. The first is that of a miner, where the interviewer accesses people's knowledge and experiences. Yeo et al. (2014) describes this as being within the positivist or post positivist arena of social science research where knowledge is viewed as a 'given'.

'The knowledge is waiting in the subject's interior to be uncovered, uncontaminated by the miner.' (Kvale and Brinkman 2009, p 48).

In the second metaphor, Kvale and Brinkman (2009) describe the interviewer as a traveller who,

‘Walks along with the participant asking questions and encouraging them to tell their own stories of their lived world’ (Kvale and Brinkman 2009, p 48).

This process of walking with the participant leads to the development of new knowledge and understanding for the interviewer. knowledge is viewed as something that is not already in existence but something to be created and developed in the interview, with both the interviewer and interviewee participating in the production of knowledge and its meaning. This reflects my own approach within the interviews, of asking broad questions and accompanying the fathers on their journey, as they recounted their stories over their experiences with their children.

There are various types of interview that can be undertaken and variation in their form. Nokes and Wincup (2004) identified three types of interview: structured, semi-structured and open. Structured interviews tend to have a range of pre-set questions and are closer to a positivist approach. Semi-structured interviews have a range of questions to structure the interview which allows for some flexibility in the interviewer’s approach. Open interviews will start with a deliberately broad question often around the participants’ story or journey.

Irvine et al. (2012) found that the style of qualitative interview varies with no one approach being superior to the others. The most important feature of interviews is that the approach answers the questions being asked (Gubrium and Holstein 2004). Face to face interviews are more common with the advantage of being able to observe non-verbal cues which would not be apparent in a phone interview and potentially less apparent online through using Skype, Facetime or Zoom. The advantages of online interviews are clear, in that the interviewer can draw from a wider pool of participants unhindered by location or distance. Where both time and funding are an issue, an online approach can allow for a wide sample with minimal costs incurred. Irvine et al. (2011;2012) does make some criticism of telephone interviews as lacking the visual benefits of face to face and online interviews.

Yeo et al. (2014) highlighted the value of semi-structured interviews as providing some structure with an ability of the researcher to maintain a degree of flexibility in order to explore responses. They identified key features which are present in the interview structure. Interviews are interactive allowing for a back and forth in subtle questioning and responses, this allows the researcher to delve below the surface of what is being said and to gain depth in the exploration. There is an ability to recap on answers drawing on the participants' past experiences which contribute to the development of new knowledge with both the researcher and participant sometimes exploring areas that neither had explored before.

In determining the interview questions, it was important to refer back to the research questions. Yeo et al. (2014) relates interview questions to cartography and the mapping of key features. Questions discern the shape and range of the terrain, with key features identified. Interviews involve an iterative process, in this study open questions were used to gain insight into the fathers' experiences. The questions were non-leading and formulated in such a way as to be sensitive to the potentially emotional experiences that fathers would discuss. Mapping questions tend to be broad with more probing questions used to follow up responses. In the majority of my interviews the questions did remain quite broad in order to introduce the fathers into an area for discussion with limited use of probing questions so as not to disrupt the narrative, although there were some areas that required further depth, particularly when trying to put issues into a timeline in order to identify turning points in their stories.

Some approaches help to guide the interview in order to avoid potential pitfalls. It is important to never make assumptions, particularly around questions as the participant may not understand the wording. Avoiding initial comments on answers, summarising or finishing answers for participants should also be avoided (Yeo et al. 2014; Silverman 2020). It is important not to close down answers to questions and to move at a pace that is comfortable for the participant. My longest interview lasted nearly one and a half hours. The father was particularly reflective and took time to think about the question and formulate answers, he also linked subsequent answers to previous areas of discussion. It is important to be sensitive to body language which is difficult with online interviews but there are visual cues which can be detected.

The interview process is a demanding one both on the researcher and participant (Silverman 2010; Rubin and Rubin 2012). Both authors identified that the interview process is challenging, psychologically, cognitively and to some extent emotionally depending on the research topic. Hammersley and Atkinson (2007) also highlighted the challenge of interviews, particularly cognitive challenge, with the researcher needing to actively listen to what is being said and at the same time consider what is not said or the sub text. Follow on questions are important here to ensure that rich data is not missed. Keeping a mental note in order to be able to return to an area of discussion is important in any interview. Other areas to consider in interviewing include developing a rapport in order for the participants to be comfortable in exploring their experiences and if possible, to engage in practice interviews or observe more experienced researchers.

The participants within the study were spread across Wales, England and Scotland. In order to interview them it was important that they had control of the environment that they would be interviewed in. King et al. (2019) discusses the importance of the physical environment for interview and the value of privacy. I gave the fathers choice over the location and venue for the interviews. I interviewed five fathers in their own homes, two via Skype, who were also in their own homes at the time of the interview, two in private rooms in their place of work and the final participant in a quiet corner of a hotel coffee area. This did mean a significant amount of travel, but I found this useful, particularly on the journey home to be able to listen to the interview recording again and to formulate early thoughts. All but one of the fathers was interviewed alone. If a partner was at home when I arrived, they tended to go out or move into another room. In one interview the mother sat towards the back of a through lounge. This was interesting as it did slightly change the dynamic of the interview as they corrected their partner from time to time when he was confused around the sequencing of events and timeframes. However, there was some value in this, in understanding the different focus that the couple had on their journey. One father was interrupted on a Skype call by his partner entering the room. Verbally and visually, the interview changed with the father reluctant to carry on discussing a specific event. There was some discussion off camera, which I could not hear and when his partner had left, he carried on discussing his experiences as he had done before.

Various authors have discussed the importance of the interview structure and the stages to be followed to facilitate the process (Rubin and Rubin 2012; Silverman 2020). Lune and Berg (2012) liken interviews to a drama with a clear opening scene, development of the narrative and finale. Yeo et al. (2014) identify stages of the interview process which I have followed in both sets of interviews within my study, as I found these helpful as a novice researcher.

Stage one involved the arrival at the interview and introductions. I had already contacted all the fathers via email and by phone to arrange the interview. For the first interviews eight out of ten were face to face. The final two interviews were undertaken on Skype, the first due to distance with the father living in Scotland and the second due to the father's working commitments and travel. For all participants I introduced myself again at the start of the interview and briefly engaged in chat about their family.

Stage two involved discussion of the focus of the research and clarification of any points from the participant information sheet, which they had received in advance. This was also an opportunity for the fathers to ask any questions or clarify any points. I discussed confidentiality, anonymity and advised fathers that if there were areas that they did not wish to explore then that was acceptable. This was the point at which the fathers signed the consent form (See appendix 6). They had been sent this via email in advance of the interview so that they had the opportunity to read the content before they were invited to agree and sign.

Stage three of the interview involved background information being obtained; age, occupation and outline of the family composition before moving on to more searching questions.

Stage four was the substantive part of the interview. In my study this was where key questions were asked and potential turning points explored at the participants pace. My opening question was to ask about the father's upbringing, as a way to gain some life history and influencing factors on their approach to fatherhood. Questions then followed around planning for children, the journey through pregnancy, diagnosis, first and follow up treatments and key points such as transfer of care. Yeo et al. (2014) highlight the importance of the flow of conversation at this stage of the interview in order to allow participants time to tell their story. In the interviews I tried to avoid interrupting and waited for an appropriate time to clarify any points.

Stage five Yeo et al. (2014) identifies that it is important to signal that the interview is coming towards an end point. In my interviews this seemed to be more natural, as the fathers generally covered the areas that they wished to discuss.

Stage six is the point immediately following the interview. It is important to ask if there is anything that the participants want to add and to outline what happens next. In both sets of interviews, I talked briefly about transcription and explained that transcripts would be returned to fathers to read prior to the second interview.

I followed the same approach in the second set of interviews. Fathers had the chance to review their transcripts ahead of the interview. I opened the second interview by asking how the family were and what developments there had been with their child's illness. I then moved on to explore the areas for discussion which mainly revolved around relationships with healthcare professionals, further treatment and interventions that could improve their experiences across the CHD journey as fathers. These were areas that had developed out of the data analysis from the first interviews.

4.7 Data Management

Data within this study were obtained in audio and then textual form. Each interview was audio recorded using a digital audio recorder and then transcribed verbatim. Following transcription, both the audio and transcribed data were stored on a password protected computer in line with university policy around data security. A back up copy of both audio and transcribed files were stored on a password protected external drive in a locked cabinet in a locked office. To ensure confidentiality files were labelled with pseudonyms. The text that appears in this thesis is also anonymised using pseudonyms. All identifying participant data has been kept in a separate secure location, from the audio and transcribed files.

The data obtained from both sets of interviews amounted to some 200,000 words that required analysing, organising and storing in an accessible format. Silverman (2000) and Mason (2002) highlight the importance of developing categories or organising terms in order to interrogate the data in an accessible way. Initially I felt overwhelmed by both the volume of data and how it should be organised. I used Microsoft word to transcribe the data and to identify key categories or turning points in each transcript. This was time consuming and at times confusing. I accessed training within the university on NVIVO. Once I had completed the training, I imported my transcripts into the software package and began coding entries. This meant that different transcripts could be easily accessed, and these were categorised with appropriate nodes. Silverman (2010) clearly identifies the advantages of using qualitative data software packages as an analytical tool in that large volumes of data can be categorised and coded saving the researcher time in trying to manually code large amounts of content. A range of turning points were established from the data analysis such as pregnancy, treatment and planning for fatherhood. Although I found NVivo helpful, I also used annotated transcripts as it helped to visualise the findings.

4.8 Data Analysis

Data analysis is a central tenet of research, which Joyce (2015) described as a process through which the data gathered are organised and structured by identifying key elements, labelling and coding. In considering data analysis there are various approaches that can be undertaken. Polkinghorne (1995) describes narrative analysis as a procedure where data are organised into a structured coherent whole. Riessman (1993) highlights the importance of not fracturing the narrative too much when analysing the data to ensure that it is presented in a way that allows the reader to gain clear understanding and insight into the participants' experiences.

Riessman (2008) identifies a range of approaches to narrative analysis rather than a standard set. Thematic or holistic analysis allows the researcher to identify the contents of story and meaning inherent within it. Riessman (2008) advocates this approach particularly for novice researchers new to both narrative and data analysis.

Structural analysis has its origins in Labov and Waletzky (1967) work with a focus on form rather than content; how the story is told and how it links to the next story. Riessman (2008) also refers to dialogic /performance analysis which is a broad interpretive approach. Holloway and wheeler (2013) find that this approach is similar to discourse analysis where there is a focus on content and form alongside the participants involved and who their story is narrated to. Riessman (2008) refers to this as a 'hybrid' approach which utilises aspects from other approaches. She does not recommend this approach for novice researchers. Finally, Riessman discusses visual analysis where the narrative focuses on photographs or other visual media.

The goal of data analysis was to analyse the fathers' stories of their experiences when their child was born with CHD. I felt that it was important to explore each participant's narrative, an approach advocated by both Polkinghorne (1995;1998) and Riessman (1993; 2008). This was to ensure that there was a depth to my understanding of the participant's experience.

To attain narrative from participants, researchers can use semi-structured interviews in which participants can present their experiences. The story told is not necessarily the experience itself verbatim, but a representation from this as memories may change over time and some parts of the narrative may be prioritised over others (Holloway and Freshwater 2007; Riessman 2008). In considering data analysis there are various approaches that can be undertaken with narrative.

Frank (1995) identified three typologies of narrative in his own work: restitution, chaos and quest. Restitution links to Parsons (1951) Sick role where the patient is seen as not being at fault with their illness and therefore free from normal responsibilities, but they must follow certain prescribed actions. The patient should adhere to the treatment as laid down by the doctor, access expert help and most importantly get better. Frank (1995) identified restitution as being the culturally preferred narrative in Western society. There is a moral dimension here to adhere to prescribed norms. The chaos narrative lacks order and structure and is told by patients with chronic, life threatening or terminal illness. In Frank's view the story can be difficult to follow as it does not present chronologically. To be effective the storyteller must be distanced from it, as the person experiencing significant illness may find it challenging to discuss. The chaos narrative can demonstrate a lack of control by the narrator over their lives. This links to the fathers' narrative in my study where the diagnosis of having a child with CHD sets the family on a journey in which they have few options and little control over. Most of the families received their diagnosis antenatally so were unable to prepare for the shock of being informed that their baby had a heart problem. Some elements of the chaos narrative appear in all of the narratives in my study. In exploring chaos narratives Frank (1995) cautions against hurrying the patient who is telling their story, as this denies the individual's right to share their experience. The quest narrative reflects the journey people take with illness or disability (Holloway and Wheeler 2013). There is an element of learning within these stories, which often appear in mainstream media and demonstrate what has been learnt throughout the 'quest'. This type of narrative is usually chronological in form, may contain a moral dimension and can be transformative to some extent as aspects of control are re-established, Frank (1995) places some importance on the differentiation of the types of narrative in order to create listening devices to hear the patient's story in its entirety. Frank's (1995) typologies were helpful in listening to the father's stories and hearing aspects of all three typologies in both interviews, and as they explored their experiences at various turning points in their child's care. Frank's approach aided me as a novice researcher in hearing the father's stories rather than using this approach as a set structured procedure for data analysis.

Polkinghorne (1995) suggested that there are two types of narrative analysis for narrative inquiry: analysis of narratives and narrative analysis. The analysis of narratives or paradigmatic mode of analysis focuses on experience as being ordered, organised with some consistency. Within this approach general features are classified into different categories. This process relies on paradigmatic cognition, which according to Polkinghorne (1995, p.10) "Produces cognitive networks of concepts that allow people to construct experiences as familiar by emphasizing the common elements that appear over and over". In qualitative research a paradigmatic approach is frequently used (Kim 2016). When this approach is used common themes or conceptual manifestations are seen in the data. In the analysis of narratives, Polkinghorne (1995) states that findings are organised around descriptions of themes that are common across the stories that have been collected. Kim (2016) described Polkinghorne's approach as identifying categories of particular themes and the relationship between them, while discovering commonalities across the different sources of data. The aim being to produce knowledge from a set of evidence across a collection of stories. Narrative analysis is described by Polkinghorne (1995, p15) as "the configuration of data into a coherent whole". In this approach the emphasis is on events and actions which combine into a coherent plot. There is a final story which is congruent with the data, establishing narrative meaning that are not always explicit in the data themselves. Ricoueur (1980) describes this approach as drawing events or happenings together into a temporally organised whole.

Methodologically, the analysis in my study was based on Polkinghorne's (1988;1995) analysis of narratives approach where common themes are evident within the stories collected from the participants. Polkinghorne (1988) states that the participants story allows for explanation of past events that account for the journey outcome. Events are brought together and organised into a plot. Kim (2016) summarises Polkinghorne's analysis of narratives (paradigmatic mode of analysis) as an approach to data analysis which describes the categories of particular themes while observing relationships among categories. Within this approach common elements are observed across a number of data sources; in my case the stories of the ten fathers within my study. From the data, knowledge is produced from the evidence found in a collection of stories.

The stories in my study reflected fathers' experiences across their child's illness trajectory. In the study there were three overarching themes: journeys to fatherhood, disruption of the expected fatherhood narrative and an uncertain future. The three themes are somewhat akin to a three- act play, where plotlines are developed out of the fathers' experiences at key points in their lives. These themes provided structure when developing the findings chapters. Within these themes were turning points which were generally common to several fathers, which in some ways was to be expected, as all had a child with CHD and were likely to experience care, treatment and ongoing management in similar ways as prescribed by national standards.

A series of turning points were established within these fathers' narratives, such as the onset of fatherhood, pregnancy and treatment. For pregnancy this would include antenatal care, the antenatal scans and for some fathers this was the point at which their child was diagnosed with CHD. My approach within the data chapters was to identify turning points to explore the fathers' dynamic experiences.

As a novice researcher I looked for guidance on how to organise and analyse the data. Both Polkinghorne (1995) and Riessman 2008) discuss approaches to narrative analysis which could involve features including content, structure, language, or performative function. Joyce (2015) recommends that when identifying a method of analysis, the aims and philosophical basis of the study should be the foremost consideration. Analysing the structure, language or performative aspects of the data would not meet the aims of the study whereas the analysing the content would in exploring fathers' experiences.

Polkinghorne (1995), Holloway and Freshwater (2007) and Riessman (2008) all discuss the identification of themes within a story. Riessman (2008) does discuss thematic analysis in some depth which fitted the philosophical premise of the study in exploring the stories presented by the participants. This placed the participants' perceptions, interpretation of their experiences and actions at the centre of the research. This also allowed me to identify overarching themes and sub-themes or turning points within and across fathers' stories (Polkinghorne 1995; Holloway and Freshwater 2007; Riessman 2008).

Both Polkinghorne (1995) and Riessman (2008), suggest approaches to thematic analysis with Riessman discussing a thematic model. However, for me this lacked sufficient detail in terms of the structure and detail which I needed to guide me. I looked at various, more detailed, guidance which led me to identify Braun and Clarke (2006) as a suitable approach which they highlight as being appropriate for a novice researcher. The analytical process that I followed was conducted in five stages which did align to Braun and Clarke (2006) which I found helpful in developing the data analysis. The first three stages were focussed on developing my understanding of the fathers' experiences, identifying both similarities and differences in their journeys and their approach to their child's illness. In the final two stages both the plot and narrative were developed.

Data analysis was undertaken in five stages:

Stage 1 - Listening to the interviews.

It was important to hear the voices of these fathers and to immerse myself in their stories. By re- listening to the recordings a number of times I was able to identify, very early on, turning points in their stories, whether this was their planning for children or the search for knowledge to gain some control and understanding of their child's condition.

Stage 2 - Transcribing the data.

Having listened to each interview a number of times I then set about transcribing the data. This took much longer than I first anticipated but assisted in the identification of further turning points in the fathers' journey. I transcribed all of the data myself, I found a real value in this approach in terms of immersing myself in the fathers' stories. Each transcription was checked for accuracy against the recording several times. Data once transcribed was uploaded into NVIVO and printed in hard copy. To ensure a focus on the research questions within the data analysis unrelated material was set aside. Polkinghorne (1995) refers to this approach as narrative smoothing. There was not a great deal of this type if data which tended to be 'side stories' from fathers around upbringing and examples such as school activities.

Stage 3 Coding

Once the data was transcribed, I set about identifying initial codes through NVIVO and manually. The codes were often broad and aligned to turning points such as the antenatal scan. Initial codes were then collated into a series of categories or turning points with some codes appearing in a number of categories. At this point codes and categories were again reviewed in relation to the transcribed data as I was anxious not to miss any significant data. The fathers' stories were populated with turning points or events of significance. A number of fathers had similar experiences, the scan, diagnosis, transfer to a CHD surgical centre and surgical procedures. Other experiences were less consistent such as the search for information, coping mechanisms, and engagement with healthcare professionals. I found NVIVO to be a useful repository for depositing and organising data. I had attended the training which was informative and helped me to process the transcripts. However, I found that transferring the data on to mind maps and colour coded notes on flipchart paper helped me to visualise the data and the fathers' shared experiences. To develop the data, I moved back and forth between fathers' individual stories and the whole data set. Ayres et al (2003) and Holloway and Freshwater (2007) discuss the importance of developing story themes, which reflect the richness of the data obtained and the complexity of the participants experience. In undertaking this part of the data analysis, I could see individual plotlines develop for the individual participants as well as shared experiences.

Stage 4 - Developing the plotlines

As the plot was organised, areas of importance for fathers became apparent such as trust in healthcare professionals, the need to protect their family in the traditional father role and for a minority, accessing the appropriate services for their child. At this point it was important to consider theory in order to inform the emerging story, particularly around fatherhood, masculinity and roles. It became apparent that these were all influential on the choices that fathers made and how they approached their child's illness. At this point stories deviated in how fathers approached their child's illness, for example, some fathers talked of burying their heads in the sand and acceptance of their child's diagnosis, while other commenced a search for detailed information and access to second opinions and experts in the CHD field.

Stage 5 - Developing the narrative

This involved constructing the narrative for each father, to represent their experiences and how they made some sense of them. There is some fracturing of the narratives as I wanted to present all of the fathers' experiences rather than exploring some more than others. The fracturing is generally around temporal turning points. The fathers in their interviews focussed on areas of importance for them. There were a number of similarities including their child's stay in critical care, trust in their local and in some cases specialist children's surgical centres. The content of the three findings chapters were then constructed around these turning points and the areas that the fathers explored. The narratives are my exploration of the fathers' experience, I recognise that others may look at them differently and come to alternate interpretations. Woods et al. (2002) identified that, like in all qualitative research, narrative data are open to various interpretations even with set data analysis procedures.

4.9 Quality in Research

Quality issues are important in both qualitative and quantitative research. King et al. (2019) highlight that in quantitative research there are universally accepted criteria for making an assessment of the quality of a study. However, in qualitative research there is less agreement about which criteria to apply (Kvale and Brinkman 2009). This study resulted in a series of unique narratives which have been developed from interaction between me as the researcher and the ten fathers included in the research. Lincoln and Guba (1985) identify four criteria as alternates to those used in quantitative research: credibility, transferability, trackable variance and confirmability. Riessman (2008) discusses quality issues with narrative research and highlights the importance of the participants' narratives, alongside the researcher's interpretation being consistent with the theoretical approach. Fundamentally, Riessman (2008) discusses persuasiveness, and the consistency and reflection of the participants experiences within the narrative which makes the findings trustworthy.

4.9.1 Credibility

Credibility refers to the appropriate use of the identified research methods and the sense that the researcher's interpretation of the participants' narratives are recorded accurately. The study involved engagement with the participants over a prolonged period of time. This ensured that there were opportunities for the fathers to review their interview transcripts after both interviews and add any comments or clarify any areas for discussion. Only one father added to their narrative, which was an expansion on a point they made in the interview about their approach when discussing their child's treatment with a surgeon. I felt there was value in telephone contact prior to the first interview and following the second, as this helped develop a sense of trust in the relationship. Prior to the first interview I ensured that there was sufficient email and telephone contact in order to be acquainted before we first met. Accuracy in recording the interviews, transcription and data management is also vital for demonstrating credibility. Silverman (2014) highlights the risk of error and bias when working with data and steps should be taken to avoid this. I attempted to reduce errors and bias by systematically analysing and processing the data, transcribing verbatim and staying close to the intended meaning in the participants stories, while remaining aware of my own thoughts, feelings and characteristics as a man, father and nurse, which could influence how the data was presented. Although the literature review and key theoretical concepts chapters informed the development of my study, it was not used to guide or structure the overarching themes or turning points within the findings. Credibility and some degree of reassurance came from presenting findings to peers, undergraduate students and qualified nurses who expressed the view that the findings also reflected their experiences in aspects of care and in supporting fathers specifically.

4.9.2 Transferability

Transferability is based on the researcher's capacity to demonstrate the extent to which conclusions from detailed data produced in one setting can be transferred to another. Geertz (1973) refers to the notion of thick description, in which the researcher provides detailed description of the identified phenomena. By undertaking a narrative study, in depth transcripts were produced which would have the potential to reflect other fathers' experiences. Certainly, when discussing turning points within the transcripts, these were similar, due to the investigation and management of their child's condition. What is not transferable is fathers' views of their own experiences and responses to the circumstances that they found themselves in. Undertaking a narrative study at a different time with other fathers, would result in further unique narratives but the journey in terms of diagnosis, treatment and management would be similar.

4.9.3 Dependability

Dependability is an indicator that the findings are based on the data collected from the participants. The data analysis involved developing categories or turning points in the fathers' experiences. These were developed both manually and within NVIVO, individual cases were populated, and nodes identified demonstrating experiences from different participants. The data collected was transcribed and reviewed by the participants.

4.9.4 Confirmability

Careful planning is important in ensuring the confirmability and objectivity of any study. King et al. (2019) highlight the fact that objectivity by qualitative researchers is challenging due to prior experiences, inherent personal values or preconceived ideas around the participants. In trying to minimise this, it was important that I reflected on my background both personally and professionally in order to minimise researcher bias.

4.9.5 Reflexivity

Reflexivity aids the researcher in recognising the influences that inform the decisions and choices that they make in their research and offers some context to them (Davies, 2020; Engward and Davies 2015). I included a personal narrative in chapter 1 of this thesis in order to inform the reader of my background and position as both have influenced the choices that I have made throughout the development of my study. Several authors discuss the value of reflexivity in undertaking research (Kleinsasser 2000; Holloway and Freshwater 2007). I kept a handwritten reflective journal during the period of the study which includes field notes but also my own thoughts and feelings at various stages of the research. This has served as a means of documenting ways in which the experience has impacted upon me as well as areas which needed to be addressed. Although there are a number of software packages that I could have used to collate my thoughts, I believe there is value in the visual nature of handwritten notes and the occasional doodle. Some notes are personal to myself and my family and the challenges that we have experienced. Others very much focus on the participants. The sense of achievement that I felt when I received ethical approval, my worries that I would not find anyone to recruit and finally my appreciation for the CHF charity when they promoted the study and recruitment commenced are all areas that I have documented. I have detailed each interview and my thoughts and feelings on that interview.

In commencing the study, I was aware that my background as a nurse specifically but also as a father and an academic might influence the fathers within the study in the way that they would respond at interview. I felt it was important to be honest and not hide my clinical background, so I did identify in the participant information sheet that I was a children’s nurse with a background in critical care. Davies (2020) highlighted her belief in the importance of being open with research participants in how the researcher is situated. During data collection it transpired that the fathers did speak about critical care in relation to the care that was delivered to their children but did not really relate this to my background. I also identified myself as a novice researcher, in retrospect I am not sure why I did this; I think it was to ensure that the fathers did not expect an experienced researcher well versed in facilitating interviews. I did not include the fact that I was a father in the participant information sheet, however, should the question arise, I would answer honestly. A number of fathers did ask, generally it was at the first interview as part of a general conversation prior to engaging in more depth.

Reflecting back on my experience, certainly during the preparatory stage I had concerns around recruitment, and whether anyone would be interested in the study. From my own perspective as a man and father, I worried about how engaged the participants would be in talking about their thoughts and experiences of having a child with such a serious illness. I was surprised at how willing fathers were to share their stories with a sense of wanting to make things better for others, or just as an opportunity to talk to someone about the impact CHD had on their lives and expectations as fathers.

4.9.6 Ethical considerations

This study was approved by the Research Ethics Committee of the School of Healthcare Sciences, Cardiff University, (See Appendix 7). Recruitment activities to undertake the study commenced after approval was granted. The Children's Heart Federation approved the study for inclusion and promotion on their website, in their newsletter and in their various social media channels.

The safety and protection of participants is paramount in any research study. A range of considerations was necessary to ensure that I protected the participants. As I was visiting fathers in their own homes and off the university site, I ensured that Health and Safety guidelines were followed at all times. I adhered to the Cardiff University (2009) fieldwork policy by undertaking appropriate risk assessments to identify potential hazards and to minimise the risk of injury or harm to myself or the participants I was visiting. I had an updated Disclosure and Barring Scheme check, which was needed as I was visiting homes where children might be present, and I ensured that my safeguarding mandatory training was up to date.

As part of the study approval process, it was important to consider both harm and disclosure. In terms of a safeguarding disclosure, I was familiar with referral processes to statutory authorities in safeguarding both children and adults. There were no issues identified within the study that required any disclosures. As well as adhering to the standards for confidentiality for my professional body, I also adhered to the Cardiff University Research Integrity and Governance Code of Practice (2015). The consent form included contact details for a member of staff within the research department who would be a point of contact if any participant identified issues with either my conduct or the study. I also ensured that I had completed the university annual information security update which is part of the mandatory learning programme for academics. Confidentiality is the foundation of nursing practice and as a registered nurse, I adhered to my responsibilities under the Nursing and Midwifery Council Code of Conduct (2018).

4.9.7 Consent

Full informed consent is a cornerstone of research, consent should be informed, voluntary and freely given (Beauchamp and Childress 2013). The voluntary nature of consent was fully explained to the participants as was the option to withdraw consent at any point or to not participate in second interviews. At the point of the second interviews, I again reiterated that the fathers could withdraw if they so wished. In order to ensure full informed consent all potential participants received a participant information sheet, (Appendix 5) which contained all information about the research in advance of their consent to participate. The participant information sheet outlined the scope of the study, the nature of the father's involvement, how data would be safely stored and issues of confidentiality and anonymity. Participants were given some time to consider the information provided and this was well in advance of any interviews taking place.

4.9.8 Confidentiality and Anonymity

All participant data was anonymised so as not to reveal the participants identity. All participants were given pseudonyms as were their children and partners, if they were referred to by name in the interviews. All participants were unknown to me prior to the study and to them contacting me via the CHF charity or through university contacts.

Participants were informed that their confidentiality would be maintained throughout the study in line with research governance, the NMC Code of Conduct (2018) and university procedures. Fathers were informed that the study was voluntary and that they could withdraw at any time. Participants were anonymised using pseudonyms rather than their actual names and the same applied to their family. Prior to commencing the study full informed consent was obtained from all participants. All clinical areas were also anonymised so as not to identify either the CHD surgical centre, referring hospital or individual healthcare practitioners. CHD services are a relatively small speciality where care is delivered in regional centres, this increases the need for strict anonymity. This was important so that fathers could speak freely. During the first interview, one father asked for confirmation that his responses could not be traced back to him prior to elaborating on an event which took place during his son's care.

Confidentiality has been maintained throughout the period of the study and all records have been safely stored in accordance with university procedures for the management of data storage and research records (Cardiff University 2011).

4.9.9 Risks

Being a father of a child with CHD can be a stressful experience. Treatments are invasive, carry risk and are ongoing. Even when the child has had corrective surgery, they will require annual reviews throughout childhood and potentially for the rest of their lives. I was cognisant of the potential distress that participation in this study could cause the fathers whilst recounting their experiences over a period of time. I was also aware of the support and counselling that could be offered by the Children’s Heart Federation and other charities as well as GP services should I have needed to signpost fathers to further support. I ensured that the interviews were well paced and that fathers could take a break if needed. I signposted one father to support services after the first interview. He continued to participate in the study and at the second interview informed me that he had accessed counselling, which he felt had benefitted him. While considering the risks it was important to remember my role as a researcher rather than a nurse (Sheldon and Sargeant 2007). My role here was in the event of a distressed father to signpost rather than care for them. I also recognised the potential for me to be affected by the fathers’ stories, this did not happen however had it happened, I would have sought support both from my supervisors and research department.

Summary

This chapter set out to describe the methodological approach used within the development and implementation of the study. The chapter began by exploring the use of narrative in research, as this was the chosen approach to achieve the aims of the study. Narrative has been described as the stories people tell in order to make sense of their experiences (Polkinghorne 1988; Riessman 2008; Rejno et al. 2014).

A narrative design was used to facilitate the participant’s individual storytelling. Narrative was considered an appropriate approach as I wanted to hear the fathers’ stories and for those stories to be as closely related to their experiences as they had presented them. Various authors have discussed the value of narrative for stories to be heard in a meaningful and authentic way by researchers (Jovcheloviatch and Bauer 2000; Polkinghorne 2007; Holloway and Freshwater 2007; Riessman 2008). Paley and Eva (2005) discuss the role of the plot and story within narrative. The plot requires a central character who experiences a problem, in the case of my study, this is the father whose child is born with CHD. The father is the central character but their relationship to other characters including their partner, child, wider family members and healthcare professionals is key to understanding the experiences that fathers have had throughout their child’s illness and treatment to date. In deciding to take a narrative approach within my research, I was also considering dissemination, and the benefits of healthcare professionals hearing the fathers’ stories in order to influence clinical practice and improve how fathers are viewed and involved in care.

The approach to data collection and analysis was discussed within this chapter as well as the ethical considerations in undertaking research such as this with potentially vulnerable participants recounting emotive experiences. At each stage of the research process, I wanted to ensure that the participants would be protected as they were discussing sensitive areas of their lives. Data were collected through semi-structured interviews in order to elicit the fathers' stories. This approach allowed me as a novice researcher to explore the fathers' experiences over a period of time. All participants had experienced at least one cardiac surgery with their child, while others had repeated surgical interventions and ongoing treatment. There was a value in having participants with a range of experiences as they presented their story across different turning points. Data analysis was challenging due to the volume of transcribed content from the interviews. I followed an approach described by Polkinghorne (1988: 1995) as the analysis of narratives where common themes are presented from the stories collected from the participants. Kim (2016) described this approach as identifying themes across different sources of data which enables the researcher to discover commonalities. Thematic analysis across narratives is discussed by several authors as being an appropriate approach for the novice researcher (Polkinghorne 1995; Holloway and Freshwater 2007; Riessman 2008).

There were three overarching themes identified within the data analysis which were temporal in nature, journeys to fatherhood, disruption of the expected fatherhood narrative and an uncertain future. These themes where significant aspects of all father's stories and are used as chapter headings for the findings chapters. Within the overarching themes there are a range of turning points, again there is a temporal organisation of these which is reflective of the fathers' journeys. I have used the turning points to structure the findings chapters for example in chapter 7, the turning points are disrupted fatherhood, waiting for something to happen, handing care to someone else and new environments. These turning points were all clearly presented within the fathers' narratives and represent their different journeys and experiences particularly around the time of diagnosis and their child's initial treatment and first surgery.

Throughout the research process I have endeavoured to gather and present the fathers' stories as individual narratives of their experiences, but with some collective outcomes. The next chapter prefaces the three findings' chapters and will introduce the ten fathers who participated in this study.

CHAPTER FIVE - Introduction to the Findings Chapters

This chapter will introduce the ten study participants and their children who have been diagnosed with CHD. A brief outline of how fathers accessed CHD services is included which is typical of UK service provision, which is centralised in eleven SCSC. Finally, an overview of the findings chapters is presented. The following three chapters then move on to discuss fathers' experiences across their child's illness trajectory building on from the father's own upbringing and planning for fatherhood through to diagnosis, treatment and the participants' views of fathering in the future. These experiences were drawn from a number of healthcare settings and treatment episodes.

The fathers who participated in the study were spread across the United Kingdom and accessed and received care and management for their child from a range of local referring hospitals (LRH). These varied from children's hospitals without a paediatric cardiac surgery centre, district general hospitals with a single paediatric ward and maternity units. For all the fathers who took part their child's care had been delivered across a number of settings. A typical picture of a father's journey would be an antenatal scan at a local maternity centre which detected a heart anomaly, referral then being made to a specialist ultrasound clinic in another hospital before a diagnosis was made in a LCCC centre. For most fathers in the study their babies were delivered in a local maternity unit, then transferred to a neonatal unit, (NICU) then on to a CHD specialist children's surgical centre (SCSC). Once the surgery or first procedure was undertaken, joint care would then be delivered between the SCSC and local hospital with a paediatric in-patient facility. This is typical of the way that CHD services are organised and delivered within the UK (NHS England 2011; 2017). This can lead to fragmentation of support for families and a reluctance to access and trust local hospitals, as will be seen in the findings. The substantive care for all families was delivered through six of the current eleven NHS CHD surgical centres in the UK.

There are various ways that these narratives could have been presented. I have chosen to focus on turning points from within the fathers' individual journeys. These narratives within the study demonstrate fathers' experiences over a varying period of time. For some fathers, this was a single year and for others twenty-two years and still ongoing. These narratives are unique to the storyteller and demonstrate the way in which fathers have rationalised and made sense of their experiences. The data exhibit the interactions of the fathers with a range of healthcare professionals and the way in which treatment decisions have been made, in conjunction with their partners, at various stages of their child's care journey. The narratives offer an interpretation of events rather than being a comprehensive interrogation of each father's whole experience. Prior to the interviews I discussed the research aims with the fathers, and we agreed that they would discuss and present areas of their experiences that they were most comfortable with.

The fathers who participated in the study are presented in the table 1 below. Pseudonyms have been used to ensure that confidentiality was maintained, and that no personally identifiable data are presented. The fathers in the study were aged from their late twenties to early sixties and came from a range of socio-economic backgrounds. All but one was white British; Ray was born in the Middle East and moved to the UK in his early thirties.

Table 1: Participants

Father	Age	Children	Diagnosis	Stage of treatment
Steve	Early 50's	son and daughter	Son, Harry, Transposition of the Greater Arteries, Ventricular Septal Defect, Reduced pulmonary valve velocity	Surgically corrected, 12-month reviews.
Anthony	Early 60's	2 sons, 1 daughter	Son Carwyn, Sub-Aortic Stenosis, Long QT Syndrome	Surgically corrected, 12-month reviews
Liam	Late 20's	1 son	Son Jack, Transposition of the Greater Arteries	Surgically corrected, 12-month reviews
James	Late 30's	3 daughters	Daughter Chloe, Supravalvular Pulmonary Stenosis, Atrial Septal Defect	Surgical interventions, ongoing treatment
Scott	Early 30's	1 son	Son Shane, Absent Pulmonary valve, Mowat-Wilson Syndrome	Pulmonary valve replaced, ongoing treatment

Alex	Mid 30’s	1 son, 1 daughter	Daughter Lara, Double Outlet Right Ventricle	Surgically corrected may require future revision of surgery, 6-month reviews
Ray	Early 40’s	1 daughter	Daughter Majida, Large Ventricular Septal Defect	Surgically corrected, 12-month reviews.
Dean	Early 40’s	1 son, 1 daughter	Daughter Alice, Left Atrial Isomerism, Heterotaxy	Surgical interventions, ongoing treatment
Stuart	Mid 30’s	2 sons	Son Joshua, Hypoplastic Left Heart Syndrome, Atrioventricular Septal Defect	3 stage procedure, two surgical stages complete.
Tom	Mid 30’s	2 sons	Son Oliver, Transposition of the Greater Arteries	Surgically corrected, 12-month reviews

The findings chapters are structured in order to present the narratives by focusing on a range of turning points within their experiences which were evident when I was listening to the fathers’ stories while undertaking the data analysis. Chapter six explores journeys to fatherhood, with the fathers’ background and upbringing alongside planning for children and the pregnancy, which for some included the diagnosis of CHD. It was important that their back story was explored as this has shaped who these men are and how they have viewed their roles as fathers within their key relationships. Chapter seven explores disruption to the expected fatherhood narrative with a focus on the treatment and care delivered across a range of healthcare settings which are turning points in the fathers’ journey. Finally, chapter eight explores an uncertain future. Within this chapter, the ongoing relationships with healthcare professionals and the way in which fathers have adapted their lives to being the father of a child with CHD are discussed. The chapter also explores fathers’ views of their child’s future, which for some will mean repeated surgery and an uncertain prognosis. The majority of children in the study are below the age of 11 years and will require ongoing treatment and care for some time which impacts on their upbringing and normal family activities such as holidays, activities and education.

CHAPTER SIX - Journeys to Fatherhood

> *'Because he's my first-born, and I didn't really know what a dad was meant to be, I didn't really know what a parent was meant to be or meant to do, or how they react in certain situations.'* Tom

6.1 Introduction

The quote from Tom reflects the thoughts of a number of fathers within the study. Some had planned for a family, while other fathers had not considered having any children. What they all have in common, is that they were unprepared for having a baby who was so seriously ill.

This chapter explores the findings gained from the early part of the interviews where discussion was focussed on the initial turning points in these fathers' lives. These primary turning points were related to the fathers' own upbringing, planning for children and the pregnancy itself. For some fathers within this chapter, I have briefly discussed the impact of the diagnosis, as for several this information was given antenatally, meaning that they had between 20 – 22 weeks living with this diagnosis, although the definitive diagnosis was often given only after the birth. These are important areas for discussion particularly around the development of the fathering role and their early experiences of engagement with healthcare professionals across a range of clinical settings, where what could be termed as 'the planned parenting narrative' was disrupted by virtue of their child's diagnosis. However, for others, the diagnosis was made only after the birth. The stories within this chapter, therefore, focus on the men's journeys to fatherhood and the alteration in their perceptions of the fathering role by virtue of their child's diagnosis. All of the fathers' narratives have been included in this first findings chapter as it is important to introduce all the fathers and to start the process of their stories, and how they are being told.

The narratives within the study demonstrate the experiences that all of the fathers faced over this period of time. For some, this was only one year but for others it was twenty-two years and is still ongoing. The narratives are unique to these storytellers and demonstrate the ways in which the fathers have rationalised or made sense of their experiences. They exhibit the interactions that the fathers had with a range of healthcare professionals and how they have made treatment decisions in conjunction with their partners at various stages of their child's care journey. The narratives offer an interpretation of events rather than being a comprehensive interrogation of each father's whole experience. Prior to the interviews taking place I discussed the research with all of the fathers, and we agreed that they would discuss and present the areas of their experiences that they were comfortable with.

In each of the first round of interviews I began by asking the fathers to discuss their own childhood and upbringing. This was to get to know them and to understand the influence that their own childhood and upbringing had on their approaches to fatherhood in later life, the relationships that they formed as adults and how this had impacted the parenting role (Henwood and Proctor 2003; Ives 2014 and Kings et al. 2017). All of the fathers came from families where both parents were present in the early formative years, however for Tom and Liam, their parents had separated during childhood. Anthony had an upbringing which was separate from his parents as he was sent to a boarding school, which had impacted on both his childhood and later life. The narratives will be presented under four typologies reflecting similar experiences around childhood and the planning for children; an unsettled upbringing, a routine and normal life, planned fatherhood and hesitant fatherhood.

6.2 An Unsettled Upbringing

The three fathers who appear within this narrative all experienced an unsettled upbringing which they identified within their storylines. For Tom and Liam, this was through the breakdown of their parents' relationships and for Anthony it was due to being sent to boarding school. Throughout the early part of their stories each of these men discussed how their change in family circumstances affected their lives in a negative way. What they had in common was the need to 'do better', as they saw it, as fathers and to be present in their children's lives. For Anthony and Liam this was apparent from the start of their relationships with their wives. Tom came to the same realisation that he needed a different approach to fatherhood after the birth of his second son who was diagnosed with CHD.

Anthony

Anthony was the oldest father in my study being in his early sixties. He was married to Carys, and they had three children, two boys and a girl. The boys had left home with his oldest son developing his career and Carwyn, his middle child, undertaking a master's degree at the time of the second interview. His daughter was studying for her A' levels and hoped to go to university. Anthony, as will become apparent, has had a varied career finally settling in social work with clients experiencing end of life care. His son, Carwyn, had a later diagnosis of CHD than the other children in the study following an unrelated illness and hospital admission. The diagnosis came as a shock to Anthony and his wife as Carwyn had an uneventful birth and had achieved his developmental milestones. Carwyn's diagnosis was sub-aortic stenosis and long Q-T syndrome. Anthony was interviewed in his home, which was located within a well-established affluent suburb of a large city.

Anthony started by discussing his early childhood experiences:

> Well... I had ... err a very challenging childhood like a lot of my social erm background I went to boarding school at 8.

This was a significant and distressing experience for Anthony:

> So, didn't really see much of that my parents because, you know, the majority of your year is spent in a totally different environment really and so sometimes you'd come back and they wouldn't be strangers but, err, it it's a very unnatural experience.

Anthony described his experiences within the boarding school at some length with his dreams of being at home and having an upbringing similar to that of his own children:

> The prep school was only about 50 miles away, but it felt like 400 miles away, I was desperately homesick, and I always had this great fantasy, of just being able to go out of my house in an area like this with a satchel on my back and just go to school and come back again whereas, you know, it's not exactly Lord of the Flies but you are just left in a very tribal atmosphere.

Looking back at Anthony's transcript it is clear that he was uncomfortable in his boarding school environment and longed for home and as a father himself, he now strives to be present in his children's lives and has taken a different approach to fatherhood to his own father. This is an area of discussion that he frequently returned to in both interviews. Anthony discussed his father's busy life and interests that were very different from his own:

> He seemed to pack his life with other things... territorial army, sport and all sorts of different events so that you know the only way you could really have quality time with him was going along with his interests like sailing and skiing.

Anthony talked about his own interests growing up and what he would have liked to do with his father in order to spend time together:

> Things that perhaps would have appealed to my cultural side, we never went to the theatre, might go occasionally to the cinema erm, never went to galleries never went really to places abroad of… cultural interest it was skiing and sailing really or beach holidays, but they tried their best I suppose.

Throughout Anthony's interviews, his focus was very much on his father's influence on his upbringing rather than his mother. This was similar to other men in the study possibly due to the focus being on fathers. My initial question at the first interview was to ask about the fathers' upbringing and the parenting approaches they had experienced. However, Anthony reflected on this much more than any other participant and frequently returned to his upbringing across both interviews. Anthony was the only participant that I interviewed who attended boarding school. He talked of his childhood and parenting being passed on to others with a sense of disruption and questioning of his parents' choices for him:

> There is a sense that they hand over responsibility to these people, you know to teachers and er, so I find I look back and…... not quite sure what I can make of my childhood, I think a lot of it was …whether it was covering up truly the real me because you have to freeze your emotions when you go to these sorts of schools to fit in with the culture. When I was 8 or 9, it was pretty hard to keep the homesickness in and so you become a split person really, you have to freeze these feelings and because you're absolutely, you've got to be convinced if your parents love you that these are the right places.

Anthony was clear in his belief that his childhood had impacted on his adult life and parenting role, particularly in relation to the expression of emotional issues. He described feelings as emotions to be suppressed and related this to the British notion of the 'stiff upper lip'. He recognised that this approach had the potential to impact relationships and possibly parenting. However, this was an aspect of his life that he saw to some extent as being in the past and he had purposefully ensured that this had not impacted upon his relationship with his wife and children. Anthony recognised that his experiences in school and the lack of emotional engagement with his parents meant that he had to find ways to manage his feelings:

> Being able to say what you feel and being immediately able to go up to a parent and pour your heart out, you know you had to put all those things on hold and I can think of various events where I didn't go to my parents about things that really I should have you know, which have traumatised me but because that was just the way it was, you

> just didn't communicate on that emotional level, it would have been embarrassing, it would have been poor form.

He has tried to take a different approach with his own children influenced by both his own upbringing and his wife's outlook. He credits Carys with supporting his own development as a father. He was clear that when the children were young, he wanted to ensure that they had a 'more normal' type of childhood:

> The one that our children had, er...and we don't seem to have done too badly you know, they have all turned out pretty intelligent, normal human beings. Well-adjusted, not preening and obsessed with superficial appearances, realising that the heart and you know some of the important things in life are how you act towards other human beings, goodness, kindness, lovingness, so you know, I put that ahead of looks or achievements.

In contrast to his feelings about his own upbringing, he valued the depth of the loving and close relationship that he has with his children. Anthony briefly talked about the impact of his son's heart defect early in the interview:

> Obviously with a heart... the fact of Carwyn's heart condition probably.... it could have turned things difficult, but it probably strengthened the situation a bit.

This is an interesting perspective, all of the other fathers in the first interview discussed the negative impact of the diagnosis and living with a child with CHD and the uncertainty around long term management and treatment. They described how it impacted on their thoughts of the child's upbringing, future development and longer-term outcomes. Anthony's son was also much older than the other participants' children in the study, having just graduated from university. Anthony can therefore reflect on a much longer period of parenting than the other fathers. Anthony then returned to his own upbringing, education and changing careers:

> I went to a public school that produced Archbishops of Canterbury, but I was told that I wouldn't get the right grades for the things that I wanted to do. I had been chapel warden, my house master suggested that I followed a previous boy and did theology, so I went to university and did biblical studies then switched to French then I went and did teacher training and then did a rather mad year in London with a fringe theatre company and then worked in a barrister's chambers and then got back on to the teaching treadmill, taught in a private school ironically and then a state school.

He reflected on the links between his upbringing and changing career and the way in which this has affected his ability to settle in a career, regularly changing roles throughout his working life. He talked about the various careers that he had, these included community work, working in theatre, in the legal profession, offering himself up for ordination and in later years working as a social worker in various roles before finally settling into his current role. He felt this brought various life experiences together and it was a role that he was good at. He highlighted the importance of family relationships despite his often-changing career and its impact on his marriage, describing Carys as despairing of him at times but always being supportive.

Anthony reflected on his role as a father over time:

> I would say I was quite involved, we never quite expected to be so involved with hospitals as it turned out you know with Carwyn, but yeah, I think I would like to think that I've been a pretty proactive parent.

He contrasted his approach with his own upbringing and recounted a story where his older brother had been dropped off at a hospital for a tonsillectomy. His brother was left to find his own way to the ward at a time of limited access and visiting. Anthony had another brother who died in childhood. He discussed healthcare approaches then with the support offered now:

> My mother wasn't allowed to be with him on what turned out to be his final night, this was in the 50's and the nurse was quite horrible. She greeted my mother, in the morning by just saying that oh yes, he died last night ... what parents had to go through then with that mentality that mindset, compare that now with the way parents are treated in hospitals and kept in touch with everything and the Ronald Macdonald projects, it does enable you to carry on as a family even with these life-threatening situations.

Anthony reflected on the positives of having children, although it was his wife who led the decision to have them, describing Carys as being more focussed on having children. He described being an active partner throughout Carys' pregnancies, ensuring that he was present in antenatal classes. He talked about the sacrifices that parents sometimes make to ensure that their children have a good upbringing but also the benefits:

> You can understand your life more through having children and I probably understand my own childhood and early years better now and my own parents through having had children.

The close relationship that Anthony had with his wife and children was clearly evident across both interviews. As he talked about them, he would point or show me photographs and talk at length, particularly about the children's achievements, with a real sense of pride. He described a closeness in spending time with them at different events both in childhood and now that they had grown older.

Tom

Tom was in his mid-thirties and had started a relatively new career as a pharmacy assistant as well as being a musician. He was married to Caitlin, and they have two sons, Tim and Oliver. Oliver is his younger son and was born with transposition of the greater arteries, which had been surgically repaired. Tom described his upbringing as challenging because his father was absent and his relationship with his parents was difficult at times. Tom's interview was conducted over Skype, and I was anxious that this might have an impact on the discussion, with the potential for the interview to be stunted. However, Tom was very open and willing to share his childhood experiences, he described his upbringing as being difficult:

> How I was brought up was extremely unique and I struggled, still struggle, to do the whole dad things, to be honest with you. My mum and dad split when I was about four. My dad was originally from Belfast, he moved down to live with his family, between Wales and Belfast.

This meant that Tom was brought up by his mother which was difficult at times as she had mental health and alcohol dependence issues which impacted their relationship. He described both physical and emotional 'attacks' from his mother across his childhood. He was very open about his childhood experiences and the desire to reunite with his father, which he did as he got older. His father was an ex-soldier and was described as a hard man who was regimented in his approach due to his army career. He explained that re-establishing his relationship with his own father gave him some structure in his life as well as discipline which he incorporated into his parenting approach with his first son. He described the fathering behaviours such as regimentation and strict discipline that he experienced as a child being repeated with his own son:

> I was overly strict; I was overly regimented and things. So, with Tim, it was a whole learning curve, and it still is. Because he's my first-born, and I didn't really know what a dad was meant to be, I didn't really know what a parent was meant to be or meant to do, or how they react in certain situations and things.

He recognised the impact of his upbringing on his approach as a father. The impact was far reaching, and seemed to have affected him across his adult years:

> I find I had a lot of demons to overcome, things that I hold against myself, ways that I've reacted…and I would say that almost all of it is influenced from how I grew up. I just didn't have the experience of having parents there. When I did finally get to spend time with my dad, by that time I was a teenager. So, other than the odd days here and there, it was pretty much just time with my mum.

Tom appeared to imply a loss in what he perceived as a 'normal' childhood that his peers had experienced, which then impacted his own approach to parenting. His strict and regimented approach changed somewhat when Oliver, his second son, was born and diagnosed with CHD. This was a turning point for Tom having to parent a critically ill child. The diagnosis was both a challenge and a turning point:

> I would say that, when I went through all of this stuff with Oliver, when you have a fragile child…I mean, all children are fragile, but when you have one where their fragility is so obvious, it really makes you take a step back and go, "Right, do I need to be raising my voice all the time? Do I need to be insisting that these things are happening?" and you do, you start to soften up a lot more".

For Tom his upbringing and first experiences as a father were more of a journey which led to challenges within the relationship between him and his wife and a wish to reset his parenting style, which Tom said he had done and attempted to rebuild a more engaging supportive relationship with his older son:

> I always say that there are many things in my life that broke and rebuilt me. What I went through with Oliver definitely did that. It broke me down and made me start the whole parenting thing from scratch and, if I could, I would love to go back and start from scratch with Tim as well, but unfortunately you can't do that.

Oliver’s diagnosis made Tom reassess his approach to fatherhood and parenting and provided an opportunity to reset his approach. Reflecting on his upbringing Tom was clear that this had heavily influenced his parenting approach, however, he expressed a wish to move forward in his family relationships. In planning for children Tom, unlike some other fathers, did not expect to have children due to his wife’s fertility issues which became a turning point in seeking medical help. The couple were offered treatment including medication which would have led on to IVF. However, Catlin became pregnant with their first child before trying IVF. Having had one child, it was clear that Tom’s partner wanted more but for him, he would have been content with having one child or having children later on in his life. Looking back on the experience Tom never appreciated that there may be fertility issues that could affect the couple’s ability to have children:

> So, we’d never resigned ourselves to the fact that we wouldn’t have kids, it was more we were going to need to have help. Then Tim came along without any help, so that was kind of… You know, we were happy about it, I suppose the idea of never being a dad had never sort of entered my mind.

Having never considered fertility issues, having a child with a health problem was not contemplated. Once Oliver had been born, the enormity of his diagnosis was recognised which had a major impact on Tom over a number of years:

> I switched off, and then I didn’t switch on until a couple of years later again. But, when you look back at what the parents go through, it is kind of understandable because it’s… You know, it’s not just a hundred miles an hour when you're in the hospital, when you leave that hospital, you don’t leave it all behind, you carry it with you and then you’ve got the environment around about you that overwhelms you, as well.

The pressure of his son’s diagnosis and treatment impacted on Tom’s marriage and led to him and his wife parting for a few years. He described this as ‘switching off’ and related it to his challenging upbringing, his approach to parenting and trying to be the type of father that takes a lead and is to some extent the protector of the family:

> From my point of view, a lot of that was to do with just my head and what I’d had to deal with. Especially being that us dads sort of throw ourselves in at the deep end.

Liam

Liam was in his late twenties and was a self-employed builder working with his own father. He has one son, Jack who was diagnosed with transposition of the greater arteries which was successfully surgically treated. I interviewed Liam at his home, which was on a new housing estate, which he described as mostly housing young families. Liam described his own upbringing as challenging and somewhat chaotic at times:

> My mum and dad unfortunately got divorced when I was 5 years old. I lived with my mum, and I spent probably the next 10 years moving about quite often as my mum, it’s fair to say my mum likes getting married and getting divorced, which unsettled us a little bit.

Liam talked about his childhood and moving from place to place without really being settled anywhere or having many friends for support. Liam acknowledged the impact that his childhood had on him growing up but also identified the positives from his experiences:

> I don't blame my mum for my upbringing because it’s made me who I am and made me appreciate things more, my old man, he's very driven, I think it’s made me very driven. It’s not like... when I was with my mum, we didn't have a lot, when I had the opportunity with my dad and when I had the opportunity to buy my first house, I snapped it up, I wanted to make sure that I could be a better parent than what my mum was to me.

He reflected on his childhood in both interviews, from this it was clear that he wanted to be a better parent than his own parents had been. He strived for a sense of stability and security being proud of buying his own house and the stability that offered. Liam was the only participant who had experienced CHD in the past, with his sister being diagnosed with the same condition as Jack. He described vividly his sister being admitted to hospital in the winter accompanied by himself and his mother and the surgeon explaining the condition and asking where they were staying. A relationship had collapsed, and they had nowhere to go. Liam’s childhood seems to have driven his ambition for a stable family home. The relationship between Liam and his parents improved as he got older and they regularly see each other now, there is some sense of resolution here:

> I hate to say it, even she’s admitted that she wasn't a very good mother to the three of us, cos I've got another sister from my dad she wasn't a very good figure for us she never ...we never had any stability with her, we were always moving schools it was

> loads of problems with her she just ... She wanted kids but didn't want to look after them.

For Liam the main support across his life has been his ‘nan’, who occupied a stable parental type of position in his life. As the interviews progressed it was clear that Liam’s nan was his main support and rock in difficult times, especially around Jack’s diagnosis and treatment. For Liam and his wife, Tracey, his son’s diagnosis of TGA came at the 20-week scan. Up until that point the routine procedure and appointments throughout the pregnancy had gone to plan:

> Then the 20-week scan everything that could have gone wrong went wrong at that time. Then we had to go all of the way through Christmas not knowing and they were doing a scan on the heart, and they said something doesn't look right, we said what is it and they said we don't know but were going to refer you to foetal medicine, so right up to that point everything was perfect.

Liam and his wife coped with the diagnosis by carrying on as they had done previously, although they did discuss the possibility of a termination of the pregnancy. This was quite short lived as Liam’s wife is a special needs teacher and was fully prepared to care for the baby regardless of the CHD or any further diagnosis. Over the remaining duration of the pregnancy Liam and his wife attended regular appointments until it was time to have the baby. He described midwifes asking him if he was ready for his son’s birth, which was described as ‘plain sailing’, in contrast to the surgery that Jack would require soon after birth. He discussed the challenge of a lack of understanding and support from wider family members around the time of diagnosis and across the remainder of the pregnancy, particularly from his father, having not received the support he felt he needed, Liam found it difficult to open up about his emotions at the time and in the first year after Jack’s birth:

> My old man kept saying, “it'll be alright, they will fix it, it will be alright” and I said, yeah, but what happens if it isn't and he said “nah, don't look at it like that it will be fine”. A lot of people ask what goes on, but I’ve never really got in to detail of the whole process just for the fact that I've tried to block it off and think ah forget about that.

Liam was clear in telling his story that he would have benefitted from more support particularly from family and when it was not forthcoming, he became more insular. In the second interview Liam revealed that he had attended counselling as he was starting to experience depression.

The three fathers in this section all experienced an unsettled upbringing. For Tom and Liam, this was due to changes within their parents' relationships and for Anthony it was his time at boarding school away from his parents that had affected him. Anthony was more reflective in describing the way in which his childhood had impacted on his adult life over a period of many years. Tom linked his upbringing to the breakdown of his relationship and described how he had worked to develop his approach to parenting, trying to make up for what he saw as his shortcomings. Liam discussed his upbringing as a past event that he had moved on from and contrasted his approach to fatherhood to the parenting that he had experienced. All three fathers discussed an unsettled upbringing and although the experiences are individual and unique, they shared a goal in ensuring that the life experiences and fathering that their children received would be much more nurturing and present than their own childhood experiences.

6.3 A routine and normal life

It is hard to define what a 'normal' childhood looks like but the fathers in this section tended to tell stories of stable childhoods and relationships with words such as 'typical', 'normal' and 'usual'. This also reflects the fathers' descriptions of planning for children as a more routine expectation rather than a planned event. This narrative explores expectations, a number of fathers expected to have children, some actively planned this, others less so. What they have in common is an expectation of fathering a well, healthy child. What they also experience is something quite different, not the usual at all and not the norm by becoming fathers of children with CHD.

Alex

Alex was in his mid-thirties and had two children. An older son called Oscar and a daughter, Lara who was born with a double outlet right ventricle which had been surgically corrected. He is married and the interview took place at his home, a modern house on a new housing estate. Alex is a senior manager working in a print business. When talking about his own upbringing he highlighted the fact that his father was very present in his life and involved in his sporting activities in particular:

> He was the one who would take me to sporting events, he would be the one who would be doing that side of things, but he'd be the quieter one of the two. It would certainly be my mum that I'd go to if there was anything that I wanted or needed.

Alex recounted his childhood memories mostly focusing on his interaction with his own father. He discussed his upbringing in terms of perceived gender specific roles with his parents:

> He was probably the stereotypical dad in many respects that you might see. He was the one who was more in the background than my mother. He's very sporty, he was a PE teacher, so he was the one who was a big advocate of me getting into sport, which did form a lot of my childhood up to university, really, even now.

Alex appeared to identify his own father's approach in his parenting style in being more active with his children's activities rather than routine childcare within the home. He also reflected on his mother and father's relationship and compared it to his own with his wife Kim and how they now approach parenting their children, including role division:

> I think I'm in a similar situation with my kids. Kim is very much the mother of the clan and I'm the one that's probably a little bit more in the background.

There is more of a tactile relationship and warmth with his children than perhaps Alex had experienced as a child although he recounted that this was typical of the time. To some extent he identified this as being contributed to by his daughter having CHD and other health problems. Lara has been admitted to hospital on a number of occasions which he acknowledged has brought him closer to his son, ensuring that he attends Oscar's sporting activities. At this point in the interview, Alex paused and recognised similarities with his approach to parenting but also some differences:

> Yes, I think, when you just look at it, and you step away and look into it, I'm probably relatively similar and I assume the sort of mentality that my dad did with me. I'd think I'm probably a little bit more of a soft touch.

As his relationship with Kim developed, Alex never actively thought of having children, this was an area of discussion from a number of the men who never really thought too much about fatherhood:

> Interestingly, I would have been the sort of person who would have been quite happy never to have kids. When I met Kim, and if she'd have said to me, "I really don't want any kids," probably I'd have seen the benefit in that.

Alex and Kim already had Oscar prior to having Lara; the children were around 20 months apart in age. For Alex this was a practical consideration in having the children quite close together. He described it as completing the family and expected a normal pregnancy as they had experienced with Oliver. For Alex, when waiting to have the scan, his main concern was the sex of the baby and what it would mean for future children as they wanted a girl and already had a boy. Antenatal scans are a routine part of care in pregnancy and for most parents these are joyous occasions. Generally, two antenatal scans are performed. The first at 12 weeks, confirms the pregnancy, gestational age and that the baby is viable. The second scan occurs around 20 weeks into the pregnancy and confirms both growth and normal development but also detects any anomalies.

Once Lara was diagnosed with CHD, Alex recognised an adjustment in the family dynamic due to Lara's diagnosis and also the time Kim had spent away in hospital with her. Prior to the scan, Alex's main concern was the sex of the baby, having already had a boy they were hoping for a girl. Alex paused when he discussed the scan and then recounted his thoughts:

> Well, for me, from the 20-week scan, from the moment I was watching it, from the moment she spent a long time on the heart everything changed. From that moment, it became that whole adage of, "As long as they're healthy," Ever since then, you look back and think "Why were we bothered about the sex?" At the time, we were still up in the air about what it was but, of course, it's almost worse at that point when you're in the early days, because you find out information and you start to learn things that you've never learned before.

Alex took a different approach in trying to stay positive despite the antenatal scans providing a potential CHD diagnosis:

> Certainly, from a dad's point of view, I was, sort of, very much trying to be, probably over-positive, trying to see what wasn't there, saying "It's not that bad, it'll be fine".

In taking this approach Alex took the view that there was little point in focussing on the negatives or potential problems, he wanted facts and from those to be able to make informed decisions. This differed from his wife, who wanted wider information and a range of options depending on the results of the antenatal scan and genetic testing. This response was similar in a number of the fathers who had received an antenatal diagnosis, which is explored more in later chapters.

Dean

Dean is married and has two children, a boy and a girl. His daughter Alice was diagnosed with left atrial isomerism and heterotaxy a rare syndrome. Alice has ongoing treatment and management of her condition. Dean's interview took place over Skype as he has a busy management job. Dean talked briefly about his upbringing which he described as normal and routine with supportive parents. He described his mother as being more involved in his upbringing, with a supportive father busy at work but in the background. Dean did not really expand on this, and I was reluctant to explore it further. Dean and his wife thought that it would take some time to conceive, but their son was born nine months after the wedding. He described being oblivious throughout the pregnancy to the routine investigations and scans which was the same approach when his wife became pregnant again:

> You go along, you have the scans. You just think, "Oh, it's just a normal pregnancy." I don't think I've really been exposed to people that've had issues. I was aware of some friends that had miscarriages, but nothing from a heart condition perspective.

Dean talked about a self-confidence that as there had not been any family history of childhood illness there was an assumption that everything would be fine. He described the moment that this changed:

> Then we got to the 20-week scan. I just thought you go along, you wave, say hi to the baby, find out whether it's a boy or girl. Not really clocking the fact that it's called an anomaly scan.

The reality for Dean and his wife was that they might not deliver a healthy baby at the end of the pregnancy. He attended NCT antenatal classes which he found challenging once he was aware that his daughter would have CHD. He described the group as being 'quite bad' and being anti-drug and all for natural birth rather than interventions such as caesarean sections:

> They did a scenario where they basically just got a person to sit down in the middle, then put about 10 people around them and said, "This is what it would be like if you're having a caesarean because you'll have these people". They were really negative which completely killed my wife because she's like, "I might not have a chance to not do that. Now you're telling me if I have to do that, because of the health of my baby, it's just going to be an awful experience." Everything that she was coming up against was just negative things. It wasn't helping, really.

Dean described the twenty-week scan where he and his wife received the unexpected news of a potential problem with the baby. The scan took place at their LRH and there was some confusion amongst the sonographers as to what they were seeing on the scan. Other members of staff entered the room and were equally confused. They informed both parents that the baby's stomach was in the wrong place, however this was not the full extent of the issues:

> "Right, we think that the stomach might be in the wrong place". You're kind of like, "Okay, I've no idea what that means." They'd never seen it, as well. It went on for quite some time, them bringing in various people to try to understand what they were seeing.

In smaller hospitals it is not unusual to be unsure of what is being seen on a 20-week scan. The incidence of CHD is 8: 1000 live births (Batchelor and Dixon, 2012) therefore it is feasible that sonographers may not see any babies with CHD in their careers. Dean and his wife then had to wait for a second scan. Dean described the difficulty of having to go home with limited information and having to return after the weekend for a more experienced sonographer to undertake another scan:

> All these things start going through your mind, you've no idea what it means. There was no real understanding of what it was. We went back on the Monday. Then the senior sonographer; I think he'd been working there about 20 years and was doing something… I'm sure it was something like 5,000 babies a year, or something, he'd scanned. He said he'd never seen it. They had to do more detailed scans; it was a little bit too early to really have the right information.

There are clear protocols in place when foetal anomalies are detected and in line with this Dean and his wife were referred to a specialist children's surgical centre (SCSC), for a more definitive scan. Their daughter was diagnosed with heterotaxy also known as Ivermark syndrome where there are errors in how the organs are formed and where they sit. Due to the rarity of the syndrome Dean and his wife were desperate to find out more information:

> When we went to the SCSC, they'd still not really given us much more indication of what it was and what we were looking at. They looked at the heart. When they looked at the heart, as well, they said, "Yes, the heart seems to be plumbed in slightly wrong." There was something that wasn't quite right there either.

To try and compensate for the lack of medical information, Dean turned to the internet, he described the way in which he and his wife took different approaches to finding out information but were left with many unknowns until their daughter was born. This was despite having further information from a private scan which took place in Harley Street by an internationally renowned specialist. Dean recognised the need for support and would have valued the input from the wider healthcare team at this point:

> Certainly, from the healthcare professional side, there was no real support on that. If you don’t have it in your own personal life… Unless someone in your family has gone through that themselves, as much as they sympathise, they’re not there. Yes, it’s definitely a lonely place.

6.4 Planned fatherhood

For the three fathers in this section there was a stronger focus on life planning and seeking to be in control of events. Ray, James and Stuart, discussed the need to progress in careers, to be financially stable and to be in secure relationships but also at an age where they were comfortable to be fathers.

Ray

Ray was in his early forties, born in the Middle East and had what he described as a stable upbringing with strong support from his parents to thrive in education and to do well. He describes his upbringing and life before moving to the UK as a strong influence on his life planning and desire to do well. At various points in the interview, he referred to his culture as being highly influential on his outlook on life. He is married to Ruth and has one daughter, Majida who was diagnosed with a large ventricular septal defect. Ray has a senior management role within public services. I interviewed Ray in a comfortable coffee shop that was in a quiet area at his place of work. Ray described his father as the more significant parent in the discussion:

> He was very supportive. He was always there. Always encouraging. I think I’ve learnt a lot from my mistakes, and he probably let me do the mistakes so that I learnt from them, but you need to experience in life to learn from them.

Ray wanted to ensure that his daughter had the same opportunities that he had and looked forward to providing similar support. He discussed a sense of responsibility to ‘do parenting justice’ and to ensure that his daughter had as much or more than his parents had given him. This was described in both emotional and material terms. He described his parents as wanting him to do well, to achieve and have success in his life. To ensure this his parents regularly checked his schoolwork and progress.

Ray had a good job but when he moved, he had to take a lower position and rebuild his career. Ray uses a British name; his own name is not difficult to pronounce but he has a sense that using the British name enables him to fit in better. It was important for Ray that he had a settled job in order to be able to look after his family. He and his wife made a conscious decision to delay having children until they were financially secure:

> At that stage, I did not think I was ready to take on many challenges, especially that I didn't have job security, etc. I didn't want to have a child and struggle and not give that child everything that they wanted, that they needed. So, I thought let's wait.

Once he had some security in his career, he began to think again. He gave parenthood a lot of thought particularly around timing. His career development is important, but he described not wanting to be too old in order to be an active father able to play around with his child. He emphasised the need to have a level of good health in order to run around with a ball. Ray felt that the optimum time both career and health wise, would be to have children in his thirties. For Ray and his wife there was a definite decision around timing which was more nuanced than had been expressed by other fathers:

> I think we're in a good place in our life where we can support that, so we did. We'd been married for five years when we had Majida, so, not that we were trying, we weren't trying at all, we just didn't want a child then.

For Ray and his partner, the pregnancy went well, they had both antenatal scans and their daughter's CHD was not detected. Ray recognised that this was a missed opportunity:

> However, knowing what I know now, you think, "Oh, wasn't it really picked up?" Because she's got a large VSD, my daughter has got a large VSD, it's quite significant. When we were at the hospital, every single person or registrar, consultant, trainee, whoever it was in that department, came over because Majida's case was extremely rare, because her heart murmur was extremely ... it stood out, it was loud, it was a great experience for trainees to come and see what it was.

Ray paused for some time after talking about the missed opportunity and then returned to the scan. He talked again about the defect being so obvious and wondered why it was not detected. Ray recognised that mistakes can be made and does not blame anyone:

> It was missed, for one reason or another. I'm not a consultant, I'm not a doctor, I don't know. We're all human, at the end of the day, we are all bound to make mistakes. I'm not blaming anyone, don't get me wrong but if it was, it is what it is, it wouldn't have changed her condition.

This is an area of discussion that Ray returned to in the second interview as his daughter had required further surgery.

James

James was in his late thirties at the time of the interviews, he was married to Jess and worked as a landscape architect for a large successful practice. He had three daughters; his middle daughter Chloe was diagnosed with supravalvular pulmonary stenosis and an atrial septal defect. Chloe has had some surgery but required further interventions. I interviewed James in a hotel coffee area, as this was convenient for him, being close to his office.

James discussed his upbringing which was within the local area where he still lived. His parents are Polish immigrants who came to the UK after the war. James had an older brother who he looked up to in his formative years. He described both his parents as very hard working, with his father taking on extra work as and when he could, in order to provide for the family. He described both parents as being skilled labourers, who had to work very long hours. He commenced a degree and at the same time set up and ran a successful business. James talked fondly of that time in his life, he gave up his degree to run his business full time as he felt this would give him a better future and later returned to education to retrain. James described his working life as managing a series of projects. His approach to working life also became apparent later in the interview, when he described how he has managed his daughter's illness. He was the most forthright father in stating that he wanted children:

> I think I've always wanted them. I just don't think I knew when I would be ready to have them. I didn't know when the perfect time… There is no perfect time, but you almost think that there might be a more ideal time.

James talked about planning and the need to have a secure income. As a couple James and Jess had been on lots of 'nice' holidays as he described them. Age was a factor, as James did not want to be too much older than his early thirties as he felt that he might not be able to keep up with any children:

> We had everything in line, and it worked for us. So, I think it was after we'd done all

> that, so after we'd done everything that we wanted to, pretty much, do, then we thought, "This is the right time now. We're getting older. It's going to get trickier as we get older." That's when it happened.

James discussed his wife's pregnancy and similarly to a number of fathers within the study, no abnormalities were detected at the antenatal scans, although his daughter was a little bit bigger than expected for her dates. James has a wide circle of friends including medical consultants who reassured him that there were no concerns being raised. James highlighted the differences in his own and his wife's outlook at that time:

> So, although there were these concerns during the pregnancy, Jess was probably more worried than I was. I try not to worry too much until there's something to worry about, because otherwise you're constantly worrying. So, I try to be, "It'll be fine, everything is okay." Until something happens, then we'll have to deal with it, but there's no point just living in nine months of worry and then everything might be fine.

In both interviews he described himself as being organised and taking a more analytical approach than Jess. This is more apparent when he discusses ongoing treatment and management for his daughter's condition and the occasional conflict with healthcare professionals. For James and Jess, like a number of the parents, health issues became apparent quite soon after birth:

> Within probably, the first 24 hours there was a problem, and that's when things became… because Jess had to go into surgery after, so she couldn't take everything in, and obviously, you get sent home as the father. You can't stay overnight. Then you come back in and "This might be an issue, that might be an issue." So, you, sort of, walk into this minefield and then come back through the door the next day. They detected the murmur, and that was where things started happening.

James reflected on his experience in light of his relationship with his wife and how they normally communicate. He described Jess as someone who worries a lot, despite not having all the information and related this to her family and upbringing. He described himself as being the opposite:

> I worry when… I'll think about it, and I'll be aware of it. It's not like I'm ignoring it, but I almost put it on the back burner in a way that it's there and occasionally I'll look a bit more into it. Yes. I was well aware of it, and we were concerned.

James and Jess also paid for private antenatal scans when a growth problem was mentioned however, as with other families, CHD was not detected. One of the coping mechanisms that James used throughout his engagement with healthcare professionals was to obtain clear advice and information. He prided himself on being prepared for discussions with doctors specifically, both prior to the birth and following it, as is illustrated in the excerpt below from an inpatient episode where medical staff were offering different opinions on the most effective treatment:

> When they do the round, you'd see them going around our bay area, and they'd talk to somebody, tell them what they thought, and then move onto the next one. Then they came to our bed, we would have an A4 list of questions of what's happening? How will this work?

James' questioning approach and need to 'project manage', as he described his daughter's condition is an area that he comes back to in the second interview. He describes how the volume of appointments, investigations and multidisciplinary meetings could be overwhelming if he did not maintain some sense of control over them.

Stuart

Stuart is in his mid-thirties and is married to Dianne. He works in a senior role in the financial industry. I interviewed him at home in a commuter belt town on the outskirts of a major city. They have two sons; his oldest son Joshua, was diagnosed with hypoplastic left heart syndrome (HLHS) and an atrioventricular septal defect. At the first interview Joshua had undergone two out of the required three surgical procedures for his condition. The surgeon's view was that the third stage was unlikely to be completed and therefore Joshua was placed on the heart transplant list. By the second interview, his cardiac function had improved, and he had come off the heart transplant list and successfully undergone the third stage of the operation to improve his heart defect.

As with the other fathers, we talked about his upbringing and planning for children in the first interview. He described his parents as good and supportive with what he referred to as the usual normal upbringing. His father worked on the railways and was described as being a 'good dad':

> Fun guy, nice guy, always a lot of time for us, we would always know we were in trouble if he was going to be telling us off, but in practice he wouldn't tell us off very often, so he was quite relaxed.

Stuart talked about incorporating his own father's parenting approach to his own approach with his children, describing himself as relaxed and looking to have fun with them. He was clear that making time to spend time with his children was very important, so much so that he turned down a very lucrative job offer as it would mean time away from his family. Stuart related this to his own father's approach:

> I don't know, small things like that; his work were quite rigid with hours and things like that, which meant he always spent a lot of time with us, and I think that probably fed into me thinking that's important.

Stuart related quality time to his eldest son, who at the time of the first interview required a heart transplant. He recognised that a transplant may not become available and therefore treatment options would be limited. Stuart identified that he always wanted children and unlike most of the other fathers it was he who had persuaded his wife to have a family. Like some other couples they waited for children until their careers had developed and they had bought a house. Stuart talked about the pregnancy being planned and at the right time with the couple expecting the 'perfect baby'. However, at the twenty-week scan at the LRH, CHD was diagnosed but the complexity of the condition was not. Similar to other fathers Stuart then undertook his own search on the internet to gain more information:

> They mentioned a heart anomaly, and I can't remember what they said, but they said enough that I went away and googled things that it could be, and actually I found out what it was, which was hypoplastic left heart syndrome, so I think they must have said, "We can't see a chamber properly", so I kind of read the worst-case scenario and it turned out to be that.

Stuart and his wife then had a second scan at a SCSC which confirmed the diagnosis. Stuart talked about the information that he had found out through the internet. The couple were then seen at a SCSC. Stuart became aware that the centre carried out very few procedures for children with HLHS and therefore asked to be transferred to a larger centre. HLHS, is a rarer congenital heart defect which requires multiple surgeries. As it is a rare condition, not all SCSC carry out the procedure. This has improved outcomes and mortality for children with this condition by having care centred in fewer hospitals with a limited number of surgeons carrying out more procedures.

Stuart in describing how he coped talked about how he managed in a different way to that of his wife, identifying differences based on gender roles:

> Yes, and I think also the men tend to support the women quite a lot, emotionally, in the aftermath, whereas I don't think we often ...I don't think that comes back the other way so much.

Stuart did talk about the need for more support of fathers but highlighted that it can be difficult for men to access. He felt that the various Facebook groups and CHD charity forum sites were occupied more by mothers who support each other, whereas there is very little for fathers. Stuart described fathers as not pushing for this engagement as perhaps they do not engage in social media in the same way. Stuart was clear that he took a more detached approach to information provided by a range of healthcare professionals:

> I think I'm less emotional about it. I think you find a lot of men are, on that kind of thing, but then I'd worry about things that she wouldn't be worried about at all.

Stuart worries about the future and about the treatment available for Joshua. He described his concerns about Joshua growing up, attending school, participating in sport and wider activities. Stuart identified key differences in the couple's approaches to information:

> I like to know the facts, and we'll sit through meetings and often we'll come out of the meeting, and she will say, "That went terribly", and I think, well actually that didn't go so bad, because X, Y, but we take in different information.

Stuart like many fathers in the study wanted factual information and a clear diagnosis. The majority of fathers did look for this information online and talked of their partners not taking this approach. He talked about exploring probabilities and worst-case scenarios in order to gain an understanding of the available treatment options. He compared this to his wife's approach which he said was to avoid the detail as she would become nervous of the future.

The three fathers in this narrative had a clear plan when viewing their future life events. They wanted stable relationships and successful well-paid careers before having children. There was a sense from all three that families were to be planned at an appropriate time, with no real expectation of any health difficulties. This is not unique to these men as none of the fathers in the study had considered having a child with a health problem. What is unique to these men is the sense of planning and control of their life events.

6.5 Hesitant fatherhood

For the final two fathers in this chapter there was an apparent reluctance, or an ambivalence, to take fatherhood on. Steve and Scott had different reasons for this; for Steve it was around the dynamic of his first marriage which led to significant changes in his life and for Scott the decision to have children was very clearly led by his wife.

Steve

I interviewed Steve in his home in an affluent commuter belt area as he described it. Steve still lives in the area where he was brought up. He is in his early fifties and married to Rowena, his second wife, they have two children a boy and a girl. His son Harry is the youngest and was diagnosed with transposition of the greater arteries and a ventricular septal defect soon after birth. Both heart defects have been surgically corrected but there may be a problem with Harry's pulmonary artery, and this might require future surgery. He described his upbringing as a 'fairly normal childhood, normal and happy'. His father worked in aviation and his mother took care of both Steve and his brother. He lived at home until he was around thirty years of age. After school he started work in a bank and is still there some thirty-three years later. Steve reflected on his parents influence and particularly how this had affected his own parenting approach:

> When you have your own kids, you think about the influence of your own parents on your life and parenting style and you, I'm sure you go I would never do that, and you find yourself saying was it me who said that or was that my mother or father.

Steve's father worked long hours and he described the majority of the parenting role being undertaken by his mother, although he mentioned his father being at home more on the weekend. Steve talked about his father being strict, which he felt was typical of the time but was fair and focussed on good manners and behaviour. He described the 'normality' of his upbringing, not experiencing anything different from his peers. He described his father as having a bit of a temper and having the occasional smack as a child which he felt was typical of the time. Steve compared his upbringing with the approach that he has taken with his own children and reflected on the fact that he and his wife have taken a more involved and encouraging approach. This manifested itself in supporting the children's choices in participating in a wide range of activities both in and out of school. Steve recognised that he is stricter at times and sees his own father's approach in this when the children are not always doing as they are told:

> You know it can get a bit tiresome if you've had a bad day that can surface quite quickly, erm no but on the whole it's a happy household and good.

He reflected on his thoughts around becoming a father and was clear that for a long time he had been ambivalent about having children. The turning points were a close bereavement, the end of his first marriage and meeting a new partner. His first wife had no strong desire for children, but Steve started to consider this option after the death of his first father in law:

> I witnessed his deterioration and actually his actual death and then quite stark situations and they get you thinking about, what life's all about and that kind of stuff and I guess that age ticking on, all those things coming together that that marriage fizzled out.

In the new relationship his partner became pregnant after only a short time together at around six months. He described the fact that he and his wife Rowena both wanted the same things however the pregnancy was not planned, but it was at the right time in their lives.

> I think after 6 months or so, Rowena fell pregnant and erm there was never even an inkling of, are we doing the right thing kind of thing so nine months later, Eloise appears erm, first child quite a shock to everyone the adjustment of it.

Although there was not a conscious decision around timing it was clear from Steve's reflection that he was comfortable with having children at this point in his life:

> I think your friends having children and you witnessing what they were getting out of it, and I think just combined with getting a bit older as well those kind of things all coming together, going right well what's life all about.

In talking about the pregnancy Steve reflected on the antenatal classes and how they both found them useful and supportive. He found the antenatal group beneficial, and Rowena and he have remained friends with most of the group. As an older first-time father Steve found the opportunity to discuss concerns and anxieties useful, the support offered went beyond the classes and saw them through the early months of parenting:

> We don't panic about things, we'll look at it, think about it talk to people if there’s; even in the early days that NCT group, there was a really good network for bouncing stuff off, as everyone had a baby that was within six weeks of each other, people saying, was yours doing this yet.

Steve, like a number of father’s, received his son’s diagnosis in the post-natal period. The twelve and twenty week scan had not shown any issues, he also paid for two other private scans in Harley Street, which again were unremarkable. The private scans were performed to reassure Steve and Rowena, they had some anxieties because they were slightly older parents and were worried about complications. Steve described the whole of the pregnancy as being normal and uncomplicated.

Scott

Scott was in his early thirties and married to Cheryl, he worked in higher education. I interviewed Scott in a quiet area in his place of work. They had one son Shane who is now 11 years old and was diagnosed with absent pulmonary valve and Mowat-Wilson Syndrome. Although Shane’s pulmonary valve has been replaced, he will require further cardiac surgery and other treatment for his wider health issues. Scott described his upbringing as being ‘pretty normal’ with his mother and father bringing him up. They were a close couple who had always been together:

> So, it’s quite a nice upbringing, they brought me up quite well, I think.

Scott felt more comfortable and confident in the parenting he had as a child, which was reflected in how he himself now approached fatherhood. He valued the presence of his parents. He describes his mother being at home more but his father being a big part of his life encouraging him to participate in sport and lots of activities. He described a good upbringing which he has taken forward into his own parenting and later life. Scott was clear that he had not really considered or planned for children:

> I’ll be honest, no, I didn’t really think about it. I don’t know how typical that is of blokes or not, but no I never really planned it and thought yeah, it would be at this time, this will be it.

Scott was clear that it was his partner who led on planning children, he was supportive of that although it was not a concrete decision at a certain time as with other fathers, such as James. Scott's wife had an early miscarriage, so they had more frequent antenatal scans during the second pregnancy which led to the birth of his son. The early scans detected some issues, and their antenatal care was transferred to the regional maternity unit attached to the SCSC.

The CHD was confirmed at a scan which was undertaken around the 18th week of the pregnancy:

> It was quite a stressful time, really, because we knew that it was something wrong, that he had something amiss with him and what they were telling us with his syndrome was quite a rare one and that they were not sure how he would come out, whether he would come out able to breathe or you know, that kind of thing, so it's quite…. I guess stressful time.

Similarly, to Tom, Scott talked about the overwhelming stress of the situation and blocking parts of the experience out. Scott and his partner carried on as normal with the pregnancy attending NCT classes but for them there were different stressors to other parents:

> I think because everybody else there was kind of different, we had a lot of worries, for us I guess those worries weren't going to come out, coz we wanted to know that he was going to come out and be safe.

He found this time stressful as did his partner. He acknowledged that parenthood for the first time would have been scary in any case, without the complexity of their son's condition.
Scott had a different approach to managing stress and coping around the time of his child's diagnosis:

> I… I don't know how to put it…but I probably take more of a back seat and things anyway…I would let my wife do more of the asking questions because one…, I'm more of a head burier, I guess, so I probably haven't got the questions, haven't thought about it, don't even want to think about it, therefore haven't thought about the questions.

In reflecting on his experiences during the pregnancy and subsequent diagnosis, Scott was clear that he coped better when there was a clear plan in place with details of what would happen and when. He needed reassurance that his son would survive. Scott described being reliant on his wife to manage their son's care, treatment and management at each stage from diagnosis to surgery. I found the interview quite challenging in trying to support Scott with telling his story, I felt this was uncomfortable for him at times, as he recognised how much responsibility his wife had taken. For Scott the whole journey to date had been stressful:

> I guess the anxiety probably is…never, never goes away…I don't know…. I'm always anxious…and then it's, it just gets more.

There was a sense of hesitancy in the two fathers in this section when they talked about planning for children. It appeared to be less of a concrete decision and was based more on life events and their wives' views. For Scott particularly, having a child with CHD, was both challenging and in a sense traumatic, as he described challenges in coping with his son's diagnosis and wider engagement with healthcare professionals. It was clear that his wife led in making decisions or engaging with healthcare professionals, which was an area that Scott felt some degree of guilt about.

6.6 Summary

This chapter introduced the participants in the study and explored their back stories presented as four narrative typologies; an unsettled upbringing, a routine and normal life, planned fatherhood and hesitant fatherhood.

These narratives drew on the father's own upbringing, planning for children and the pregnancy, during which some fathers were given the initial diagnosis for their child. All of these fathers reflected on their upbringing and identified experiences and traits that they now recognise in their own parenting which has informed how they have approached and experienced their child's illness. Although I did not ask specifically about the participants' own fathers, most chose to focus on themselves when recounting their experiences of childhood and how they have evolved their own parenting style. The men differed in their approach to planning for children, with some effectively following their own expectations of marriage and fatherhood, while others had not planned to have children at all or would have been content if they had not done so. For other fathers such as Ray and James, there was planning, and real thought given to the timing of children which needed to be when they felt secure both in their relationship and career.

Within this chapter there are clear links to the theoretical literature around gender, masculinity and fatherhood. Both Anthony and Tom had perhaps experienced the most traditional upbringing which involved fathers who were strict and removed from the more current approach to involved or caring masculinities with parental roles divided on traditional gender lines. Tom regretted the fact that this had translated into his own interaction with his first son. However, this had changed with the birth of his second who was diagnosed with CHD. From this point there was a sense of reflection and wanting to make amends or start the relationship over in order to be the father that he felt should be. For Tom, the CHD diagnosis seems to have enhanced his role as a father. For Anthony, his own sense of abandonment at a public school has had an impact on his life. He talked lovingly about his children and how he has engaged with them to ensure that, as a father, he is present in their lives. His approach clearly links to concepts of caring and involved masculinity in approaching fatherhood and caring for a sick child.

For Steve and Scott, children were not planned for, but both adapted readily to fatherhood. In Steve's narrative, children were not part of his thinking and outlook on life until a number of significant life events over a short period of time led to a new relationship. Scott, although not opposed to having children, was very much led by his wife's decision on children. Scott referred to his wife as being the more involved in care and any decisions that needed to be made about their son's treatment, which was different to how most of the men described their role. I did not really view this as a division on traditional gender role grounds but in Scott protecting himself from the emotional impact of his son's diagnosis and treatment journey.

For most of the fathers, there was some degree of planning for the pregnancy once the decision to have children had been made. During the pregnancy most attended antenatal classes, although for a number, like Dean, Scott and Alex, the benefit of these classes was limited as they and their partners had been given the diagnosis and were not expecting a healthy baby, like other members of the group, and were now journeying into the unknown. However, Steve highlighted the fact that antenatal classes were a positive event in which the couple made new friends who they have remained in touch with.

The narratives presented in this chapter follow journeys to fatherhood and focus on the disruption of anticipated expectations, and for some fathers, adjustment to the reality of their child's diagnosis. This is seen against their own upbringing and expectations of parenthood. The next chapter will explore the fathers' narratives around the definitive diagnosis, the first experiences of treatment and the impact on their parental role of caring for a sick child; all of which were significant further turning points in these fathers' experiences and led to a disruption of the expected fatherhood narrative.

CHAPTER SEVEN – Disruption of the expected fatherhood narrative

> *'You suddenly enter into a world that's completely alien to you and terminology and things that people use and they expect ... that the way it's received, they expect you to understand what it means, you know, I didn't even know what congenital meant until that point.'* Steve

7.1 Introduction

Following on from the last chapter where the fathers were introduced with narratives focussed on their upbringing, planning for children, the pregnancy and, for some, the initial diagnosis, this chapter will explore turning points associated with the father's experiences across the various stages of diagnosis and treatment. The narratives will be presented by identifying turning points or significant events in their journeys. There is a temporal relationship in this approach with turning points, as fathers tended to present their stories from the point of diagnosis, through to treatment and then on to life afterwards. There was a degree of divergence as not all children had completed their treatment. Some children were accessing CHD services for annual reviews, while others were still awaiting further procedures.

The experience of definitive diagnosis varied for the fathers as is the typical pattern across the UK. Six of the ten fathers had a preliminary diagnosis at the twenty-week scan so knew that their child would be born with CHD however, there were some unknowns about the severity. For four of the fathers, the diagnosis of CHD followed the birth of their child, this occurred following a sudden deterioration and admission to hospital of a previously well baby, as was the case with three fathers. Anthony's experience was somewhat different, his son had a late presentation following admission to hospital with meningitis which was treated successfully.

7.2 Disrupted fatherhood

Disruption to fatherhood occurs in different points across these fathers' narratives. Diagnosis is a key turning point and for a number of fathers, and this usually occurred during the post-natal period. All of the fathers discussed their expectations for parenting, and it was clear that having a child, where there was a health issue, was not at the forefront of their mind. The diagnosis of CHD is a stressful and emotional experience for parents.

Steve and his partner had no idea that their son would be born with CHD as it was not detected on the antenatal scans:

> Harry had a really early scan and then on the two NHS ones, no nothing picked up or anything so erm, yep, the pregnancy proceeded straight forwardly, the birth here at home, the post birth checks all fine next day.

Steve and his partner Rowena had accessed an early scan to reassure themselves that the Harry was developing normally and that there were no health issues. This appeared to give them some confidence in expecting a healthy baby, within the anticipated narrative of a pregnancy that had gone well and the excitement of parenting a new baby.

Harry's deterioration and presentation was typical of babies born with undiagnosed transposition of the greater arteries and an immediate disruption to the expected antenatal period:

> Rowena was saying like, "Oh he's making a bit of a kind of a grunty noise", but new-born babies all look kind of bit battered and bruised … that was a Saturday morning he was born and then the Sunday morning a midwife rang and said, "oh I'm going to pop in" and Rowena was like "oh no, you know everything is fine, you know it's my second".

Although Steve and Rowena identified that Harry was grunting, they thought this was normal and reassured themselves that this was fine:

> I walked around the corner to the shops, which is a 10-minute walk and the midwife hadn't arrived, and I'd got halfway and the midwife, I got a phone call. The midwife had arrived taken one look at him, erm asked if, what my ethnic background was because she could see the blue in him and then Rowena rang and she said "right, its something's not right" and she called an ambulance and by the time I got back, as I say I was only halfway there, the kind of paramedic fast response unit was here.

As with most parents when their child experiences a sudden deterioration this came as a shock to Steve both in terms of his son being ill and the visual impact of seeing the paramedic stabilise his son:

> So, he was breathing for himself until the paramedics arrived and then they put him on to oxygen and when I walked back in, he was on the floor with a mask on him and I think the oxygen was kept going all the time from that point.

Steve described the trauma of recognising that his son was seriously ill and then receiving a CHD diagnosis, as an adjustment to the inconceivable. In Steve's story there was some initial uncertainty about the diagnosis until an ultrasound scan was performed at the hospital. The family were then taken to the local hospital and from there transferred on to a SCSC:

> He was then basically taken, blue lighted to the local hospital, they checked him and said that its either a heart or a lung problem and they spoke to the consultant at the SCSC drove down, scanned him and confirmed it was a heart problem. He had transposition, plus two or three other complications, and they transported him in this space age kind of ambulance thing up to the SCSC and he was straight into Intensive care, and they were checking various stats, every ... you know every hour.

This episode is reflective of care delivered in various parts of the UK with families transferred between centres. In Wales the CHD standards have evolved to ensure that all hospitals that admit children have a paediatrician who is able to carry out a diagnostic cardiac echocardiogram, this will then inform clinicians on the most appropriate facility to transfer the child to:

> So, erm yeah, there was I guess, well from the point of coming back and he's on the floor and they were, you know they were explaining that his oxygen levels were very low erm, he kind, of he could be at that point they didn't really know what it is, but they suspect you know a heart or a lung problem. We get to the local hospital, they did an ECHO, they can see certain things, but I guess they're not qualified to make that confirmed diagnosis.

The visual appearance of seeing their child deteriorate is an aspect of the fathers' experience that they return to, both from the point of first realising that their child is ill through to surgery and the various interventions required when their baby is hospitalised.

When the diagnosis was made it came as a complete shock as they had the security from the antenatal scans which were normal and the successful home birth of their son. Steve remembered the overwhelming impact of the diagnosis:

> At 1.30am in the morning, the consultant came back in cos he obviously wasn't happy with whatever the numbers were showing, he had a hole between the two pumping chambers which was allowing the blood to cross, so they went in and made that hole bigger, and you know his oxygen saturations were 34%, something like that and then they went up to 64% something like that, so erm he was in there for about a week.

Steve and Rowena were then thrust into a new world with their baby being diagnosed with a life-threatening condition:

> You suddenly enter into a world that's completely alien to you and terminology and things that people use and they expect .... that the way it’s received, they expect you to understand what it means, (laughter) you know, I didn't even know what congenital meant until that point.

There is a sense of a change in story here from the family with a healthy new-born baby to one of uncertainty and disruption associated with a baby diagnosed with CHD. Steve described this experience as one of the most critical times in his son’s CHD journey. As well as expressing a lack of knowledge and understanding of CHD Steve also expressed a sense of accomplishment in explaining his son’s condition to wider family:

> I can remember one bit, we when we came back from erm, the SCSC or the local hospital. Rowena’s parents were here, they had come up and they had to sit down, and they were obviously trying to regurgitate what we’d absorbed from the various medical staff who tried to explain what his problem, what his situation was, what the problems were and what potentially, what they were going to do about it and suddenly Rowena said, “blimey you explained that really well”.

There is a type of ‘hero’ narrative emerging here that is apparent in a number of the fathers who have a need to understand their child’s illness in perhaps more technical terms but also to have a feeling of security in their role. This is an area that a number of fathers discuss both in relation to diagnosis and treatment but also in how they approach interaction with health care professionals.

There is some sense of loss here around the expectation of having a healthy full-term baby following a normal term pregnancy. Steve described having days where he could not believe what was happening to his son and family as everything preceding his son’s collapse had been fine. He referred back to the reassurance of the antenatal scans and the situation that the couple found themselves in as living in a daze. Steve reflected on the challenge of supporting his wife and coming to terms with the diagnosis himself:

> Rowena is obviously in a post birth, very emotional state and suddenly this baby is on, you know... potentially on the brink of dying, because you know it was obviously a very serious situation so you're trying to ... support her, erm and be strong for her, cos you know she's very emotional about it, but you're also just trying to absorb it yourself.

As is typical with a diagnosis of transposition there was a delay between diagnosis and surgery:

> I can't remember the exact number of days we then, we went and made arrangements for him to have surgery when he was 1 month old, so he came home and then a nurse used to come in every day and check his oxygen saturations. I think he was on some drugs to help the blood move around and relax some of the muscles in the heart as well.

Similarly, to Steve, Ray and his wife had an uneventful pregnancy although their daughter was taken to the neonatal unit (SCBU) as she was born slightly premature:

> So, she was in SCBU. They put her in an incubator as she was jaundiced, yes, because she was getting a lot of that, had a thorough set of the blood tests. Generally, they didn't have many concerns, apart from she was premature. So, that was the thing, they were keeping her on track, just so…. they had a nasogastric tube in, so we were feeding her through that.

Ray and his wife settled into a routine while in the SCBU, with his wife staying at the hospital and Ray returning to work. He had chosen to not take his paternity leave at that point in time as he wanted to enjoy time with his daughter when they were discharged home. He described his routine of phoning his wife every morning to make sure everything had been okay with Majida overnight before briefly visiting and then travelling on to work. He would then go back to the hospital on his way home to spend time with his wife and daughter. He described the routine of each day and a sense that this would be a short-lived disruption to the start of fatherhood. As he settled into the routine, Ray started to think about bringing his daughter home:

> On the eighth day, similar, I was at work, when my wife called me around midday and she said, “They have a cardiology”, No, “The hospital cardiologist is here, they're a bit concerned about the baby’s heart”. Obviously, she was in tears, and she was broken down.
>
> So, she called me, she said, “Can you come?” Well, she said it in the nicest way possible, really, she said, “I have to stay in here but, if you want” … I said, “No, I’ll come”. By the time I got there, she was in tears, and she was really broken, she was broken to pieces. So, I had a catch-up with her, with the consultant there, and they said, “Well, we have a few concerns about her heart condition. We are waiting for a specialist, a paediatric cardiologist, to come from the SCCC to give his opinion and a proper diagnosis”.

This was the first time a heart issue was mentioned to the parents, so it came as a shock:

> So, I asked my wife to leave, I said, “Just go home”. I said, “Go home, you’ve been at the hospital for too long, you're tired, you need a break, you need some sleep, your days and nights are... Just go home, leave it to me. Trust me, I’ll take care of whatever it is”. To be fair, the consultant came. So, I was there around three, four o’clock. The consultant came around nine o’clock at night. They scanned her, echo scan, for two hours. It was a big thing. So, he left around 11 o’clock, almost close to midnight, when they came over and they said, “Right, this is the case, and we are going to move her to the cardiology centre that’s where she belongs”.

There are some elements of the hero narrative similar to Steve in taking some degree of control and gaining understanding of the condition. There was some confusion for Ray as the pregnancy had gone well with no CHD defects detected on the anomaly scan:

> The scans were fine. Would they have picked up her heart condition by the scans? Maybe. The head consultant, paediatric cardiologist, the head of the service in the Cardiology centre, was surprised when we said it wasn't picked up at pregnancy. However, there was no family history or any indication. So, I guess it’s a balance between time, how many minutes does a nurse, or a radiologist have? Or a midwife, I don’t know.

Ray’s approach was to question why Majida’s condition was missed and what could have been different. In relaying this part of his story, Ray looked upset, it clearly brought back difficult memory’s. Ray returned to this area in both interviews and in some ways, he was questioning himself, trying to gain an understanding of the circumstances around the diagnosis. Ray reflected on the complexity of obtaining an antenatal diagnosis in the time allotted for each scan:

> How many minutes do they have on each patient? If they spent three hours on each patient, scanning them they'd probably pick it up. But, given the ten minutes, there wasn't something that really stood out in the scan, then I don't think they would have…and, you know, working in the health service, I do appreciate everyone is under a lot of stress and, if they didn't pick up; not that they did it intentionally.

Having voiced the view that he could see why the defect was not detected Ray then spent some time reflecting on the significance of this:

> However, knowing what I know now, you think, "Oh, wasn't it really picked up?" Because she's got a large VSD, my daughter has got a large VSD, it's quite significant. When we were at the hospital, every single person or registrar, consultant, trainee, whoever it was in that department, came over because her case was extremely rare, because her heart murmur was extremely……It stood out, it was loud, it was a great experience for trainees to come and see what it was.

Ray detailed the interest various healthcare professionals took in his daughter's defect as it was so obvious:

> At some point, we had trainees lined up in our room. Obviously, they asked for our permission but, from my perspective, it's not going to affect me, it's not going to affect my daughter if they put that thing, but it will enhance their education, their training, and for them to identify in the future.

Although trying to be helpful in some ways this interest compounded Ray's uncertainty around why the defect was not detected:

> But it was so obvious that, when you think about it now, just thinking about it, why wasn't it really picked up? I mean, you can just put your hand now on my daughter's chest and you know how…You can feel it, yes, you can feel the heart murmur and you can feel the It was missed, for one reason or another. I'm not a consultant, I'm not a doctor, I don't know.

Finally, Ray concluded:

> We're all human, at the end of the day, we are all bound to make mistakes. I'm not blaming anyone, don't get me wrong, it is what it is, it wouldn't have changed her condition.

Ray was by far the most questioning father when it came to how and why the diagnosis was missed. In some ways he rationalised this himself in considering how antenatal scans are performed, the time given to each expectant mother and the experience and ability of the professional scanning. In contrast other fathers such as Tom and James were more questioning of the professionals caring for their children within both the SCSC and LCCC following the birth and diagnosis of their children, rather than events in the antenatal period.

7.3 Waiting for something to happen

All of these fathers talked about waiting. This was a constant in all the narratives; waiting for the diagnosis, waiting to have care transferred to a SCSC, waiting for the treatment options and waiting for surgery itself. These were also turning points; from diagnosis to initial treatment across different care environments, and in the next part of the chapter I will explore these turning points further.

All the fathers experienced transfer of their child's care to a SCSC. There are eleven SCSC's in the UK and all of the fathers in the study lived some way from them which necessitated the transfer of care to one of these centres. This was not a conscious element of the recruitment strategy but happened by chance. The length of time between the birth of their baby and transfer varied. Tom, Scott and Ray's stories reflected the different experiences the fathers had during the transferring of care. The three narratives in this section reflect the various types of transfer evident across all the fathers: critical, urgent and routine.

Tom's experience was rushed in that his son Oliver, was delivered as an emergency and deteriorated very quickly as is typical with a diagnosis of transposition of the greater arteries.

> It got to the point where I had been awake for over 24 hours, so Rowena said, "go home, get some rest, I think you're going to need it." So, I came home, I had a cigarette, I went to bed, with my clothes on. I went to bed, with my clothes on, and I think I must have laid there for about two hours, just under maybe, and then I got a knock on the

> door and Rowena's mum came through the door and she went, "Get up, get dressed, you need to go, they are transferring him to the SCSC".

Although Tom knew that his son was unwell, he had no idea that it was a serious congenital heart defect which was life threatening at this point, without transfer and urgent treatment to stabilise his condition Oliver would have died:

> So, I hadn't even been asleep by this point. I got back to the local hospital, Rowena had a little more information, that they thought there was something wrong with his heart, he wasn't oxygenating blood properly. They had him in intensive care. They were getting a blue light through to the SCSC and that was apparently the best place for kids with heart problems. At this point, we'd never even heard of the SCSC, but this was the best place.

Tom was told that he needed to go in the ambulance with his son. At this point he only had a rucksack with a change of clothes and a bag of crisps. He did not even know the city but was told that there would be somewhere to stay. Tom had left his wife behind to be with his older son which he found both challenging and distressing:

> When I saw Oliver properly for the first time, I would say that was one of the hardest moments, was when we were in…We went up to the neonatal intensive care unit (NICU), he was in the incubator. They'd sort of strapped him down and things like that, and then wheeled him through all the corridors, down into the ambulance and then got the ambulance to go to the SCSC. That whole time was just horrific, because they had a little baby that would literally fit in the palm of my hand, he was like a 'reddy-purply blue' colour, who was clearly distressed by being strapped down, but had to be strapped down for his own good.

Tom reflected on his feelings and lack of control at this time:

> That was my son, and I just wanted to console him and pick him up, stroke his face, do something, take the straps off, but I couldn't, and it was an hour, give or take, however, long to get through to the SCSC, and I just sat there the whole time.

Tom expressed the need to be close to his son and comfort him while at the same time recognising that Oliver required care that Tom could not give. Tom recognised and valued the support provided by the transfer team:

> You know, the person in the back of the ambulance with me was fantastic. They tried talking to me the whole time and explaining what was going on and trying to give me as much information as they could. Explaining what the SCSC was and who was there and things like that. They just tried to keep my mind on something other than the fact that we were in the ambulance.

Ray, like Tom was faced with a transfer from the local hospital but this time to a Specialist Children's Cardiology Centre (SCCC) and then later on to a SCSC. This is not an unusual experience for families whose baby is born in a local hospital and then transferred to an SCCC for definitive diagnosis. What is more atypical in Ray's story is the rapid transfer from LCCC to the SCSC so soon afterwards and the associated disruption to the family:

> So, next morning, a team came, I don't know which team, I've had so many teams come to my daughter, bless her. There were two teams, basically, one was Welsh, one was English, I think, because of the distance, so I'm assuming it was the Welsh team, but they work across anyway.

Ray's transfer demonstrates the difficulty of providing CHD services in a limited number of centres:

> So, they came, because we couldn't transfer her ourselves, they had to put her in a special incubator and a special oxygen tank etc. So, they came, they moved her to the cardiology centre, obviously, we moved as well in the car. We went straight to the Ward and then to paediatric intensive care (PIC) and then she was transferred to the SCSC.

Ray had seen his baby admitted to a NICU in one hospital, transferred to the ward of another, then to PIC and then a transfer to the PIC of SCSC all in a matter of a few days so that she could have her operation. Some aspects of the transfer remain a blur for Ray:

> I just can't remember. Imagine, how blurred things were and how quick things were, and I can't really remember. I remember the ambulance service telling me, "Don't follow me, go on your own. We have the right to use blue lights, just don't…" That I remember. I don't know why I remember; I don't know where it was, which service it was because, as I said, she moved so many times, I've lost track.

Being transferred to hospitals and cities that he did not know proved a challenge in practical terms:

> Jesus Christ. I got there and I’m thinking, “The reception, I couldn’t call anyone, the reception is dead. I don’t know where I am. I don’t know where I am. I know I’m heading to the SCSC but apart from that, I don’t know where I need to be. I don’t know where they’ve taken them, which room they are in”.

In critical transfers and retrievals, it is normal practice that parents do not travel in the ambulance. This can cause significant anxiety for parents who may be travelling to a city and hospital that they may not have visited before. Ray reflected on the whole transfer experience and the rapidly changing situation:

> Once the diagnosis was made, that’s when they escalated her case very rapidly. So, at that point, from the moment they diagnosed her, on the eighth day, they diagnosed her with the heart condition. The next morning, we moved to the cardiology centre. Then, they moved us to PIC or NICU. On the Thursday, it was, they had I think the joint collaboration. That’s when they had discussed my daughter’s case. On Friday, the team from the SCSC came, they moved us to their centre and then, on Monday or on Tuesday, she had her operation. So, it was very rapid.

Ray talked about the impact on himself, his wife and his daughter:

> It’s not tough on me, it’s tough when you're sat there and looking at the baby, and you think, “My God, what are you going through?” Fortunately, it happened so quickly that we didn’t have the time to digest it. So, it happened so quickly that you couldn’t even sit down and think about it for half a minute, it was just run. It’s like you're in the passenger seat and they're just driving you.

The realities of the transfer of care for Ray are typical of the fathers’ experiences as most lived some way from the SCSC. This has an impact on parents in accessing services but also having confidence in the ability of their local hospital to provide ongoing care and support.

Scott experienced a more routine transfer of his son for specialist care:

> He was born in the local hospital…so…yeah, they obviously decided that he would be born in there and then that he would be kind of, taken to the SCSC the next day, so, he was, so luckily he came out, and it was actually planned that he would come out,

> but I mean he did in the end need a caesarean because he kind of, I think as they were monitoring him, he started getting a bit, I think basically he wrapped his cord round his neck anyway, so he managed to get in to a right mess, so they did a caesarean, and then he stayed, stayed with Cheryl overnight and then went to the SCSC in an ambulance the day after, and obviously coz Cheryl had a caesarean, she couldn't go, so I had to follow behind in the car.

This is a typical experience of parents when a transfer needs to take place soon after birth from a local hospital to a SCSC. Often transfers are completed within 24 hours leaving the mother to follow on a short time later if she cannot be discharged from the maternity unit.

> She was here, I was there, yeah, following, coz I couldn't fit in the ambulance, coz there was a big incubator in, and then a couple of staff, and so I followed in the car. He was wheeled into the neonatal unit at the SCSC and sent back again, so he could get bigger. I guess they, they didn't know when they could operate…within days of the birth they could operate…. I think they try to leave it as long as possible so the better his chances are…so in the end yeah, he was sent back, and I think he had it when he was four months.

Scott was somewhat exasperated by this experience of a transfer to a SCSC, further tests and the transfer back to his local hospital, although this is standard practice in order to gain a definitive diagnosis. This caused Scott and his wife an inordinate amount of stress, although they recognised the need to plan for the surgery and operate at the optimum time.

7.4 Handing care to someone else

Once a definitive diagnosis has been provided, surgeons and the cardiology team will usually decide on the optimum time to perform the surgery. For some fathers, due to the critical nature of their child's condition, this meant that surgery occurred very close to birth, and, for others, a short delay was appropriate as their child was currently stable. For surgery to take place, the child has to be stable pre-operatively, there has to be space on the surgical list and a Paediatric Intensive Care (PIC) bed must be available for post-operative recovery.

Steve reflected on the overwhelming information given by the surgeon on his son's condition:

> I was just sat there, I hoped I had just kinda picked it up properly, but you're hit with these terminologies that are alien most of the time to you, you know pulmonary and

> you know, fuck, I don't know anything about the heart you know which ones the problem with, oh it’s both, is it you know he’s got this valve problem and he’s got a constricted pulmonary artery (laughter) which one feeds the body and which ones from the lungs you don't, you’ve no

Steve highlighted his need to understand the physiology of his son’s cardiac defect but highlighted the difficulty in comprehending the explanation provided:

> The surgeon who happened to be up at the hospital came in and he was drawing a picture and at the time I thought he'd drawn this thing and I'm looking at it that doesn't look like a heart to me. I don't know what you’re drawing there, and he’s drawing, trying to draw with it showing flows and all this kind of stuff and I was thinking wouldn't it be great if they had a model or a 3D printed thing of it. I’m kind of very visual, if I can see a picture of it or I can touch it, I understand it better. I think having some things like that would help not just fathers but mothers both understand things.

Steve went on to discuss the nature of the clinical environment that the family found themselves in immediately prior to surgery and the need to assume trust in the surgeon and other professionals operating on their child:

> You are in a world that is completely alien to you, that you’re suddenly in, you’re not prepared for, but you need to understand it very quickly because you know within a few hours you could be signing a consent form and you really need to understand, what decision you’re making. I think it’s not through the fault of any individuals but I think they need to recognise people are entering a world where you’ve got somebody who you have never met before in front of you telling you about the life of your child and what they are going to do and you know, other than that they happen to be employed by the hospital, you have no knowledge of capability or anything about them you kind of immediately fall into an auto trust situation about it.

After the urgent retrieval to the SCSC Tom had very little sleep and was faced with the prospect of imminent surgery for his son:

> I think, for the first day that we were in the SCSC, I mean, we went through in the morning. Although I hadn’t been to sleep, it was morning. We went through, he was made stable and put in a cot. They did tests on him, and I think, within the first day,

> they knew that it was a problem with his heart. I think it was the next day, or the day after, I think it was the second or third day, when they went, “Right, this is what it is.”

From this point there was a need for further clinical investigations prior to surgery:

> I think it was the second day when we got it, they very quickly went, “We need to get him in for surgery, but he needs to be fattened up first.” Yes, because Caitlin came after a few days and I remember spending a lot of time just going through different feeding with him and things like that, because he didn’t take the certain foods and stuff at first. So, what we were putting into his stomach, he was bringing back up again, which they were struggling with too.

As the hospital stay developed Tom was given further information about the diagnosis:

> I think it was the second day, when we got the sort of, Well, transposition of the great arteries, at that point, complex transposition. I don’t know at what point they added on the ‘complex’ bit, but that was the complex bit.

To try and improve Oliver’s circulation he underwent two cardiac catheter procedures:

> The third day, they were adding little bits on. To be honest with you, actually, because he had two intrusive operations fed in through the groin, I believe it was. So, he had that done twice, before the eleventh day, before the open-heart surgery. So, they were adding little bits on. To be honest with you, although we say its complex transposition of the great arteries, the actual diagnosis, the full list of it, is like four lines long.

As the investigations continued further detail was added to the diagnosis making an already challenging surgical procedure harder:

> With all the different things that they added on but the main one was he’s not oxygenating blood properly; he’s got transposition, the great arteries are wired back to front. He had, you know, other things, as well. For example, the two chambers were actually sitting side by side. So, when it came to do the open-heart surgery, they had to move them, so they were sort of one on top of the other, which is why he had to have his chest left open for an extra day, because of all the movement, there was extra swelling.

Leaving the chest open post cardiac surgery is not uncommon due to swelling and the size of the baby's chest cavity. The open chest is covered with a dressing. Other complications then arose which Tom was not prepared for:

> When he had his open-heart surgery, they realised that he doesn't clot properly, so he was in... he was supposed to be in for… I could get you the actual numbers. I think he was supposed to be in for 8 hours, and he was in for 15, he was in for 7 hours more than he was meant to.

The waiting was difficult during the surgical procedure:

> So, we were sitting, waiting for a phone call, and then we had seven hours of sitting, debating whether or not to phone the hospital. Yes, it was 14, 15 hours they were adding little things on the whole time. And the whole time, you're sitting in the NICU.

Anthony received a much later diagnosis of CHD for his son. This is typical for less 'critical' CHD. Children will often be diagnosed later on in childhood either due to other illness as in Anthony's son's case or because they are struggling to physically keep up with their peers (Veal and Bailey, 2018).

For Anthony, the diagnosis was a significant change for the family, with his son Carwyn having an operation at three years of age and then again at thirteen years of age. This had an impact on Anthony which was still evident in the way he reflected on his son's experiences:

> I've had to come to terms with what the heart is all about. The surgeon tried to explain it to us that there was this sort of flap that was... protruding under the aortic valve that would then get in the way of the valve itself, would knock against it and stop the blood flowing through naturally and then the danger was you get endocarditis because it was it would be sort of splashing around the pericardial area and erm that that was how it was explained to us and that therefore they needed to cut away as much as they safely could, without you know, going to close to the electrical bits, erm, you know to reduce that risk but they said, you know made it clear that a second operation would probably be needed, you know during the years that he would grow and similarly the stenosis would grow and er so that's….. that's what I understand sub aortic stenosis to mean.

In both interviews Anthony expressed his fears around the time of the operations and subsequently as his son has grown, developed and moved away from home to university. Anthony highlighted the impact that the second operation had on his son:

> For seven years he was alright and then of course, the breathlessness started coming back again and it’s not just the physical I remember, it’s the emotional, mental and the counsellors and you know the terrible darkness that he went in to even as an 11 or 12 year old.

The surgery went well but there were some complications:

> We did have a crisis in that fluid built up after the operation so that they had to do an emergency drainage. I remember the surgeon had to come in very much on an emergency and everyone was a bit panicked.

He reflected on the wider impact of the surgery in emotional and psychological terms on Carwyn:

> Thirteen is a very crucial time, I mean psychologically, emotionally, when you’re only 3, I know its horrendous, but you haven't got any of those angst that you've got when you are 13 and it was…. was far more difficult, far more challenging the second time around, even though they we knew what it was all about by then but all in terms of his perception of himself as a young teenager and er, the feeling you know he went through, the stuff, all his gone through in terms of feeling, why has this happened to me, what do people think of me, you know it’s what sort of person am I, you know, to have this and physical self-consciousness about your appearance, the scar and everything, none of that was really relevant when he was 3, as tiny kids do, he just bounced through it.

In the latter part of the second interview this is an area that Anthony returned to by reflecting on his son’s CHD more broadly and thoughts of ‘giving his son this disease’.

CHD surgery is complex and requires critical care to be provided. For some families this may be preoperatively in a NICU and post operatively in a PIC. The fathers discussed their experiences in both, and I have separated these out in the following two sections.

7.5 New environments

> *‘He's in the intensive care unit well you can come and see him and er... you go into the intensive care unit which is like the bridge of the Enterprise it’s quite impressive.’* Steve

A number of fathers discussed the nature of care and the visual aspect of seeing their child in clinical environments including NICU and PIC and the challenges of finding their role in these strange new environments.

Neonatal Intensive Care Units (NICU) provide care for babies born prematurely and term babies who are ill at birth. Six of the ten fathers experienced some care delivery within NICU. Generally, this was for the purpose of stabilisation prior to transfer to the SCSC or prior to discharge home when it had been confirmed that their child was medically stable, and that an immediate surgical intervention was not required.

Alex highlighted the difficulties of managing family life when you live some distance from the NICU and have other children:

> Obviously, we’ve got another child to think about as well, so you have to think about him, and someone really needs to be back… You can’t just ignore the fact that he was here with my parents, although he was great, he still needs… I was really conscious that, throughout all of this, with the initial scans and everything going on… You forget that he was then whisked away.

Alex and his wife had to think about both of their children and whether it would be okay for their son to visit NICU. The anxiety was around him becoming distressed by seeing his sister in a critical care environment and the visual aspect of it:

> He came up and he went, “What’s that? Where has she had those two Teletubbies from?” He was more interested in what new stuff she had, “Where’s my present?” To be fair, it just went over his head.

Alex worried about the longer-term impact on their son:

> You worry that they start thinking, “I don’t know, they’re not bothered about me, all they’re bothered about is my new sister.”

Alex's wife, Kim was present in the interview, and they talked briefly about settling in to the NICU routine:

> Kim: I tended to stop with Lara in Birmingham, and you tended to come home, didn't you? What we used to do because, to be fair, you were at work anyway until 6:45pm each night, it was only the first week, wasn't it?

Alex remained quiet at this point of the interview; Kim carried on with her recollections:

> But you weren't set up there with me, were you? You weren't there.

Alex responded by highlighting his input:

> I did a mixture of both, yes. I was a lot more than you think, because my parents brought Oscar up, and your mum's brought Oscar up in the waiting room of the neonatal. I think I was home, obviously, more so than you, but for that neonatal bit, I was certainly there more than, probably than other bits.

Alex appeared to want to justify his approach during this time:

> Certainly, I had a week that I had after the holiday, where I was not working but yes, I was the one who was coming home. I was the one who was sorting Oscar out and then coming back in the morning and probably dropping Oscar off and then coming back to make sure we'd switch. We were doing… Obviously, the feeding was a thing, wasn't it, whereby we were trying with a bottle and then she was tube-fed. It was me coming home and Kim doing the night shift, certainly.

Alex reflected on the different approaches he and Kim took during the neonatal period:

> I think, certainly, as the dad, I was very much the one who was, "No, she's okay." Kim would be saying, "Oh, I think she's going a bit blue around the lips, so I think she's going a bit pale, "Oh, I don't think she's struggling there?" and I'd be, "Oh no, she's alright, she'll be fine". She struggled like hell. We had hell with her milk, because now we know it's more related to the breathing. The feeds were a nightmare, weren't they?

Alex recognised that overall, Kim took on most of the care for their daughter:

> Obviously, Kim took the brunt of it through work, but we tried… You know, at night-time, I'd be doing the 11 o'clock feed, which is the one that I'd do before I went to bed. Oscar would be a doddle when you look back, and it would be taking you over an hour to do a feed with a bottle and you're thinking to yourself, "What's going on?" They'd be coughing and spluttering.

Kim highlighted the inconsistencies in information that they received from the healthcare team in NICU:

> A week in neonatal then they said, "Oh, they'll see you at Birmingham in a week". In that week, she was totally fine. I was a bit, like, "Maybe they've got it wrong on the scans," if you remember. Then we went and saw the cardiologist and then he picked up another problem with the mitral valve. He was, like, "To be honest, from what I can see, she'll be having her first lot of surgery within the next few weeks".

Following the transfer of Oliver to NICU Tom engaged with other families:

> Eventually, somebody came and saw us, one of the nurses, they explained that Oliver was upstairs in one of the intensive care units. It was weird, we were meeting the other parents that were in there and learning about their diagnosis and learning what they mean and what operations they'll need.

It is common for families to establish relationships which last beyond the hospital admission:

> There was one child that was in the bed opposite Oliver, because there's only six in a room. There was one child who was opposite who we still speak to the parents now. Their son was in, and he ended up having a tracheostomy, the thing in the throat. He has only just got that out, a couple of months ago, it has been a long time.

Tom recognised the impact that CHD and the care and treatment required can have on families and relationships over a long period of time:

> It's interesting to see how a lot of the couples that we still speak to are no longer a couple. Part of me always wondered how much of that has to do with what we go through, as parents. Because Caitlin and I separated for a long time, as well. We are back together now, but yes, we separated for a fair few years, as well.

Tom related this to the father’s role and the need to manage the situation:

> From my point of view, a lot of that was to do with just my head and what I’d had to deal with. Especially being that ‘us dads’ sort of throw ourselves in at the deep end, as it were. So, every time Oliver had to go in for an operation and had to be put to sleep, it was me with the surgeons and anaesthetists, and I would discuss with them what would happen, and I would be made aware of what could go wrong, and I had to sign that little bit of paper, saying that I give them permission to do it. At the time, it was, “I might have just signed my son’s life away”.

Dean reflected on the visual aspect of seeing his daughter Alice in NICU:

> I went up into NICU there, to then go and be with Alice. She was lying there, she looked alright but obviously had loads of monitors attached to her. She seemed to be fine. They said, “The heart rate is fine, she seems to be breathing fine”. Obviously, they wanted to keep her in for longer than normal because they wanted to, obviously, do some checks. I just stayed up there with her.

At this time his wife was in theatre for the caesarean section:

> Mandy was in theatre for quite some time. It was nice bonding time. All the horror stories that you’ve been reading about, start to disappear a bit, once you’ve got this little baby in front of you that, on the face of it, looks completely fine and normal. You wouldn’t know any difference. I gave her a feed and just, kind of, sat there just holding her hand and stuff.

There was a reassurance here that a number of the fathers expressed in that outwardly their babies appeared to be normal, healthy children.

Liam highlighted the lack of initial contact and bonding with his son due to the urgency of the care required:

> They said we'd be in NICU for a couple of days and that never happened my wife was in recovery and they said right it was 2 o'clock in the afternoon cos he was born at 7am and they said right were moving him straight down to the SCSC, NICU and we saw him and he was so ill, he was blue and that night we felt so rough, cos my wife had spent no time with him and he'd been gone, they moved her up to NICU at 2pm and

> she had a quick cuddle with him and that was it, he'd been moved down to the big hospital.

Liam was torn between staying with his wife and visiting his son:

> That's when I met the matron and my wife was struggling to express and she said, she'd expressed a little bit, this sort of nurse come and she said right I want you to take that down and I said but there's nothing there and she said, “I don't care” and she really pushed me to go down.

Liam was later grateful for the insistence from the nurse that he took the milk to his son:

> I'm glad I did cos he'd had his emergency balloon septostomy by then and I didn't even recognise him, he looked like he does now, full of colour and I thanked her for that and I said, “that's the best thing you have done for me cos it brightened my day up” and he got really...he had his balloon septostomy and it took about a week before his surgery, but he was up in one of the HDU.

Liam highlighted the changes in emotion and stress across his son’s admission and surgery:

> The night we left him before his surgery he just kept getting better and better they never, he was one of the children that they didn't have to worry about. He was like, they classed at low risk and then he had his surgery, that was the worst time of our lives because he was out for 4 days.

Paediatric Intensive care units provide treatment and care to children and young people who are critically ill. Children are admitted to PIC with a range of conditions such as meningococcal septicaemia, croup and head injuries. The admission criteria for most units revolves around the need to provide invasive ventilation and one to one care in a closely monitored environment. Children diagnosed with CHD will be cared for in a PIC post operatively as they will usually be ventilated. The duration of the stay will depend on post-operative recovery and cardiovascular stability amongst other physiological indicators.

Alex remembered the visual aspects of seeing routine procedures performed on his daughter in PIC:

> She had the PA band; she went straight back to intensive care. We opted to see her extubated in intensive care, I'd never necessarily do that again because of the… Someone mentioned adrenaline to Kim, and she nearly passed out because she's watched too many episodes of bloody Casualty.

Seeing his daughter on a ventilator did affect Alex:

> That wasn't very pleasant because she had to have a bit of assistance with breathing to start off with.

The visual aspects of seeing their baby or child in a critical care environment is an area that all of the fathers discussed.

Alex had some difficulties in staying with his daughter:

> It was a whirlwind, certainly from my perspective. This isn't necessarily all fathers, but certainly from me, I'm very much…I was in and out, I've always been… I don't like it because I've got no control.

Handing over control to other people was something that Alex struggled with:

> I like to be a person who can affect something. If it's not working, I'd like to help put it right or I'd like… You're in that position where you can't do anything.

To adjust to the situation Alex found his own way of managing:

> All you can do is stand and watch… I was saying, "I'll pop off to the shop. What do you want from the shop?" I was there for... You see that ... I'll do it for five minutes and then, "I'm just going to get something from the shop". That's how I personally dealt with it, and I've dealt with it like that since.

A number of fathers discussed how they coped in PIC and at other critical points in their child's care, for some fathers, work was a distraction but also a stress reliever. Alex had some difficulty with the conflicting information provided by different teams who have input in PIC:

> I mean, we had one doctor tell us… Funnily enough, any issue we found tends to revolve around the doctors, in the sense that the one doctor, when she'd had the

> pulmonary artery band, and she was getting better, we thought, “She’s doing great here”. We were trying to get her to have a dummy, which she wouldn’t have. They said, “That’s good,” but then her saturations were 96, 97, 95 or whatever they were, they were mid-nineties, they were okay.
> Then the doctor said, “They shouldn’t be that high, there’s something…” We were thinking, “What? What do you mean, they shouldn’t be that high?” The surgeons’ been around who did the … He never said… What’s this…? I remember taking that with a bit of a pinch of salt. “I think we asked someone in the end, didn’t we?” The response came; “Don’t pay any attention to that, that’s the intensive care doctor, just ignore that”.

The visual aspects of PIC are an area that Alex returned to:

> Other than the initial, seeing that for the first time, because it’s such a small baby at four weeks with… She hadn’t the experience being on a children’s intensive care unit. I mean, I wouldn’t wish it on anyone if they weren’t of the mental disposition to deal with it. I said to my mother before she came on it, “Just prepare yourself for what you’re going to see.” I said, “It’s amazing, amazing, but they’re treating really, really sick people, not just sick people, sick children. I mean, you have to see it, to witness that. I mean, personally, I dealt with it by the in and out method of going to the shop, getting a coffee…I’ve never offered her so many teas and coffees”.

Alex reflected on the adjustment that he experienced as time in PIC went on, the ability he had to cope and rationalise what he was seeing:

> When we got there, the nurse who was working around… Initially thinking, “She’s so ignorant, she hasn’t said a word to us”. We were there immediately. Obviously, she’d only just been brought back from theatre and we’re there, “They’re doing this,” and all the tubes and the drugs that are being administered through the machines that do it.
> You’re looking and thinking… It was staggering. Obviously, they do the checks. When they’re doing the checks every… Whatever it is, I hadn’t considered this, it’s one nurse per bed.

As time progressed Alex was less stressed by what he was seeing and started to take minor changes in his stride:

> You think to yourself, “I’ve never seen that before”. The monitors aren’t the little ones you see on the wards, they’re big TV screens they’ve got there. You see the bleeps

> and you sit. I was like that, not so much with wanting to… I knew what they wanted, because I'd find out from reading about it, then you'd hear a "Beep, beep," and the saturations have dropped down to 93 from 96 and you think "Oh.".
>
> Eventually you have to teach yourself, "Hold on a minute, it will do that, and it varies when they're asleep and you get…" I don't think I've ever got used to that. I couldn't say now that I've ever got used to that, but… Let's be honest, all the things I'm talking about were just, for me, for us, it was never for Lara, she did great.

Steve like many fathers compared his own son's illness and dependency to others within the PIC:

> I remember being stood around the unit he was in the intensive care unit which wasn't spacious, and the nurses were in and out often. You kind of look at the child in the next, don't know what you call it the next station or whatever and there was you know... I remember looking at Harry and thinking ... you might be sick but there are some very, very sick babies in here.

Steve talked about his changed life now being faced with such a sick baby:

> You're suddenly introduced to this life, they had about 60 or 70 beds in the intensive care unit, there was like 10 or 12 real high care and then, I don't know a high dependency and as you step down before you get back on to the ward and er there was like this 24 / 7 life going on that you, it's happening right know where there is 60 or 70 babies in there who you know, some mums are in there for weeks.

Steve found that his work helped him to cope with the situation:

> I remember one woman, she had twins and she they were both premature and she was trying to feed them and she, she was literally just in there for weeks until, obviously they were got big enough to come out, and that's going on you know all the time so your suddenly in a completely alien world of all sorts of things that's quite difficult to er adjust to. I guess in some ways my work brings that kind of change and challenge quite a bit so maybe it was maybe a little bit easier to kind of deal with some of that.

Steve reflected on how he and Rowena coped in PIC:

> The first few days he was in like an incubator type thing erm, couldn't even touch him but you know we'd have a break go and sit in the whatever it was it was Costa or whatever.

While Harry was in theatre, Steve and Rowena struggled with a lack of updates:

> The communication between the ward and the theatre wasn't great so we’re like and then when Rowena starts getting in to panic mode, something had gone wrong, that it had got complications and actually it wasn't any of that it was just yeah it just what it is a long time, or they didn't start on time.

Steve reflected on how he and Rowena approached the lack of information differently:

> You’re trying to reassure her but then yourself thinking, “Oh maybe there is something wrong and they’re not telling us” and getting in to all that, the nurses are saying were trying to get hold of them but we can’t get hold of the person, you think that's because it’s all hands to the pump there must be something must have gone wrong, you get into quite a frantic state because there is a lack of information erm, you try to, for me you try to deal with that yourself but Rowena was getting quite anxious with it. You’re trying to calm her and reassure her again, always trying, you’re filling a void with a lack of information and automatically jumping to the fact that there is a problem and actually it’s just a void of information and let’s just deal with the facts as they come, but still more difficult I think, for her to deal with that.

Steve described the visual impact of the PIC care post-surgery:

> Right, he's out, he's in the intensive care unit, well you can come and see him and er... you go into the intensive care unit which in the SCSC, is like the bridge of the Enterprise, it’s er, it’s quite impressive and then there's this little baby in amongst this bank of machines and he’s got tubes and pipes coming from everywhere.

Steve highlighted the importance of the reassurance provided by the nurses:

> The nurses were really good cos they were very quickly on to, he’s fine it’s gone really well, cos when you walk in, your like oh my god, erm, and then there’s this release of emotion if you like at the point that your hearing the words that its gone fine erm, you kind of… having the last couple, 2 - 3 hours thinking it’s all gone disastrously wrong

> because there was this lack of information suddenly your seeing this image that’s quite ... It’s not a healthy baby.

Steve was relieved that Harry had an uneventful recovery:

> He was in there a number of days, I can't remember how many exactly now but there were one or two points during that time were his erm rhythm hadn't quite got erm, to erm, where they wanted it to be which they, they leave a little, I guess a little kind of pacemaker in don't they? and they did that and it went to where they wanted it to be and erm that was it really, he didn't have any other post op complications really so we erm that was... the staff in there were really good.

Steve’s experience was more complex, his son was taken to the local hospital and then transferred to the PIC of a SCSC. However, they arrived on the day that surgery was halted due to an investigation into safety at the SCSC. Steve and his partner were then faced with decisions of where to be transferred to:

> Yeah, then at 1 month old, he went to the SCSC. We could have gone to another centre. We chose it as the surgeon happened to be visiting the original SCSC. We were there and he was in intensive care, and he explained erm, the kind of only real options that he had erm so we were, so this surgeon was kind of one of the top three surgeons in Europe so we thought we would go there.

There were other influences on their decision as it was not a straightforward choice due to the distance:

> So, another reason for us being in the new SCSC was the friend who had originally suggested to Rowena about having the scan at this place in Harley Street. She's a health reporter and that was who Rowena was in journalism college with. Through her health reporting she knows the SCSC very well. She’s done load of features there, sat in on operations knows lots of the surgeons and stuff and she told us about the set up and everything there so er that's why we went there.

Tom remembered being in PIC with his son and needing more information and insight into the procedure and care:

> That was probably the hardest, I mean, I did some weird things. When Oliver had his open-heart surgery, he came back afterwards, he was lying in the bed and he had like a little cloth over him... and they were like, “He’s got a cloth over him, so you won't see the chest, because the chest is still open,” because obviously they need to wait for the swelling to go down first. I was like, “I want to see”. They said, “What?” I was like, “I want to see” ... and Caitlin was like, “I don’t want to see.”

Tom explained why he wanted to do this:

> I do feel like this is very rare. Although I didn’t finish university, I went to university to do Forensic Biology, so for me, it was a very rare opportunity to see a very unique medical case and unique medical things interest me, it’s kind of what I was going with in the first place. So, I’ve done some strange things, that I think other people would find much harder.

Tom summarised the overall experience:

> I remember lying in bed, on one of the first nights, and Oliver was in the hospital bed. I was lying there, thinking, “I’ve been blue-lighted through to the SCSC, I’m in Ronald McDonald House in a room in a place I don’t know, with people I don’t know, in the middle of nowhere. This is completely bonkers. How does anyone do this?” Then I heard a helicopter and I looked out the window and they were airlifting a kid from, it later turned out, from one of the furthest islands. It was like, “I’m lying here, and here comes a helicopter with a kid”. You know what I mean? It was just constant bemusement about what was going on around about you.

The overwhelming impact on Tom became clear during his reflection on the early period of hospitalisation and in how he coped afterwards:

> So, I went through, and I sat in the ward, and I sat there on my own for about three hours, I think, as Caitlin worked out for me, I couldn’t tell you. By this point, I had switched off. When we were in the ward and I was looking at the heart machine and it flatlined and I looked at the midwife, I looked at her because I knew that it was time for them to go. That’s the point where my head switched off and I went into automatic mode. I didn’t come out of that mode for a good, well, we were in the SCSC for three months. When I got home, it was about another year before I had a mental breakdown,

> it was another two years before I started to come out of automatic mode. That was the point when my head switched off.

7.6 Chapter summary

This chapter has explored four key areas of the fathers' experiences; disrupted fatherhood, waiting for something to happen, handing care to someone else and new environments. The sense of disruption to the expected fathering narrative was clear in all these father's stories. The nature of CHD, and the potential life threatening or life limiting aspects of all the conditions, meant that the fathers were faced with a new reality following diagnosis. For some, the diagnosis was made at the twenty-week scan which meant they had a period of adjustment to not expect the completely well, healthy baby that they had anticipated. For fathers like Liam, the anxieties of this period settled until he and his wife got closer to the delivery date of their new baby and for others, including Alex, this was a period of time where he remembered searching for further information online. This was an approach that several fathers discussed as being in contrast to their wives' approach, in terms of coping and seeking information on their child's illness.

Other fathers, including Steve and Tom, had no prior warning of their child's illness and were very quickly exposed to their child's collapse and subsequent rapid transfer to the SCSC. The disruption to fatherhood was clear in these men as they moved to a position where they were suddenly waiting for something to happen. What this might be, however, was unknown. There was initial uncertainty around diagnosis but also for Steve the availability of CHD surgery in his nearest SCSC. He was faced with his son having a complex heart defect requiring immediate surgery and the eventual halting of surgery at his SCSC. This added a layer of complexity in considering where to have his son's surgery performed.

The nature of CHD means that not all children require immediate treatment. This came as a shock for some fathers, including Scott in being transferred to a SCSC and then being discharged home for his son to await further treatment. All of the fathers, however, talked of waiting for investigations, surgery, post-operative care and the alien clinical environments that they found themselves in. The care and management of CHD, like all serious conditions, involves a significant amount of time spent either in hospital or planning for the next treatment or review.

Admission for surgery and the stay in Paediatric Intensive Care was a significant event for a number of the fathers. Having to hand over the care of your child, signing the consent form, and then waiting for them to come out of surgery, are significant stressors. The sights, sounds and visual impact of the intensive care unit and their child's vulnerable place within it was a significant memory. The fathers also discussed their role during the stay in critical care environments with differing views. Tom expressed interest in the sights, sounds and seeing his own son's open chest following surgery. Whereas Alex very clearly expressed views around the challenge of fulfilling the traditional role of father as protector and support for his family, whilst also finding this a challenge. This meant he spent a lot of time away from PIC in order to be able to cope with the stressful situation he now found himself in.

The next chapter will move on to discuss the fathers' reflections on their roles, the aspects of care that could be improved and how they saw the future with their children.

CHAPTER EIGHT – An Uncertain Future

> *'You think this is short term, and things will just go…Everything is going to resolve and it going to back to normality, and then you realise it's probably never going to be normal in that sense.'* James

8.1 Introduction

Following on from the previous chapter which explored the narratives around the initial care and treatment, this chapter will explore different scenarios which demonstrate how fathers navigated both services and relationships with healthcare professionals. In this chapter, in contrast to the previous, there is a sense of an end to the journey for some fathers whose children had completed their surgery and were moving to the point of annual reviews. For others their futures were more uncertain. Four turning points are discussed; you don't know who is flying the plane and my ability to find information on people is better than most, explore fathers' relationships and experiences with healthcare professionals with examples of specific interactions which formed fathers' views. The final two turning points; a restoration narrative and I'm not a carer but in a sense, I am, reflect on the end point of my journey with the fathers and where they find themselves in the treatment trajectory with their children.

8.2 You don't know who is flying the plane

All the fathers discussed the importance of support and engagement with healthcare professionals throughout their child's treatment both at the local hospital, SCCC and the SCSC as well as antenatally. For most of the fathers these experiences were positive, but they also identified some areas where greater support could have been offered. For others, particularly those who had encountered clinical issues or who had sought second opinions, these relationships at times had been more challenging. Steve had little choice with an abrupt halt placed on surgery at his local SCSC due to the need for a clinical investigation. He had experienced transfer from his local hospital to his local LCCC and then to a more distant SCSC:

> The surgeon from another SCSC happened to be at our SCSC when the surgery was halted when we were there, and he was in intensive care, and he explained the kind of only real options that we had. So, this surgeon was kind of one of the top three surgeons in Europe, so we thought we would go there. He came in, the consultant who we'd been dealing with brought him in to explain.

CHD services generally are well monitored and audited since the Bristol Inquiry (Kennedy, 2001). Several fathers in the study had experienced disruption to service provision at some centres whilst investigations into clinical practice took place. Steve reflected on the move to an alternate SCSC which did not appear to affect his trust in the new team:

> Well, I don’t know, if you get on a flight, you don't know who is flying the plane do you, (laughter), but erm, you just assume somebody’s up there who knows what they’re doing, and I guess to a degree you have to do that.

The confidence of the surgeon also helped Steve to rationalise his decisions:

> The consultant surgeon had been very bullish, certainly about the way he articulated this to us about you know, “We do this, we do this, we do quite a few of these, it’s a bit complicated here and it’s not without risk”, but you know, it was all good and then the real machine comes along, so you get the anaesthetist comes along and talks you through stuff whatever, this could happen and “This could happen and this could happen and this could happen and this could go wrong,...... could you sign here,” it’s not quite the way he put it.

Steve recognised the importance of him trusting the surgical team and wider healthcare professionals. However, he also acknowledged that the support could have been better, especially as families enter an alien world where diagnosis and sometimes very limited options are provided:

> You’ve got somebody who you have never met before in front of you telling you about the life of your child and what they are going to do, and you know other than that they happen to be employed by the hospital, you don’t know their capability or anything about them, you kind of immediately fall into an auto trust situation.

A number of fathers discussed aspects of care where consent had to be given. For more minor procedures either parent tended to sign the consent but for surgery it tended to be the fathers who took responsibility. Steve expressed a need to relieve his wife of the burden of consent while trusting those who were responsible for his son’s care:

> I don't know but for some reason I felt I was the one that needed to sign the paperwork, it kind of felt like you were taking responsibility for potentially signing his life away and I didn't want Rowena to do that.

Steve reflected on the lack of any real choice in making decisions due to the severity of Harry's condition but also the support offered by the nurses in PIC. He talked about the need for honesty so that parents were fully informed of their child's potential outcomes. He also highlighted the value of supportive relationships at various stages of his journey:

> Each of those beds in intensive care has a dedicated nurse, you build up quite a relationship with one or two of them during that time, because you get you feel like you've got a rapport with someone who's looking after your most precious possession.

For Alex and his wife, it was important to have some consistency in the information that they were receiving from the LCCC and SCSC:

> I think the valves were mentioned but not really. I think that was to do with how it would grow and how it would cope, but it was all to do with thickness of the septum wall and how this left-hand side of the heart would grow. I think, from that moment, from that third visit, it became a lot clearer. As I say, we walked out with a much better picture. I think we actually had a physical diagram of how these things were working.

As is common with CHD it took some time to develop a clear understanding of the extent of the surgery that was needed:

> It was certainly explained to us quite categorically that Fontan circulation was a distinct possibility, it wasn't just a… It was, "Look, I need to tell you this, we hopefully will be able to correct, but there is a big hole and there's basically nothing there, it is just a gap, and the position of the artery is quite a long way over, and it would take a patch that would be quite curved and quite substantial in size, so it will be difficult."

When Alex and his wife met with the cardiologist and surgical team, they received consistent information and a clear plan of care. There was consistency in the information provided and this did not change. This meant that, as a couple, they had trust in the healthcare professionals who were caring for their daughter. He also gained confidence in the knowledge of the staff that he met with which was reassuring. He did highlight some differences of opinion during the family's time in PIC:

> Funnily enough, any issue you tend to find, we found tends to revolve around the doctors in the sense that the one doctor, when she'd had the pulmonary artery band, and she was getting better, we thought, "She's doing great here." We were trying to get her to have a dummy, which she wouldn't have. They said, "That's good," but then her SATS were 96, 97, 95 or whatever they were okay.
>
> Then the doctor said, "They shouldn't be that high, there's something…" We were thinking, "What? What do you mean, they shouldn't be that high?" The surgeons' been around who did the … He never said… What's this…? I remember taking that with a bit of a pinch of salt. I think we asked someone in the end, didn't we? They said…Don't pay any attention to that, that's the intensive care doctor, just ignore that.

At this point he distinguished between staff who he perceived had greater knowledge and understanding of Lara's condition and, therefore, who he had trusted more. Alex reflected on the benefits and challenges of surgery in a SCSC. The main benefit is expertise, but a challenge was meeting three out of the four cardiac surgeons who operated there. Due to cancellations different surgeons were potentially going to be operating on Lara. Demands on both surgeons and PIC beds were high. Alex found the uncertainty of the operation challenging as well as being unsure which surgeon would operate on his child, it was down to bed and surgeon availability on the day. He had confidence that they were all equally capable and he trusted the consultant cardiologist who was a constant in Lara's treatment. Alex highlighted that there were aspects of his journey that could have been improved. He talked about the early experiences and the information to support his wife postnatally that was missed:

> She'd just gone through the whole process of giving birth, then the baby got whisked away. She hadn't seen her because she was having her own problems. They kept her in for several days, then, doing more tests and checking stuff. My wife struggled to feed. The midwife was bloody useless at the time. She kept forcing her to try to feed, and Lara wasn't putting on weight or feeding properly. It was only when they had a changeover, after about three days that the new midwife came in. She was like, "You lost a load of blood, didn't you?" She was like, "Yes." She was like, "Yes, your milk won't have come in properly if you haven't got enough iron in you. We need to get enough iron in you, then your milk will come in properly, then it'll be alright. Let's just feed her on the bottle". That just added to all of her stress, it was like, "Why didn't anyone tell me that? Day one, if that was the case, I would've been happy with that,

> no problem, let’s do that”. To feel like she was… She felt like she was being made to feel inadequate because she couldn’t feed. Actually, medically, she couldn’t anyway.

He felt that greater support was needed, particularly in the early days following diagnosis where he expressed that there was a lack of input following the cardiac scan. There was a sense that the baby was fine in utero and therefore there was a waiting period until the birth before anything would happen during which time there was an information deficit:

> Unless someone in your family has gone through that themselves, as much as they sympathise, they’re not there. Yes, it’s definitely a lonely place.

Liam on the whole had a positive experience apart from early on in the local hospital following the birth of his son Jack, in the maternity unit. He described a lack of support for fathers and sleeping on the floor for three nights. This was eventually resolved following the intervention of one nurse:

> She was old school and she said, “What are you doing?” And I said, “I’m sleeping on the floor” and she said, “I'm not having that”, it’s like little things they wouldn't even let me make a cup of tea, she said, “I’m not having any of that and she kicked off and she looked after me”.

Liam also recounted the care that his wife received at the midwifery unit which he felt fell short of what they expected:

> They weren't very helpful cos my wife had an emergency C-section and she was up on her feet letting her go the next day and there was a nurse who came in , she started crying and she said, “I’m really sorry”, ...I'm really sorry cos my wife was crying cos she was in so much pain we got down to the hospital and they said, “What's your wife doing here she should be in bed for at least 3 days”, but we wanted to get down to the hospital but they let her go she was out the next day. It was really bad practice; we've never made any fuss about it because it’s done and dusted but they wouldn't even given her any painkillers, I had to go to the pharmacy to get her painkillers.

Liam often stated that he was so grateful for everything that staff had done for the family, even when care fell far short of expectations. He was reluctant to complain and found ways of navigating through the system. He was clear that if his son became unwell, he would bypass his local hospital with a paediatric inpatient area and travel directly to the SCSC. Once Liam arrived at the SCSC the support was better with information provided and accommodation for himself and his wife. He talked about the hospital environment and its atmosphere:

> It’s a real child friendly place with nice bright colours it doesn't feel like a hospital that's what I liked about it because you didn't feel like you were in a bad place it felt like a positive place, all of the nurses were positive you could have a laugh with them, and I think that's what aided the recovery.

Liam generally built relationships with healthcare professionals through humour, which is part of his character, and he recounted one particular episode with the surgeons:

> In the hospital they were really good well I was having a laugh with the doctors and that, but you could have a crack in the hospital and one of the surgeons come in and he was in his blue scrubs and there was another surgeon in pink scrubs, and he was taking the mick out of him, and I said, “My old man thinks that's salmon not pink”. The surgeon said, “I like that one, you’ll be alright, I'll make sure you'll be alright”. Just having a laugh... and it took all the pressure away. That's all it is, little wins

Liam returned to his thoughts on the support provided by his local hospital and fathers’ needs, exploring this in gendered terms. He discussed men and women going through different experiences, such as mothers giving birth and the pain and stress involved in that event. However, he felt that fathers were overlooked:

> I don't want fathers to be the centre of attention, cos that's not what it’s all about but just a little bit more thought on their part. They didn't really think... I felt like they didn't want me there when she was in the ward, they made me feel so bad and all I wanted to do was to stay with her.

Following treatment at the SCSC Jack was transferred back to a hospital nearer home, which Liam found challenging rather than comforting, now being closer to discharge. He expressed anxiety about the discharge and had initially asked that Jack stayed at the SCSC. He talked about the local hospital in less favourable terms due to the organisation of care and approach to families:

> It was quite bad it was the first night that me and my wife had been apart, cos they wouldn't let me stay there and she had me on the phone going, “They've got this norovirus next door” and I rang them up and said, “My son has just had open heart

> surgery and you've put him in the room next door”. They quarantined it and she said, “I want to come home” and they wouldn't let them, I said look... I had the surgeon, and I had the doctor on the phone, and I said, “Look mate, I don't want him in there because if he picks anything up he could die” and he was going “Yeah… yeah” and I said, “I don't care what I have to do if I have to bring him back every day I just do not want him in the hospital”.

Having resolved the situation, Liam found that he would have to attend the same hospital for Jack’s cardiology clinic. Liam also recounted another experience at the same hospital:

> I took him back and a doctor come and sat with us she took his heart ... she listened to his heart, and she said, “There's something wrong with his heart” and I said, “I’m not surprised he's just had open heart surgery”. She made us wait for nearly four hours and then come in and sat down with us and said, “You do realise your son could be slow?” ... she said, “Well he could be slow upstairs and everything”. Well of course really unprofessional and er, and then I said I want to speak to someone else and then she wasn't having none of it, she made it hard for us and in the end another doctor came in and he listened to his heart and he said that there's nothing wrong with it, considering he's just had open heart surgery its fine there's nothing wrong with his heart you can go home straight away sorry for the inconvenience.

Liam was unhappy and disappointed with the way this information was given and this has had an impact on his trust in the local paediatric service, however, again he did not raise a complaint referring back to his gratitude for everything that the NHS has done for the family.

Scott, on the other hand, had a mostly positive experience

> As a dad, pretty…I think in, in the most parts pretty positive I think…. I think, I’m sure that there have been times where, well it depends how, it depends how Cheryl would be, and I think there have been times where we’ve been frustrated, I thought I’ve been frustrated with certain aspects of care, but that’s been on, maybe more on the general side of the taking him in sometimes and just not gone the right.

Scott associated the positive care with the more major surgical interventions for his son’s CHD and scoliosis. He did reflect on the fact that he let his wife lead on the main interactions with healthcare professionals:

> I guess from a lazy point of view I let my wife take more of the active role in asking questions….so then they, the people would always talk to her more.

Scott did single out the cardiac nurse specialist as a particularly good source of support both pre- and post-surgery in preparing the family for the interventions and hospital stays. Scott also talked about engagement with the surgeon, placing your trust in someone that you have never met before. Scott lives a similar distance between two SCSC, so had the option of which centre to be referred to. He made the choice based on the logistics of the ease of travel with one centre having a more direct route. He described the journey to his SCSC as being easier from a travel point of view and then added that it was also the way he and his wife felt in the hospital. In describing the surgery and consent that his wife signed, Scott reflected on his own approach at that time:

> Me being a coward, she's the one who takes him downstairs, you know only one person goes through… so it was her…Yeah…it's horrible innit!

For the fathers following this positive narrative there was a sense of belief in the healthcare professionals who cared for their children particularly at the SCSC. There was an implicit level of trust and respect because of the roles that the healthcare staff held rather than any significant insight into their capabilities or clinical outcomes.

8.3 My ability to find information on people is better than most

For the fathers in this section of the narrative there was perhaps a more questioning approach in their engagement with healthcare professionals. For some this has meant challenging approaches to treatment, moving SCSC and seeking and obtaining second opinions. Most of the men discussed this approach in gendered terms as needing to maintain some element of control and protecting their family.

Tom discussed the importance of establishing good relationships with healthcare staff but also highlighted some areas that he found challenging, describing one unfortunate incident early on in his son, Oliver's treatment:

> I had been just at the side of the cot and one, I don't know if they call them bed nurses or round nurses. Whatever, she was one of the women who was just coming around and making sure everyone was okay. I'd been at the side, and I think I'd been stroking Oscar's face, or something like that, just trying to keep him nice and calm, because he

> was wriggling about a bit. Caitlin was with me at this point, and she came over, and I can't remember the exact words, but she said something along the lines of, "You need to be really careful, you shouldn't be touching him if you don't have to, because it could cause", She didn't say, "It could cause problems with his heart," she said something about, "It could get him excited," or something along those lines, it was. But, in my head, all I heard was, "Your son has got a bad heart and you're messing with his heart".

Tom recognised that this was a stressful time for him and to calm down he left the unit but was followed by the nurse who tried to calm the situation and make sure that Tom was okay, but what he wanted was time alone:

> She explained a little bit and then I very politely but very firmly went through it like a ton of bricks and explained how, "That's fine, and I understand what it is you were trying to say, but the way in which you said it made me think this and that was wrong. You should be very careful how you word that with other parents in the future". I realised that, as much as I've got nothing but respect for the woman and the job that she does and everything, I realised, at that point, that there were some people that I would click with and there were some people that I wouldn't.

Tom felt it was important that he and Caitlin had confidence in the staff caring for his son and recognised that he could be quite obsessive around capability specifically. He recognised that he may encounter staff who were skilled at their jobs and staff who he perceived were less so. Following this episode, he changed his approach to a more forensic one:

> Every time Oliver went for an operation, I would have a consultation with the surgeon and the anaesthetist first. It became very much like an OCD. Every time there was something added to the notes, every time there was a test done, I would sit and talk to the person who was testing them and ask them about the machines – "What does it do and what does that- Show us what is it you're seeing here, what is it you're looking for?" I grilled everyone there.

Tom found that most healthcare staff were comfortable with his questions and were happy to support him with the quality and quantity of information that he needed. He described his role as a father who needed to understand the detail of the procedures and surgery performed and to have confidence in the surgeon operating on his son. Tom was aware of the surgeon who would operate on his son and took the opportunity to explore both his and the anaesthetist's background to ensure that there were no concerns:

> I used to work in internet surveillance and things like that, so my ability find information on people is better than most. I spent time researching who the anaesthetists were, who the surgeon was.

Tom was unusually direct with the surgeon:

> The surgeon is very well known for what he does and, when we were sitting in the consultation, he asked me, “Are there any other questions you want to ask me?” I said, “The only thing I want to ask you is, how do you feel about this operation?” and he was like, “I’ve never been asked that before. I’m confident that we are doing the best thing for him. I’m confident that I will do it to the best of my ability”.

Tom was reassured by this response which gave him confidence in the surgeon undertaking the procedure. He has maintained this approach as further procedures have been undertaken describing situations where he has asked for various healthcare staff to be removed from Oliver’s care. He gave an example of a surgeon who was due to operate on Oliver for a non-cardiac condition. He felt that the surgeon did not display the level of confidence in performing the surgery which would reassure Tom and therefore refused to have the surgeon involved in Oliver’s treatment. Tom also felt the need to take ownership of signing the consent:

> So, every time Oliver had to go in for an operation and had to be put to sleep, it was me with the surgeons and anaesthetists, and I would discuss with them what would happen, and I would be made aware of what could go wrong, and I had to sign that little bit of paper, saying that I give them permission to do it. At the time, it was, “I might have just signed my son’s life away,” you know.

Tom saw this as part of his role as a father, to make decisions for his son and to protect his wife. He expressed his views in gender role terms as being a father and protector. If he did not have confidence in staff, he would not want them involved in Oliver’s care. He compared this to Caitlin’s approach who he described as more placid and accepting of people. He considered his wife’s feelings and thoughts around blame and responsibility for Oliver being born with CHD. He described Caitlin as ‘dealing with her emotions,’ particularly in the early days following diagnosis. Tom saw his approach as a way of protecting Caitlin so if anything did go wrong in surgery, he would take that responsibility:

> We were only 11 days in, when he was having his open-heart surgery. But, by this point, she was already saying, “It’s my fault. I felt there was something wrong, I should have said something. I knew it”. So, she was blaming herself, “It was the pre-eclampsia, maybe my diet should have been better”. Neither of us had a clue about cardiac heart defects, at the time, she was playing the blame game and I was just playing the protective dad.

He reflected that his approach was unusual but for him necessary:

> I don’t know if perhaps, people feel it’s rude. Certainly, when I asked, I was like... “What I’m really wondering is how do you feel about this?” It gave me the reassurance that he was confident he was doing the best he could. That was the most I could hope for in that situation, that was enough for me to sign that little bit of paper.

James talked about the challenging time they experienced following the birth of Chloe as she had a number of health problems as well as CHD. He describes navigating the NHS and counted that they had been seen by thirteen different consultants in a short period of time. This was a challenging time as many had different views on the best ways to treat Chloe’s CHD and wider health problems. He described his SCCC as being a large teaching hospital which is good in terms of expertise but challenging as the consultants often have narrow fields of practice. On some occasions James met with a consultant once and would never see them again, as care was passed on to other colleagues. He described the difficulties in getting a healthcare professional to address their concerns:

> We were in A&E quite often, she wasn’t putting on weight, she wasn’t growing, and no one knew why. But within a month, we were in hospital, and she got bronchitis, and she was in over Christmas. She got out before the New Year, so that was when she went on a feeding tube, so she went to the hospital that was meant to be a couple of weeks just to get her hydrated. But she was over six months. So, it was just very slow, and almost, we had to force that to get something prescribed, and almost arguments in the waiting area for the children’s assessment unit in the SCCC.

James’ experiences led him to seek further information and to obtain a range of opinions from medical staff outside the SCCC, consequently he put pressure on the staff at the SCCC to undertake further investigations:

> They were like, “Oh, no. There are no tests that can be done at this age”. While our friend who is a radiologist was saying, “We do this from birth. We can scan her”. So, by arguing and saying, “We need to see somebody else,” we got the consultant. The registrar left; the consultant came. Then he was like, “We can do this, we’ll get you on some ranitidine. I’ll give you my personal number. We’ll work this out”. So, things started to help, but by then, like I say, it was already too late.

James talked about the relationship and trust deteriorating with his SCCC and original SCSC, thus leading to a search for further information. James described his approach of using existing friends and contacts to find specialists who had national and world renown in treating Chloe’s condition. He also explored the medical literature in an attempt to gain an understanding of the treatment that Chloe would require:

> The second opinion was conversations with the cardiologist at another SCSC, because it obviously is our choice if, we want a second opinion, but we’re not confident in the information that has been given to us. Because the symptoms we see on a day to day basis, we were sort of told, “Ignore that. She hasn’t got any symptoms”. But we can see symptoms, and everything, all the literature suggests there are symptoms. You just can’t ignore them because you see how it affects her.

He described his need to have confidence in the information that he had been given and that they, as a family, were following the right treatment plan. He very much saw this as part of his role as a father. The conflicting information provided was the most challenging aspect of the relationship with medical staff, he recounted one discussion with the SCCC cardiologist:

> We’ve had conflicting letters where it said one thing, and then the next day they’ve said completely the opposite thing. You’re just lost. The first letter was like, “We’ve seen this child…I’m very confident that where the issue is, is within the valve. We’ll be able to resolve this with hopefully the balloon dilation, and it will be okay”. Then it’s almost discounting that, a lot of the cardiologists we went to that said they thought it was indications that it was the supra valve and potentially valve as well. He had, sort of, discounted that. “It’s just all in the valve I can see”. We questioned him, because we’d seen a lot of people before, four different… Because some of them left, unfortunately, from the SCCC. We said, “That’s not what the previous letters have said”. He was like, “Well, you’re dealing with me. You’ve got to have confidence in me okay”. That’s why we went in for the balloon dilation and the diagnostics, essentially, was abandoned because they determined it wasn’t in the valve then it’s like, “No. It’s

> not what I said it was”. There’s no keyhole surgery for this. We’re going to have to have open heart surgery, but I’m watching her today because we’ve just gone from crisis to try immediate interventions.

For James this interaction typified his experience and coloured his view of healthcare professionals. James recounted how, as a family, they had asked for a change of cardiologist and a referral to a second SCSC. James’ search for second opinions led to a deterioration in his relationship with staff both at the SCCC and the original SCSC. He described not caring who deals with the family and not being concerned around the egos and reputation of staff but wanting to have confidence in the expertise of Chloe’s consultants. He described the impact of the relationship with one consultant who he had questioned:

> We’ve seen her since, and we’ve got a decent professional relationship. It wasn’t like there was a shouting match, or anything like that, but it was almost like we were questioning her judgement and she didn’t like that. But at the end of the day, obviously a lot of mistakes have been made, and I’m not afraid to ask, because the only person that’s going to suffer is Chloe. A lot of doctors have been doing the wrong thing, they haven’t diagnosed but we’ve had amazing doctors as well.

James recounted the approach taken when their daughter was admitted to the hospital for any treatment. He described his wife as being less questioning but no less protective of their daughter. Kate is a medical sociologist, and James explained that he felt she almost knew more about the subject than the consultants they spoke to. He described their approach when they have been admitted to the ward environment:

> When they do the round, you’d see them going around our bay area, and they’d talk to somebody, tell them what they thought, and then move onto the next one. Then they came to our bed, we would have an A4 list of questions of what’s happening? How will this work? You’d see other people looking like, “Maybe we should be asking questions. How do these people know?”

He expressed a sense of pride in this approach but identified that there was an impact to this with a different approach from medical staff when he was with his wife than when he was alone. When together he felt that medical staff engaged with his wife and him more equally but when he was alone, he felt that the communication and engagement was less and somehow different. James felt that this may have been due to his questioning nature and him taking the lead on second opinion requests and the transfer of care from one SCSC to another.

For Stuart it was important to meet and ask questions of the surgeon who would carry out the procedure. He described the need to have prepared questions due to limited time with the surgeon. He contrasted this to his wife, Dianne, who he described as being stunned and quiet in such meetings whereas he would have asked twenty questions, he thought this was a common difference in approach between mothers and fathers. He valued the time spent with the surgeon which he felt was important and gave him the confidence to sign the consent. He has also experienced transfer between two SCSC as he was unsure of the ability of the first SCSC to perform the complex procedure that Joshua required. In making complex decisions Stuart needed to have honest and realistic answers from the surgeons, particularly around the long-term prognosis and quality of life:

> I wanted to find out whether they thought there was a realistic chance that it would be a good quality of life or not and they thought yes, so we pushed for the surgery, but if we'd have got different answers to those questions, we might not have, or if it was really uncertain, we might have gone down the palliative route.

Having explored the options and potential risks Stuart was happy to sign the consent for initial surgery for Joshua and to proceed. As Joshua has required several surgeries, Stuart has continued with this approach.

As Alice has wider health issues Dean and his wife have searched for someone with experience of Heterotaxy as this is a rare condition. Following the initial consultation in his local SCSC Dean trawled the internet both in the UK and abroad to find experts in the field. This led to him asking to be referred to a larger SCSC as there was a consultant immunologist and cardiac team there who could offer further support to the family.

> We only found an immunologist because someone else recommended that we go to see them. We reached out to a consultant in a different SCSC, who is absolutely amazing. Any questions about, "Oh, she's come in contact with this or that, do we need to worry about this?" He'll answer emails at any time of night. No one from the healthcare environment has directed us to him. It was only someone else with the condition that said, "Really, you're not under an immunologist because the spleen?"

Dean talked about using social and personal networks in order to find medical staff with the level of knowledge and experience that he felt was appropriate for his daughter's care. Dean also talked of this as being a challenge to overcome but also as a scary prospect, he did not know what he would have done if he had been reliant on the ‘standard care’ as he described it. Dean found that there was a lack of overall coordination in his daughter’s treatment and in support of the family which prompted his approach to finding experts in their speciality. He describes a lack of overall support and a ‘full wraparound process’, which meant that there was a focus on stages of treatment such as diagnosis, investigations and follow up. What he found missing was someone to ask how they were doing as parents and how they were managing the situation. He also talked of the benefit of signposting support groups, having recognised a gap he established a support group himself which is online.

The fathers who followed this narrative identified themselves as questioning and being prepared to do whatever it took to protect their family. All the fathers made connections outside of the usual NHS referral pathways and were confident to ask for wider referral to other centres and specialists. They tended to describe their actions in relation to their role as a father, protector and provider and often contrasted their approach with how they saw their wives and other parents.

Various elements of the fathers’ narratives were discussed in both interviews. By the end of the second interview some fathers were experiencing a return or restoration of the more traditional father narrative that they had expected at the start of the pregnancy. They now had children who had undergone various surgical procedures, who were required to access annual reviews which would be the case for some years ahead, but no further treatment was expected. For other fathers, the future was far more uncertain with further surgical interventions imminent or certainly on the horizon. The next section will explore restoration narratives which reflected a return to some sense of balance in the family.

8.4 A restoration narrative

The majority of fathers within the study reflected on their need to have a sense of normality in their lives, both for themselves and their families. This was evident across different parts of the study, but particularly in the second interview where some fathers had reached the end of treatment and could look ahead to having a ‘normal’ life. Liam expressed relief that the surgery had been a success and that no further treatment was required. He had what he described as different but small worries and was specifically concerned that Jack may be treated differently and was trying to ensure that this did not happen:

> The only way you would know that he's had surgery would be if you took his shirt off, he's like a normal child really, so don't want him to be treated differently as I don't want

> him getting a complex that there's something wrong with me. I think because of everything that's happened to him we take and just find him that little bit more precious …I don't want him to think he's got something wrong with him, but I don't want him to be brought up to be spoilt.

Liam on the whole was content with his experience at the SCSC but felt more attention could have been paid to his needs during his wife’s pregnancy following the diagnosis and after the birth, prior to transfer from the local hospital to the SCSC:

> I think because the pregnancy is always sort of looked at over the mother, which I agree with, because she's having the child, but I think sometimes the father does get a little bit forgotten. I certainly felt like that, not in the SCSC Hospital, but the hospital that he was born in, I really felt that the father was put to one side. They didn't make me feel very welcome, I slept on the floor, I couldn't even get a blanket out of them.

He rationalised his experience by considering how other families interact with staff. He talked about mothers being present and fathers less so, either because they were no longer in a relationship or did not want to visit. He stated that he wanted to be there to support his wife and son and that should have been acknowledged in some way. Liam felt that overall, this experience could have been improved:

> I think just a little bit more education towards the fathers really. It's not a down it’s not having a go at them. It's just little things really, just like some of the nurses I think it's just because they might not have been trained in that or they just focus on the mother, because that's what they are there to do.

Anthony, while recounting his child Carwyn’s achievements to date, was keen to stress the need for normality and taking the opportunities available and not being identified by his illness. Carwyn had been transferred to adult services and was not requiring any further treatment at the point of the second interview. He discussed the support that they as a family had experienced over the years wanting people to behave as naturally as possible with Carwyn:

> You don't want him feeling as if he is some sort of specimen or freak, but erm just there were lots of photos taken but he wanted them to be taken.

Anthony went on to recount a range of Carwyn’s achievements from success in school, to university life and involvement in both politics and international charity work. Anthony also reflected on Carwyn’s potential moving forward, despite his heart condition never being very far from Anthony’s mind:

> If you asked him now, despite of the heart condition, you know do you think your life has been a good one and worth you being on this planet? he would say despite all his ifs and buts, the last few years have justified everything. So, whatever he does in the future because he's found himself, I'm sure that he'll make his mark in this world

Anthony felt that healthcare staff needed to value his role more as a father. He could understand why fathers could get side-lined but recalled a specific experience after Carwyn’s first operation when he wanted to stay with his son but felt unwelcome:

> During the night, in intensive care, and I still remember that sort of pinging of the machines, I think they were wondering why I needed to stay, you know, it was sort of ...we can look after him, so you can go off and sleep I just thought the professionals thought, what's he doing here, he doesn't need to be here.

He felt there were other times when he was not welcomed to stay with his son. He was unsure whether this was something that could easily be addressed but having staff who would engage more with fathers was one suggestion that he made to try and improve the situation. He highlighted that there would have been value in having someone available to talk to him when his son was going through major procedures:

> I should maybe have spoken to the Hospital Chaplain, about the sort of you know the spiritual bit because I think that would have been interesting and perhaps helpful for me to try and assimilate everything, I did go into the chapel a few times at the hospital and that was quite helpful.

He talked of his wife being a sounding board but saw value in speaking to a ‘third party’. He talked about his faith and its importance for him, he valued space and time for reflection in order to process events. He also recognised that the experiences that he had with his son now span twenty years, but they will always stay with him. Anthony looked to the future with an optimism that he says has developed out of the knowledge that his son is healthy and progressing in his own life.

Alex expressed the view that he and his family were heading towards ‘normality’. Although their daughter had her heart defect repaired, she still had some wider health issues in relation to nutrition and losing weight. Alex expressed his wife's view, as she was a special needs schoolteacher, and was much clearer on outcomes than he was. She was used to tube feeding having had children who had CHD in her class. She felt that if this was the only issue then family life could return to normal. Alex also talked about Oscar and the fact that they had another child grounded them in routines and it was important that his needs were not overlooked:

> Obviously, we've got another child to think about as well, so you have to think about him. You can't just ignore the fact that Oscar was here, I was really conscious that, throughout all of this, with the initial scans and everything going on, he had needs of his own.

8.5 I'm not a carer, but I am, in a sense

Some men in the study felt that there would never be a sense of normality in their lives again due to their child's ongoing health issues. These men have seen their roles change from father to carer or project manager. James talked about his role and how he manages his daughter's care which initially impacted his career. James encountered issues with his employer due to needing time off for his daughter's surgery and medical appointments:

> I had to leave my previous employer and move jobs, because people are very good at understanding health, or illness, but not fluctuating between stable illness to critical illness. There's no wellness, essentially, and they don't get that.

He described the multitude of appointments at various clinics that his daughter needed to attend, some at the SCSC and some at his local hospital. He reflected on the initial support offered by his employer but as time moved on, they became less supportive:

> It was almost like it became a battle that, "Yes, we understand, but we don't really understand". The compassion goes quite quickly.

James and his wife have been reluctant to share information about their daughter's condition as it is personal to them, and they want to maintain a sense of normality. James talked of Chloe having a normal childhood and not wanting to disclose everything about her treatment in case she was treated differently. The reality became different as Chloe grew and had further health issues which necessitated more input from both health and education services. He summarised the family's journey and ongoing treatment:

> You think this is short term, and things will just go…Everything is going to resolve and it going to back to normality, and then you realise it's probably never going to be normal in that sense.

James has had a challenging experience across his daughter's illness, this is reflected in his view of the way in which healthcare professionals have engaged with him. He felt that fathers were second rate with healthcare professionals focusing more on mothers' needs. He identified in written correspondence that healthcare professionals have noted his wife being present and him not. He felt there was a point being made here, possibly due to him being a father or related to his previous disagreements with healthcare staff. James expressed disappointment in this approach as he had taken the lead on organising his daughters care and appointments but feels that this is not recognised in communication with healthcare staff:

> I do a lot of the chasing, because I'm probably quite good at it, like, phoning, chasing appointments, but they always seem to speak to Mum first.

He stated that he felt that if both parents were present the other would be spoken to and engaged with first. He felt that staff were not as interested in his questions and that there was a lack of equality in how they were approached. James identified ongoing aspects of care that need addressing in order to help the family:

> Someone to coordinate, that still doesn't take place, a massive problem we found all along is a lot of people come into the mix and a lot of promises are made that then aren't followed through on, or for whatever reason, we're not saying that they deliberately don't want to, obviously the caseload is quite high, your child is essentially a number, where as soon as you're out the door, the next child is important and they recognise that, so you're the one that has to.

James sees his role as a father being changed as a result of Chloe's health needs:

> I think people don't realise that you're the project manager, you're the one that's controlling everything. If an appointment doesn't come through you need to be phoning for it, you need to be chasing for it, because you can ask your community nurse because they say, we'll help you, we'll go to appointments with you, not once has a community nurse been to an appointment with us, and very it took a long time for a

> paediatrician, for us to even get a paediatrician to go to, to direct us to the specialists, that we needed.

The pressure involved in caring for a child with CHD and other health problems is clear:

> It was just us, working, looking after a clinically unstable at that time child, and managing a diary that was full of like 120 appointments in the first year and it's not as bad now, but it's still ... I'm still the one chasing appointments that if one doesn't come through, we need it, because we know how quickly she can deteriorate. Having someone to do that, whether I trust them to do that now I don't know.

James is clear that having a key worker or a healthcare professional to take on some of this load from the family would be beneficial. He describes a changed future to the one he envisaged at the start of their marriage.

Scott also discussed the lack of normality in his family life. He reflected on expectations he had when his wife told him that she was pregnant and talked about how they had changed over the years. His son Shane is now thirteen years old and has successfully transitioned into a high school for children with special needs due to his syndrome. At the time of the second interview, Shane was due to go into hospital to have a stent inserted into his pulmonary artery. Scott had noticed over a period of a year or so that his son was tiring easily and lacked energy. He went for his annual cardiac review, and they were told that Shane would need the procedure. Scott talked of the constant need to be vigilant over his son’s health and the multitude of appointments that he has to attend to meet his son’s needs. He recognised that his wife takes the lead in this. Scott had described himself as a ‘head burier’ in the first interview and he reiterated that he had not changed much in this approach but was perhaps more aware of his sons’ needs and the possible outcomes:

> As he grows, I tend to look ahead in the short term, the next investigation, next procedure that’s how I cope.

He talked of the differences in approach between himself and his wife and acknowledged that he will avoid difficult conversations about the future as it is unclear whether Shane will survive into adulthood with CHD and epilepsy which is associated with the syndrome. He described the different approaches he and his wife take. Cheryl will access the various online forums associated with CHD and their son’s syndrome whereas Scott cannot see any benefit in that. He acknowledged that he does not really talk to anyone about his feelings as he prefers to keep them to himself. This has caused some issues in the relationship with his wife, but they have resolved their different approaches.

Towards the end of the second interview Scott reflected on his entire journey. He talked of the loss of the child that he thought he would have. He linked this to images of fatherhood; watching his son play football, engaging in sporting activities, spending time together playing games. Shane's condition includes substantial additional learning and communication needs which has limited the range of activities he can undertake. Scott talked lovingly about how he approaches this by spending time in activities that Shane gains pleasure from. At the end of the second interview, he reiterated his 'one procedure, one appointment' approach as being the best way forward for him, acknowledging an anxiety around Shane's future as he gets older and how his needs may change. He described this as an area that causes him worry as access to health and social care support services have been challenging.

Stuart described living with a child with CHD. At the first interview Joshua had undergone two of the three surgical stages to improve his condition. He was then too ill to undergo the third stage and was therefore placed on the transplant list. By the time of the second interview Joshua had improved and undergone the third stage and was well. Stuart described his approach which he referred to as 'managing' his son's conditions. He described the importance of developing good relationships with healthcare professionals. He viewed some as friends:

> You get to know them over a long period of time, and they become friends, I think having that relationship is good as they can pull strings and you get things done.

He described this approach as offering something more than most families get. He described families not staying with their children and not engaging with them to the same extent as he has done in order to develop good relationships. He considered this to be an advantage describing how healthcare staff reply to his messages after hours and when off duty. He compared this to care at his local hospital which he felt was less focussed on their family:

> It's different there, the care isn't the same. If we thought our son was really ill, we would bypass them and go directly to the SCSC as they would have to transfer us there anyway.

Stuart described what he thought the future held for him and his son who will require further procedures. He recognised that despite all the treatment Joshua may still require a heart transplant or palliative care:

> You have to be realistic, take each episode as it comes as you can't look too far ahead.

He talked about activities, school and sports and 'mourning' the loss of the child he expected to have. He reflected on being depressed at times and qualified that by talking of the love that he has for his boys while at the same time missing the activities that Joshua cannot take part in. He talked of Joshua being unable to walk short distances before the last operation and regretted trying to push him to do more and having to step back from that. He described uncertain futures both for his son and for him as a father which he has learned to cope with.

8.6 Summary

This chapter has explored various turning points in the fathers' experiences during treatment and beyond. Trust has been a recurring issue for a number of fathers, either in the SCSC and provision of care, or in their own local hospitals for which a few fathers including Stuart and Liam, now have little faith. Some of the fathers, like Steve, were impacted by wider issues in CHD provision with sudden, abrupt halt in the surgery undertaken at his local SCSC, however this did not impact his trust in those caring for his son and the surgeon specifically. Other fathers including Tom, had their own ways of reassuring themselves of the surgeon's ability, by very direct questioning and reviewing credentials and experience.

A number of these fathers had sought second opinions or transfer of care to other centres. James and Stuart both spent time developing knowledge of their children's' conditions and found national and international experts in order to be confident that the surgical opinions and treatment offered are in their child's best interests. This does also reflect these fathers' approach to planning for children, in terms of career development and being financially secure. Both were very clear in their approach to their children's care once the diagnosis of CHD was made. In discussing his background and upbringing James appeared very organised, ambitious and driven. He approached his daughter's illness as he approached his work within project management. He organised appointments, sought second opinions, found ways to access leading specialists and was content to seek alternates when he lost faith in his local service. Ray was similarly focussed on his career, being financial stable and choosing the right time to have children. Where Ray differed, was in his approach to healthcare professionals. He was clear in expressing some anxiety that his daughter's diagnosis was late and possibly should have been detected antenatally. However, he was reluctant to challenge healthcare professionals. There was an evident deference in Ray's approach, which was somewhat evident in discussing his upbringing in the Middle East and the faith put into professionals who hold significant positions in society, like doctors. At times across Ray's interviews, it was as if he wanted to complain and challenge, but never quite let himself do that. Each statement around his daughters undetected diagnosis was caveated with explanations of how busy antenatal and acute healthcare staff are which may have led to her VSD being missed.

Consent was an area that several fathers discussed which they very closely linked to their wives and their thoughts and feelings of blame for their child's condition. For Liam and Steve, signing the consent was a way of sharing the responsibility with their wives, should something happen in theatre while the surgery was being performed. Scott took a different approach and generally left the organisation of his son's treatment and the signing of consents to his wife. He describes this as a coping mechanism but also describes himself as a 'head burier', to avoid the worry of what might happen. This approach was somewhat atypical of the fathers that I interviewed. Some fathers were more engaged with their children's care than others but most discussed being present and involved in the major decisions. In both interviews Scott talked about his wife taking a lead in all of the major care decisions often attending appointments alone or if he did accompany her, Scott did not really contribute to the discussion. In Scott's discussion about his background, upbringing and planning for children he was clear that others often made decisions which he then followed. In many ways Scott's approach did not reflect the traditional paternal role and gendered views of fatherhood that I explored in chapter 2. However, Scott did reflect the move to a more caring masculinity and direct involvement of his own son's care in the home environment.

For most fathers, the acute phase of treatment was already over, and they had settled into the routines of annual reviews where their children were doing well with no further planned interventions. For other fathers including Scott, James and Stuart the future was more uncertain as their children would definitely require further surgery's.

8.7 Summary of findings chapters

The three findings' chapters have explored fathers' journeys from their background and upbringing through to planning for children and fathering and living with a child with CHD. Specific turning points in the fathers' journey have been discussed following disruption of the expected fathering narrative. Journeys to fatherhood are explored in chapter six, with the fathers' back story around their upbringing, planning for children and for some the initial diagnosis. I felt that this was an important aspect of the fathers' narrative as it clearly explored how fathers developed their parenting role which was influenced by their own upbringing and current relationships.

Disruption to the expected narrative is explored in chapter seven with a focus on care and treatment episodes alongside engagement with healthcare professionals. Finally, chapter eight discussed the findings around an uncertain future. For seven of the fathers the immediate future was mapped out with annual reviews, but no planned surgery or interventions. However, all fathers recognised that this could change with a sudden or unexpected deterioration, which was understood and accepted by the men. For three fathers there was certainty for the ongoing need for more surgery and interventions. Scott, James and Stuart knew that their children would require further surgeries, for Stuart there was also a possibility that his son would need a future heart transplant although he had undergone complex surgery, the long-term outcomes in early adulthood were unclear.

There are some clear links between the fathers' approach to their child's illness and their reflections on their upbringing. The fathers who experienced a disrupted upbringing; Tom, Liam and Anthony, have all strived to be present in their children's lives and have adopted a caring and involved masculinity. For Tom, this approach was brought about by his second son's diagnosis having had a very strict and regimented approach to his first son. Tom expressed regret at his initial approach to fatherhood with a wish to turn the clock back. For Anthony and Liam this was an approach to fathering that they wanted to take in response to a lack of paternal presence in their own childhoods. As their children's illness progressed all the fathers wanted to be present and engaged in supporting their wives and children. Anthony was the most reflective of the three fathers, drawing on his own upbringing and considering how that influenced his journey with his son. Anthony wanted to be involved and engaged and expressed frustration at various times when he felt excluded from clinical environments or at the very least not welcome. He described needing more support than was available and environments which were generally more accommodating of mothers' needs. Anthony's experience is one that appears in the literature around family centred care and the lack of representation and visibility of fathers (Hayes and Savage 2008; Higham and Davies 2012; Friedman et al. 2015). There were similar experiences in several men's narratives including Liam, Dean, Tom and Alex who all cited incidences where further support, involvement in care and time for fathers would have benefitted them. These examples all involved engagement with healthcare professionals who were mainly doctors and nurses. The clinical context of these experiences varied, with Liam feeling excluded immediately following the birth of his child, at one point having nowhere to stay, with his son in one hospital and his wife in another and being unsure where to be. Being with their children, feeling supported by healthcare professionals and having confidence in those delivering care were all important aspects of the fathers' experiences and is again reflected in the literature (Harvey et al. 2013; Kosta et al. 2015; Bratt et al. 2017). All of the fathers reflected on their experiences prior to and in the immediate post-surgery phase of treatment. All also discussed the nature of the NICU and PIC environments which was challenging of their role. Alex particularly identified with the trait of fathers as being 'protectors' (Finn and Henwood 2009; Miller 2011) but found that seeing his daughter in PIC, he was then unable to do this due to the overwhelming nature of the environment and found reasons to leave the unit frequently. Tom recounted an experience of trying to touch his son and being told not to. This interaction was significant and made Tom realise that there would be challenges in his relationship with some healthcare professionals.

All fathers engaged with healthcare professionals. In hearing their stories, it was clear that fathers wanted to present positive actions in protecting and caring for their children. A number of fathers described turning points which involved engagement with medical staff. Stuart, Tom and James all challenged medical staff in different ways. For James and Stuart, the focus was on ensuring that their children received the best care from the most appropriate SCSC to manage their specific needs. Both sought out experts within the CHD speciality, both national and international, and both changed their child's SCSC. The need for parents to have confidence in clinicians' knowledge and expertise has been recognised in several studies (Docherty et al. 2009; Rempel et al. 2012). I now see Tom's approach as different, in some ways, as he wanted to ask the surgeon a very direct question about their ability and confidence to perform the surgery on his son on that day. He talked about having traditional masculine traits which stemmed from his upbringing and own fathers regimented approach. Tom needed the security of the surgeon's 'word' that he could perform the surgery safely and confidently.

Several fathers sought to maintain some degree control in order to make decisions for their children. Stuart and James decision to change SCSC, stand out as examples of control. For James this was due to a breakdown of relationships. He linked this to taking a project management approach to his daughter's illness in seeking out the best care as he saw it for his child. Stuart was equally focussed in identifying the best SCSC for his son, but fostered good relationships, which he referred to as friendships, which he felt meant he had access to a more supportive and accessible service, with medical and nursing staff responding to him out of hours. He described the fostering of good relationships as being pivotal to receiving the best care.

Throughout these chapters, most fathers displayed traditional masculine and gender-based roles in parenting their children. All demonstrated caring and involved masculinity at various stages of their child's journey. It was evident to me that all of fathers would have benefitted from more support, particularly around the time of diagnosis and in acute environments, where at times they did not actually know what their role or position was in providing care. Recognising the men's different needs is important and is an area of both children's nursing and medical practice that needs to be addressed.

The following chapter will provide a discussion of the key findings of this study in relation to the aim, objectives and questions of the research. I will also include an outline of my plan to disseminate the findings as well as areas for future research which could be developed.

CHAPTER NINE- Discussion Chapter

9.1 Introduction

In this chapter, I present a discussion about the extent to which these findings, presented in the previous chapters, have answered my research aims, objectives and questions, namely, to explore the experiences of fathers whose children are born with CHD. My interviews were spread over a 2-year period and produced rich data exploring the fathers' narratives which allowed me to gain insight into:

- The fathers' perceptions of their role within the family and wider societal context
- The journey and experiences of fathers when their child is born with CHD
- How fathers engaged with healthcare professionals and the support offered or needed

9.2 Key issues in the findings

The key findings within my study relate to the importance of turning points across the illness trajectory and the influence that healthcare professionals can have on fathers' experiences. Gender and role were obviously important in terms of the participants roles as fathers, but also the provision of family centred care and the approach of both parents in terms of understanding and coping with their child's condition. Family centred care is seen, mostly uncritically, as the cornerstone of children's nursing practice (Mikkelson and Friedriksen 2011; Shields et al. 2012; Coyne 2015). However, at key points in the men's journey there was a sense of them being somewhat removed from the opportunity to participate in care or being seen as different with needs that were less well catered for. All of the men talked about coping and, for most, they perceived this as being different from the approach that their partners had taken. A number of men including Alex, Stuart, Dean and James talked about the turning point of the diagnosis. They all discussed online searches for information, which Dean described as leading him to some dark places. The men viewed this approach as being different to their partners, seeing this as something they would not do. In broader terms most men discussed their own jobs with a number using work to ground them in routine which could be seen as a coping mechanism. The majority discussed needing more support and input for fathers, but they were on the whole unclear as to what form this would take.

The fathers' relationship with healthcare professionals varied and there were examples in all the interviews where good practice was demonstrated. Challenges within relationships with healthcare professionals tended to revolve around key treatment decisions, the request for second opinions or referral to more specialist centres. Several fathers experienced issues with either trust in individual healthcare professionals or with a service that was under some form of investigation, although this was not directly related to the care of their child. A number of fathers also highlighted a lack of trust in their local referring hospitals preferring to access all care at the SCSC, regardless of whether the issue was related to their child's CHD, although for most this was not an option. This is an issue that is highlighted in several studies (Kosta et al.2015; Bratt et al. 2017; Franklin et al. 2021).

9.3 Fathers perceptions of their role within the family and wider societal context

The men in the study described their roles as fathers and the influences that their own upbringing and interaction with their parents had on them. This is where the narrative approach to the study yielded insights that other methods might not have in telling their back stories (Holloway and Freshwater 2007). The majority of the men talked about their father's influence on them, but less insight was provided into the role of their mothers. It was clear that for three of the fathers, namely Anthony, Liam and Tom, there was a narrative of a disrupted childhood which they sought to avoid in their own fathering approach in response to CHD.

There are a number of threads which appear in most of the stories relating to traditional views of fatherhood (Coper and Sparrow 2015; Medved 2016). The fathers' need to protect their family, and to maintain some sense of control and normality for their children became apparent in most storylines (Miller 2011; Bright et al. 2013). How this was achieved to a greater or lesser extent by these men varied, as did their individual approaches to their journeys with CHD over a number of years. There is not one story that can be presented to reflect all the fathers' experiences but rather multiple scenes and turning points which make up the whole storyline for each individual.

All the men in the study explored their own journeys to fatherhood. For some fathers, including Stuart, Ray and James this was a role that was planned, sought in advance and expected, whilst other fathers were more hesitant, like Steve, who had experienced significant changes in his life leading to a new relationship as well as children. For other fathers including Alex and Dean, fatherhood was a routine expectation following the expected masculine role (Dermott 2008; Adamsons 2010). Stryker (1968, 1980) discussed the acquisition of status in relation to socially prescribed roles, in this case fatherhood. He proposed that an evaluation takes place when a social role is taken on alongside the attributes of that role; nurturer, protector and provider create an identity which the individual then adopts and follows. For some men, the acquisition of the fathering identity, and the role itself, was more challenging. Tom reflected on a disrupted upbringing which had impacted his own approach to fatherhood. He described his own father as not always being present in his life and when he was, he followed a disciplined approach which Tom incorporated into his own approach with his first son. Adamsons et al. (2013) discuss the importance of early relationships in forming the fathering role identity. Feedback from ‘others’, is important in establishing and maintaining such roles. In Tom’s story he identified how prior feedback from his own father’s approach, and his current partner in confirming to him that his approach with his first son was the most appropriate way to parent. His parenting style was reflective of the authoritarian head of the household role which Seidler (2006) described as consistent with masculinities within the ‘Abrahamic’ tradition which is common in more westernised societies. When his second son, Oliver was born with CHD his approach had changed based upon having what he described as a ‘fragile’ child’. Feedback from others was included in most of the interviews and generally related to how fathers now saw themselves in relation to their child’s illness. Steve recounted a story of explaining the anatomy and physiology of his son’s condition to his own parents. He demonstrated a sense of pride in this, which was reinforced by his wife congratulating him on explaining the condition so well. Knowledge of their children’s conditions was highlighted in a number of stories including James, Stuart and Dean, particularly around the time of diagnosis in relation to the search for information. All three men developed in depth knowledge of their children’s condition, the treatment available, outcomes and alternatives. This enabled James and Stuart specifically, to engage with healthcare professionals from all clinical backgrounds, with a level of understanding that demonstrated their knowledge. There was a sense of ‘networking’, here which reflected their careers and how they worked in their day to day roles.

Supportive feedback was demonstrated in a number of scenes from the men’s narratives. This was often obtained from healthcare professionals with fathers viewing themselves as taking the right approach on supporting their family. This is reflective of Adamsons and Pasley (2013) who discuss identity commitment, in that the more identity is supported by family and friends or other significant people, the more enacted the role will be. Identity commitment and extensiveness are important concepts within the father’s role (Stryker and Serpe 1994). The majority of fathers in my study presented themselves within the fathering identity to both family and healthcare professionals, particularly at key turning points such as attending hospital appointments at the SCSC.

The majority of men also followed traditional gendered roles when presenting themselves to healthcare staff. Goffman (1959) viewed masculine roles as acting to reinforce the prevalent stereotypes. The gender display is a presentation of the culturally ideal role which becomes more evident when they are broken. Milestone and Meyer (2012) discuss the breakdown of roles which became apparent in some of these men's stories. For instance, Alex described needing to be present in the hospital setting, particularly in PIC. He described the intensity and visual aspect of the environment with monitoring, ventilators and tubes. He saw his role in gendered terms of being strong and protecting his family. However, he also reflected on his inability to maintain this role in PIC. He described a need to be present but an inability to sustain this presence, making the comment, 'I have never made so many teas and coffees. This was, as he described it, an opportunity to escape the environment and to gain some respite. Other fathers took a different approach. Scott's approach was different to all of the other fathers in the study and did not follow traditional stereotypical gender lines. Scott described hospital stays, when his son had required CHD surgeries, as a 'whirlwind'. He highlighted the fact that his wife usually took the lead in interactions with healthcare professionals and was more present during hospital stays than he was. In the first interview when discussing his role as a father, he talked briefly about avoidance in recognising his son's illness describing his lack of interaction as being a 'coward'. In the second interview Scott described further surgical interventions that his son had required but again referred to himself negatively with regard to his input into his son's care. Clearly, some men judged their performance as fathers in this crisis situation and found themselves lacking in some way. Scott was particularly negative in his own assessment of his role as a father and ability to support his wife and how that was presented to me as an interviewer. Scott clearly felt uncomfortable in describing his role however he did participate in the second interview but again referred to himself in negative terms.

A number of these fathers described specific examples where they had taken on the protector role. This was more evident at key turning points, particularly at diagnosis, and when invasive treatment was required. Signing the surgical consent form was one example that was a common and memorable event to a number of them. Liam, Steve, Tom and Dean all described taking the responsibility for this process in order to protect their wives if something should go wrong in surgery. They described taking ownership and seeing it as their role. This aspect of the men's narratives was particularly visible around the time of diagnosis when aspects of coping and control were being discussed. There appeared to be different motivations around this approach with Tom as it appeared to be related to his upbringing and regimentation with a need to maintain control. For Liam, it was about the emotional support of his wife which he discussed at length and appeared linked to his upbringing and his father being separated from the family. Liam discussed his closeness with his wife and need to be as supportive and caring as possible. Steve's and Dean's situation was different and perhaps were more nuanced in weighing the risk of the surgery and possible poor outcomes which were described in a slightly detached, logical manner.

9.4 The Journey and experiences of fathers when their child is born with CHD

The diagnosis of CHD is a stressful and emotional experience for parents. Fonseca et al., (2012) and Kaasen et al., (2010) both found higher levels of psychological distress than is found in parents whose babies are born healthy. Rempel et al. (2013) described the trauma of recognising that your child is acutely ill and then receiving a CHD diagnosis, as an adjustment to the inconceivable. This realisation and adjustment occur over a short period of time from the baby becoming unwell, through to diagnosis and prognosis in terms of a longer-term treatment plan.

Most of the fathers within the study talked of the need to maintain some sense of control in their lives as they went through diagnostic and active treatment periods. Harvey et al. (2013) found that handing care and control to others, including nurses, surgeons and cardiologists was a significant stressor, particularly during the early period following diagnosis. Control manifested itself in various ways for the men in my study. For some this was in trying to assimilate the information that was being provided by healthcare professionals and for others, like James, it was in trying to 'project manage', his daughter's illness. Once the initial diagnosis had been made James talked about trying to find out what the diagnosis meant both in the short term in terms of initial treatment but also in the longer term in what his daughters CHD might mean for her development and upbringing. This was consistent with Bright et al. (2013) who found that fathers expressed concern both about the present and also about their children's future health and development, as they tried to rationalise what CHD would mean for the family as their child grew older. A number of fathers sought information from the internet regularly. James, Steve, Alex, Dean and Stuart all described receiving the diagnosis and then, as Stuart described it, 'googling the hell out of it'. Kosta et al. (2015) described parents' need for information as particularly important during the diagnostic period and during key interventions. Most parents wanted more information, but Scott, reported that he had received too much information and he found this overwhelming. This correlates with Scott's description of wanting limited information and not looking too far ahead. This suggests that fear is a constant reality in this situation.

The search for information as a way of controlling the disrupted narrative following diagnosis of CHD is consistent with Robinson's (2016) description of a consumerism relationship impacting trust in healthcare professionals. There is a confidence in the individual's own ability and competence in managing the illness with some degree of responsibility for problem solving and decision making. Dean described his approach as leading to some dark places on the internet when researching his daughter's condition and potential outcomes. He described making contact with other parents whose children had the same condition but also his despair at the content he encountered which painted a bleak outlook. Other fathers, including Steve, Alex and James, followed a similar approach of internet searching, however their wives did not do this. Liam, Anthony and Scott did not take the approach of in-depth searching, they were content with information as it was provided for them by healthcare professionals.

A number of fathers, through their searches, were able to access specialists in specific aspects of their child's condition. James and Stuart both made contact with medical staff who were considered to be specialists in their field. Robinson (2016) described this consumerist approach as a means to obtaining the desired level of care. Participants reported that they were creative in contacting key healthcare staff in order to facilitate their needs. James, for example, used various channels to make links with a specialist that he had been referred to and who was outside the SCSC. He joined online forums, attended conferences and asked for a second opinion. Although this did not change the course of his child's treatment, it did reassure him that he had done everything possible to ensure his daughters safety and quality of care. Rempel at al. (2013) describe the diagnostic and early period of treatment as adjusting to the inconceivable, this was reflective of all the fathers' experiences as none had considered that their child might be born with CHD.

9.5 How fathers engaged with healthcare professionals and the support offered or needed

Several fathers discussed the issue of trust in healthcare professionals. Entwistle and Quick (2006) state that trust supports cooperation and allows patients and families to experience a less threatening world. There have been a number of high-profile inquiries into the failure of clinical services to provide high quality and safe care (Alitt 1994; Kennedy 2001; Royal Liverpool Children's Inquiry 2001; Francis 2013; NHS England 2014; Grey and Kennedy 2016). Fathers within this study exhibited differing levels of trust in healthcare professionals. Robinson (2016) describes trust in healthcare professionals as being an important measurement of care quality. Various authors identify trust as being pivotal in ensuring effective therapeutic relationships (Thorne et al. 2000; Hupcey and Miller 2006; Calnan and Rowe; 2006; 2007). Trust is especially important where there will be ongoing clinical relationships. Calnan and Rowe (2006) and Robinson (2016) highlight that this is particularly important for patients with chronic or serious illness where a degree of trust in those caring for patients is important. Hall (2006, p45) states that trust will depend on a patient's or client's, "overall assessment of the physician's personality and professionalism, and it is driven fundamentally by the vulnerability of patients seeking care in the compromised state of illness".

Some fathers within the study expressed variation in the trust they had in various healthcare professionals. For many of the fathers there was less confidence in their local referring hospital. As discussed in the literature review, the quality of service provision varies. Some fathers' local hospitals were small and, although aligned to SCSC, were not cardiology centres. A number of fathers highlighted the fact that if their child was unwell, they would bypass the local hospital and present directly at the SCSC. Stuart discussed a lack of trust in the ability of his local hospital to provide care for his son who has been diagnosed with hypoplastic left heart syndrome. He talked of the various services that were available and the paediatrician's experience. He concluded that even if his son had a non-cardiac related health problem, he would still bypass his local hospital in case it turned out to be a more serious clinical condition. Liam was typical of a number of fathers who were content with the care and treatment that their children had received from the SCSC, but less confident in the local hospital. When this was the case there tended to be a trigger episode where some aspect of care had been below the standard that the fathers expected. For Lee, a specific incident occurred after his son was newly discharged from the SCSC. He was admitted to his local hospital and placed in a ward area next to a patient with norovirus. Liam requested a transfer back to the SCSC which was refused and later discharged his son from the hospital. His lack of trust in the hospital was later reinforced when attending an outpatient clinic where a doctor referred to his son as potentially being 'slow' due to his cardiac surgery and having something wrong with his heart. When a more senior paediatrician listened to his heart, it was found to be as expected post-surgery. Hall (2006) found that patients and families' trust in healthcare professionals was motivated by a feeling of being vulnerable due to illness, while at the same time having a perception of risk in their care. Out of this viewpoint an 'informed trust' is developed based on a range of factors including the knowledge that the available healthcare may be limited or inconsistent and that families need to be active participants in their relatives' care in order to achieve the best outcomes for their relative (Hall, 2006).

Informed trust develops from a greater understanding of the family's own responsibility and those of healthcare professionals to deliver effective care. Within this relationship strengths and limitations on both sides are recognised**.** Robinson (2016) described this as a form of alliance that is conditionally based on cautious trust underpinned by various attributes including ethics, integrity, motivation as well as clinical competence. A number of fathers within the study sought to foster good relationships with healthcare professionals, particularly medical staff. Liam described using humour to develop relationships and highlighted a specific interaction in PIC where he was ‘having a laugh’, with two doctors over the colour of their scrubs. He expressed some sense of satisfaction that he could have a joke with the doctors as it appeared to reassure him that everything with his son’s care would be okay. A point that was reinforced by one of the doctors who said that ‘You’ll be alright, I’ll make sure that you’re alright’. Liam described this as reassuring and a little win, which was a term that he used frequently in the description of his son’s journey.

Trust is a two-way process and some authors have acknowledged that healthcare professionals also need to trust patients and families (Williams et al. 2005; Calnan et al. 2006; Broome and Buelow 2014). Tom questioned the surgeon’s confidence and capability in carrying out the cardiac surgery on his son, he described this questioning approach as being part of who he was. To his surprise the surgeon replied that he had never been asked that before but welcomed the question. Other fathers described how they needed more information from healthcare practitioners in order to feel confident in their ability. James described having an A4 pad with questions on, this was done in preparation for ward rounds when his daughter was an inpatient. He described other parents surprise at this approach, some responded to by considering whether this was a method that they should use. This suggested that questioning was not a common practice, or not to the extent that James engaged in it.

Some degree of breakdown in trust was seen within a number of fathers’ stories. This tended to become an issue close to the time of diagnosis when there was uncertainty over the best treatment options or where the CHD was rare. Stuart, James and Dean all sought second or specialist opinions on their child’s condition and explored likely treatment options. In the UK there is no legal right to access for a SO, but it is generally supported by the NHS (Larcher and Brierley 2020) and considered to be good practice in medicine (General Medical Council 2014). Hillen et al. (2017) undertook a systematic review of twenty-five studies, reviewing the literature on second opinions (SO) in oncology. The range of request for SO across studies varied from 1 - 88%. Motivation for requesting SO were associated with a need for some degree of certainty or confirmation of the diagnosis. This was reflective of three of the fathers in my study due to the rare nature of their child’s CHD. A lack of trust, the need for a more individual approach to information giving and frustration with communication were all issues that contributed to SO (Hillen et al. 2017). Again, this reflects the situation for a number of fathers in my study. James found the information provided by his local SCSC did not meet his needs, he was active in insisting on referral for a SO from two different SCSC’s. One being for the opinion of a specialist cardiologist and the second for referral to a surgeon who had, what he perceived to be, more experience in operating on children with the same condition as his daughter. James described his role as both a carer for his daughter and a project manager in trying to maintain communication amongst various healthcare professionals, he described a lack of coordination and felt they would have benefitted from having a key worker in place to support the family.

The establishment of key workers who work across various settings including health, education and social services has been recommended for some time (Well Child 2018). Noyes et al. (2014) described the benefits of having a key worker who could provide more comprehensive communication, greater accessibility and coordination of services and to act as an advocate for the family. Service fragmentation and a lack of coordination amongst professional groups and clinical services has long been highlighted as an issue for parents who are caring for a child with a long-term condition (National Collaborating Centre for Cancer 2005; Noyes et al. 2014; McGirr and Richardson-Reed 2018). Over the past ten years the NHS has attempted to address these issues and there has been an increase in the number of roles being established. This may help address coordination/key worker issues, such as clinical nurse specialists, and all the fathers mentioned this as a gap in CHD services although for James this has not been the case. Organisational and service barriers remain problematic especially in services such as SCSC which may be some distance geographically from the family home. Current policy attempts to address this with a more targeted approach to service delivery (Scottish Government 2016; Welsh Government 2019; NHS England 2019). Scott had a different experience to James as he was told that a key worker would be provided because his son had a range of complex issues apart from CHD. However, this had not yet happened meaning that Scott and his wife find themselves trying to negotiate their way through various services which has proved challenging. Scott and James had very different approaches to these issues. For James these were issues to resolve and overcome. Scott expressed gratitude for the input that the family had received and was far more reluctant to challenge any lack of support. In both interviews he described himself as ‘putting his head in the sand’ and not being confrontational. Although James was not satisfied with various elements of communication and service provision, he had been successful in obtaining more support and access to services and engagement with healthcare professionals whereas Scott had not. James expressed a sense of accomplishment in providing care for his daughter and follows the hero narrative of protecting and providing for his family.

SO are usually associated with patients or families who are older and more highly educated having accessed some form of higher education (Czarja et al. 2003; Morrow et al. 2009; Mordechai et al. 2015). All but one of the fathers in the study had accessed higher education although not all had completed. Mordechai et al. (2015) was one of the few studies which explored SO in paediatrics. Similar to other studies this was primarily related to oncology and haematology conditions. They examined SO consultations by physicians to explore the family and patient factors leading to the request for a SO to be made. One hundred and fifty parents who had been treated for cancer were interviewed by telephone. Results found that thirty-seven (24.7%) parents had sought a SO. They found that higher education and socioeconomic status were linked to SO requests. The reasons for the SO request were usually to obtain confirmation that their child was receiving the most appropriate treatment, to ascertain the competence of the medic treating their child and to find out the clinical outcomes of the treating hospital. The study found that 25 parents received more information on their child's disease, 13 were advised to change treatment and centre and 9 found the SO unsettling. Parents who gained an SO during the diagnostic period found it particularly confusing.

For the three fathers herein, who had obtained a SO, it offered some degree of reassurance. Stuart and Dean were perhaps more content with the outcomes than James who asked for an SO, and changed cardiologists, initially accessed treatment in a different SCSC but was then referred back to his original centre. At the time of the second interview James described issues which were mostly related to ongoing care at his SCCC, and he had even asked for some medical staff to be excluded from his daughter's care. Tom had similar experience however he had never sought an SO but did ask for staff to be removed from his son's care when he felt that they lacked confidence to perform procedures or in Tom's view did not deliver the quality of care that he expected.

In telling their stories, these participants reflected the three illness typologies (chaos, quest and restitution) as described by Frank (1995). Fathers moved between these storylines depending on the narrative they were discussing at the time, but all started from the same point. For most of these participants there was also a sense of restitution with their children coming to the end of treatment following successful surgery. The children were still attending annual reviews, but no further interventions were planned. For four of the ten fathers, the future was more uncertain with ongoing surgical interventions planned for later in childhood or the potential for heart transplantation being required. In Anthony's story, his son had already transitioned to adult services, and he described now being one step removed from his son's CHD management but still with the same sense of responsibility that he felt as Carwyn was busy growing up.

9.6 Implications of the research for healthcare practice and policy

It is important that healthcare practitioners and policy makers have a greater awareness and insight into the experiences and needs of fathers more broadly and fathers of children with CHD specifically. Family centred care is well established and adopted, usually uncritically, within children's nursing practice. However, this study has shown that within this model of FCC fathers' needs are often overlooked leading to a sense of detachment during inpatient episodes or when engaging with healthcare professionals.

It is essential to recognise that fathers will present themselves, and their needs, in different ways and may appear to be content with their experiences and involvement in care. They may potentially take this approach to present the 'strong protective' character that is often expected of a man and father specifically, as these man's narratives have shown. Fathers can and do involve themselves in care delivery in a range of clinical environments yet there is limited recognition and understanding of this in the literature, or indeed in practice developments. Fathers within my study often referred to feeling insecure in clinical environments. Bruce et al. (2016) found that fathers needed to feel safe, supported and involved in care as this led to a validation of their role and a recognition from healthcare professionals of fathers' input to their child's care. Alex was interviewed when his wife present in the room, and he talked of wanting to be in the PIC environment, and to assist with care, but feeling reluctant as he was not sure what his role was or should be. He described being 'in and out' of the unit and never having made so many teas and coffees. He recognised that this was his way of coping in an emotionally challenging situation. In contrast his wife talked about being 'set up' at the hospital, there was a sense of the environment being more comfortable and accommodating of her needs. A number of fathers discussed how they coped in PIC and at other critical points in their child's care, for some fathers, work was a distraction but also a stress reliever. Golfenshtein et al. (2017) examined parents coping mechanisms and found that activities such as changing the times that they visited their child, spending time together as a couple for a meal and interacting with other parents helped to support parents in the immediate post-operative period.

These men should be encouraged to better express how they feel and should be provided with greater support which addresses their needs. A number of fathers talked of mothers supporting each other, whereas fathers tended not to engage in conversations about the way they were feeling and did not ask for help. Anthony talked of the need for support from more than other fathers, this was drawn from experiences across his son's various admissions from diagnosis to more recent treatment. He was unclear what form that support would take but considered counselling, psychologists or chaplains as some options. Other fathers, including Tom and Liam, had accessed counselling services to address the impact of their child's diagnosis and wellbeing on their mental health. At the first interview Liam identified that his motivation to participate in the research was partly the opportunity to talk to someone about his experiences. By the second interview Liam had accessed counselling which he found to be beneficial. Others identified that some sort of online group for fathers might be useful, but they often caveated that by saying that they might not actually use such groups. It appeared that they were identifying potential sources of support but also saw them as being for others rather than themselves. Dean was an exception in that he had set up and participated in an online group for fathers as his daughter's condition was rare. He used this as a source of information and to gain insight into specialist CHD treatment within the UK and internationally, however, the group had not been maintained in the long term.

Exploring fathers' experiences when their child is born with CHD has generated new insights into their experiences and needs of fathers of ill children. However, wider and comparative insights could also be gained from undertaking research with fathers of children with other long-term conditions. It would be useful to see, for example, how fathers engage with different healthcare services for children with cystic fibrosis, diabetes or kidney disease.

9.7 Limitations of the study

It is important to acknowledge that while this study has presented an insight into the fathers' journey and experiences from a narrative perspective, it only represents the stories of ten individuals within a given timeframe. Further research is now recommended in order to explore fathers' experiences at different stages of their CHD journeys, particularly at the time of diagnosis and specific treatment episodes such as first surgery in order to gain a greater understanding. Further studies would also be useful in generating more data to inform healthcare professionals of fathers' needs and to inform innovations in practice.

All ten fathers participated in the first interview and nine out of ten participated in the second. Although some data would have been missed there was sufficient data to meet the intended outcomes of the study and to answer the research questions.

The study can be criticised for its lack of diversity both in terms of race and fatherhood. Nine out of the ten fathers were white British, with one father, Ray, being born in the Middle East. All the fathers were married and apparently heterosexual. The incidence of CHD in BAME ethnic groups is similar to those in the Caucasian population. The lack of ethnic diversity may have been due to recruitment constraints; however, I have no evidence for this either way. The same is true of fatherhood. In recruiting to the study, I described the role of father as any adult with caring responsibilities, this included biological and non-biological parents and those with caring responsibilities. Following recruitment, it transpired that all of the men were biological fathers and were currently married to the children's biological mothers. In any future research it would also be beneficial to access advice and support from researchers who have experience in recruiting more diverse populations successfully and submit my recruitment materials for review to see if the wording implied any sort of bias towards biological fathers.

9.8 Contribution of the study

The strengths of the study are in the depth exploration of the fathers' narratives across a period of time. Research which explores fathers' experiences when their child is born with CHD is limited (Doherty et al. 2009; Franich- Ray et al. 2013; Fonseca et al. 2014). Existing research tends to incorporate fathers into wider parental or family research or indeed does not represent their experiences at all. I could not find any study which had explored fathers' journeys through different treatment episodes from diagnosis through to definitive treatment and beyond. The in-depth nature of the study over a period of time allowed me to capture the fathers' experience at various turning points. All the fathers had experienced at least one treatment episode or review between the first and second interviews. Although some fathers had come to the end of their child's treatment, apart from annual reviews, several children had undergone surgical interventions. By interviewing the fathers twice, I was able to build a relationship with them and this provided increasingly rich data. I was surprised at the men's openness and willingness to share their stories, particularly in the first interviews during which some fathers described their own upbringings as challenging and at times emotional.

The use of a narrative approach, although not unique, enabled me to gain insight into the fathers' own past experiences and to present them with sensitivity. In using a narrative approach my research presents the fathers' stories as they saw them as part of their life stories. Having the benefit of two interviews, fathers were also able to review their transcripts at two time points, after the first and second interviews. Only one father, Tom, added a comment to his first transcript regarding his use of a questioning approach. It was important to ensure that participants had this opportunity in order to present their version of their story in the way that they had wanted.

9.9 Practical Implications

The study inevitably leads to the potential for further research. It would be beneficial to explore family centred care further in relation to fathers' experiences. It appears that fathers are, at times, treated differently to mothers and it is possible that the gender and role differentiation has developed from the early development of family centred care from the 1950's onward.
I have very limited evidence for this assertion, however a number of fathers, including Anthony and Liam, talked of episodes in the clinical area where they felt unwelcome. For Liam it was following the birth of his son while his wife was in the maternity unit. He described not having had a drink, eaten or having anywhere to stay until a midwife who he described as 'old school' intervened. Anthony discussed his son's time in paediatric intensive care with a notion that he was less welcome when he was on his own and at night. He described times where he felt that staff were encouraging him to leave or wondering why he was still with his son late at night. Part of demonstrating family centred care is ensuring that there is a partnership with parents and that they feel welcome in clinical environments (Smith and Coleman 2010). This was less apparent in a number of father's description of their interactions with healthcare professionals.

Several studies which explore masculinities and the father's role highlight a change in how these are performed (Stevens 2015; Banchefsky and Park 2016) however, change takes time which was illustrated in Massoudi et al. (2010) where Swedish nurses identified that working with fathers was a positive experience although their participation in care was lower than mothers. It was also found that nurses rarely recognised that fathers may become distressed with their child's illness and might be in need of support. Although the focus of my study was on fathers, it would be interesting to explore the experiences of families from a range of backgrounds including the LGBTQI community to understand how their experiences of care provision, within the concept of family centred care varies from those discussed within my research.

Exploring fathers' experiences at the time of antenatal diagnosis would be useful. All fathers discussed their lack of preparedness for their child's diagnosis, but this was particularly apparent in those fathers where CHD was detected at the time of the antenatal anomaly scan. Fathers felt unprepared for their child to be diagnosed with any congenital abnormalities, the majority expressed a feeling of loss both for the expected narrative of a well and thriving baby with a certain future and the experience of an uneventful pregnancy. It would be pertinent to explore mothers' experiences of this stage of the journey also as it appears that mothers and fathers approached the diagnosis and the aftermath in different ways.

A number of fathers discussed the challenges of understanding their child's condition. Some discussed meeting with the surgeon who drew their child's anomaly on a piece of paper. This appeared to be a common occurrence. The development of both visual and interactive resources to support parents at the point of diagnosis would be helpful to families, particularly around the time of diagnosis.

There was a view expressed by a majority of participants that they had less confidence in referring and local hospitals once they had experienced care in a SCSC. This would be worth exploring further to measure what influences parents' confidence in care provided locally and at SCSC, and how relationships between service providers can be developed and maintained. All participants received care for their children in a number of hospitals which appeared to be a challenge in providing consistent care, information and support for fathers.

9.9.1 Dissemination

The purpose of the work, as well as exploring fathers' experiences, was to inform and develop practice to promote an awareness of fathers' specific needs within the family when experiencing significant healthcare interventions for their child. I would hope that the findings will question widely held healthcare professionals' assumptions around the father's role, needs and level of participation in CHD care. This will hopefully raise practitioners understanding in hearing the paternal voice and enhance nurses and other healthcare professionals' appreciation of fathers' needs and input. I would also hope that the available support for fathers will be built on in a way that meets their needs.

In order to achieve these goals, I plan to add to a limited body of research relating to fathers, both those whose children have CHD and others with long-term conditions who may experience similar journeys. I feel that there are various aspects of the research that could potentially be turned in to papers; fathers understanding of family centred care, issues around trust, healthcare relationship breakdown and the support needs of fathers. Alongside papers, I will incorporate my findings into my teaching across the undergraduate, post registration and postgraduate programmes. I will also submit applications to present at conferences both local, national and international. In undertaking this study one of my goals was to hear the fathers' stories, now my goal is to try and improve their future experience.

Some dissemination activity has already taken place with other activities planned as detailed in the table below.

Activity	Where	When	Delivery
Presentation of Findings	Congenital Cardiac Nurses Association Conference	June 2021	Concurrent Session Presentation
Presentation of Findings	RCN International Research Conference	September 2021	Concurrent Session Presentation
Presentation of findings around transfer of care to SCSC	Cardiff & Vale UHB Conference/ Aneurin Bevan UHB Conference	Awaiting dates	Concurrent or poster presentation
Fathers coping strategies following diagnosis of CHD	Journal of Child Health Care or Nursing Children and Young People	By late 2022	Journal article
The challenge of fathers in family centred care	Journal of Advanced Nursing	By late 2022	Journal article
Findings around fathers' experiences in critical care and transfer	UG & PG Nursing Curriculum	Ongoing	Lectures, workshops and clinical simulation

The final chapter will provide a brief conclusion and my final thoughts on the study.

CHAPTER 10 – Conclusion and final thoughts

10.1 Conclusion

CHD is the most common congenital problem in childhood affecting around eight in a thousand babies born in the UK (NICOR 2019). The seriousness of the disease and the transition from expectant father to parent of a sick baby is significant and has a long-term emotional impact on the family unit. The various turning points in each fathers' journey are substantial and impact on all aspects of daily life. Transfer of care to specialist children's surgical centres, investigations, diagnosis and treatment all disrupt the expected narrative of fatherhood. However, their responses are also shaped by individual life experience and past narratives.

The aim of this thesis was to present how ten fathers with children born with CHD made sense of their experiences and the fathering role. I have explored these fathers' narratives as they have presented them to me, which was very much understood in terms of turning points which were significant and memorable to them. A number of turning points were common to all fathers, which was perhaps to be expected considering that the management of CHD is evidence-based and consistent across surgical centres. What was different and unique was how the fathers negotiated their individual journeys and found different ways to cope with this unexpected diagnosis. Liam summed up the fathers' experiences well, when he said 'It's all about the little wins'. This was around small but steady improvements which meant that he could bring his son home as originally expected.

The thesis has allowed me to explore areas of personal and professional interest which stem from my own clinical nursing background. The findings have provided an insight into how fathers navigate their child's illness and the complexity that surrounds it, not only in terms of the presenting condition but also the provision of various healthcare services across a number of clinical, and sometimes distant, settings. The findings also highlight the support and care offered by a range of healthcare professionals to fathers within my study. Undertaking the study, and writing this thesis, allowed me the opportunity to share this new knowledge with a range of healthcare professionals including colleagues in clinical practice and new generations of students to inform and change practice for the better.

However, I recognise that doctoral study is a starting point for me to develop as a researcher. The findings within my study would lend themselves to further exploration and collaboration both with fathers, wider family members and clinicians. I have been fortunate in presenting at two conferences this year which has furthered my ambition to continue with my research, and to work and collaborate with more experienced researchers to learn from their experiences, and to develop the knowledge and skills required to become an independent researcher.

10.2 Final Thoughts

It has been a privilege to explore the experiences of the fathers within my study. Their willingness to share their stories and offer me an insight into their thoughts, feelings and experiences has been surprising and inspiring. I have remained in touch with the fathers throughout the writing up process and all of their children are well. Most are now in the position of attending annual reviews and those that have had further surgery have recovered well.

In the introductory chapter I included a photograph and quote from James, which showed a photograph of his daughter's medical notes to date, and the acceptance of her continuing health challenges. His quote demonstrated the impact that his daughter's CHD diagnosis has had on him. His narrative across these chapters also reflects the acceptance of his changing role as both a father and a carer, which he talked of as a continuing role which had severely impacted his family and expectations of parenthood. To end, I have included a photograph from Steve, which alongside his quote, highlights a more optimistic future with a move towards the traditional fathering role and pride that Steve had hoped for.

> *'Harry loves sport, he got the most valuable player award. Whilst it makes me proud of him, the reason the picture means a lot is that it sums up what he can achieve even though he had a difficult start in life and still has an underlying heart condition. He excels at all sports, and it brings a special kind of smile to my face whenever I watch him'.* Steve.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List of Appendices

Appendix 1

The Florence Nightingale
Foundation

34 Grosvenor Gardens, First Floor Front, London SW1W 0DH
Tel: 020 7730 3030
Fax: 020 7730 6262
Email: admin@florence-nightingale-foundation.org.uk
www.florence-nightingale-foundation.org.uk

10 July 2015
Mr Peter McNee

Email: mcneep@cardiff.ac.uk

Dear Peter

THE FLORENCE NIGHTINGALE FOUNDATION RESEARCH SCHOLARSHIP: THE MENATTRUST RESEARCH SCHOLARSHIPS 2015-2016

The Selection Panel were delighted to have the opportunity to meet you at your recent interview.

Through the generosity of The Menat Trust, we are pleased to offer you an award of **£2,026**. This is to assist you in undertaking the second year of your Doctorate in Healthcare. The title of the study is: 'Fathers' experiences when their child is born with congenital heart disease.' This money will be paid either to the University where you are undertaking your course or directly to you, as required. In either case, we would need to have sight of an invoice or receipt as appropriate.

The terms and conditions of acceptance of this scholarship are:

- The Foundation and The Menat Trust require a short six month review report by the end of April 2016 to update us on your progress. This needs to be a brief update of around 500 words which can be sent to the Office Manager at admin@florence-nightingale-foundation.org.uk as an attachment in a word document.

- **I attach some notes for guidance on report writing plus a front cover for your report.** A full report on your research (two hard copies and one on CD or stick) should reach The Foundation On completion of your studies covered by this award.

  Your report should include an acknowledgement of your sponsor and The Florence Nightingale Foundation and be presented in a clear plastic cover.

- You should also send a copy of the report to your sponsor at the end of your scholarship.

- Your final report should be submitted within 3 months of completion of your year of study but no later than 19 December 2016.

- Your sponsor may also ask you to give a formal presentation on the outcome of your studies at a future meeting; we will liaise with you on this nearer the time.

- If asked, you should be willing to present your work at a Foundation conference.

- We also expect you to publish something as a result of your scholarship. By accepting this award you will name the Foundation and sponsor in any publication. **I am attaching a copy of our publishing guidelines for scholars.**

- By accepting this award we also hope that you will be happy to become an Alumni of the Foundation to help support future scholars within your area of expertise. Unless you inform us otherwise we will keep your electronic personal date on file and contact you with relevant information and opportunities to collaborate with the Foundation.

- If your home address or employment details change before you have submitted your report, you are required to keep the Foundation up to date with your contact details at all times.

- If you have a significant period of sickness or **any event** that may impact on the completion and/or submission of your final report, you are required to inform the Foundation as soon as possible to negotiate a new submission date if required.

- In the event that you do not undertake the study and produce an acceptable report for which this award is being made, you will return to the Foundation the money you have received, in order that it may be used to fund another Scholar.

If you accept the award in accordance with the conditions set out above in this letter, ***please sign one copy and return it to me as soon as possible, but by 28/07/15 at the latest*** keeping the second copy for future reference.

If you require any further information, please do not hesitate to contact

this office.With best wishes and congratulations on this award.

Yours sincerely

Professor Elizabeth Robb OBE
Chief Executive

Appendix 2 Key Articles from Search Strategy

Author	Topic	Method	Key Findings
Bennett et al. (2008)	CYP with cancer Fathers of children with cancer: Involvement, Coping and Adjustment 20 Fathers / 20 mothers	Questionnaire	Treatment teams needed to be mindful fathers Fathers spent more time in work MDT needs to actively pursue opportunities to engage with fathers
Bratt et al. (2017)	Transfer of CYP with CHD to adult services parental concern, 18 parents	Semi-structured interviews	Need to be kept informed Concerns of move to adult services Concerns experiences in adult care Removal of the familiar CHD services and support
Bright et al. (2013)	Examines the father infant relationship in infants with CHD. Infant Cardiac surgery and the father – infant relationship: Feelings of strength, strain and caution 63 fathers	Mixed method	This study is one of the first to examine father–infant relationships in infants with CHD. The use of both qualitative and quantitative methods allowed for a more comprehensive picture of fathers' experiences and perceptions of their relationship with their infant following CHD surgery. lower levels of affection and pride and pleasure in interaction when compared to community norms. Reluctance to get close to the baby initially
Bruce et al. (2016)	Lived experience of support for Fathers of Children with Heart Defects. Five fathers	Phenomenology	Fathers secure in staff experience and knowledge Need for further support

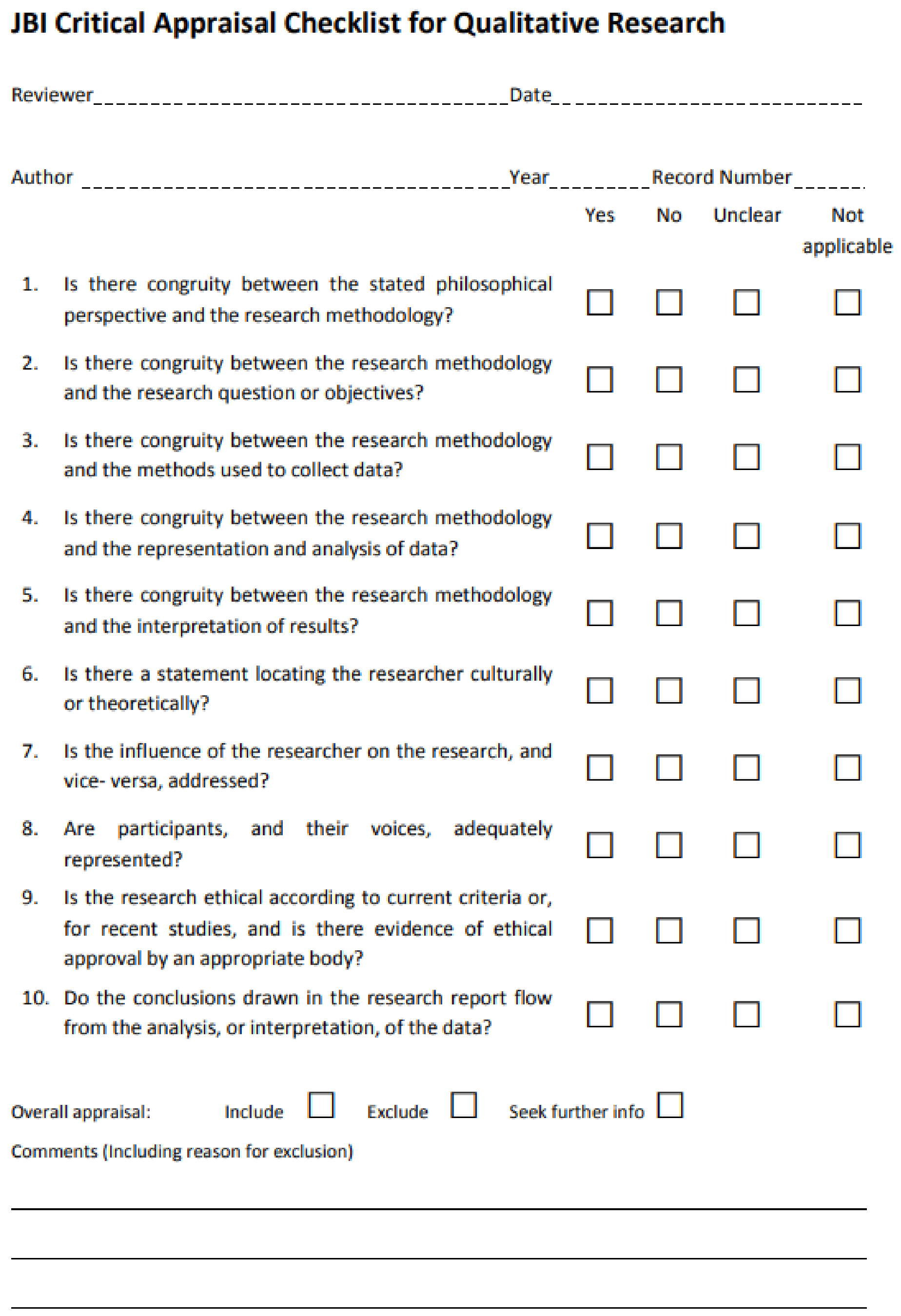
			Uncertainty of diagnosis treatment options and management all significant stressors
Coyne et al. (2011)	Families' expectations of family centred care.14 couples	Semi-structured interviews	Parents both contributed to care Parents negotiated the acquisition of skills to care for their child Fathers protective of long-term needs Mothers focussed on current care
Darbyshire (1994)	Living with a Sick Child in Hospital 30 parents, 27 staff Children's wards	Phenomenology	Parents described moving to a state of defensive parenting Parents felt pressured to be involved in care
Doherty et al. (2009)	Predictors of psychological functioning in mothers and fathers of infants born with severe congenital heart disease Parents of 70 infants	Questionnaires	Variation in coping methods Elevated stress in mothers. Distress not based on severity but own coping Maladaptive coping methods used
Espezel & Canam (2011)	Experiences of parents' interaction with nurses in a hospital setting. Eight parents	Thematic	Nurse led care Negotiation and partnership not collaborative Parents felt pressured to meet nurses needs
Fonseca et al. (2014)	Parenting an infant CHD An exploratory study on patterns of adjustment from diagnosis to six months post birth Parents 43 infants	Qol questionnaires	Higher anxiety in mothers Uncertainty of diagnosis and treatments impact on parental relationship
Franklin et al. (2021)	Barriers and facilitators to discussing parent mental health within child health care: Perspectives of parents raising a child with congenital heart disease. 56	37 open ended study questions posted on an online platform	Multiple barriers to mental health support Expectation to stay strong Fear of negative judgement Individual support preferences

	mothers and 23 fathers		Desire to maintain focus on CYP Developing personal connections with team
Friedman (2015)	CYP asthma Mothers/ Fathers 63 families	Mixed method Semi -structured interviews and QoL questionnaires	Mothers more involved day to day care Mothers rated father's contribution more than fathers did themselves
Govindaswamy et al. (2019)	Stressors of parents of infants undergoing neonatal surgery for major non-cardiac congenital anomalies in a surgical neonatal intensive care unit Quantitative 111 parents	Likert scale	Parental role alteration is the greatest stressor for parents in the surgical NICU. Reducing stress for parents of infants undergoing neonatal surgery requires management of the infant's pain and strategies to support parents in their role in the NICU.
Hayes & Savage (2008)	Emotional Impact of caring for CYP with Cystic Fibrosis. Eight fathers	Semi-structured interviews	Supportive interventions not geared towards fathers Fathers had difficulty communicating concerns Fathers describe being less emotionally involved
Hovey (2003)	48 fathers CF compared to 51 fathers of healthy children The needs of fathers parenting children with chronic conditions	Quantitative Family Perception Inventory	CF fathers concern long term condition, health, and prognosis
Kosta et al. (2015)	Examined parental experiences when their infants were hospitalised for cardiac surgery. Parents 154 91 mothers and 63 fathers	Semi-structured interviews	Need to be near child Unexpected diagnosis Need to feel secure with staff knowledge/ experience

			Living in hospital
Massoudi et al. (2010)	Fathers' involvement in Swedish child health care - The role of nurses' practices and attitudes.	Postal Questionnaire	Working with fathers positive experience Nurses did not recognise fathers might be distressed or require support Many nurses ambivalent to fathers caring for their children
McNeill (2007)	Juvenile Rheumatoid Arthritis Fathers of Children with a Chronic Health Condition: Beyond Gender Stereotypes. 22 fathers	Grounded Theory Semi-structured interviews	Some father's traditional views, provider protector Perceived partners less able to cope with technology social stereotypes
Peck and Lillibridge (2005)	Chronic illness Normalization behaviours of rural fathers living with chronically ill children. 4 fathers	Unstructured interviews	Emotional impact chronic illness not recognised Fathers experience range of emotions particularly when condition exacerbated
Pelenstov et al. (2016)	The supportive care needs of parents with a child with a rare disease 301 parents 91% mothers	Online questionnaire	Fathers small part of sample underrepresented Childs and parents needs unmet regardless of disease
Rempel et al. (2012)	Focus young children CHD Parenting Under Pressure 10 fathers parenting young children with life threatening congenital heart disease	Grounded Theory	Four key themes were established; realising and adjusting to the inconceivable, growing increasingly attached, watching for, and accommodating the unexpected and encountering new challenges. Although the focus of the study was parents, grandparents were also included as participants
Swallow et al. (2011)	14 Fathers and mothers developing	Joint semi-structured interviews	Mothers worried about child's current

	skills in managing children’s long-term conditions		needs fathers worried about the longer term Parents negotiated skill acquisition with each other

Appendix 3



JBI Critical Appraisal Checklist for Qualitative Research

Reviewer__________________________________Date_________________________

Author ___________________________________Year________Record Number______

		Yes	No	Unclear	Not applicable
1.	Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2.	Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3.	Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4.	Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5.	Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6.	Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7.	Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8.	Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9.	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10.	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

Appendix 4

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

School of Healthcare Sciences

Web Recruitment Request Information

Hello, my name is Peter McNee and I am a research student in the School of Healthcare Sciences at Cardiff University.

I am currently researching fathers' experiences of care when their child has been born with congenital heart disease. I am defining a 'father' in the broadest terms so this could be biological, stepfather, adoptive father, carer, or a male who identifies themselves as having a fathering role or responsibility for children.

I would like to find out more about how fathers have experienced care across a number of settings from first diagnosis through to treatment and what that experience has been like for them.

If you are interested in participating in the study or would like more information on this project, please contact Peter McNee via email: mcneep@cardiff.ac.uk.

Appendix 5

School of Healthcare Sciences
Cardiff University

Participant Information Sheet

Study Title: Fathers' experiences when their child is diagnosed with congenital heart disease

You are being invited to participate in this study, as you are a father of a child who has been diagnosed with congenital heart disease. I am defining a 'father' in the broadest terms so this could be biological, stepfather, adoptive father, carer, or a male who identifies themselves as having a fathering role or responsibility for children. To help you to decide whether to participate in the study or not I have provided some information about the research and what your participation would involve. Please take some time to read the information and if there is anything that you would like to discuss further my contact details are on the last page. Thank you for your time and consideration of this study.

Who am I?

My name is Peter McNee, and I am conducting this study as part of my studies for a Doctorate award at the School of Healthcare Sciences, Cardiff University where I also work as a lecturer. Clinically my background is in children's critical care having worked on both children's General and Cardiac Intensive Care Units.

What is the purpose of the study?

The purpose of the study is to explore fathers' experiences of their journey through healthcare environments when their child has been diagnosed with congenital heart disease. To do this I want to hear your story of this journey whether your child is at the start of treatment or has had surgery or corrective treatment.

What does the study involve?

The study involves you telling me the story of your role as a father in your child's journey through their treatment for congenital heart disease. This approach is qualitative in research terms, which is based on the view that experiences are unique to the individual who experiences them. For the study, I would like to meet with you on 2 occasions over a period of 6 – 9 months but this can be negotiated individually. I would use a semi –structured interview approach to enable you to tell your story. The interviews would be recorded with your permission, and you would be able to review the content of your interview at any time. The first interview would explore your experience of being a father and the period of time up to your child's point of diagnosis. The second interview would focus more on your experience of your child's treatments, interventions, and interactions with healthcare staff.

What are the possible benefits of the study?

It is hoped that the results will contribute to enhancing knowledge around how fathers experience care delivered to their child in a range of clinical environments. This will inform healthcare professionals of fathers' specific needs when delivering family centred care and potentially lead to greater involvement of fathers in care and decision-making.

Are there any potential disadvantages in taking part?

I will make every effort to ensure that you do not experience any distress during the interviews when telling your story. You can stop the interview at any time and if you feel uncomfortable answering a specific question we can move on to the next. Your participation in the study is voluntary and you can withdraw at any time without providing any explanation.

Do I have to take part?

No, it is entirely up to you whether you participate in the study or not. If you decide to take part, you can withdraw at any time without any explanation. Within the interviews, you can choose not to answer a specific question or if you answer a question and later decide that you would not want that included within the study you can let me know and I will delete it from the recording and any notes that I have made.

Can I withdraw from the study?

You can withdraw from the study at any stage without providing and explanation. If you have already been interviewed, you can decide whether any information that you have provided can be used or not.

Will my participation remain confidential?

For the purpose of the study, you will choose a pseudonym. Your name and any details will be fully anonymised to ensure confidentiality. Following completion of the study all recordings will be erased however, transcribed data will be kept for 5 years in a secure, locked space before being destroyed.

What will happen to the results of the study?

The results of the study will be written up by me and form part of a thesis which I will submit to Cardiff University to qualify for a PhD degree. From the findings, I expect to publish articles in professional journals and present at conferences. You will not be identified in any thesis, report, publication, or conference presentation.

Has the study been reviewed?

The study has been reviewed by the Research Ethics Committee of the School of Healthcare Sciences at Cardiff University.

What if I want to make a complaint?

If you have any concerns about the study, please contact Peter McNee in the first instance. Alternatively, if the issue cannot be resolved please contact:

Contact Details Removed

What happens next?

Please feel free to contact me on the email or phone number below if you have any questions. If you decide not to participate in the study, I would like to thank you for reading the information and considering the study.

If you decide to participate in the study, please contact me on the email below.

Email: mcneep@cardiff.ac.uk

Appendix 6

Participant Consent Form

Title of the study: Fathers' experiences when their child is diagnosed with congenital heart disease

Name of the researcher: Peter McNee

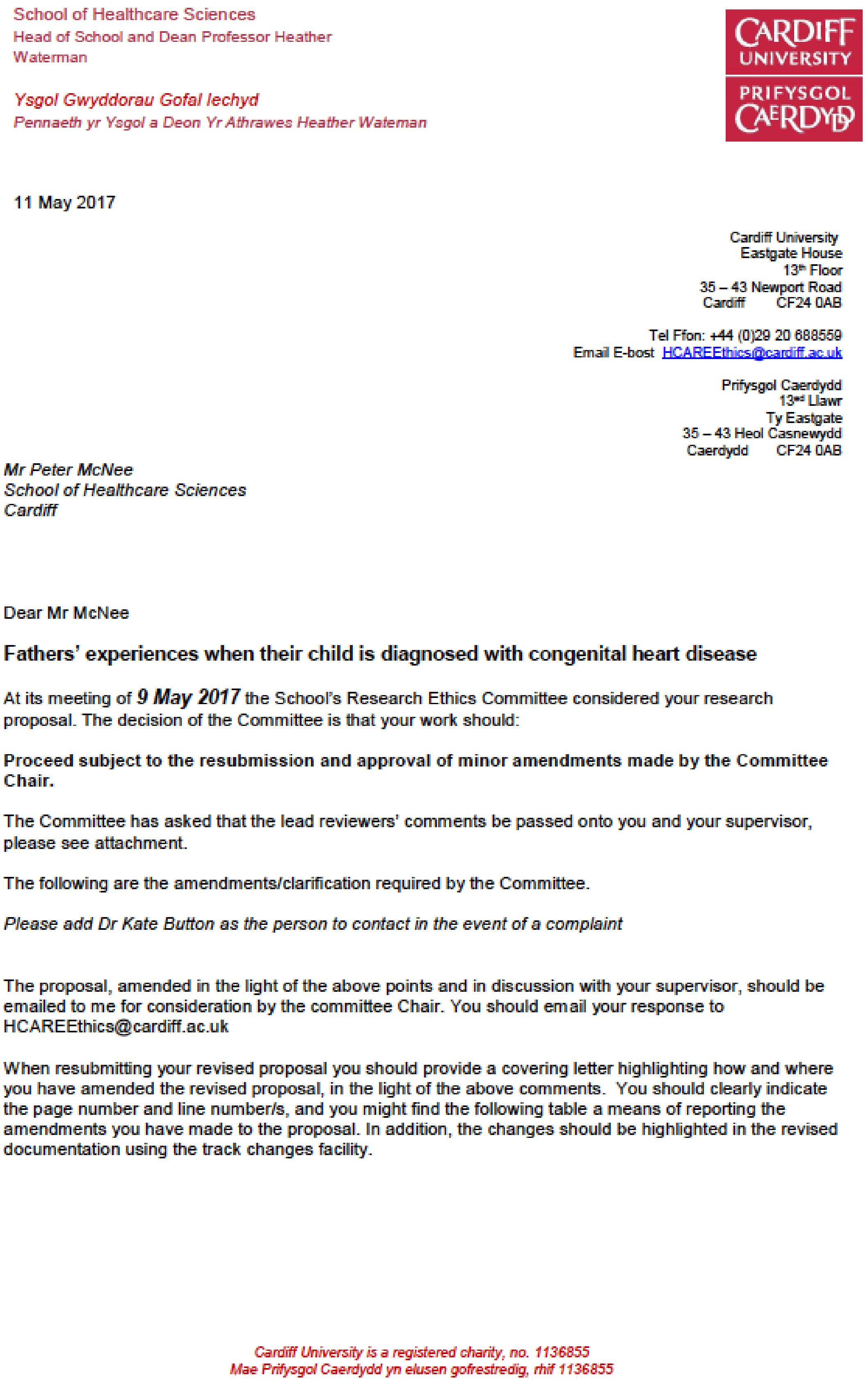
Please initial the box at the end of each statement if you agree

- I confirm that I have read and fully understood the participant information sheet for the above study.
- I confirm that I have had the opportunity to ask questions and have had these answered to my full satisfaction.
- I understand the project and confirm the study has been fully explained to me.
- I understand that confidentiality will be maintained throughout the project.
- I understand that interview sessions will be audio recorded and I consent to that.
- I understand that my participation in the study is voluntary and that I am free to withdraw at any time.
- I agree to direct quotes being used in any future publications. Any such quotes will be anonymised ensuring my confidentiality.
- I understand that my identity will not be disclosed and any information that I give will not be personally identifiable.
- I understand that any information I provide will be anonymised, stored securely and password protected.
- I have a copy of Peter's contact details.
- I agree to participate in this study.

Name of participant:
Signature:
Date:

Name of researcher:
Signature:
Date:

Appendix 7



School of Healthcare Sciences
Head of School and Dean Professor Heather Waterman

Ysgol Gwyddorau Gofal Iechyd
Pennaeth yr Ysgol a Deon Yr Athrawes Heather Wateman

11 May 2017

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Mr Peter McNee
School of Healthcare Sciences
Cardiff

Dear Mr McNee

Fathers' experiences when their child is diagnosed with congenital heart disease

At its meeting of ***9 May 2017*** the School's Research Ethics Committee considered your research proposal. The decision of the Committee is that your work should:

Proceed subject to the resubmission and approval of minor amendments made by the Committee Chair.

The Committee has asked that the lead reviewers' comments be passed onto you and your supervisor, please see attachment.

The following are the amendments/clarification required by the Committee.

Please add Dr Kate Button as the person to contact in the event of a complaint

The proposal, amended in the light of the above points and in discussion with your supervisor, should be emailed to me for consideration by the committee Chair. You should email your response to HCAREEthics@cardiff.ac.uk

When resubmitting your revised proposal you should provide a covering letter highlighting how and where you have amended the revised proposal, in the light of the above comments. You should clearly indicate the page number and line number/s, and you might find the following table a means of reporting the amendments you have made to the proposal. In addition, the changes should be highlighted in the revised documentation using the track changes facility.

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Please do not hesitate to contact me if you have any

questions.Yours sincerely

Mrs Liz Harmer –
Griebel Research
Administration
Manager

Cc : Professor Danny Kelly & Dr Dikaois Sakellariou