Title - Living with complex congenital heart disease: exploring the experiences of adolescents and parents- a qualitative enquiry.

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Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or institute of learning.

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Presentations and publications relevant to the study

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Abstract

Background: Advances in diagnosis, surgery and long-term cardiac management mean that most infants born with congenital heart disease (CHD) now survive into adolescence and adulthood. For young people with complex CHD, this developmental period involves not only significant physical and medical challenges but also complex emotional, relational and social transitions. Parents similarly face uncertainty as they balance protection with supporting their adolescents' autonomy. A deeper understanding of these interconnected experiences is needed to inform holistic, family-centred care.

Theoretical Framework: Positioned within an interpretivist epistemology and relativist ontology, this study acknowledges that experiences of complex CHD are socially, emotionally and relationally constructed. The research prioritises participants' meaning-making and the contextual nature of family life.

Methods: A qualitative design, guided by Braun and Clarke's Reflexive Thematic Analysis (RTA), explored the subjective experiences of adolescents with complex CHD and their parents. Seventeen semi-structured online interviews were conducted over twelve months (eight adolescents / nine parents). Adolescent and parent datasets were analysed separately and then comparatively to identify convergences, divergences and negotiated understandings within family relationships.

Findings: Three overarching themes captured shared and distinct experiences across families: (1) Feelings of uncertainty and unpreparedness: encompassing gaps in understanding, inconsistent communication and worry about prognosis and transition to adult services. (2) Conflicts around control and responsibility: reflecting tensions between parental protection and adolescents' desire for autonomy as they assume increasing responsibility for their health. (3) A sense of community: highlighting the importance of supportive relationships within families, peer groups, schools and healthcare, although access to consistent psychosocial support was variable. Together, these themes illustrate how adolescents and parents co-construct meaning around CHD and engage in ongoing emotional and relational work that is often invisible within clinical encounters.

Conclusion: This study provides new insight into how adolescents with complex CHD and parents navigate illness, identity, autonomy and transition as a shared family process. The findings emphasise the need for developmentally attuned

communication, integrated psychosocial support and collaborative, family-centred transition planning. By examining adolescent and parental perspectives side by side, the study extends current knowledge and strengthens relational, developmental and organisational approaches to complex CHD care.

Keywords: Congenital Heart Disease (CHD), complex, adolescent, young person, parent, mother, father, experience, qualitative, reflexive thematic analysis, feelings, quality of life, transition.

List of Figures

List of Tables

List of Appendices

Abbreviations

ASD	atrial septal defect
ADHD	attention deficit hyperactivity disorder
AVSD	atrioventricular septal defect
CF	cystic fibrosis
CHD	congenital heart disease
CINAL	Cumulative Index to Nursing and Allied Health Literature
COVID-19	Coronavirus Disease 2019
ECMO	extra corporeal membrane oxygenation
GDPR	General Data Protection Regulation
HCP	healthcare professional
HE	higher education
HEI	higher education institutions
HTAD	heritable thoracic aortic disease
HLHS	hypoplastic left heart syndrome
IBD	irritable bowel disease
IPA	Interpretative Phenomenological Analysis
IPCCC	The International Paediatric and Congenital Cardiac Code
IRAS	Integrated Research Application System
LTC	long-term condition
LV	left ventricle/ventricular
MD	muscular dystrophy
NHS	National Health Service
NICE	National Institute for Health and Care Excellence

PA	pulmonary artery
PAP	pulmonary artery pressure
PIS	patient information sheets
PPI	patient and public involvement
PDA	patent ductus arteriosus
PFO	patent foramen ovule
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
QR	quick response code
RTA	reflexive thematic analysis
SDI	socio-demographic index
TGA	transposition of the great arteries
TOF	tetralogy of fallot
T1D	type 1 diabetes
TAVI	transcatheter aortic valve implantation
UK	United Kingdom
VSD	ventricular septal defect
WHO	World Health Organisation
YPAG	young person's advisory group

Table of Contents

Contents

Chapter One: Introduction and Background to the Study

Behind every repaired heart lies a family learning to live with uncertainty. Congenital heart disease (CHD), the most common birth defect in the United Kingdom (UK), now allows most children to survive well into adolescence and adulthood due to advances in diagnosis, surgery and medical care (Savaş et al, 2024). Yet for many, survival marks the beginning of another challenge, one defined by ongoing medical surveillance, repeated interventions, and a lifelong awareness of health uncertainty, emotional labour, and the search for normality amid difference. Alongside these clinical realities, adolescence is the turbulent, pubescent bridge between childhood and adulthood, marked by rapid physical change, emotional intensity and the search for identity (Best and Ban, 2021). Adolescents and their families must navigate these profound social challenges as they search for normality amid difference.

There remains a critical gap in understanding how adolescents with moderate or complex CHD, and parents, make sense of living with the condition, within the context of everyday family and social life. While research has advanced understanding of medical outcomes and psychosocial adjustment, it has largely focused on clinical, behavioural, and quantitative perspectives. Consequently, the relational and emotional dimensions through which young people and parents experience and navigate CHD remain underexplored.

This study addresses that gap, exploring the perspectives of adolescents with moderate or complex CHD and their parents, seeking to understand how families navigate the practical and emotional realities of long-term cardiac care. While the study focuses on experiences of adolescents with complex congenital cardiac conditions, it also includes a small number of participants classified as having moderate complexity according to European Society of Cardiology (ESC) criteria, where additional clinical or psychosocial needs contribute to comparable levels of functional and care complexity.

1.1 Overview of Thesis Structure

This thesis is organised into nine chapters. Reflective pitstops are included throughout the thesis to demonstrate the author’s developing understanding and critical self-awareness (Sabnis and Wolgemuth, 2023).

Chapter One outlines the study purpose, research question and objectives. It introduces CHD by providing historical and medical context, including developments in treatment and care. The political context and rationale for the study are discussed, and the challenges associated with living with moderate or complex CHD.

The literature search strategy is described in Chapter Two and presents a critical overview of the current evidence relating to adolescents and parents living with CHD. This review identifies key themes and gaps that inform the design and focus of the study.

Chapter Three situates the methodology within qualitative philosophical foundations, framing methods as co-constructed and interpretive. Reflexivity and reflection as ongoing practices are introduced.

Building on the methodological foundations, Chapter Four sets out the research design, showing how philosophical commitments were translated into practical decisions. It includes the use of patient participant groups, recruitment strategies, sampling criteria, consent processes, data collection methods, and the approach to data analysis. The practical challenges associated with conducting research during the coronavirus disease (COVID-19) pandemic are discussed. The chapter also describes the use of Braun and Clarke's (2022) reflexive thematic analysis (RTA), which guided a data-driven interpretation of participants' lived experiences.

Chapter Five provides a focused discussion of ethical considerations when conducting research with adolescents. It explores issues related to recruitment, consent and engagement, and reflects on the responsibilities of researchers working with this age group.

The findings from the data analysis are examined and presented in Chapters Six (adolescent perspectives) and Seven (parent perspectives). Across both groups, three overarching themes were generated: (1) Unpreparedness and uncertainty, (2) Control and responsibility, and (3) A sense of community. These themes are illustrated using anonymised data extracts to ensure authenticity and coherence. To support deeper engagement with participants' stories, anonymised participant profiles are presented as caricatures.

Chapter Eight offers a critical discussion of the findings, considering their implications for CHD practice and policy. It reflects on the methodological approach and outlines the contribution this study makes to existing knowledge.

Finally, Chapter Nine presents a conclusion to this study and offers evidence-based recommendations to improve CHD care for adolescents and parents.

This thesis concludes with a reflective pitstop that explores the personal challenges and achievements encountered throughout my MPhil research journey.

1.2 The Research Question

This Master of Philosophy (MPhil) seeks to explore "How do adolescents with moderate or complex CHD, and parents, experience and make sense of the psychosocial challenges of living with the condition, and how do they navigate these within family life and healthcare transitions?"

1.2.1 Research Purpose

This study explores the experiences of adolescents with moderate or complex CHD and their parents. A qualitative approach is adopted, informed by an interpretivist epistemology and a relativist ontology, recognising that multiple realities exist and that meaning is socially and emotionally constructed. This positioning supports an in-depth understanding of participants' experiences and enables exploration of the nuanced ways families make sense of and manage life with CHD, insights that are not readily captured through quantitative approaches (Hall and Liebenburg, 2024).

1.2.2 Aims and Objectives

The aim of this study is to explore how adolescents with moderate or complex CHD and their parents understand and navigate the practical and emotional challenges of long-term cardiac care, and to identify patterns of meaning within and across their accounts.

The objectives are to:

a) Explore how adolescents describe and make sense of their condition, and how this shapes their identity, emotions and relationships.
b) Examine how parents account for supporting an adolescent with CHD, including emotional, practical and relational aspects of care

c) Identify shared, differing and negotiated meanings across adolescent and parent perspectives, with attention to how these are expressed within family life.

1.3 Congenital heart disease (CHD)

CHD refers to structural abnormalities of the heart or great vessels that develop in utero and are present at birth (Stout et al., 2019). These defects can impair normal cardiac function and alter blood flow through the cardiovascular system (Gaze, 2018). The heart, a muscular pump located in the mediastinum between the lungs, operates within a closed network of arteries, veins and capillaries (Peate, 2016). The heart delivers oxygenated blood and nutrients to tissues and removes metabolic waste via the pulmonary and systemic circulation. CHD can disrupt these processes, with consequences for survival, growth and long-term health.

CHD is the leading birth-defect–related cause of infant mortality in developed countries (Marelli et al., 2007). Globally, it affects an estimated 1.35 million newborns each year (van der Linde et al., 2011; Liu et al., 2019). Advances in diagnostics, peri-operative care and surgical techniques have resulted in improved survival, and a growing number of children with CHD now reach adulthood.

The global burden of CHD has increased over time. In 2017, an estimated 11.9 million people were living with CHD worldwide, an 18.7% rise from 10.1 million cases in 1990 (Zimmerman et al., 2020). Current estimates place global birth prevalence at 8.2 per 1,000 live births (Liu et al., 2019).

Prevalence and outcomes vary significantly between regions. Mortality has declined in countries with higher Socio-Demographic Index (SDI), reflecting improved access to specialist care and early detection and intervention. In contrast, most CHD-related deaths occur in low- and middle-SDI regions, where diagnostic resources, surgical capacity and long-term follow-up services are limited (GBD, 2020). As a result, survival into adulthood is now common in high-income countries but remains substantially lower in resource-constrained settings.

1.3.1 Congenital heart disease (CHD) Classification

CHD complexity was considered in line with the European Society of Cardiology (ESC) guidelines for the management of adult CHD (ACHD) (Baumgartner et al, 2020). The ESC classifies congenital heart conditions into three anatomical complexity

categories: mild, moderate, and severe, based on the structural characteristics of the underlying lesion and its anticipated lifelong clinical implications. Mild complexity conditions include lesions with minimal haemodynamic impact and limited need for specialist follow-up (e.g. small isolated septal defects or bicuspid aortic valve without significant dysfunction). Moderate complexity conditions typically involve repaired or unrepaired lesions requiring ongoing specialist surveillance, such as repaired Tetralogy of Fallot (ToF) or repaired coarctation of the aorta. Severe complexity conditions comprise the most anatomically complex lesions, often associated with cyanosis or single-ventricle physiology, including Fontan circulation and complex transposition of the great arteries (TGA). This classification is lesion-based and is used to guide lifelong follow-up and care settings, rather than to describe current physiological status (see Table 1: Categorisation of CHD).

Table 1. Categorisation of CHD:

Complex category	**Description (ESC definition)**	**Examples of congenital heart conditions**
Mild (simple)	Lesions with minimal haemodynamic impact, low risk of complications, and often limited need for specialist lifelong follow-up if no significant residua are present	• Small isolated atrial septal defect (ASD) • Small ventricular septal defect (VSD) • Patent ductus arteriosus (PDA) (small/closed) • Pulmonary valve stenosis (mild) • Bicuspid aortic valve *without* significant stenosis or regurgitation
Moderate	Lesions of intermediate anatomical complexity frequently require surgical or catheter intervention in childhood and lifelong specialist ACHD follow-up due to the risk of residual lesions or late complications.	Repaired TOF • Repaired coarctation of the aorta • Atrioventricular septal defect (AVSD) • Ebstein's anomaly • Partial anomalous pulmonary venous connection (PAPVC)
	The most anatomically complex lesions, often	• Single-ventricle physiology / Fontan circulation

Severe (complex)	associated with cyanosis, single-ventricle physiology, or complex surgical palliation and require specialist multidisciplinary ACHD care throughout life.	• TGA with atrial or arterial switch • Pulmonary atresia with VSD • Truncus arteriosus • Unrepaired complex cyanotic heart disease

1.4 Fetal Circulation

CHD represents the most common group of birth defects, encompassing structural abnormalities that disrupt normal cardiac development and function. During fetal development, the cardiovascular system functions differently from the postnatal circulation, as the foetus relies on the placenta rather than the lungs for oxygen and nutrient exchange (Cindrova-Davies and Sferruzzi-Perri, 2022). Fetal structural heart abnormalities, such as those seen in CHD, can affect the pattern of blood flow in utero and may influence the newborn's ability to adapt at birth.

In utero, the ventricles work in parallel, and oxygenated blood is directed through specialised shunts rather than the lungs. At birth, rapid physiological changes occur almost simultaneously, shifting gas exchange from the placenta to the lungs (Marelli and Aboulhosn, 2022). Most neonates make this transition with minimal assistance, establishing effective breathing and remodelling the cardiovascular system to function in series rather than parallel (Michel and Lowe, 2017).

Congenital defects detected at birth include patent foramen ovale (PFO), a fetal atrial opening that usually closes after birth but may persist, causing interatrial shunts (Alakbarzade et al., 2020). Similarly, PDA, a connection between aorta and pulmonary artery, should close within hours to days after birth, or in some cases, several years (Jennings et al, 2022). Failure increases pulmonary blood flow, straining the heart and lungs.

1.5 Childhood experiences and the effects of Congenital Heart Disease (CHD)

While the previous section explored the physiological differences between normal fetal and neonatal circulatory adaptation and the alterations associated with CHD, it is also important to consider how these early cardiac differences can influence children's lived experiences and wellbeing throughout childhood. The childhood experience of living

with CHD extends far beyond the physical impact of the condition itself. Children with CHD often navigate complex emotional, social and developmental challenges alongside ongoing medical care and treatment. Understanding these experiences is important in recognising how CHD can shape everyday life, relationships, identity and wellbeing throughout childhood.

Chong et al. (2018) offered a synthesis of qualitative studies exploring children's experiences of congenital heart disease (CHD). Their work brought together a broad range of international evidence and highlighted how children made sense of living with a long-term cardiac condition within everyday life.

Across the studies included in their review, several recurring experiential themes were constructed, providing insight into the emotional, physical and relational dimensions of living with CHD in early life. Children described a mix of psychological challenges such as fear, anxiety, uncertainty and frustration, alongside efforts to maintain a sense of normality in everyday life. They also reported physical challenges, including fatigue, limitations in activity and the impact of symptoms or treatment on daily routines.

Family relationships played a central role in how children coped, with many relying heavily on parents for emotional support, information and protection. At the same time, some children experienced tension around overprotection or restricted independence.

Peer relationships were also important. Children described both positive support from friends and difficulties related to feeling different, being excluded from physical activities or experiencing stigma.

Growing up with CHD involved navigating developmental challenges, particularly as children became more aware of their condition and began to take a greater interest in understanding their bodies, limitations and futures. Hospital experiences featured prominently across studies, with children describing both reassurance and distress associated with procedures, hospital stays and interactions with healthcare professionals (HCPs).

Overall, Chong et al. highlighted that children's experiences of CHD are shaped by emotional, physical, relational and developmental factors. Their synthesis emphasises the complexity of living with CHD across childhood and illustrates the importance of family, peers and supportive healthcare relationships in shaping wellbeing.

1.6 Adolescence and the Impact of Congenital Heart Disease (CHD)

As children with CHD grow older, the challenges associated with living with a lifelong cardiac condition often evolve, making adolescence a particularly important stage for exploring changing emotional, social and developmental experiences. The World Health Organisation (WHO) defines adolescence as ages ten to nineteen (WHO, 2026), a period of rapid physical, cognitive, and social development, shaped by significant brain maturation that influences reasoning, behaviour, and emotional regulation (Rhoshel, Lenroot, and Giedd, 2006). Identity formation, increasing independence and peer relationships play central roles in adjustment, while developmental changes such as puberty and social pressures can heighten vulnerability to risk-taking and emotional challenges (Blakemore, 2019).

For adolescents with moderate or complex CHD, these developmental tasks occur alongside the demands of a long-term medical condition. Structural abnormalities of the heart and great vessels can impair cardiac function, leading to symptoms such as dyspnoea, fatigue, dizziness, arrhythmias, cyanosis, recurrent infections and reduced exercise tolerance (Jennings et al., 2022). Severe or persistent symptoms can restrict physical and motor development, influencing emotional wellbeing and cognitive growth (Mari, Cascudo and Alchieri, 2016).

Neurodevelopmental challenges are also common in this population. Research indicates increased rates of cognitive impairment, attention deficit hyperactivity disorder (ADHD), motor delays, speech and language difficulties, visual–motor deficits and learning disabilities (Wernovsky and Licht, 2016; Liamlahi and Latal, 2019). These difficulties may contribute to poorer academic performance, social integration challenges, reduced self-esteem and behavioural concerns, with associated impacts on overall quality of life (Waber et al., 2022; Musetti et al., 2019).

Alongside these physical and neurodevelopmental considerations, adolescents with CHD must also navigate the psychosocial implications of visible scarring, activity restrictions and recurrent medical interventions. These factors can influence body image, peer relationships and developing identity (Dorfman et al., 2023; Chong et al., 2018; Moons et al., 2021). Parents often experience parallel strain as they balance supporting their adolescent’s autonomy with the ongoing responsibilities of managing

complex health needs (Alkan et al., 2017; Werner et al., 2014; Lumsden, Smith and Wittkowski, 2019).

1.7 The Historical Context

Major advances in paediatric cardiology and surgery over the past century have transformed outcomes for children with CHD. Early anatomical descriptions (Dodson and Prendergast, 2022) and landmark surgical innovations such as PDA ligation, coarctation repair in 1944 (Kvitting and Olin, 2009) and the Blalock–Taussig shunt (Renno and Johns, 2018) laid the foundations for modern CHD management. The development of cardiopulmonary bypass in the nineteen fifties enabled complex open-heart repairs, including ASD closure and later repair of ToF, Ross, and Fontan procedures (Brida and Gatzoulis, 2019). Although open-heart surgery carries risks such as infection, embolism and reduced quality of life (Hokkanen et al., 2021), less invasive options, including percutaneous interventions, Transcatheter aortic valve implantation (TAVI), Extracorporeal membrane oxygenation (ECMO) and vascular stenting, have expanded treatment possibilities (Moisa et al., 2022).

Diagnostic advances such as pulse oximetry screening, magnetic resonance imaging, computed tomography, and prenatal ultrasound screening have further improved detection and reduced postnatal prevalence (Minnella et al., 2020). Consequently, over ninety per cent of infants with CHD now survive into adulthood (Jennings et al., 2022; Moons et al., 2010; Gilboa et al., 2010), with more adults than children living with the condition (Rao and Agarwal, 2022). The volume of CHD procedures continues to increase, although recent years have seen reductions in paediatric surgeries (National Institute for Cardiovascular Outcomes Research (NICOR), 2024).

1.8 Summary

Despite substantial medical progress, adolescents with moderate or complex CHD and their parents continue to face psychosocial and relational challenges that are less well understood than the clinical aspects of the condition. Existing research often examines parents and adolescents separately or prioritises medical outcomes, offering limited insight into how families experience CHD as a shared, evolving process. This study addresses that gap by exploring how adolescents and parents understand and manage the condition, how these meanings shape identity and relationships, and how families negotiate the emotional and practical demands of long-

term care. Recognising that these experiences are embedded within wider developmental, relational and healthcare contexts, the next chapter reviews current evidence on the psychosocial, developmental and family dimensions of growing up with moderate or complex CHD. This provides the conceptual foundation for the study and situates it within contemporary debates in paediatric and adolescent cardiac care.

Chapter Two: Literature Review

Chapter One introduced the context, aims and philosophical foundations of this study. The purpose of Chapter Two is to locate the research within current literature related to the psychosocial experiences of adolescents with CHD, and the parents who support them. Although advances in surgery and medical care have improved survival, living with CHD involves long term emotional, social and developmental challenges. This chapter reviews existing evidence about how adolescents and parents understand and navigate these challenges and identifies gaps that justify the focus of this study.

Following a description of the search strategy, the review is structured into three main areas. First, it explores how adolescents with moderate or complex CHD understand their condition and how this affects their development, identity, relationships and daily life. Second, it considers parental experiences, including the emotional impact of caregiving and the relational tensions created during adolescence. Finally, it examines the transition from paediatric to adult CHD services, which represents a significant life stage for both adolescents and their parents. The chapter concludes by outlining the gaps in the literature this study aims to address.

2.1 Literature Search Strategy

The purpose of this literature review is to critically examine existing evidence relating to the psychosocial experiences of adolescents with CHD and the parents who support them, in order to situate the present study within current knowledge and identify gaps that justify its focus. While advances in diagnosis and treatment have improved survival, less attention has been paid to how adolescents and families experience CHD as part of everyday life, particularly during adolescence and transition to adult services. This review therefore adopts a qualitative and experiential focus, aligned with the study's interpretivist orientation.

In developing the search strategy, the existing systematic review by Chong et al. (2018), as discussed in section 1.5, was used as a methodological and conceptual foundation. Chong et al.'s work provides one of the most comprehensive syntheses of children's experiences of CHD and offers a transparent and well-structured approach to literature searching and synthesis. However, rather than replicating this review, the

present study builds on and extends its scope to address areas that remain underexplored.

Specifically, this review shifts the focus from childhood to adolescence, recognising that developmental, relational and healthcare experiences change significantly during this period. It also incorporates parental perspectives and the transition to adult services, both of which are central to understanding CHD as a shared and evolving family experience but were not the primary focus of Chong et al.'s review. In this way, Chong et al. (2018) serves as a conceptual baseline, informing the structure and direction of the search, while allowing the present review to develop a more targeted and contextually relevant synthesis. Rather than positioning Chong et al. as a definitive account, their findings are used here as a developmental and conceptual baseline from which to consider how experiences may evolve during adolescence and within family contexts. This is particularly relevant given that adolescence introduces new developmental, relational and healthcare challenges that extend beyond those captured in childhood-focused research.

Searches were conducted in PsycINFO, CINAHL and Medline, as these databases capture a broad range of psychological, nursing and medical research relevant to CHD. Inclusion criteria focused on peer-reviewed, English-language studies exploring the experiences of adolescents with CHD and their parents. Studies from any country were included to reflect the diversity of healthcare contexts and family experiences, supporting a broader understanding of CHD within and beyond the National Health Service (NHS). (see Appendices A and C)

To ensure that recent and emerging research was captured, the search was extended beyond the time frame of Chong et al. (2018) and supplemented with searches in Google Scholar and LJMU Discover. This approach supports a comprehensive and up-to-date synthesis while remaining aligned with established review practices. Study selection followed PRISMA 2020 guidance (Page et al., 2021), ensuring transparency in the identification, screening and inclusion of studies (see Appendices B and D).

2.2 Narrative Synthesis Approach

Following study selection, a narrative synthesis approach was used. Narrative synthesis is particularly suited to reviews that aim to explore subjective experience and context rather than to generate standardised comparisons (Popay et al., 2006;

Snyder, 2019). It supports the integration of qualitative studies that vary in design, setting and theoretical approach, and allows attention to meaning, relationships and lived experience, which are central to this research. This approach aligns with the study's interpretivist orientation, which views knowledge as socially constructed and shaped by context. It also complements the use of RTA (Braun and Clarke, 2022) in the empirical phase, as both methods emphasise reflexivity, interpretation and the co-construction of understanding rather than the pursuit of fixed or objective themes.

Narrative synthesis also shapes how the literature is presented in the following sections. Rather than organising studies by methodology or outcome, the review is structured around key areas of lived experience relevant to adolescents with CHD and their parents. This allows attention to be directed towards meaning, relationships and context, reflecting the interpretivist focus of the study. The themes presented do not seek to provide an exhaustive account of all available evidence but instead offer a conceptually informed synthesis that highlights patterns, tensions and gaps within the literature.

Although formal critical appraisal tools such as CASP were considered, a structured appraisal checklist was not applied within this literature review due to the broad range of methodologies included across the evidence base. Instead, studies were systematically reviewed and compared using a detailed data extraction and evaluation table developed by the researcher, which enabled consistent consideration of study aims, methodology, sample, analysis, key findings and limitations across all included papers. This approach allowed for a more flexible and inclusive evaluation of qualitative, quantitative, mixed methods and review studies, while still maintaining transparency and rigour within the review process. A literature extraction table (Appendix K) detailing the key characteristics of the reviewed literature, is included to support transparency and facilitate systematic comparison across studies.

The purpose of narrative synthesis in this thesis is to build conceptual insight into how adolescents and parents experience CHD, without attempting to exhaustively catalogue all published work or aggregate findings. The following sections present the themes identified across adolescent and parent-focused studies. These are interpreted alongside the core experiential themes reported in Chong et al. (2018),

which provide a conceptual baseline for the narrative synthesis and support continuity with earlier qualitative research in CHD.

2.3 Living with Congenital Heart Disease as an Adolescent

Adolescence is a period marked by rapid physical, emotional and social change and these developmental tasks can be significantly shaped by the presence of a lifelong condition such as CHD (Hewitt et al., 2024; Sawyer et al, 2018). Young people with moderate or complex CHD navigate everyday life while managing symptoms, hospital appointments, treatment histories and uncertainty about the future. Their experiences are influenced not only by medical factors but also by relationships with family, peers, schools and HCPs. The existing literature highlights a range of psychosocial challenges and strengths among adolescents with CHD, although findings vary according to individual circumstances, communication practices and the level of support available. The following sections explore these experiences in more depth, focusing on psychological wellbeing, school and social participation, relationships and reproductive health, and the coping strategies that support resilience.

2.3.1 Psychological and Developmental Challenges

For adolescents with moderate or complex CHD, psychological and developmental changes occur alongside the demands of a lifelong condition. The literature consistently shows that adolescents with CHD experience higher levels of anxiety, worry about deterioration and challenges to identity formation compared with their healthy peers (Gonzalez et al., 2021; Monti, Jackson and Vannatta, 2018). These difficulties are linked to repeated medical procedures, uncertainty about the future and the need for ongoing surveillance.

Young people often describe feeling different or out of step with their peers. Visible scars, reduced stamina and periods of hospitalisation reinforce this sense of difference (Chong et al., 2018; Vankerckhoven et al., 2023). Feelings of embarrassment or stigma may lead adolescents to conceal their condition or withdraw socially, which can limit opportunities for belonging at a time when peer acceptance is crucial. These challenges are shaped by adolescents' understanding of their condition. Studies show that inconsistent communication and limited health literacy can undermine confidence in self-management, leading to frustration, confusion, or helplessness (Gray et al., 2018; McLoughlin, Matthews, and Hickey, 2018).

Adolescents also describe emotional strain linked to unpredictability. Unlike some other long-term conditions, CHD symptoms can worsen rapidly or without clear warning signs (Hansen et al., 2024). This contributes to heightened vigilance and difficulty trusting their own bodies. The emotional labour involved in balancing fear with the desire for normality is central to many young people's accounts.

Although many adolescents show resilience and adaptability, the literature emphasises that resilience is shaped by context rather than by personality traits alone. Supportive family relationships, clear information and collaborative communication with HCPs are consistently linked with better emotional wellbeing.

2.3.2 Educational and Vocational Experiences

School form a major part of adolescents lives, yet young people with CHD often face disruptions that affect both learning and social participation. Hospital appointments, fatigue, and cognitive challenges can reduce attendance and performance (Lum et al., 2017; Cohen and Earing, 2018; Bolduc et al., 2023). Evidence suggests that adolescents with CHD are less likely to progress into higher education (HE) and may require additional educational support to meet their potential (Al Khalil et al., 2025).

Neurodevelopmental difficulties, including issues with attention, processing speed and executive functioning, are reported at higher rates among those with moderate or complex CHD and can influence classroom engagement and independence (Monti, Jackson and Vannatta, 2018; Liamlahi and Latal, 2019). Teachers may not always understand the nature of CHD related fatigue or concentration problems, sometimes misinterpreting them as behavioural issues (Violant-Holz, Muñoz Violant and Rodrigo Pedrosa, 2023). These misunderstandings can contribute to stress, reduced confidence and a sense of being undervalued.

Friendships and social relationships also play an important role in how adolescents experience school. Limited participation in sports or extracurricular activities can reduce opportunities for bonding with peers and may lead to social isolation (Watkins et al., 2023). Despite these challenges, many adolescents express strong aspirations for the future and hope to pursue further education, employment and independent living. However, concerns about employability, discrimination and the physical demands of work are common (Deng et al., 2019; Nicolarsen, 2017). Guidance from HCPs, educators and career advisers is recommended but is often inconsistent.

2.3.3 Relationships, Social Identity and Reproductive Health

During adolescence, relationships, social identity and the development of greater independence become increasingly important. Young people with CHD describe a wide range of experiences related to friendships and forming connections with others. Many report that peers do not always understand what CHD involves, which can contribute to feelings of difference or isolation. Concerns about appearance, including visible surgical scars or chest shape, are common and can affect confidence in social situations or when meeting new people (Chong et al., 2018; Savaş et al., 2024).

Reproductive health is an area in which many adolescents report limited information and support. Young women frequently express anxiety about the potential risks associated with pregnancy, particularly in relation to the increased strain pregnancy may place on the heart (Miner et al., 2017; van Hagen and Roos-Hesselink, 2019). Young men may have questions about fertility, heredity or how their condition might affect future family plans. Although clinical guidelines recommend early and clear reproductive counselling for this group, studies show that only a minority of adolescents receive advice about contraception, pregnancy or preconception planning from HCPs (Burström et al., 2022; Stokes et al., 2023). As a result, many feel uncertain about how their condition may influence future decisions.

Adolescents are also exposed to social pressures involving alcohol, smoking, tattoos and piercings. These activities can carry increased health risks for individuals with CHD, yet young people report that guidance is often inconsistent or not offered proactively (DiFusco, Schell and Saylor, 2019; Snygg Martin et al., 2021). Clear, age-appropriate information that enables safe and informed choices is therefore recommended across the literature.

2.3.4 Coping, Resilience and Support Networks

How adolescents cope with the demands of CHD depends heavily on the quality of their support networks. While some young people develop strong coping skills through open communication, family support and positive involvement with services, others struggle with isolation, uncertainty and limited access to emotional support.

Resilience among adolescents with CHD is not simply an individual trait. Instead, it reflects the influence of family, peers, schools and HCPs (Chong et al., 2018). Peer support interventions can improve adolescents' behavioural and emotional symptoms

(Killackey et al., 2025), enabling them to express their fears, ask questions, and gradually assume greater responsibility. Parents often play a central role in managing symptoms, mediating information and interpreting clinical advice (Hsiao et al, 2024). However, this parent-dominated management can, without effective communication and structured transition support, delay the development of adolescents' independence in self-management (Gray et al, 2018; Lerch and Thrane, 2019).

HCPs play an important role in supporting resilience through clear explanations, consistent messaging and opportunities for adolescents to participate in discussions about their care (Dorfman et al., 2023; Smith and Kendall, 2018). When communication is rushed, inconsistent or not pitched at the right developmental level, adolescents report feeling anxious or excluded. These challenges highlight the importance of developmentally informed communication and proactive psychosocial support within CHD services.

While the literature provides valuable insight into the psychological, social and developmental challenges experienced by adolescents with CHD, much of this work considers young people in isolation from their family context. As a result, less is known about how these experiences are shaped through ongoing interactions with parents and within family life. This highlights a need for research that examines adolescent experiences relationally, rather than as individual phenomena.

2.4 Living with Congenital Heart Disease as a Parent

Parents play a central role in supporting adolescents with moderate or complex CHD, often acting as caregivers, advocates and sources of emotional reassurance. Their experiences are shaped by long-term exposure to uncertainty, frequent contact with healthcare services and the challenge of balancing protection with their child's growing independence. The literature highlights a mixture of anxiety, resilience and practical problem solving in parents' accounts, although emotional and social pressures can vary considerably between families. The following subsections examine key themes within parental experiences, including emotional wellbeing, caregiving roles, gendered patterns of support and the systems that help parents manage ongoing demands.

2.4.1 Emotional and Psychosocial Impact

Parents of adolescents with moderate or complex CHD frequently describe long-term emotional stress, including persistent fear of deterioration, anxiety and uncertainty

(Lappalainen et al., 2021; Dorfman et al., 2023). Many parents also report sadness, exhaustion and symptoms of depression, particularly when facing repeated hospital admissions or complex treatment decisions (Woolf-King et al., 2018; Kolaitis, Meentken and Utens, 2017).

The emotional impact of caregiving can shape family relationships. Parents often place their child's medical needs above their own, sometimes at the expense of their wellbeing or other family members' needs (Lumsden et al., 2020). Siblings may feel overlooked at times, which can lead to resentment or emotional distance (Amaro et al, 2025). Financial strain, employment challenges and social isolation can further affect family functioning (Lawoko and Soares, 2003).

Despite these pressures, many parents describe deep commitment, pride and resilience. Their accounts often reflect a combination of ongoing stress and the development of strong coping strategies over time. These strategies are shaped by previous experiences, personal beliefs and the availability of support from professionals, family and peers.

2.4.2 Gendered Experiences of Parenting

Parents' experiences are also shaped by gender. Mothers often assume the primary caregiving role and report higher levels of emotional burden, which may be linked to societal expectations around care and emotional labour (Javalkar et al., 2017; Postavaru, Swaby and Swaby, 2021). Fathers are increasingly involved in care and decision-making, yet research shows that they may feel less visible in healthcare settings and less comfortable expressing emotional distress (Gower, van Meures and Bailey, 2017; Spurr et al., 2023).

Fathers more commonly use problem-solving or information-seeking as coping strategies, which may mask their emotional needs and reduce their likelihood of seeking support (Dellafiore et al., 2017; Hoffman et al., 2020). When fathers feel excluded or unsupported, this can contribute to frustration and distance within the family.

More inclusive and family-centred approaches are recommended to ensure that both mothers and fathers are involved in discussions, supported in their roles and recognised as partners in care (Lisanti, 2018; Bruce, Lindh and Sundin, 2016).

2.4.3 Parental Coping and Support Systems

Parents rely on a range of coping mechanisms to manage emotional strain. These include seeking information, connecting with other parents, drawing on faith or personal beliefs, and developing strong relationships with HCPs (Carlsson, Klarare and Mattsson, 2020; Carlsson and Mattsson, 2022). Peer support is highly valued, as other parents with similar experiences can offer understanding, reassurance and practical advice. However, formal support groups are not always available or easy to access, and psychological support services for parents are often limited or subject to long waiting times (Woolf-King et al., 2018; Wray et al., 2024).

Support from HCPs is a particularly important protective factor. Parents value clarity, empathy and continuity, especially during periods of uncertainty or crisis (Dellafoire et al., 2017; Cole, Ridings and Phillips, 2024). When communication breaks down or feels rushed, parents report feeling overwhelmed and uncertain about how to support their child (Pagel et al., 2019; Marino et al., 2023). Strong, trusting relationships with clinical nurse specialists, cardiologists, and other staff can help reduce anxiety and promote effective shared decision-making (Wei, Roscigno, and Swanson, 2017).

Parents also interact with education and community services, which can influence stress and coping. Teachers may not fully understand the complexities of CHD, leading to misinterpretations of fatigue or behaviour. This can heighten parental anxiety and reinforce the need for advocacy (Giroux, Wilson and Corkett, 2019; Delaney et al., 2021). Improved communication between health and education services is therefore important for family wellbeing.

Although this body of work provides important insight into the emotional and practical demands of parenting a young person with CHD, parents are often studied separately from their adolescents. This separation limits understanding of how parental experiences are negotiated alongside adolescents' developing independence and identity. Consequently, the relational and interdependent nature of family life remains underexplored.

2.5 Transition from Paediatric to Adult Services

Transition from paediatric to adult CHD services is widely recognised as a critical and emotionally demanding period for both adolescents and their parents. As adolescents approach adulthood, they are expected to develop greater independence, including

managing medications, recognising symptoms, and communicating directly with HCPs. However, many report feeling unprepared for these expectations and uncertain about what adult care involves (Uzark et al., 2015; Liu, Jackson and Menahem, 2023). A consistent finding across the literature is that adolescents frequently perceive the transfer as abrupt or poorly explained, particularly when they have developed strong relationships with paediatric teams (Gerardin et al., 2019).

Recent evidence shows that transition remains a vulnerable point in the care pathway. Fewer than one-third of adolescents successfully complete transfer to adult services, indicating persistent gaps in transition planning and follow-up (Ricci et al., 2023). This aligns with earlier concerns about discontinuity of care during this period and highlights the importance of structured, proactive transition processes.

Parents also experience transition as a time of mixed emotions. They often describe pride in their adolescent's growing independence, while simultaneously feeling anxious about stepping back from their long-standing role in monitoring symptoms, interpreting medical information and coordinating care (Elissa et al., 2018; de Maat et al., 2021). These concerns are particularly prominent among adolescents with limited health literacy or who rely heavily on parental involvement. Parents report fears about their young person's ability to recognise urgent symptoms, attend appointments and advocate for themselves within adult services.

Communication emerges across the literature as the most influential factor shaping transition experiences for both adolescents and parents. Clear, repeated, and developmentally appropriate information helps families feel prepared and more confident as they navigate the shift to adult care. Conversely, inconsistent or minimal communication contributes to confusion, anxiety and disengagement from services (Gerardin et al., 2019). Adolescents emphasise the importance of honest discussion about expectations, changes in service structure and opportunities to ask questions well in advance of transfer (Liu, Jackson and Menahem, 2023).

Structured transition programmes represent one approach to improving continuity and supporting skill development. The TRANSITION-CHD Randomised Controlled Trial (Bredy et al, 2024) demonstrated that a formal transition programme significantly improved health-related quality of life and disease knowledge among adolescents and young adults with CHD. This provides some of the strongest evidence to date that

coordinated transition support can lead to measurable improvements in outcomes. Digital health tools to complement transition support are considered a necessary aid to strengthen patient engagement and lifelong CHD care (Blake and Gatzoulis, 2025).

Service quality also remains a focus in contemporary research. Thomet et al. (2023) developed a set of twelve quality indicators for transition and transfer in CHD, offering a meaningful framework for evaluating service provision. Their indicators emphasise readiness assessment, collaborative planning, involvement of both paediatric and adult teams and attention to psychosocial needs. These indicators provide a basis for benchmarking practice and assessing the quality and consistency of transition pathways across different services.

Recent studies further highlight the role of psychological and social factors in influencing successful transition. Adherence to cardiac follow-up among young adults with CHD was associated not only with structural aspects of care but also with psychological variables such as illness perception, emotion regulation and symptoms of depression (Ehmann et al., 2025). This suggests that effective transition must address more than procedural handover and should include support for emotional wellbeing, confidence-building and self-management skills.

Consistent with earlier guidance (NHS England, 2016; Moons et al., 2021), recent literature reinforces the need for holistic, family-centred and developmentally tailored approaches. A recent qualitative synthesis (Ruban et al., 2026) identified persistent barriers, including inadequate preparation, inconsistent pathways, limited communication and insufficient recognition of family dynamics. Despite increasing awareness and growing evidence for structured transition interventions, implementation remains uneven, and many adolescents and families continue to report variable levels of support and preparation.

Taken together, contemporary research portrays transition as both a developmental and a structural process that requires coordinated planning, accessible information and meaningful involvement of adolescents and parents. These gaps in practice and the emerging evidence for targeted interventions underscore the importance of understanding transition as a shared family experience and provide a strong rationale for the present study's focus.

2.6 Summary and Rationale for the Present Study

Taken together, the literature demonstrates that adolescents with moderate or complex CHD and their parents experience significant emotional, social and relational challenges. However, existing research tends to examine these groups separately, limiting understanding of how experiences are shaped within the context of family life. This represents a critical gap, as family relationships influence how adolescents develop independence, how parents manage uncertainty and how both navigate transition.

By examining adolescent and parental experiences together, this study addresses this gap and offers a more integrated understanding of living with CHD as a shared and evolving process. This interpretivist approach enables exploration of meaning, relationships and context, providing insight that extends beyond individual experience to the relational dynamics of family life.

Chapter Three: Methodology and Methods

This chapter outlines the philosophical and methodological foundations alongside the research design of the study. It introduces the relativist ontology and interpretivist epistemology that shaped the approach to knowledge and meaning-making and explains the use of qualitative methods to explore the experiences of adolescents with moderate or complex CHD and their parents. RTA is used to identify and interpret patterns across participants' accounts (Braun and Clarke, 2022).

Clarifying the philosophical foundations of a study supports coherence between its aims, methodological choices and interpretive processes. Alignment between ontology, epistemology and methodology provides the conceptual structure that guides research decisions (Crotty, 1998). The following sections outline the philosophical stance adopted in this study and show how it informed the qualitative design and analytic approach.

3.1 Philosophical Foundations

A philosophical paradigm shapes assumptions about reality (ontology), knowledge (epistemology) and appropriate methods (Brown and Dueñas, 2019). Ontology concerns what exists and how it can be understood, while epistemology concerns how we come to know it (Crotty, 1998). Positionality lies on a spectrum, ranging from realism to relativism.

Realist positions generally assume that an external reality exists independently of human perception, though the degree of emphasis on this varies across realist traditions. In contrast, relativist perspectives argue that reality is understood, interpreted and constructed through social, cultural and historical contexts, meaning that multiple subjective realities can coexist (Braun and Clarke, 2013; O'Reilly and Kiyimba, 2015). While positivism aligns closely with realism, emphasising objective measurement and hypothesis testing (Crotty, 1998), interpretivism reflects a relativist stance, prioritising context, meaning, and the co-construction of knowledge, focusing on understanding phenomena within their social and cultural contexts (Alharahsheh and Pius, 2019). This distinction highlights how paradigms differ not only in methodological choices but in their underlying ontological and epistemological assumptions.

This study adopted a relativist ontology, recognising that experiences of moderate or complex CHD are shaped by personal histories, family relationships, healthcare contexts and broader social norms, and that multiple subjective realities coexist. This aligns with a constructionist, interpretivist epistemology, in which knowledge is understood as co-created through interaction, interpretation, and shared meaning (Ryan, 2018; Walliman, 2016). Rather than seeking one objective truth, the study is concerned with how adolescents and parents understand and make sense of their lives with moderate or complex CHD.

This philosophical stance supports a qualitative design aimed at understanding how individuals interpret their lived experiences. RTA was chosen because of its theoretical flexibility and suitability for examining meaning-making in context (Braun and Clarke, 2022). Within RTA, themes are treated as analytic interpretations rather than objective entities, and the researcher's role is understood as active, iterative and reflexive. This alignment among ontology, epistemology, and the analytic approach supports coherence across the study's methodological decisions (Creswell and Poth, 2018; Crotty, 1998; Handema et al., 2023).

Guided by an interpretivist epistemology, the study viewed knowledge as subjective, contextual, and shaped by lived experience and culture (Ryan, 2018; Walliman, 2016). This contrasts with positivist approaches that prioritise objectivity, measurement, and generalisability, and with pragmatic mixed-methods approaches that focus on problem-solving across paradigms (Denscombe, 2017). An interpretivist stance enabled in-depth exploration of how adolescents and parents interpret experiences of moderate or complex CHD and how they construct meaning within family life.

Engaging with these philosophical foundations shaped my development as a researcher. I have come to understand knowledge as constructed through context, interpretation and lived experience (Crotty, 1998; Braun and Clarke, 2013). Recognising the relevance of a relativist, interpretivist stance (O'Reilly and Kiyimba, 2015) strengthened my reflexivity, particularly in acknowledging how my background as a nurse, mother and grandmother informs interpretation. This awareness helped me justify methodological choices and embrace subjectivity as an inherent and valuable element of qualitative inquiry, viewing research as a collaborative process of meaning-making between researcher and participant.

3.2 Methodology - A Qualitative Approach

The ontological and epistemological positions outlined above underpin the methodological approach taken in this study. A relativist and interpretivist stance assumes that knowledge is co-constructed through interaction and interpretation, which makes a qualitative methodology appropriate for exploring the lived experiences of adolescents with moderate or complex CHD and their parents. Ensuring alignment between philosophical assumptions and methodological choices supports coherence throughout the research process.

A qualitative design was chosen to explore how adolescents and parents make sense of their lives, providing insight into the meanings constructed within particular social, cultural, and healthcare contexts (Merriam, 2009; Creswell, 2009; Holloway, 2016). Unlike quantitative approaches, which are typically grounded in positivism and focus on hypothesis testing, measurement, and prediction (Pyo et al., 2023; Durdella, 2019), qualitative inquiry values depth, context, and the co-construction of meaning between researcher and participant. Although sometimes viewed as less objective (Ormston et al., 2014; Carminati, 2018), qualitative methods offer a nuanced understanding of lived experience, making them suitable for research underpinned by an interpretivist paradigm.

Contemporary healthcare increasingly emphasises patient-centred practice and service improvement (NHS England, 2023). Qualitative research is central to this agenda, offering insight into patients' and families' knowledge, perceptions and experiences of care (Bellamy et al., 2016). By enabling adolescents and parents to describe their experiences of moderate or complex CHD, this study contributes a nuanced understanding that can inform future practice and service design. While adolescents were the primary population of interest, parents were included as participants to capture the relational and contextual dimensions of transition.

Several qualitative methodologies were considered. Interpretative Phenomenological Analysis (IPA) offers a detailed exploration of a small number of cases, focusing on how individuals make sense of their experiences (Smith, Flowers and Larkin, 2009). However, the present study sought to examine shared patterns of meaning across a larger, heterogeneous dataset, making IPA less suitable. Descriptive phenomenology, which aims to bracket researcher influence and uncover the "essence" of experience

(Moustakas, 1994; O'Reilly and Kiyimba, 2015), was also not aligned with the reflexive, interpretive stance adopted here.

Grounded Theory aims to generate new theoretical models through systematic coding and constant comparison (Charmaz, 2014; Creswell, 2013). As this study sought to interpret experiences rather than construct substantive theory, a grounded theory approach was not appropriate. Ethnography, which requires prolonged immersion in participants' social worlds (Kramer and Adams, 2017; Denscombe, 2017), was similarly not feasible or aligned with the research question.

RTA offered the closest fit for exploring the diversity of experiences of living with moderate or complex CHD, while aligning with the study's relativist and interpretivist foundations. Its flexibility supports iterative, reflexive analysis and acknowledges the researcher's active role in constructing meaning (Braun and Clarke, 2022). Reflecting on alternative methodologies strengthened my methodological understanding and reinforced RTA as the most coherent choice for this study.

This study did not adopt a single pre-existing theoretical model to guide the analysis. This was an intentional methodological decision, informed by the study's relativist ontology and interpretivist epistemology, which position experience as contextually situated, relationally constructed and open to multiple interpretations. Within this framework, the application of an a priori model was considered potentially constraining, as it may have imposed predetermined categories onto participants' accounts and limited the exploration of nuanced, context-dependent meanings.

Reflexive thematic analysis (RTA) does not require adherence to a specific theoretical framework and instead offers analytic flexibility, supporting an inductive and interpretive engagement with the data (Braun and Clarke, 2022). This approach enabled themes to be created through close and iterative interaction with participants' narratives, rather than being shaped by existing theoretical assumptions. Such flexibility was particularly important given the relative lack of research exploring the shared and relational experiences of adolescents with complex CHD and their parents.

Rather than seeking to test or apply theory, the study aimed to generate a rich, contextualised understanding of how meaning is constructed within family life and healthcare experiences. In this sense, theory is not absent but operates at a broader conceptual level through the study's interpretivist positioning, informing how data are

understood and interpreted. This approach supports a more nuanced and participant-centred account of living with complex CHD, while remaining consistent with the epistemological and methodological commitments underpinning the research.

3.3 Reflexivity and Reflective Practices

Reflexivity is a core principle of RTA, acknowledging that the researcher actively shapes knowledge production (Braun and Clarke, 2019, 2021). Engaging with one's own subjectivity is considered central to the credibility and trustworthiness of qualitative research (Bloomberg and Volpe, 2016; Smith, 2015; Olmos-Vega et al., 2023). Throughout this study, I reflected on my positionality, assumptions and values, and considered how these influenced decisions during design, data collection and analysis. These practices support transparency, ethical integrity and analytic rigour.

'Reflective pitstops' are included throughout the thesis to make this reflexive process visible and to demonstrate how my identity and perspectives informed the research. As a mother, grandmother and registered adult nurse, I brought empathy, communication skills and relational awareness to the research. At the same time, CHD was a relatively unfamiliar clinical and personal context for me, which positioned me as both an insider (in my relational experience) and an outsider (to the specific condition). This dual positionality supported the interpretive, meaning-making processes central to RTA (Braun and Clarke, 2022).

Keeping a research journal facilitated continuous reflexive engagement and helped me to manage emotional responses during analysis (Braun and Clarke, 2013). Journalling and supervisory dialogue enabled ongoing examination of my assumptions, such as tendencies to prioritise medical perspectives or to anticipate certain emotional responses. These practices strengthened the study's rigour and transparency and supported my growth as a critically aware qualitative researcher.

3.4 Summary

This chapter has outlined the philosophical foundations and methodological approach underpinning the study. Grounded in a relativist ontology and interpretivist epistemology, the research adopted a qualitative approach to explore how adolescents with moderate or complex CHD and their parents make sense of their experiences. RTA was selected for its theoretical flexibility and alignment with an

interpretivist, meaning-oriented framework, enabling the identification and interpretation of patterned meanings across participant accounts. Together, these elements provided a coherent methodological framework that supported the study's aims and guided the interpretive process. Building on these methodological foundations, the next chapter outlines the research design and details how the study was operationalised in practice.

Chapter 4: Research Design

Building on the study's relativist and interpretivist foundations and the use of RTA, this section outlines how the research was conducted, commencing with the use of patient and public involvement (PPI) groups to shape the study design. The subsequent sections describe the recruitment process, study population, sampling strategy, data collection, and data analysis. Ethical considerations specific to adolescent participation are explored further in Chapter Five.

4.1 Patient and Public Involvement (PPI)

Patient and Public Involvement (PPI), the meaningful involvement of service users in the planning, design and conduct of research (Grundy, 2018), was instrumental to the study design. Involvement is a key expectation in UK and international health and social care research, supporting the development of patient-centred studies (Brett et al., 2014). PPI informs research questions, shapes study design and guides recruitment and data collection. National bodies, including the National Institute for Health and Care Research, provide standards to support inclusive PPI involvement (De Simoni et al., 2023; UK Standards for Public Involvement, 2019).

PPI enables meaningful partnerships with researchers, generating diverse perspectives on research design (Rolfe et al., 2018). Challenges arise when contributions are not fully acknowledged or perceived as tokenistic (Oliver et al., 2001). Meaningful collaboration is particularly important in research involving children and young people, to ensure their voices are respected, promote ethical practice and lead to more authentic and impactful findings (Castro, Swauger and Harger, 2017).

I involved an adult PPI group within a cardiac specialist NHS hospital trust to review my designed parent and adolescent participant information sheets (PIS) (Appendix E), consent/assent documentation (Appendix F), recruitment poster (Appendix G), and Interview schedules (Appendix I). The group provided useful feedback on clarity and accessibility, including adding helpline details to adolescent information sheets and clearer wording to ensure that ten- to fifteen-year-old participants understood that the decision to have a parent present during the interview was theirs. They advised against including my facial photograph in my 'Introduction to the Researcher' section within the PISs, as they felt this would be patronising to the participants.

However, challenges arose. The group expressed concerns about social media recruitment and advocated for the inclusion of non-English-speaking participants with interpreters. While I recognised the importance of these recommendations, funding and governance constraints limited the feasibility of providing interpretation, and social media remained a key route to adolescents who predominantly communicate online (Vannucci et al., 2020). Over time, it became clear that the PPIs' priorities did not closely align with the study's specific aims and constraints, and engagement became increasingly difficult. After discussion with my supervisors, a decision was made to discontinue collaboration with this group and the associated Trust.

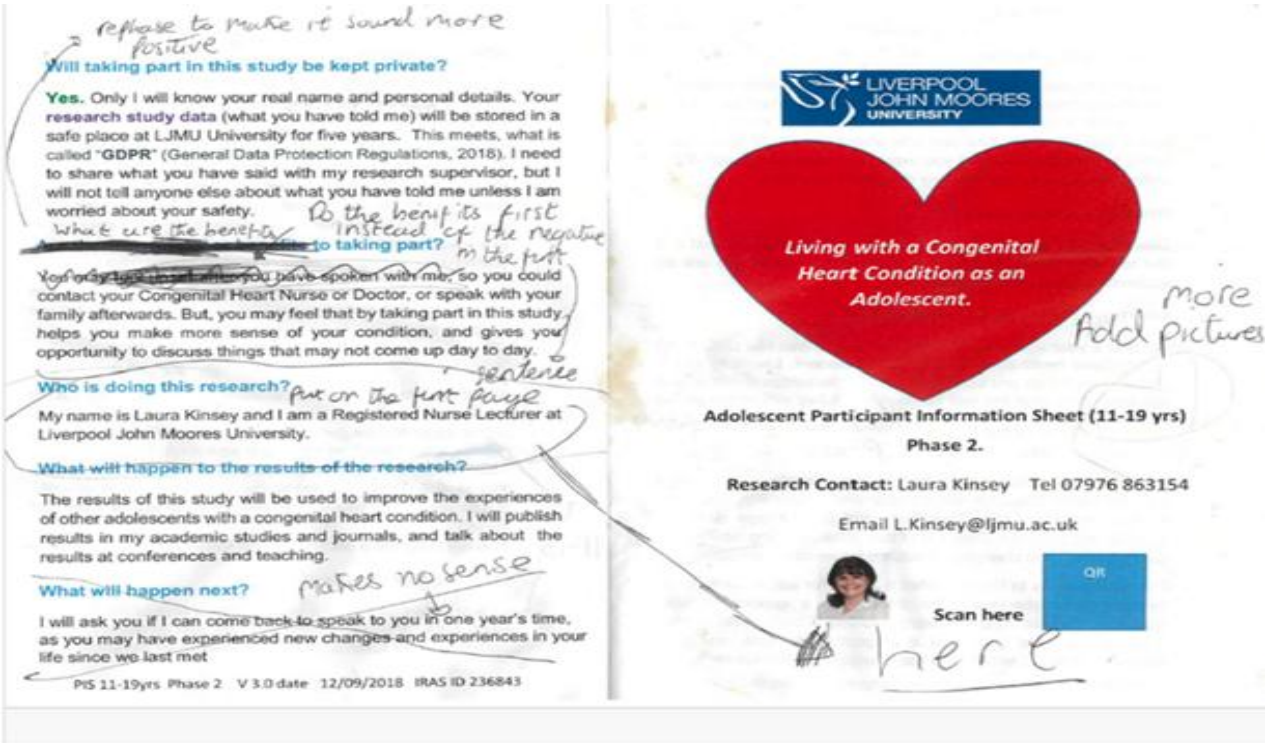
Reflective pitstop

This experience highlighted that PPI is not inherently straightforward or universally beneficial; it depends on the fit between the group, the research aims and the practical context. I learned that involvement must be purposeful, relevant and appropriately matched to the population of interest. The tensions encountered reinforced the importance of clarifying roles, expectations and boundaries from the outset, and of recognising the negotiated nature of collaboration. Although disappointing, this experience deepened my understanding of PPI as an ethical and relational process rather than a procedural requirement.

Recognising the need to centre young people's perspectives, I sought input from a Young People's Advisory Group (YPAG) linked to a paediatric NHS research facility. YPAGs are commonly used to involve young people across stages of research (Pavarini et al., 2019). The group reviewed adolescent-facing documents, including the PIS and accompanying animated video (see Appendices E and H), consent/assent forms and interview schedules. Their feedback informed the PIS layout, language, and the use of infographics. Examples included changing *"I want to speak to you" to "I wish to speak to you*", and "*I would like you to answer me in as much detail as you can"* to "*…as much depth as you can".* They advised using less clip art images and strengthening how I worded phrases around withdrawal from the study, changing the question "*Can I change my mind?"* to "*you can leave the study at any point and data will be removed."* YPAG participants liked the use of varied coloured font headings, and emphasising pertinent words in bold such as ages, adolescent, and recording equipment to be used. They also confirmed that including my photograph and a brief

professional introduction on the PIS helped build rapport rather than appearing patronising, as previously advised by the adult PPI group. YPAG involvement ensured that materials were relevant, understandable, and acceptable to the target age group, and supported the principle that young people have a right to influence research that affects them (Brady et al., 2023). Finalised documents can be found in appendices E-I). Figure 1 shows an example of feedback from the YPAG.

Figure 1: Feedback from the YPAG:



The involvement of working with PPI groups reinforced the value of drawing on multiple perspectives and highlighted that meaningful PPI involves balancing clarity, tone and relational connection, not simply gaining a single endorsement.

4.2 Recruitment Strategy

The recruitment strategy for this study was to engage both parents and adolescents as key participant groups. While tailored recruitment materials were developed to address each group separately, ensuring that the language, format, and content were appropriate for their respective perspectives, the initial intention was to recruit family units, comprising at least one parent and one adolescent from the same household. This approach was motivated by the original analytical aim of examining patterns not only within each group (i.e., between adolescents and between parents) but also

across family dyads, thereby enabling a richer understanding of shared and divergent experiences within the family context.

4.2.1 Recruitment Process

Recruitment in qualitative research is an important methodological consideration, as ineffective recruitment can compromise the depth and diversity of data (Negrin et al., 2022; Topolovec-Vranic and Natarajan, 2016; Coyne, Grafton and Reid, 2016). For this study, strategies were developed to access participants through NHS organisations and a charity support group. Employing multiple recruitment routes was essential to maximise the likelihood of engaging both parents and adolescents from diverse backgrounds, thereby enhancing the sample's diversity and representativeness and supporting the study's aim of capturing a broad range of family perspectives (Goldman et al., 2023).

Access to NHS sites required standard pre-employment checks and occupational health clearance, including vaccinations necessary to protect vulnerable adolescents. These processes culminated in a research passport, a mechanism that allows HE institutions (HEIs) to share pre-engagement information with recruiting NHS organisations (National Institute for Health Research, 2019). The research passport provided evidence that NHS Employment Check Standards had been met and supported letters of access to participating Trusts (Laterza et al., 2016).

Recruitment was also undertaken through social media and charitable organisations. Social media has been shown to be an effective means of reaching large numbers of potential participants, including those with specific health conditions (Topolovec-Vranic and Natarajan, 2016; Darko et al., 2022; Collins, Shiffman and Rock, 2016). Online recruitment can widen access to geographically dispersed or underserved groups while reducing costs (Lane, Armin and Gordon, 2015; Frandsen, Walters and Ferguson, 2014).

I approached The Somerville Foundation, a UK-wide charity supporting adults and young people with CHD, to assist with recruitment. A study poster was designed and shared in the charity's closed Facebook group and in their quarterly journal (Appendix G) following the charity's consideration. I was advised to change the wording to recruitment to adolescents only, not parents, as the charity was focused on adolescent

support. The poster was also disseminated in another closed CHD Facebook group, with the administrator's permission.

Reflective pitstop

Feedback from The Somerville Foundation highlighted the importance of aligning recruitment materials with the identity and membership of partner organisations. The original poster invited participation from adolescents and parents, but the charity requested that the parent recruitment information be removed to align with their membership focus. This experience reinforced that recruitment materials are not neutral and must be tailored in collaboration with gatekeepers to ensure appropriateness and acceptability. It strengthened my understanding of relational ethics and the need for flexibility and responsiveness when recruiting through external organisations.

Recruitment was further supported through professional referral. My supervisor, having previously worked with families who met the inclusion criteria, identified several families and sought their permission for me to contact them. This strategy facilitated participation from families who might not have engaged with social media or charitable organisations.

Interested individuals contacted me via email or phone. I confirmed eligibility, discussed the study, and arranged interviews with those who provided consent. One potential participant was excluded as they were not resident in the UK and had not received care through existing NHS pathways. In total, seventeen participants were recruited.

4.2.2 Recruitment Challenges

Recruitment challenges, such as limited responses to re-advertising and non-engagement from some invited parents, likely shaped the sample. Parents of children with medical complexities may be less inclined to participate in research due to time, emotional and practical burdens (Kim et al., 2024). The final sample consisted exclusively of individuals who identified as white, and all parents were in paid employment, potentially excluding perspectives of families experiencing financial hardship, unemployment, or navigating CHD within different cultural contexts. The

predominance of mothers in the parent sample may have biased the findings toward maternal viewpoints.

Recruitment strategies and their limitations were considered further in relation to sample representativeness and potential bias. Social media recruitment can exclude individuals without digital access or those who do not engage with online groups (Topolovec-Vranic and Natarajan, 2016), however, recruiting from researcher selected online networks may reflect the researcher's own preferences or connections (Vaughan-Johnson et al., 2024). These factors, along with the sample's demographic characteristics, are acknowledged as influencing the transferability of the findings and the potential health equity implications (Pardhan et al., 2025).

4.3 Sampling Strategy and Participant Groups

The sampling strategy applied was related to both population groups, adolescents and parents. Adolescents were the primary focus of the study; however, parental participation was incorporated to capture the relational and contextual factors influencing transition. Whilst the aim was to recruit within dyads, the recruitment strategy allowed non-dyad recruitment as a backup, which was subsequently implemented. Sampling is a critical methodological process that enables researchers to investigate a defined population by selecting a smaller, representative subset (Taherdoost, 2016; Bhardwaj, 2019).

This approach addressed the practical constraints of time, cost, and accessibility that often make studying an entire population unfeasible, while still allowing valid findings to be generated. The effectiveness of sampling lies in its ability to capture the essential characteristics of the target population through a carefully designed strategy, whether probability-based, ensuring each unit has a known chance of selection, or, as in this study, non-probability-based, which prioritises depth and contextual richness over statistical representativeness (Creswell and Creswell, 2018). By aligning the sampling method with the research objectives, epistemological stance, and analytical framework, the study enhanced both the credibility and transferability of its conclusions.

4.3.1 Sampling Strategy

A purposive, maximum variation sampling approach (Etikan, Musa and Alkassin, 2016) was adopted to recruit adolescent–parent dyads, ensuring a broad range of

experiences and perspectives were represented. Recruiting targeted families affected by moderate or complex congenital anomalies, with deliberate variation, sought key characteristics such as the adolescent's age, gender, and the severity and type of anomaly. This strategy aimed to capture diversity both within and across dyads, enabling exploration of how different demographic and clinical factors might shape individual and shared experiences of healthcare transition. By sampling across this spectrum, the study sought to generate richer, more nuanced insights that could inform practice for a wide range of family contexts.

Sampling was restricted to adolescents with moderate or complex congenital anomalies, as condition severity is known to substantially shape experiences of illness, care and transition. Severe anomalies typically require ongoing, multidisciplinary management, intensifying the emotional, practical and social demands placed on adolescents and their families during the transition to adult services (Colver et al., 2018; Kirk, 2008). Research highlights the central role of parents in coordinating complex care and navigating fragmented systems, particularly where care needs remain high (Reiss et al., 2005; Watson et al., 2011). Focusing on this subgroup enabled in-depth exploration of the most demanding transition pathways, while also supporting a more coherent and comparable dataset by reducing variability associated with differing prognoses and care requirements. This approach aligned with evidence that adolescents with moderate or complex conditions are at increased risk of care discontinuity and poorer outcomes without targeted transition support (Schmidt et al., 2020).

4.3.2 Sample Size

Although qualitative research requires smaller samples than quantitative studies, questions of sample sufficiency remain important for assessing rigour (Vasileiou, Barnett and Thorpe, 2018; Hennink and Kaiser, 2022).

From the perspective of Braun and Clarke, RTA exhaustively captures all possible themes or reaches a point where no new information 'emerges'. RTA views meaning-making as an active, interpretative process shaped by the researcher's theoretical lens, questions, and analytic focus. Because data are always open to multiple interpretations, there is no finite point at which analysis is "complete" in the saturation sense. Instead, adequacy is judged by the richness and depth of the data in relation

to the research aims, and by the coherence and transparency of the analytic narrative. In this approach, the decision to cease data collection was guided by pragmatic considerations such as time, resources, and the sufficiency of data to meaningfully address the research questions rather than by the pursuit of saturation. For this study, seventeen participants were interviewed, a sample size considered sufficient in qualitative research. Sufficiency was approached in terms of the richness and variation of accounts and their capacity to address the research questions.

Specific inclusion and exclusion criteria were applied to adolescents and parents. These generally overlapped, meaning no one was excluded if their associated dyad had been included.

4.3.3 Adolescent Sample

Clear inclusion and exclusion criteria ensured that adolescent participants could provide meaningful insights while safeguarding their wellbeing and maintaining focus (King, Horrocks, and Brooks, 2019; Cash et al., 2022; Pyo et al., 2023). Inclusion criteria defined who was eligible for the study, while exclusion criteria identified factors that might limit participation or compromise safety and quality (Connelly, 2020; Patino and Ferreira, 2018).

4.3.3.1 Inclusion Criteria

Adolescents between ten and nineteen years of age, who had a diagnosis of clinically complex CHD, had undergone corrective cardiac surgery or intervention, and were residing in the UK

4.3.3.2 Exclusion Criteria

Adolescents who were unable to communicate in English or lacked the mental capacity to give informed consent or assent.

4.3.3.3 Sample Description – Adolescents

A total of eight adolescents participated in the study. ESC criteria were used to classify disease complexity, with the sample comprising predominantly complex CHD and one participant with ESC-defined moderate disease whose clinical complexity warranted inclusion. Participants ranged in age from eleven to nineteen years, with a mean age of fifteen and a half. The group consisted of six females and two males. At the time of the interviews, four adolescents were in secondary education, two were in further education, and two were studying at HE level. They presented with a range of clinically

complex congenital heart problems, including Shones Complex, Hypoplastic Right Heart Syndrome, TOF and TGA.

4.3.4 Parent Sample

Inclusion and exclusion criteria for parent participants were established to ensure the collection of relevant, high-quality data while safeguarding participants' wellbeing and maintaining the study's focus (King, Horrocks, and Brooks, 2019; Cash et al., 2022; Pyo et al., 2023). These criteria defined eligibility and identified factors that could limit participation or compromise research integrity and safety (Connelly, 2020; Patino and Ferreira, 2018).

4.3.4.1 Inclusion Criteria

Parents who live with an adolescent aged 10-19 years with a clinically complex congenital heart problem, who have required corrective cardiac surgery or intervention and were residing in the UK.

4.3.4.2 Exclusion Criteria

Parents who were unable to communicate in English or lacked the mental capacity to give informed consent.

4.3.4.3 Sample Description- Parents

A total of nine participants participated in the study, comprising six mothers and three fathers. Participants ranged in age from forty-one to fifty-one years. No mean age could be calculated because not all parents' ages were recorded.

4.4 Exclusion Limitations

The exclusion criteria introduced several limitations. Excluding non-English-speaking participants reduced cultural and linguistic diversity and limited the transferability of findings to minority ethnic groups. Excluding individuals lacking capacity, although ethically pragmatic, may have underrepresented adolescents or parents with cognitive or neurodevelopmental differences. Limiting recruitment to UK residents also prevented comparison across different healthcare systems.

4.5 Participant composition: Dyads, Triads, Families and Independent Participation

The seventeen participants represented varied family structures, consisting of three family dyads (adolescent and mother), two family triads (adolescent with both parents),

one family group (mother, father, and two children), and one adolescent interviewed independently.

Adolescents were usually interviewed alone to encourage independent expression. However, three younger adolescents had a parent present, who occasionally prompted or clarified responses. During the interviews, the adolescents and parents were interviewed on the same day. In two triads, parents opted to be interviewed together. The adolescents and their parents were interviewed on the same day, at their request. These variations were documented and considered during analysis.

The participant demographics and a visual representation of participant relationships, illustrated using caricatures, can be found within Appendix J. Demographic information is presented to contextualise participant accounts and support transparency regarding the composition of the sample, rather than to suggest causal relationships between participant characteristics and thematic meaning

4.6 Expected contribution to research aims

The inclusion of both adolescents with a clinically complex CHD and their parents enabled exploration of how meanings are constructed and negotiated within family life. Dyadic and triadic interviewing illuminated not only what participants think at the individual level, but also how they think together to generate shared, nuanced meanings (Bayuo et al, 2025).

The adolescent sample spanned key developmental stages and educational contexts, supporting examination of identity, understanding, and emerging autonomy. Parents' accounts, including those of fathers, provided insight into the ongoing emotional, practical and relational demands of care. Together, these dual perspectives enabled the study to identify shared and differing experiences across families, directly supporting its aim to understand how adolescents and parents navigate the challenges of long-term cardiac care.

4.7 Ethical Approval and Governance

When planning and designing a qualitative study, researchers must anticipate and address ethical considerations to ensure participant protection and research integrity (Creswell, 2013; Wu et al., 2019). This section outlines the ethical procedures relevant to this study, including ethics training, governance approvals, consent procedures, and data management.

In preparation, I completed the required university research ethics training, which included guidance based on the Declaration of Helsinki (World Medical Association, 2024). As a relatively inexperienced researcher, I found this training reinforced the need for ethical attention throughout the research lifecycle, from design and data collection to dissemination and archiving (UK Research and Innovation, 2022). Confirmation of training completion was required before progressing to NHS Research Ethics Committee (REC) review.

Formal ethical approval was then sought to ensure that the study design aligned with recognised standards of participant safety and integrity (Lenton et al., 2021). Approval was granted to conduct the study within NHS settings, confirming compliance with relevant regulations (Wilkinson and Wilkinson, 2019). Recruitment was initially planned through NHS Trusts specialising in CHD, in accordance with the Health Research Authority's guidance on site access and permissions (NHS HRA, 2024).

An application was submitted through IRAS for Proportionate Review, including the study protocol, participant-facing materials, data management plans and safeguarding procedures. Following screening, the REC requested a full review due to material ethical considerations, including the involvement of adolescents and the use of online interviews. A favourable opinion was granted, subject to minor conditions requiring correction of typographical errors and clarification of wording in the adolescent and parent PIS.

Given the sensitive nature of the topic, it was important to anticipate and minimise the potential for distress (Whitney and Evered, 2022). Age-appropriate PIS were developed for adolescents aged ten to fifteen years, adolescents aged sixteen to nineteen years, and parents (Appendix E), informed by HRA guidance on clarity and proportionality. Signposting to support services was included.

Reflective pitstop

Before this MPhil, I viewed NHS research governance as complex and intimidating, shaped by colleagues' accounts of lengthy approval processes. Developing the IRAS application required multiple revisions and detailed justification for every design element. While at times frustrating, the process deepened my understanding of ethical review as a mechanism for ensuring transparency, participant protection, and

methodological coherence, rather than as a purely administrative hurdle. Attending the NHS REC meeting and responding to requested amendments increased my confidence in presenting and defending methodological choices and strengthened my appreciation of ethics as integral to qualitative research practice.

4.7.1 Informed consent

Facilitating informed consent is central to interpretive research, as it fosters relationships built on trust and mutual understanding while respecting participants' autonomy to choose whether to participate (Klykken, 2022). Informed consent was obtained from all participants prior to the interviews. For adolescents under sixteen years, written parental or caregiver consent was secured alongside the adolescent's assent, ensuring that participation was voluntary and age-appropriate, as discussed further in Chapter Five. Prior to the interviews, PIS, consent, and assent forms were emailed to participants using their preferred email addresses. Participants completed, signed, and returned the forms to the researcher's work email. Participants were given further opportunities to ask questions and engage with the consent process, supporting informed and voluntary participation (Grant, Hamilton and Ormita, 2025). All participants were informed of the study aims, procedures, confidentiality measures, and their right to withdraw at any time without consequence.

4.8 Data Collection Methods

Given the study's interpretivist orientation and use of RTA, data collection methods were selected to capture participants' meanings and lived experiences (Merriam and Tisdale, 2015). Qualitative inquiry prioritises rich, contextualised accounts of experience through open-ended methods (Bloomberg and Volpe, 2016). Semi-structured interviews were chosen, allowing participants to describe their feelings, interpretations, and personal contexts in depth while offering a flexible framework to guide the conversation (Denscombe, 2017).

Three interview schedules were developed: for ages eleven to fifteen, sixteen to nineteen, and parents (Appendix I), designed to encourage open, detailed discussion and to generate rich data (Bearman, 2019). The interview schedules were developed following a review of the literature and refined through consultation with patient participant groups. Interviews were conducted flexibly, with the order and phrasing of questions adapted in response to participants' narratives, and follow-up prompts used

to facilitate deeper exploration, consistent with interpretivist research that values responsive dialogue and nuanced exploration (Percy, Kostere and Kostre, 2015).

Data were collected via Microsoft Teams. Face-to-face interviews were initially planned but became unfeasible due to COVID-19 restrictions, which required remote approaches to ensure safety and compliance with guidance (Oliffe et al., 2021; Saarijärvi and Bratt, 2021; De Villiers, Farooq and Molinari, 2021). While in-person interviews are valued for rapport and depth, advances in communication technologies have supported the increasing use and acceptance of virtual interviews in qualitative research (Khan and MacEachen, 2022). Evidence suggests that video-call interviews can generate data of comparable quality, with additional benefits in relation to time and cost (Krouwel, Jolly and Greenfield, 2019).

Online interviewing presents challenges, including limited capacity to offer in-person support, technological problems and digital exclusion for those without appropriate access (Irani, 2019; Foley, 2021). To mitigate these issues, participants were contacted in advance to confirm access to suitable technology, and interviews were scheduled flexibly.

Reflective pitstop

Conducting online interviews presented practical and analytical challenges.

I had prior academic experience using Microsoft Teams and Zoom.

Some participants experienced difficulty accessing links or intermittent connectivity, which occasionally disrupted the flow and required repetition.

Automated transcription services sometimes misinterpreted heavily accented speech, which necessitated careful manual correction. Although time-consuming, this process improved transcript accuracy and deepened my engagement with the data.

As my confidence in interviewing grew, I became more aware of how my own assumptions and conversational habits influenced participants' responses. I recognised that interruptions or premature summaries, intended to show engagement, may have limited opportunities for fuller elaboration. This awareness prompted greater attention to pacing, silence and the importance of allowing participants space to lead the conversation.

4.8.1 Data Protection and Storage

Participant data collection complied with the General Data Protection Regulation (GDPR) (European Union, 2016) and the Data Protection Act (UK Parliament, 2018). Qualitative data were managed collaboratively with my supervisory team to ensure accuracy and security (Creswell and Creswell, 2018).

The close-knit nature of adolescent CHD communities increased the risk of deductive disclosure, particularly when using direct quotations (O'Reilly and Kiyimba, 2015). Interviews were recorded via Microsoft Teams with automated transcription; transcripts were verified against recordings, anonymised by removing identifiers, and assigned pseudonyms to maintain anonymity while still allowing for meaningful analysis of the data (Gaudet and Robert, 2018; King, Horrocks and Brooks, 2019).

In line with Liverpool John Moores University (LJMU) Research and Knowledge Exchange Data Management Policy (LJMU, 2023), data were stored in an encrypted, access-controlled OneDrive folder, and printed transcripts were kept in a locked office cabinet. Version control and regular team discussions maintained data integrity and transparency throughout analysis.

These procedures developed my understanding of ethics as an ongoing practical responsibility, not solely a formal requirement.

4.9. Data Analysis

In qualitative research, data analysis involves understanding, explaining and interpreting the phenomena being studied (Cohen, Manion and Morrison, 2017). This section outlines how data were analysed using RTA (Braun and Clarke, 2019, 2022).

4.9.1 Approach to Data Analysis

RTA was chosen for its flexibility and congruence with the study's relativist ontology and interpretivist epistemology. The approach positions themes as interpretive constructions rather than objective truths and acknowledges the researcher's active role in meaning-making. Analysis was iterative and reflexive, shaped by ongoing engagement with the data, the research aims and my positionality.

RTA is a theoretically flexible method for identifying and interpreting patterns of meaning across qualitative data (Braun and Clarke, 2019, 2022). Unlike coding reliability approaches, RTA emphasises subjectivity and reflexivity, viewing themes as

analytic outputs developed through the researcher's interpretive lens (Braun and Clarke, 2013; Byrne, 2022). This aligned with the study's aim to explore how adolescents and parents make sense of their experiences of moderate or complex CHD within social and cultural contexts.

Braun and Clarke (2022) describe six phases of RTA:

1. Familiarisation with the data
2. Coding
3. Generating initial themes
4. Developing and reviewing themes
5. Refining, defining and naming themes
6. Producing the report.

These phases were approached as recursive rather than linear, moving back and forth as understanding developed.

4.9.2 Phase 1: Familiarisation with the Data

Interviews were audio-recorded using Microsoft Teams. Several recordings were transcribed by a university-approved transcription service, while others were transcribed by me. For the service-produced transcripts, I reviewed each interview by listening to and watching the recordings multiple times and carefully checked the transcripts for accuracy. For the interviews I transcribed myself, I listened to and watched each recording several times and transcribed it sentence by sentence in Microsoft Word.

Participants used several hesitation markers, such as "um" and "uh", and discourse markers including "*you know*" ", *so*" and "*well".* I transcribed using a clean verbatim approach, which omitted such filler words and non-meaningful vocalisations (da Silva Nascimento and Steinbruch, 2019). While fillers can sometimes convey hesitation (Tian, Maruyama and Ginzburg, 2017), their removal was judged appropriate to improve readability without altering substantive meaning.

I immersed myself in the data by repeatedly reading transcripts and re-listening to recordings, noting initial impressions, questions, and emotional responses in my

personal research diary. Familiarisation was treated as an active engagement with the data rather than a passive process (Braun and Clarke, 2013). I paid attention to both what participants said and how they said it, while reflecting on my own assumptions and reactions.

Reflective pitstop

Some interviews were initially transcribed by the university's transcription service due to my full-time employment and supervisory advice to use available resources. However, I soon chose to undertake further transcription myself. Engaging directly with the audio recordings allowed deeper immersion in participants' voices, rhythms, and expressions, and facilitated early identification of patterns.

I realised that while outsourcing transcription could be efficient, it risked creating distance from the data. Transcribing personally enhanced my familiarity with participants' accounts and strengthened the connection between data collection and interpretive analysis, reinforcing the reflexive underpinnings of RTA.

Consistent with an RTA approach, I reflected on the interview context during data analysis, particularly when interviews were conducted in the presence of a spouse or when adolescents were in close proximity to their parents. I considered how these relational dynamics may have shaped participants' accounts, including the potential for socially desirable or constrained responses. This reflexive engagement informed theme development, with attention given to both explicit content and underlying meanings, including silences, hesitations, and what may have been minimised or left unsaid.

4.9.3 Phase 2: Coding

Saldaña (2016, p.20) refers to the challenge of managing "quantities of qualities," capturing the tension between the richness of qualitative data and the need for systematic organisation. In RTA, coding is an interpretive rather than mechanical process (Braun and Clarke, 2022). Codes are developed to capture meaning rather than frequency, and their refinement reflects the researcher's evolving understanding.

Coding was conducted inductively, guided by the research question and interpretivist stance. I aimed to engage deeply with the data, recognising that meanings were constructed through my interpretive lens rather than existing as objective truths waiting

to be uncovered. NVivo software was used to organise and manage the dataset, facilitating systematic coding and retrieval of data segments. While NVivo provided practical support, coding decisions remained reflexive and analytic rather than driven by software. This is consistent with RTA's rejection of coding as a technical exercise (Braun and Clarke, 2022).

A complete coding process was undertaken, with all data relevant to the research question coded across the dataset. Codes were developed to capture both semantic content (e.g., "fear of surgery") and latent meanings (e.g., "loss of control"). Visual aids, such as highlighted transcripts and post-it notes, were used to map emerging ideas and relationships among codes, supporting later theme development (see Figures 2 and 3).

Figure 2: Transcript highlighting:

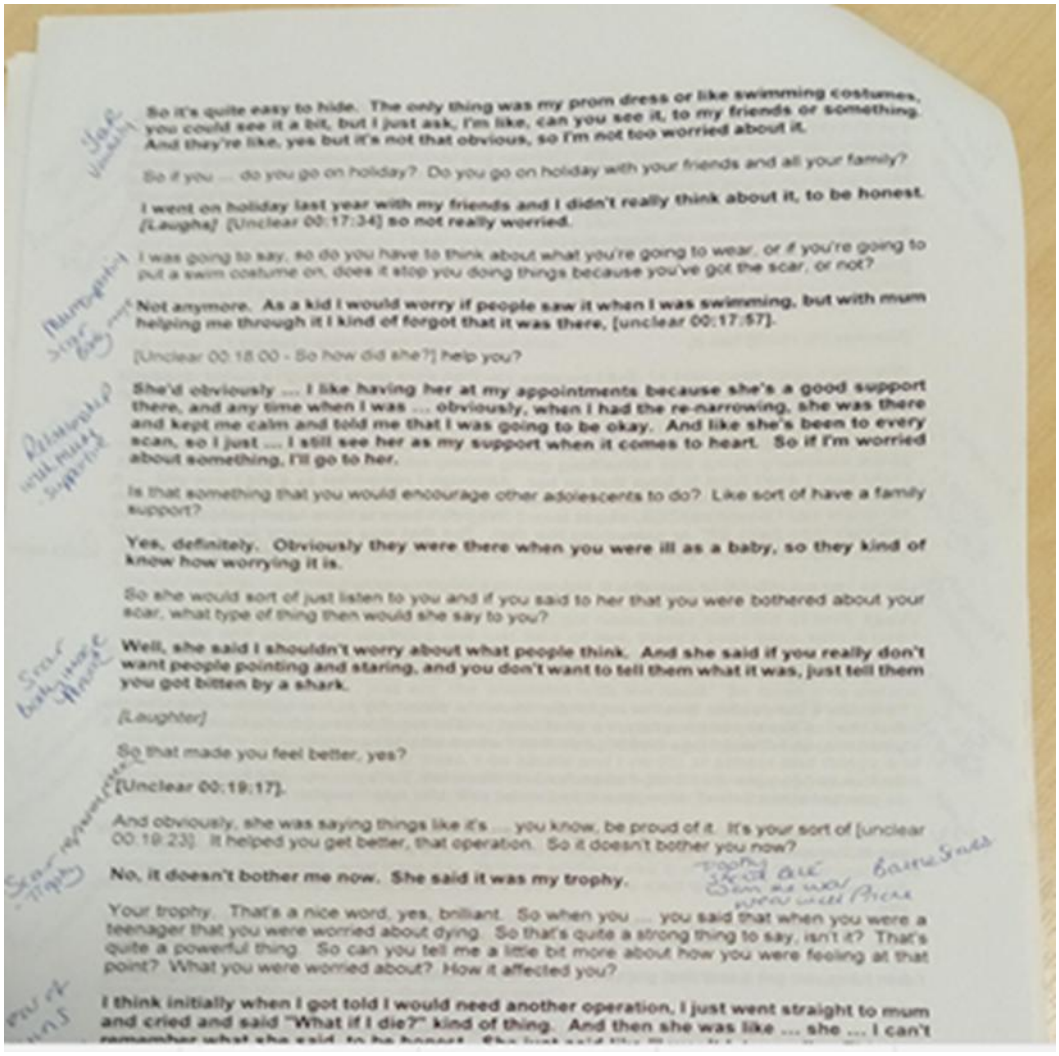


Figure 3: Post it notes

Reflective pitstop

My initial use of NVivo yielded over 400 discrete codes for the parent interviews alone, reflecting my inexperience and a tendency to treat all data equally. I struggled to “let go” of codes, concerned that discarding any might diminish participants’ contributions.

By revisiting Braun and Clarke’s guidance and discussing my approach with my supervisors, I began consolidating overlapping and conceptually similar codes into more manageable groups.

This iterative refinement helped me to move from cataloguing to interpreting and highlighted that valuing participants’ accounts does not mean retaining every detail as a separate analytic category. Instead, it involves using judgment to build coherent and meaningful patterns of shared meaning.

4.9.4 Phase 3: Generating Initial Themes

In this phase, I began to construct shared patterns of meaning across the coded data (Braun and Clarke, 2022). Moving beyond description, I asked what ideas and experiences recurred and how they related to the research questions. Themes were conceptualised as dynamic and evolving rather than fixed categories.

For example, an early candidate theme labelled “Managing emotions” initially captured accounts of anxiety and sadness. As analysis progressed, it became clear that these emotional experiences were often embedded in relational dynamics, particularly parents’ efforts to balance adolescents’ independence with protection. This theme was therefore reworked into “Navigating uncertainty,” illustrating the interpretive nature of RTA, in which themes are actively created rather than passively generated.

Many candidate themes were initially created: thirty-one for parents and fifty-five for adolescents. These provided a starting point for more focused refinement in the next phase.

4.9.5 Phase 4: Developing and Reviewing Themes

During this phase, I refined candidate themes to highlight the most important patterns of shared meaning in the dataset. Given the large number of initial themes, substantial revision was necessary (Braun and Clarke, 2022). I examined how codes related to one another and grouped them into potential themes that captured coherent patterns across participants.

This involved repeatedly moving between codes, data extracts and the full dataset to assess how well each theme reflected the richness and complexity of participants’ accounts. Some themes were combined, others separated, and some were discarded if they lacked sufficient analytic weight or relevance. For example, candidate themes such as “Trust and collaboration,” “Positive HCP relationships”, and “The importance of friendships” were eventually understood as aspects of a broader theme related to supportive networks and were later refined into “A sense of community”.

4.9.6 Phase 5: Refining, Defining and Naming Themes

In this phase, I moved from developing themes to clearly defining and naming them. Following Braun and Clarke’s (2022) guidance, each theme was examined to ensure it captured a distinct and coherent aspect of participants’ experiences, underpinned by a clear organising concept. Themes were reviewed across the entire dataset to

confirm that they were adequately supported by the data and that distinctions between themes were meaningful.

Through this process, overlapping themes were merged, and those combining multiple ideas were separated. For example, themes relating to healthcare relationships, peer support and family connections were brought together under the broader theme “A sense of community”, with subthemes capturing more specific relational contexts. Subthemes were used to show the layered nature of meaning within each theme, allowing a nuanced analytic account.

Following this iterative process, three overarching themes were constructed, with subthemes reflecting the perspectives of adolescents and parents, presented at the beginning of Chapters Six and Seven (see Tables 2 and 3). These provide the analytic structure for the presentation of results. I acknowledge that these themes were not treated as inherent within the data but were actively constructed through reflexive and interpretive engagement with participant accounts.

4.9.7 Phase 6: Producing the Report

The final phase involved writing up the analysis, integrating interpretive commentary with vivid data extracts to construct a coherent analytic narrative (Braun and Clarke, 2022). The findings are presented in two chapters: Chapter Six focuses on adolescents’ experiences, and Chapter Seven on parents’ experiences. While there is thematic overlap across groups, presenting them separately supports clarity and allows both shared and divergent meanings to be explored.

Participants’ own words are used to illustrate and ground analytic claims, recognising their expertise and lived experience (Sandelowski, 1994). Extracts were selected to be both representative and illuminating, illustrating key patterns while conveying the diversity of voices. As discussed, particular care was taken to avoid deductive disclosure within a small community by altering potentially identifying details and using pseudonyms (King, Horrocks and Brooks, 2019).

Across all interviewed dyad and triad family groups, no major tensions were reported. Families generally described collaborative approaches to care and decision-making. One mother–father pair mentioned minor friction, with the mother noting occasional disagreements from “double-checking” each other’s actions.

Reflective pitstop

Initially, I hoped to present highly detailed, portrait-style narratives of participants to foster connection and bring their stories to life. Supervisory feedback and further reflection highlighted the ethical risks of deductive disclosure in a close-knit CHD community, even when pseudonyms were used. This prompted a shift towards presenting participants through simplified avatars and removing certain contextual details.

While this reduced the descriptive richness of individual portraits, it strengthened confidentiality. This process illustrated my growing understanding of anonymity as more than a procedural requirement and my willingness to prioritise participants' safety over narrative detail**.**

4.10 The COVID-19 Pandemic: Implications for the Study

The onset of the COVID-19 pandemic had significant implications for the design and conduct of this study. National restrictions and the suspension of non-essential in-person research rendered the original plan for face-to-face interviews within NHS settings no longer feasible. Researchers were required to avoid travel and physical contact, and many studies either paused or transitioned to remote recruitment, consent and data collection (Vindrola-Padros, Chisnall and Johnson, 2020).

I remained in communication with the identified NHS Trust regarding the potential resumption of face-to-face research. However, the Trust prioritised Urgent Public Health COVID-19 studies, and many staff were shielding or absent due to illness. As a result, NHS-based recruitment could not proceed. The original ethical approval covered recruitment within an NHS setting and through a single CHD charitable organisation. In response to the evolving context, I submitted a formal amendment via Integrated Research Application System (IRAS), requesting permission to extend recruitment to additional UK-based CHD charities and online groups and to conduct interviews remotely. This amendment was approved.

These changes required careful consideration to maintain methodological coherence and participant safety. Moving to online recruitment and interviewing was a pragmatic response to public health restrictions, but it also opened the opportunity to reach a

wider geographic spread of participants. It highlighted the need for flexibility in research design and the importance of responding ethically to unforeseen circumstances.

Reflective pitstop

Adapting the study in response to COVID-19 represented a key stage in my development as a researcher. Navigating ethical amendments, revising recruitment plans and shifting to online interviews demanded flexibility and problem-solving, while maintaining alignment with the study's philosophical stance. The process reinforced my understanding of research as responsive and iterative, and of ethical integrity as something that must be actively maintained in changing conditions. It also increased my confidence in navigating governance processes and in negotiating unavoidable changes without losing sight of the study's core purpose.

4.11 Summary

This chapter has outlined the study's methodological design, grounded in a relativist and interpretivist framework and operationalised through RTA. It described the role of PPI, recruitment strategies, sampling decisions, and data collection and analysis processes, emphasising reflexivity, rigour and secure data management. Methodological challenges, including recruitment constraints, pandemic-related adaptations and the risk of deductive disclosure, were critically considered. Together, these decisions highlight the ethical complexities of qualitative research with adolescents, particularly in balancing autonomy, protection and meaningful participation within small clinical communities. The next chapter, therefore, focuses on ethical recruitment and the processes of informed consent and assent with adolescent participants.

Chapter Five: Recruitment, Consent, and Engagement of Adolescents

This chapter explores the ethical and methodological considerations involved in recruiting and engaging adolescents with moderate or complex CHD in research. Adolescents formed a distinctive participant group in this study, reflecting the study's overall aim to foreground their lived experiences. Conducting research with adolescents requires careful attention to ethical, legal, and relational issues to ensure that young people understand the study, feel respected, and can participate safely and meaningfully.

Engaging adolescents in research is essential to understanding their needs, developing appropriate interventions, and ensuring that healthcare services are accessible and acceptable to them (Faruqui et al., 2024). The emphasis on the voices of children and young people in policy, practice, and research has increased following the United Nations Convention on the Rights of the Child (UNICEF, 1990), which was ratified in the UK in 1991. Article 12.1 affirms that children capable of forming their own views have the right to express those views freely in matters affecting them, in accordance with their age and maturity. Despite this, adolescents' perspectives have historically been underrepresented in health research.

Services for adolescents have often been designed with limited involvement from young people themselves (Meldahl et al., 2022). Meaningful participation became more formally embedded within national guidance when the National Institute for Health and Care Excellence (NICE, 2013) required children and young people to contribute to the development of standards informed by their perspectives and experiences. Sociologists increasingly argue that childhood and adolescence are shaped by society, not just biology, emphasising that young people are active contributors who understand their own lives, rather than passive individuals who simply follow adult decisions (Kutrovátz, 2017; Nishiyama, 2018)

This chapter outlines the ethical framework underpinning adolescent recruitment, the processes used to obtain informed consent and assent, strategies employed to address power imbalances, and the use of digital tools to enhance understanding. It also examines the ethical and practical considerations of virtual interviewing with

adolescents and concludes with reflexive insights into my development as a researcher.

5.1 Ethical Framework for Research with Adolescents

This section demonstrates the ethical principles underpinning the inclusion of adolescents in this study and establishes how vulnerability was addressed without excluding young people from meaningful participation.

Adolescents are commonly considered a vulnerable research population due to ongoing physical, cognitive, and psychosocial development, identity exploration, mental health challenges, and the influence of family and social environments (Tariq et al., 2024). These factors necessitate heightened ethical awareness when designing and conducting research involving young people. As a researcher, I acknowledged the importance of balancing adolescents' inherent vulnerability with the need to study their unique needs and perspectives in my methodology and research design (Crane and Broome, 2017).

I acknowledged the importance of balancing protection with participation, ensuring that adolescents were safeguarded from harm while being supported to contribute meaningfully. Adolescence is a period characterised by significant transitions and competing demands, including education, healthcare, and social commitments, which can affect willingness and ability to participate in research (Murray and Xie, 2024). Ethical research design, therefore, required flexibility, sensitivity, and respect for adolescents' time and autonomy.

Researchers have a responsibility to minimise risk, promote wellbeing, and ensure that participation is voluntary and informed (UK Research and Innovation, 2024). In this study, potential risks, including emotional distress when discussing personal health experiences, were clearly outlined in the participant information sheets (PISs), alongside signposting to appropriate support services. These measures reflected an ethical commitment to transparency, beneficence, and respect for adolescent participants.

5.2 Consent, Assent, and Capacity

This section demonstrates robust ethical and legal standards in the consent process, illustrating how adolescents' developing autonomy was respected while statutory requirements for parental responsibility were met.

Obtaining lawful and informed consent from adolescents involves complex ethical and legal considerations regarding capacity, competence, and parental responsibility (O'Reilly and Dogra, 2017a; Fenton, 2020). Researchers must respect young people's decisions to participate or decline involvement, recognising their developing autonomy (Alderson and Morrow, 2020).

In the UK context, Gillick competence provides a legal framework for determining whether a child under the age of sixteen has sufficient understanding and intelligence to consent independently to participate in research (Griffith, 2015; National Society for the Prevention of Cruelty to Children (NSPCC), 2024). When adolescents were deemed competent, they could provide their own consent. Nevertheless, involving families in decision-making remains good practice and supports shared understanding and trust (NHS Health Research Authority, 2024).

Where adolescents lacked the capacity to consent independently, parents or legal guardians acted in the child's best interests (Palmer and Gillespie, 2014). In these cases, parental consent was sought alongside the adolescent's assent, acknowledging that, although cognitive maturity may be limited, young people should still be actively involved in decisions affecting them (Levine, Abbruzzese, and Mason, 2022).

To support informed decision-making, I developed a suite of electronic PISs (Appendix E), consent forms, and assent forms (Appendix F). These materials used clear, age-appropriate language, avoided technical jargon, and were designed to be accessible and engaging. Visual elements were incorporated to illustrate the research process, supporting comprehension and understanding. This was also complemented by an animated video linked via a QR code embedded on the front sheet of the PIS (see Appendix H). Feedback on the design and content of these materials was sought from a Young People's Advisory Group (YPAG), as discussed in Chapter Four, to ensure that the information was meaningful from an adolescent perspective.

When parental consent was required, parents were provided with their own PIS and consent documentation. Importantly, regardless of parental consent, assent was always sought from adolescents themselves. This recognised that young people may feel pressure to participate due to parental influence and reinforced respect for their right to decline or withdraw.

5.3 Addressing Power Imbalances in Recruitment and Consent

This section explicitly demonstrates how power differentials between me, as the adult researcher, and the adolescent participants were recognised and mitigated through the study design and recruitment practices.

Power imbalances are inherent in research relationships between adults and young people, placing adolescents at potential risk of coercion or undue influence (UK Research and Innovation, 2024). Addressing these imbalances was therefore a central ethical consideration in the recruitment and consent processes.

Non-confrontational, non-invasive approaches were adopted to reduce power imbalances between me, as the researcher, and the adolescent participants (Davidson, 2017). Age-appropriate language, transparency about the study's purpose, and clear explanations of how the data would be used were integral to fostering trust and reducing feelings of vulnerability. Involving YPAG members in developing study materials further demonstrated respect for young people’s voices and expertise.

Adolescent autonomy was emphasised through explicit messaging that participation was voluntary and that withdrawal was possible at any stage without negative consequences. Adolescents were offered choices regarding how they engaged with the research, including preferences for online interviews, decisions about parental presence, and selection of interview times and dates. Providing these choices empowered participants and helped create a more equitable and respectful research environment.

5.4 Enhancing Informed Consent Through Digital and Visual Methods

This section justifies the use of digital and visual methods as an ethical innovation to enhance comprehension, accessibility, and autonomy in adolescent consent.

The use of digital and visual tools to support informed consent was guided by evidence that multimedia approaches can improve research communication with children and adolescents. Animated and video-based information has been shown to enhance understanding, increase recruitment, and foster trust in research processes (Knapp et al., 2023; Stoffel et al., 2022).

To enhance adolescents’ understanding of the study, I created a short, animated video using Rawshort software. The video summarised key aspects of the research in a

concise, visually engaging format and was embedded in the Young Person's PIS via a quick response (QR) code (Appendix H). This allowed participants to access the information easily using their own devices, supporting autonomy and flexibility.

The use of QR codes reflected adaptations to the changing research landscape, particularly after the COVID-19 pandemic, when digital access to information became increasingly common (Sharara and Radia, 2022). This approach aligned with adolescents' familiarity with digital media and supported accessibility for participants who preferred online engagement.

As recruitment strategies were adapted in response to the pandemic, with face-to-face approaches replaced by online methods, the animated video played a key role in strengthening adolescents' understanding of the research and the steps involved in participation, supporting ethical and informed consent. This approach aligns with broader shifts towards recognising children and adolescents as competent social actors capable of making informed decisions about their involvement in research (Morrow and Richards, 1996; Parsons, Sherwood and Abbott, 2016).

Reflective pitstop:

My supervisor advised using an animated video and a QR code to enhance the PISs. Initially, this activity filled me with anxiety, as I had no prior experience with or little understanding of these technological concepts, and the use of IT was not one of my stronger skills. However, on reflection, with guidance and support from fellow postgraduate students and technology staff, I am now immensely proud of the creation of the RAWSHORT video and QR code. A perceived unachievable skill became a reality, and quite enjoyable!

5.5 Data Collection with Adolescents in Virtual Spaces

This section demonstrates methodological adaptability and ethical sensitivity, with particular attention to safeguarding, rapport, and power dynamics in virtual interviews.

Data collection was initially designed and ethically approved to take place face-to-face, with telephone or online interviews offered as alternatives. However, COVID-19 restrictions necessitated the transition to fully virtual data collection. Even after restrictions eased, adolescent participants preferred online interviews, highlighting the importance of flexibility and responsiveness to their needs.

Virtual interviewing with adolescents required careful consideration of ethical and practical issues, including safeguarding, privacy, and power dynamics. Research interviews inherently involve power imbalances, which may be amplified when working with children and young people (Nishiyama, 2018). Establishing trust and rapport was therefore prioritised to help adolescents feel safe and respected (Rogers et al., 2021).

At the start of each interview, rapport was built through informal conversation, transparency about the research purpose, and reaffirmation of participants' rights. Establishing rapport at the start of the virtual interview was essential, so I asked everyone to turn on their cameras to foster a sense of human connection. Since the child could interact with me in real time during the virtual interview, it became easier to establish rapport, which is necessary for safeguarding the young person and ensuring the quality of the interview (O'Reilly and Dogra, 2017b). Adolescents' preferences regarding parental presence were revisited, recognising that concerns about being overheard may inhibit disclosure in online settings (Meherali and Louie-Poon, 2021).

Creating a supportive and relaxed interview environment, often incorporating humour and genuine interest, was intended to help adolescents feel that their contributions were valued and confidential (Pinock and Jones, 2020). This approach aimed to encourage openness and enhance data quality, whilst supporting ethical engagement throughout the research process (Dianiska, Simpson and Quas, 2023). Throughout this process, I also reflected on my own assumptions and positionality when interviewing adolescents.

Reflective Pitstop:

Coming from an adult nursing and academic background, I had limited experience interviewing adolescents and initially felt uncertain about how to engage them in a way that was both professional and approachable. I became very conscious of how I spoke, deliberately adapting my language to avoid sounding overly academic and focusing on being relatable. To build rapport, I took time to explain the interview process clearly, reconfirm assent, and check whether a parent should remain present. Starting with simple icebreakers about hobbies, school, or football teams helped ease young participants into the conversation.

I also quickly learned that adolescents' schedules are shaped by school, social commitments, and family routines, so I needed to be highly flexible. Many interviews took place in the evening, and I became increasingly attentive to non-verbal cues such as yawning or reduced concentration. These moments reminded me to check in, offer comfort breaks, and ensure the young person felt able and willing to continue. This experience reinforced the importance of sensitivity, adaptability and genuine attentiveness when interviewing young people, and helped me develop greater confidence and reflexivity in my approach.

5.6 Summary

This chapter has outlined the ethical and methodological considerations underpinning the recruitment, consent, and engagement of adolescents with moderate or complex CHD in this study. By situating adolescents as active social actors rather than passive participants, the chapter demonstrates how ethical principles, legal frameworks, and participatory approaches were integrated to support informed, voluntary, and meaningful involvement. Strategies to address vulnerability and power imbalances, alongside the use of age-appropriate digital tools and flexible virtual methods, ensured that adolescents' autonomy, safety, and voices were prioritised throughout the research process. The reflexive insights presented further highlight the researcher's ongoing development and commitment to ethical qualitative practice. Together, these considerations provide a robust foundation for the data collection and analysis presented in subsequent chapters.

Chapter Six: Adolescents' findings

This chapter presents the findings from the adolescent interviews, addressing the research question from the perspective of young people themselves: what is it like to live with clinically complex CHD as an adolescent? The analysis responds directly to the study's objectives by exploring the experiences adolescents identify as significant in the context of growing up with a long-term cardiac condition, and examining how these events shape their daily lives, relationships, and developing identities. The chapter also contributes to the broader aim of the study by illuminating areas where adolescents feel they need greater support, thereby highlighting implications for enhancing quality of life for both young people and their parents.

Following the analytical process employing Braun and Clarke's six phases of RTA (Braun and Clarke, 2022), the adolescent data findings created three main themes: (a) Feelings of uncertainty and unpreparedness; (b) Control and responsibility; and (c) A sense of community. The structure of this chapter will focus on these three themes, each with associated sub-themes (see Table 2).

Table 2. Representation of adolescent themes and subthemes:

Themes		
Feelings of uncertainty and unpreparedness	Conflicts around control and responsibility	A sense of community
Sub theme	***Sub theme***	***Sub theme***
• Issues with communication • Understanding their CHD condition • The transition to adult CHD care • Body image and the perception of others • Uncertainty for the future	• Becoming responsible for their CHD • Relinquishing parental control • A sense of normality • Managing restrictions on life	• The adolescent/parent relationship • The adolescent and Healthcare Professional relationship • Support networks

• Uncertainty and effects of mental health		

A justification will be presented for both main themes and subthemes, with supporting, verbatim quotes and stories from the adolescents to provide context for the reader. To enhance readability, the use of an ellipsis […] was used to edit out unnecessary or redundant words or sentences (Thorne, 2021). The end purpose of this chapter is therefore to tell an overall story of the adolescent experience of living with an adolescent child with clinically complex CHD.

6.1 Theme (a): Feelings of uncertainty and unpreparedness

Adolescents with clinically complex CHD often face lifelong physical, emotional and practical challenges, leading to uncertainty and anxiety. Identifying key milestones or triggers for the data is essential to understanding these feelings.

6.1.1 Issues with communication

The data unearthed feelings of uncertainty and unpreparedness from a breakdown in communication, with the sense that the adolescent participants experienced mixed messages and limited advice from HCPs:

 Angie reflected on her confusion and vulnerability, caused by inconsistent communication and systemic gaps:

"I'm also very confused about that whole situation because I was told that is what I'd need, and then in my referral letter to the Heart Failure Clinic, and the transplant team, they had looked at a cardiac catheterisation I'd had done in (year) […] and they said from that data, my lung pressures are too high to do a heart transplant."

 Angie also highlights feeling overlooked during COVID-19, despite being clinically high-risk:

"*[…] with COVID because although I never actually got a letter to shield or anything like that, which we personally think is a big gap in the whole system because*

someone like me will probably die if I get it […] but I wasn't on the list of really vulnerable people."

 Samantha describes inconsistent advice about safe activities, leading to confusion and risky choices:

"I wanted my ears pierced when I was ten, mum was like, we need to ask the cardiologist first, so then I was allowed. But then the following year they'd said, oh kids with heart problems shouldn't have them […] I wasn't supposed to be doing sparring, obviously, in case I got hit to the chest. And I never got told that until, again, when I had my two operations at twelve and thirteen."

 Samantha discussed her uncertainty when finding out about an undisclosed bicuspid aortic valve murmur and a leaky pulmonary valve:

"I was kind of confused because […] why did I not get told? And I was kind of worried, […] maybe they didn't tell us because it wasn't that serious. So, I was keeping that in my head because I was quite worried […] and I was like, what, another thing that I didn't know about."

In contrast,  Samantha reflected on her positive experience in adult care, where clear, detailed explanations using visual aids helped her feel informed and comfortable:

"*You're kind of treated as a child, and they don't really explain things to you […]. They (paediatric CHD Team) just kind of say, oh you look fine, I'll see you next year […] I never really got explained what my heart conditions were, and then once I moved on to the adult one, the cardiologist there, she literally took the model heart and explained everything. I feel comfortable with her."*

Samantha's story illustrates how poor communication in paediatric services undermined confidence, while relational, explanatory communication in adult care improved understanding and coping.

6.1.2 Understanding their CHD condition

Adolescents' understanding of their heart condition varied significantly by age and experience. Younger participants often demonstrated limited knowledge, reflecting both the complexity of CHD and the tendency for parents and professionals to shield them from medical details during childhood.

 Becky admitted she knew very little beyond having surgery and a pacemaker:

"I can't tell you a lot… I just know that I wasn't very well for a long time […] That's all I really know […] I'll probably know a lot more when I'm older."

Her comment suggests a passive role in her care and an expectation that understanding will come with maturity, highlighting developmental influences on health literacy.

Similarly,  Poppy described her condition in vague terms:

"I don't know what I have… I think it's something called 'A-something' […] I don't really know what it was […] I think I've had two surgeries, to be honest, but I don't know what they are. I know it's something window, something like that."

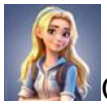
Her uncertainty reflects both memory gaps from early surgeries and limited engagement in later explanations.

 Martin echoed this pattern, relying on his mother to recall the diagnosis:

"So, I've forgotten what it's called. Mum, what is it called again? (Mum speaks) *Yeah, Tetralogy of Fallot. And I think one of the pipe thingamajigs in my heart was blocked up."*

His casual phrasing, "*pipe thingamajigs*", illustrates how technical language remains inaccessible for some adolescents.

In contrast, older participants demonstrated greater awareness, though medical terminology still posed challenges:

 Claire attempted to name her defect but stumbled over the term:

"I had a straggling, straddling, I don't know the exact word, tricuspid valve."

 Angie provided a more detailed description of anatomical issues, noting:

"It affects all the left side of my heart […] coarctation of the aorta, and aortic stenosis […] the general gist is all the tubing on the left side of my heart is narrow or incorrect."

These accounts suggest that while understanding improves with age and experience, gaps remain, particularly in mastering complex terminology.

Overall, these narratives reveal a developmental trajectory in health literacy, shaped by age, parental involvement, and communication practices. Younger adolescents often rely on simplified explanations or parental recall, while older adolescents seek more detailed knowledge but struggle with technical language. This emphasises the need for age-appropriate education and ongoing dialogue to support informed self-management.

6.1.3 The transition to adult CHD care

Transitioning from paediatric to adult CHD services was described as a significant and often unsettling milestone. Older adolescents, who were closer to the point of transfer, frequently expressed feelings of anxiety and unpreparedness. For example,

 Angie recalled:

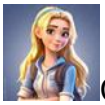
"I was not prepared at all. […] My transfer to adult care wasn't smooth […] they kind of just said right, you're of the age now where we need to move you and said, 'you'll be going to this hospital' […] then I heard nothing from that hospital until they decided it was time for my appointment."

Her account illustrates how limited communication left her feeling excluded from the process.

Similarly,  Samantha described minimal engagement with the adult team, noting that although she was invited to visit, circumstances prevented her from attending, and no further contact was made:

"They never really did, to be honest […] They did invite me down, but I think I was on work experience, so I couldn't go down, then I rarely heard from them after that."

These experiences suggest that transition planning was inconsistent and, for some, lacked flexibility to accommodate individual circumstances.

In contrast,  Claire's narrative reflected a more structured approach, with multiple preparatory appointments and visits to the adult hospital. Despite this, she emphasised the emotional challenge of leaving a familiar environment:

"I have a lot of appointments with the Cardiac Liaison Nurses, and they sort of talk through everything that's going to happen with me. And I've been to the (name of adult NHS Trust) three times now, so I think I'm going to go again before I transition. "It's a scary thing […] I think it would be more abnormal if I didn't feel scared […] At first, I did not want to move at all, I still don't sometimes. I think (paediatric hospital], it's like my safe place, it's where I've been looked after for so long. And going somewhere new, you don't know the environment, it is a scary thing […] I just don't like the unfamiliarity of it."

Her words highlight that even when practical support is provided, emotional attachment to paediatric services and fear of unfamiliarity remain powerful barriers.

Younger adolescents, by contrast, appeared less focused on transition, often because it felt distant rather than because they felt reassured.

 Poppy admitted she could not recall any detailed conversations:

"I don't really remember, to be honest. They've probably mentioned it once or twice […] don't know to be honest. I don't really know […] I don't think they've really sat us down and talked to us about that."

 Becky remembered some discussion but was vague about arrangements, saying:

"*Yeah, they have talked to us about that […] I always thought it was eighteen, but I'm not too sure if they make any […] arrangements for the families, it's a little early, so I don't worry about that kind of stuff."*

This suggests that while information was shared, it may not have been fully understood or retained.

Overall, these narratives reveal that while some adolescents received structured support, others experienced fragmented communication and limited involvement. Even when practical steps were taken, emotional readiness remained a challenge, underscoring the need for transition models that address both informational and psychological needs.

6.1.4 Body image and the perception of others

Concerns relating to body image were constructed across participant accounts as a recurring aspect of experience, particularly in relation to surgical scarring and its influence on self-esteem. For many adolescents, scars were a visible reminder of their condition, yet their responses varied widely, from indifference to deep insecurity.

Younger participants often described their scars as "normal" or unimportant, reflecting long-term familiarity.

For example,  Poppy explained:

" *I've had it (scar) for my whole life, […] I think it's just normal, so it didn't bother me or anything.[…] I don't think it is a bad thing to be honest, I just think it as completely normal […] I don't mind wearing any clothes […], I don't mind it being visible."*


Similarly, Martin dismissed the significance of his scar, noting that he rarely looked at it and simply told peers he had heart surgery when questioned:

"*I don't really look at it* (*scar), to be fair. […] People ask me questions about it, and I just answer them […] They ask me, 'Why have you got that white line down your chest?' I say, I had a heart operation when I was four months old."*


Becky echoed this sense of acceptance, saying it was *"almost invisible*" and rarely noticed by others:

"It's not a bother; it's just something that's there. I've never had anyone come up to me and say, 'Oh, what's that?' or 'Why do you have that?' […], it's just kind of, it's almost invisible, so no one really does anything about it […] mostly I don't notice it."

In contrast, older adolescents expressed more complex feelings.

Samantha  recalled intense insecurity during early adolescence, fearing her scar would prevent romantic relationships:

"*And then the insecurity with your scar, because there is that point in your life where you just feel like crap and you're really insecure about it […] I didn't think I was going to get a boyfriend […] at the time, you just think you're really ugly."*

Although she later reframed her scar as a *"trophy*," her narrative highlights how body image concerns can peak during developmental stages associated with appearance:

"(*Mum*)*said it was my trophy […] I was like six, seven, and I really hated it […] and that it's weird and whatever and nobody's going to like you for it. […] It's quite easy to hide. The only thing was my prom dress or swimming costumes, you could see it a bit, but I just ask can you see it, to my friends. And they're like, yes, but it's not that obvious."*

Angie  narrative constructed the smaller chest drain scars as particularly uncomfortable, partly because they were more difficult to explain to others:

"My actual scar I don't mind so much most days, some days I don't like it. And then I have scars all like down at the bottom of my chest where there were chest drains and things. […] they're more difficult to explain. Like the big one, I'm just like 'oh it's from my heart surgery', but the little ones, if people were to see it, might not necessarily think it's from my heart surgery. I feel more insecure about them than the actual big one."

Her account illustrates how surgical outcomes can influence perceptions of femininity and self-image, noting changes to her chest shape that felt unnatural:

"The way I feel like since they've done my surgeries […] I feel like my boobs are quite far apart. That is quite a weird thing to be insecure about I'm aware, but that feels like something to me that feels slightly unnatural. They just, I don't like it very much, I don't feel like they're very close together. I'm quite aware of it, if I were to take a photo or see myself like that. Sometimes I will be, like, they look a bit weird, unnatural, I guess."

Experiences of body-related comments were common, with some women reporting overtly rude remarks about their appearance:

For example,  Samantha shared:

"[…] women sometimes are quite rude […], they're like, oh you're so skinny and make comments […] but it's trying to explain to them like, one, this is the way I am, and two, I'd rather be skinny because I don't want anything wrong with my heart, I'd rather keep healthy. My mum goes to Zumba, and I joined her one time, and we we're both thin, […], but they were like, "oh why are you here, we're here because we're fat […] you guys are skinny."

Such comments highlight how assumptions about body size can lead to exclusion and judgment, even in spaces intended for health and wellbeing.

Practical aspects of care also shaped experiences of dignity, highlighted in the following experiences:


Becky described embarrassment during examinations, particularly when required to expose her chest, and stressed the importance of staff sensitivity:

"*When you get to my age, you want to keep yourself covered up, so just be aware that people do have their boundaries."*

This suggests that body image concerns extend beyond peer interactions to clinical encounters, where adolescents value choice and privacy.


Angie reflected on intimacy and how partners may perceive her scarring, and disclosed her boyfriend's reaction to her scars:

"*he* (*boyfriend*) *was quite good with it and understood it quite a lot. I was a bit nervous […] that he would think they looked worse. […] I'd shown all my little scars […] and explained them all to him. I was a bit worried when he saw them in person that it would be different."*


Samantha used to believe her scars made her unattractive and worried she would never have a boyfriend. Her experience proved those fears wrong, as her partner didn't even notice the scar, which surprised her and challenged her assumptions:

"*I didn't think I was going to get a boyfriend, which was weird to think of now, but at the time you just think you're really ugly and that it's weird and whatever and nobody's going to like you for it […] And I've got a boyfriend now, so I've proven myself wrong. I was kind of worried, but then he turned around, and he said, "What scar"? And I was like, what, you didn't notice it? It's flipping huge."*

These accounts illustrate how scarring can create anxiety about intimacy and self-image, yet they also show resilience and positive reframing. Angie's narrative reflects initial fear of rejection and the need for reassurance, while Samantha's experience demonstrates how real-life interactions can challenge negative assumptions. Together, these stories highlight that although body image concerns are common, supportive relationships often mitigate these fears and promote acceptance.

6.1.5 Uncertainty and mental health

Living with uncertainty was closely linked to poor mental health outcomes in adolescents with moderate or complex CHD. Many described heightened anxiety, fear of deterioration, and traumatic memories of previous hospital experiences, which continued to affect their emotional wellbeing.

Claire's account illustrates the enduring psychological impact of serious health events. Following a stroke four years earlier, she reported persistent health anxiety and symptoms of PTSD:

"I get really bad health anxiety about getting ill, needing to go into hospital, you know, things that would happen. […] every time I got a headache, I would be like, 'I'm having a stroke again […] I still find the experience of being in hospital, being poorly, traumatic."

Despite counselling, Claire explained that recovery was uneven, noting that while her body healed, her mind remained *"not fully there yet,"* highlighting how physical recovery does not necessarily equate to emotional resilience.

Samantha similarly described how fear of complications disrupted her education and daily life. She recalled breaking down after learning about new defects and the risks associated with surgery:

"I was crying quite a lot because I was worried […] before my operation they had to tell me, like, oh you could have a stroke, you could die."

Her narrative conveys how repeated exposure to life-threatening scenarios created lasting anxiety, which resurfaced during routine scans and follow-up appointments.

These experiences demonstrate that uncertainty about health trajectories not only influences future planning but also shapes adolescents' mental health in profound ways. Feelings of vulnerability, coupled with traumatic memories, can lead to persistent anxiety and depressive symptoms. While some adolescents accessed psychological support, others appeared to manage these fears alone, underscoring the need for integrated mental health care within CHD services.

6.2 Theme (b) Conflicts around control and responsibility.

Transitioning to adult CHD care was not only about changing hospitals, it also meant shifting responsibility from parents to adolescents. This change was often abrupt and emotionally challenging, leaving many young people feeling unprepared.

6.2.1 Uncertainty for the future.

Adolescents frequently reflected on the unpredictability of their health and its implications for life planning. Concerns ranged from future surgeries and deterioration to mortality and fertility, revealing how uncertainty shaped both emotional wellbeing and everyday priorities.

For some, fear of dying overshadowed academic and social aspirations:

Samantha's account illustrates how health-related anxiety can erode motivation and create a sense of futility:

"I went through so much worry as a teenager about obviously dying and something going wrong with my heart and things like that […] I just didn't really try in school […] what's the point of trying if I die."

Others expressed apprehension about adulthood and family life:

Holly worried about whether her condition would worsen and whether motherhood was possible:

"It's just a bit scary, […] I wonder if I'll get worse […] thinking about having babies and stuff, I don't know if I can have them or not."

Angie's narrative conveyed the emotional impact of conflicting medical information. Initially told she needed a heart transplant, she later received a letter suggesting she was unsuitable:

"I had a massive breakdown […] I was told that I needed this heart transplant because my heart's going to stop, and then I got another letter being like 'we don't think you're suitable'. So, I'm just going to die, is that it?"

Her words underscore how inconsistent communication can amplify distress and feelings of hopelessness.

Even younger participants voiced existential concerns, albeit in simpler terms:

 Becky remarked *"I kind of wish I was immortal"*, reflecting a childlike response to the fear of mortality.

These comments demonstrate that uncertainty permeates all age groups, though its expression varies with developmental stage.

Overall, these narratives reveal that uncertainty about health trajectories profoundly influences adolescents' mental wellbeing, shaping their outlook on education, relationships, and future life plans. Consistent, sensitive communication and psychological support are essential to help young people navigate these fears.

6.2.2 Assuming responsibility for CHD management and relinquishing parental control.

Several adolescents described the sudden expectation to manage their own care as overwhelming.

 Angie recalled the moment when HCPs addressed her directly, rather than her mother*:*

"They started talking to me rather than my mum […] I didn't know what was going on […] I felt like it's all on me now, and I just started crying."

Her reaction reflects how limited prior involvement in decision-making left her ill-equipped for independence.

Similarly,  Holly admitted:

"It just feels like loads of responsibility. My mum and dad still do my appointments […] I still look to them."

For her, the expectation of independence conflicted with ongoing reliance on parental support.

Together, these accounts suggest that transition policies often assume readiness without considering individual confidence or prior experience, creating stress rather than empowerment.

Despite the push for autonomy, adolescents consistently valued parental involvement as a source of reassurance. Parental involvement remained crucial for many adolescents, yet access to this support was often constrained in adult settings. When HCPs discouraged or restricted parental presence, young people described heightened anxiety:


Angie described feeling *"overwhelmed"* when COVID-19 restrictions required her to attend appointments alone:

"You're above 18, you have to go alone […] I find it helpful to have another advocate with me."


Samantha echoed this sentiment, expressing frustration when staff discouraged her mother's presence:

"They say the room's too small, but I want her there. She's always looked at my scans with me."

These narratives highlight how rigid enforcement of independence can undermine emotional safety, particularly when adolescents still rely on parents for advocacy and support.

Overall, this theme reveals a tension between healthcare systems' expectations of independence and adolescents' ongoing need for parental involvement. While autonomy is an important goal, these findings suggest that a gradual, flexible approach, tailored to individual readiness, may better support young people during transition.

6.2.3 A sense of normality

Despite living with clinically complex CHD, many adolescents described their lives as normal, framing their condition as something in the background rather than a defining feature. This perception often stemmed from long-term adaptation and supportive family environments.

 Becky articulated this clearly, saying:

"I'm just, like, a regular teenager. It's just something that's happened to me in the past […] My parents are great, they just treat me and my sister like any regular kids […]. Because at the end of the day it's just [...] a bad thing that's happened, but I'm not letting that control my life or anything."

Her words reflect a conscious effort to maintain normalcy and resist being defined by illness.

 Similarly, Poppy repeatedly emphasised that her scars and medical history did not make her feel different:

"And just be normal, […] don't think you're a horrible person just because you've got those scars, you're beautiful just the way you are […] I just think it's normal to be honest."

Martin and Ted echoed this sentiment, highlighting how stability in health can foster a sense of normality over time:

 Martin described himself as *"Exactly the same as everyone but just with a heart disorder […] I'm exactly the same as everyone but just with a heart disorder."*

 Ted explained "*These days, I don't even know I have it really."*

However, this perception was not universal:

 Samantha reflected on how her understanding shifted during adolescence: "*For the past 12 years beforehand, I just thought I was that normal kid that had a scan now and again. I kind of thought I was normal, like I only go to hospital every year to get a scan. And then it kind of hit me, I was like, wait, no, I do have something wrong with me, I haven't just been going to the hospital like a normal kid."*

Her account illustrates how developmental changes and increased medical awareness can disrupt feelings of normality, even after years of perceived stability.

Disclosure played a key role in reinforcing or challenging this sense of normality. Some adolescents were open about their condition:

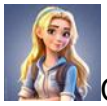
 Angie stated "It's *not like it's a big secret or anything. If people ask, I'll be happy to tell them everything."*

Others, such as Ted  , felt no need to share unless relevant, suggesting that normality was maintained by limiting disclosure:

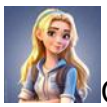
"*But I don't really feel like I need to tell them because it's not like it affects my life."*

Conversely,  Samantha's experience of posting about her condition on social media led to negative reactions, demonstrating how external responses can influence self-perception:

"I've had a few people remove me from Facebook […] because of the amount I've been posting."

 Claire's experience during her transition to university illustrates disclosure as a protective strategy and highlights the emotional complexity of moving into a new environment while managing a chronic condition. Her initial reaction: "*Why am I here? What am I doing?"* reveals acute anxiety linked to uncertainty and vulnerability.

This was amplified by the context of COVID-19, where the stakes of disclosure were higher due to health risks.

Faced with the heightened risks of COVID-19,  Claire proactively informed her peers:

"I'd appreciate it if you'd just stick to the guidelines and are mindful."

This revealed that disclosure was framed as a protective measure rather than a plea for sympathy. Importantly, Claire clarified boundaries*:*

"You don't have to tell them things like, 'I'm going to struggle doing that'."

Her narrative reflects a careful balance between vulnerability and independence, aiming to ensure safety without inviting pity.

Disclosure was experienced as a complex and deeply personal process for adolescents with CHD, shaped by context, confidence, and perceived benefits. For some, disclosure was pragmatic and situational.

 Holly shared her diagnosis casually when breathlessness affected her social interactions:

"I'm like, can you walk a bit slower because I'm getting out of breath?"

This reflects disclosure as a functional tool to manage immediate needs rather than a deliberate identity statement.

Others experienced disclosure as externally imposed:

 Martin described being asked to show his scar during a school lesson:

"We're moving on to heart things in school and what she (teacher) wants me to do is show everyone my scar and explain to them what it was like […] and I just say, well, I was blue and then I had an operation."

His minimal explanation suggests discomfort and limited understanding, highlighting how enforced disclosure can feel intrusive and undermine autonomy.

Conversely, some adolescents framed disclosure as empowering and purposeful.

 Poppy expressed a strong desire to normalise CHD and support peers:

"I want to show children that it's nothing to be ashamed of […] there are lots of children out there who've got the same heart problems, similar problems that you have, and it's nothing to be worried about."

Similarly,  Becky viewed sharing her story as a way to help others, noting:

"*It is really important, to share stories, to show that […] it is quite tough."*

Overall, these varied experiences reveal that disclosure is not a single act but an ongoing negotiation of identity. Adolescents weigh the benefits of openness, such as safety, advocacy, and connection, against risks of stigma or unwanted attention. Supporting young people to navigate disclosure on their own terms may help preserve autonomy and promote psychological wellbeing.

6.2.4 Managing restrictions on life

Adolescents described navigating lifestyle restrictions imposed by their CHD, often balancing medical advice with personal desires for autonomy and normality. These restrictions ranged from avoiding strenuous activities to abstaining from tattoos, piercings, and certain social behaviours.

For some, restrictions were accepted pragmatically:

 Becky explained how her pacemaker limited participation in sports and fairground rides:

"It made me feel a bit down […] but I knew it was just to keep me safe."

Her account reflects a rationalisation process that acknowledges disappointment while prioritising health.

 Holly expressed similar frustration about missing out on physical education and social activities:

"It upsets me sometimes, because I want to do it […] you know you shouldn't, know you can't, but I knew it was just to keep me safe, and if I'd gone on it (*rollercoaster*)

something could have happened, and I could have ended up back in hospital again. So, it's probably for the best to be honest with you."

These narratives highlight the emotional tension between safety and inclusion.

Accounts from older adolescents constructed restrictions on self-expression as a significant source of frustration:


Angie described her desire for tattoos and piercings, despite medical advice warning of infection risks:

"I'm really annoyed and upset about it […] I completely understand wanting to self-express, but we just have to find other ways."

Her solution, using hair colour and makeup, illustrates adaptive coping strategies:

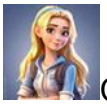
"That's *why I've got crazy hair, and I do quite a lot of different makeup because I like that. That's one of my ways to self-express […] I've got a fake set of piercing which is like a clip thing you put in. I wear that sometimes because that I quite like that."*

Yet her words convey lingering frustration at the loss of choice:

I'm really annoyed and upset about it […] Tattoos, there's not a way around it. I'm upset about that one […] I even re-asked my doctor […] really want my septum pierced, and I really want tattoos, is there any way I'm going to be able to get them?"

Social behaviours such as drinking and smoking were generally rejected, aligning with health recommendations:


Samantha noted *"I don't really see the whole getting drunk and hurting yourself… I don't know what the appeal is."*


Similarly, Claire reported no interest in alcohol, suggesting that restrictions were internalised as personal values rather than external impositions:

"I've never, ever been interested in stuff like that. Like, in terms of drinking […] I've never been drunk […] it's not something I particularly do."

However, not all restrictions were fully understood:

 Ted expressed confusion about why certain activities were prohibited:

"I don't really understand why I can't do them […] It made me feel pretty sad, a bit envious."

His account highlights the importance of clear communication to prevent feelings of unfairness and isolation.

Lifestyle adaptations sometimes led to negative social reactions, compounding the emotional burden of restrictions:

 Samantha recalled feeling hurt when her decision to avoid heavy lifting was dismissed as laziness:

"I was quite upset […] I'm just doing it because I'm obviously looking after myself."

Similarly,  Angie described being openly criticised for wearing a mask during the COVID-19 pandemic:

"*A couple shouted at me, 'Why are you wearing a mask? It does nothing, you're just being stupid' [...] They kept looking at me and were like 'All these people wearing masks' […] They were talking loud enough so that I could hear them. It seemed purposeful."*

These accounts highlight how misunderstanding and stigma can undermine adolescents' efforts to protect their health, reinforcing feelings of isolation.

Overall, these narratives reveal that lifestyle restrictions can evoke mixed emotions, ranging from acceptance to resentment, depending on how well adolescents understand the rationale and whether they can find alternative ways to maintain autonomy and identity.

6.3 Theme (c): A sense of community

Data findings revealed how social support networks, such as charities, friendships and role models, can enhance quality of life for adolescents with clinically complex CHD. Positive experiences were linked to relationships with parents, HCPs, charitable organisations and peer groups.

6.3.1 The adolescent/parent relationship

Parents were positioned within adolescents' accounts as central figures in experiences of living with CHD, providing emotional security, practical support and advocacy. For many, these relationships were described as a source of comfort during hospital admissions and transition periods, although tensions were also constructed as adolescents navigated increasing expectations of independence.

Several adolescents spoke warmly about their parents' unwavering support:


Angie described her mother as:

"*Super understanding […] without any training, she could be a nurse because she was basically my nurse for the time I was in hospital."*

She recalled how her stepfather provided practical help by driving her to appointments:

"He does a lot because he's really supportive."

Her words convey deep appreciation for both emotional and practical care, framing her parents as indispensable during critical health episodes.


Samantha similarly credited her mother for helping her overcome insecurities about scarring:

"She's the reason that I'm no longer insecure […] she told me they're like my battle scars."

This metaphor reframed her scars as symbols of resilience, illustrating how parental reassurance can shape body image and self-esteem.

 Claire echoed this sense of closeness, noting that shared experiences of illness strengthened family bonds:

"We're a lot closer than we would have been because we've been through so much together… it makes you close in so many different ways."

However, these supportive dynamics were not without strain:

 Martin expressed frustration when his mother made decisions about his treatment:

"It's not fair, it's a bit frustrating as it's not her body."

 Angie also described moments of tension when her mother struggled to respond to her distress:

"She uses this phrase which I don't like 'if I could take it away from you and give it to me I would."

These accounts suggest that while parental involvement is valued, it can also create friction as adolescents seek autonomy.

Overall, these narratives reveal that parents remain pivotal in adolescents' CHD journeys, offering emotional and practical support that fosters security and resilience. Yet as young people move toward independence, balancing parental involvement with autonomy can be delicate and sometimes challenging.

6.3.2 The adolescent and Healthcare Professional relationship

Relationships with HCPs played a pivotal role in shaping the adolescents' care experiences. These interactions influenced feelings of trust, comfort, and understanding, yet accounts revealed a striking contrast between positive and negative encounters.

For some, familiarity and continuity fostered reassurance:

 Poppy expressed deep gratitude toward her paediatric team:

"I am so grateful, if it wasn't for (*paediatric hospital*), *I don't think I would have been here today."*

Her words highlight how long-standing relationships create a sense of security during vulnerable moments.

Similarly,  Martin described his loyalty to a trusted doctor:

"I only let him do it because I only trust him."

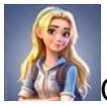
These narratives underscore the importance of relational continuity in promoting confidence and reducing anxiety.

Continuity of care was constructed within adolescents' accounts as an important contributor to feelings of safety and trust. Familiarity with healthcare professionals was described as providing emotional stability within an otherwise unpredictable healthcare journey:

 Poppy expressed this clearly:

"I don't want someone who I don't really recognise and know […] It makes me feel pretty happy to know that this is a doctor that's known me almost my whole life."

Her words highlight how long-standing relationships foster reassurance, and why their loss during transition can amplify feelings of vulnerability.

 Claire echoed this:

"I think the relationship is so important because it makes you feel more comfortable. Even though the experience of going into hospital isn't nice, when you see somebody you know, and you trust, it makes it easier."

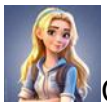
When these relationships were disrupted during transition to adult services, adolescents often felt exposed and uncertain:

 Angie's experience illustrates this contrast:

"It was very much not talking to me, not even much talking to my mum."

Her account suggests that fragmented care and impersonal interactions can undermine confidence, leaving her feeling isolated and uninformed. This reinforces the need for gradual handovers and opportunities to build rapport with new providers.

Positive experiences were also linked to specialist understanding:

 Claire reflected on her referral to a cardiac psychologist:

"It really helped […] talking to people that understand it […] it makes you feel more comfortable."

Her account illustrates how tailored psychological support can address the emotional burden of living with CHD, complementing physical care.

However, other adolescents reported feeling disconnected from professionals:

 Angie described her cardiologist as "*quite a stern man*". Whilst not explicitly criticising his competence, it reflects a perceived interpersonal distance, suggesting that his authoritative demeanour limited opportunities for relational connection.

 Samantha echoed similar frustrations, particularly with liaison staff: *"She's not very supportive […] I kind of avoid phoning her."*

These accounts suggest that when interactions are transactional rather than relational, adolescents may disengage from care and feel less empowered.

Overall, these narratives reveal that trust and communication are central to adolescents' healthcare experiences. While positive relationships foster comfort and understanding, negative encounters, marked by poor communication or perceived

indifference, can amplify feelings of vulnerability. Consistent, empathetic engagement is therefore critical to supporting adolescents through complex care pathways.

6.3.3 Support networks

Beyond family and HCPs, adolescents experienced a range of external support systems that contributed to their emotional wellbeing and sense of belonging. These included charities, peer groups, and friendships, which often provided reassurance and opportunities for social connection.

Charitable organisations were seen as life changing.  Poppy recalled a holiday provided by one such charity:

"It was absolutely life changing, the charity was amazing […] they take care of you so well, they are so skilled with what they need to do."

Poppy's words convey how structured support outside the clinical setting can foster confidence and create positive memories, counterbalancing the stress of medical care.

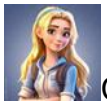
Martin  discussed encouragement from his sports coach:

"If you encourage them then it gives them like a boost… if he says well done to everything, like, you do good, then it might pump you up a bit."

This illustrates how positive reinforcement from non-family adults, such as coaches, can serve as an informal support network, boosting confidence and motivation. It shows that support is not limited to healthcare or family; it extends into everyday environments like school and sports.

Friendships also played a vital role in promoting normality and reducing isolation.  Becky explained how shared experiences within her peer group created understanding:

"My little friendship group, we all have something wrong with us […] so we all kind of know what it's like to be in a hospital environment."

Similarly,  Claire described turning to a friend for emotional support during a difficult moment:

"I just messaged her and was like, 'I'm a bit upset, could you come to my room?' And she came and sat with me, and we just spoke through everything, and I think that really helped."

Friendships were often described as protective, offering understanding when health restrictions limited participation:

 Claire explained:

"I don't go out as much because I just want to stay home… most of the time, I think I've got good friends around me that understand… Before I had my surgery, I used to feel more left out […] all my friends did D of E (*Duke of Edinburgh*)*, I can't do D of E, but now I'm not particularly bothered about doing it."*

Her account illustrates how peer empathy can reduce feelings of isolation and how adolescents adapt emotionally to ongoing limitations.

These accounts highlight how informal peer support can provide comfort and validation. However, maintaining friendships was not always easy:

Holly described feeling *"lonely […] and you feel left out quite a lot."* when social media connections failed.

 Angie's experience of returning to school after surgery revealed the fragility of peer support:

"I finally did go back to school… nobody's talking to me. I would go up to the group and be like, oh, nobody's talking to me."

Such experiences underscore the vulnerability adolescents face when health-related absences disrupt social continuity. These accounts underscore the importance of maintaining social connections and fostering inclusive environments for adolescents with CHD.

Some adolescents expressed a desire for more structured peer support.

 Ted articulated this need clearly:

““I’d like to maybe find a group of children that have something similar to me, because we could share our stories and we could really like learn what’s happened to us and how we’re not alone.”

Similarly,  Martin described how friendships with others living with clinically complex CHD provided meaningful support:

“We just talk about how we're getting on and that […] me and (*name*) *were having the exact same operation and the exact same problem.”*

These comments reflect the potential value of peer networks in reducing isolation and fostering shared understanding.

Overall, these narratives reveal that support networks, whether through charities, friendships, or peer groups, play a crucial role in enhancing the quality of life for adolescents with CHD. While positive experiences promote resilience and social integration, gaps in support can lead to feelings of loneliness and exclusion, highlighting the need for accessible, inclusive resources.

6.4 Summary

This chapter explored the experiences of adolescents living with a clinically complex congenital heart problem. The findings highlighted that the transition from child to adult care was often abrupt and overwhelming. Adolescents described feeling unprepared to assume responsibility for their condition, with many continuing to rely on parents for practical and emotional support. The enforced exclusion of parents from appointments, particularly during the COVID-19 pandemic, intensified feelings of vulnerability.

Communication with HCPs was constructed within adolescents’ accounts as a central aspect of their experiences. Adolescents described valuing opportunities to be included in discussions with staff but also spoke about difficulties understanding or

recalling information without parental support. Parental presence or absence in consultations directly shaped their sense of confidence and security. These accounts also revealed the emotional burden of living with CHD during adolescence, including anxiety about health, the future, and navigating peer relationships.

Overall, this chapter demonstrated that while independence is expected within transition policies, adolescents with a clinically complex CHD often felt underprepared for this shift. Their narratives emphasise the importance of gradual, supported transitions that recognise the continued significance of parental involvement.

Chapter Seven: Parents' Findings

Building on adolescents' accounts of feeling underprepared for independence and reliant on parental support, it is essential to examine parents' experiences during this period of transition. Exploring parents' perspectives provides critical insight into how they navigate ongoing responsibility, shifting roles, and exclusion from care while continuing to support an adolescent with a clinically complex CHD. This chapter presents parents' experiences of living with an adolescent with clinically complex CHD, addressing the research aim to explore what it is like for parents in this situation. The analysis aligns with the study objectives by identifying significant life events, exploring the emotional and practical impacts of caregiving, and highlighting areas where parents require greater support to enhance quality of life.

Following the analytical process employing Braun and Clarke's six phases of RTA (Braun and Clarke, 2022), three overarching main themes were constructed, mirroring the same themes as the adolescents (a) Feelings of uncertainty and unpreparedness; (b) Control and responsibility; and (c) A sense of community. The structure of this chapter will focus on these three themes, each with associated sub-themes (see Table 3). These themes illustrate how parents navigate the ongoing demands of CHD, balance shifting roles as their child moves towards independence, and draw on relationships with professionals, family, and peers to sustain their caregiving role.

Table 3. Representation of parental themes and sub-themes:

Themes		
Feelings of uncertainty and unpreparedness	Conflicts around control and responsibility	A sense of community
Sub Theme	**Sub Theme**	**Sub Theme**
• Issues with communication • Not being heard • The transition through education	• Relinquishing control for healthcare management	• The parent / Healthcare Professional relationship • The parent/ education staff relationship

• The transition from paediatric to adult CHD services • Anticipatory anxiety • Uncertainty for the future • The transition from adolescence to adulthood • Navigating through COVID-19	• Striving towards independence	• Supportive networks • Tensions between the family • Spousal support • Collaborative working to provide support

To aid the reader to connect to the participants as real people, I have anonymised and presented them in the findings as caricatures

7.1 Theme (a): Feelings of uncertainty and unpreparedness

Parents expressed ongoing uncertainty and unpreparedness in managing their adolescent child's clinically complex CHD, especially during key transitions like healthcare shifts, education changes and the move to adulthood. These feelings were intensified by poor communication and major events like the COVID-19 pandemic, leading to anxiety and reduced confidence in support systems.

7.1.1 Issues with Communication

Clear, consistent and compassionate communication was experienced as a central issue for parents, shaping how they understood their child's condition, engaged with care, and coped with uncertainty.

Parents reported mixed experiences of communication with healthcare, education and government services. For some, open dialogue and clear explanations fostered reassurance.


George, a father to twin girls both diagnosed with complex CHD, reflected that:

“90% of the staff were fantastic […] great at their job, but also socially knew how to talk to parents.”


Similarly, Julie described positive experiences of ongoing, transparent communication:

“It’s always been a very open dialogue between us, the doctors, the hospital, the family […] he’s been growing up hearing all this the whole time.”


However, such experiences were not universal. Joan recalled feeling dismissed when she expressed fear before surgery:

“I said to the surgeon, I don’t want to sign; I’m scared. And he said, okay, she dies. That’s not the right way to respond to a parent.”

She explained that empathetic communication would have reduced her anxiety and enabled her to process the information more effectively.

Other parents highlighted how risks were not always explained:


Joan noted that the possibility of complications had never been raised, leaving her unprepared when they occurred:

“I don’t think it had ever been mentioned it was a possible risk […] it’s obvious now that was what was happening.”


George also commented on surgeons’ lack of interpersonal skills:

“They don’t seem to be able to communicate with the kids or the parents.”


For Beatrix , communication had a direct emotional impact on her daughter. She recalled:

“The surgeon said to her you might not wake up. Six months later she was screaming, and we couldn’t get her down to theatre. She was twelve years old, what are you telling them at twelve?”

 Beatrix also described the shock of learning the true extent of her daughter's condition only after reading a report at home:

"We only thought she had coarctation of the aorta […] then at home we saw the report said ASD, AVD as well. I cried. Nobody told us."

This lack of transparency left her family living "day to day," waiting for check-ups for reassurance.

Language and terminology were another source of tension:

 Beatrix explained that many parents disliked the term' disease,' finding 'defect' more accurate. She was also upset by a national advert that described children as "mended":

"Parents phoned me upset because our children are not mended."

Conflicting information over time was a further concern:

Maria  described contradictory messages as her daughter grew older:

"The doctors say things, and when she gets older, they go, "no, we didn't say that" […] I want more information, to be on the same page with the hospital and their treatment."

These accounts show that when communication lacked clarity, consistency or compassion, parents felt more uncertain and unprepared, making it harder for them to anticipate risks, make informed decisions and feel confident in their child's care.

7.1.2 Not being heard

Parents frequently described feeling that their expertise, built from living with and caring for a child with a clinically complex CHD, was dismissed by HCPs and educators. This dismissal left parents uncertain about whether their child's needs were being properly addressed and often forced them to adopt the role of advocate.

For some, this meant relying on their own judgment rather than deferring to clinicians.

 Joan captured this sentiment clearly:

“Just go with what you think, not what the health professionals think. You know your own child best.”

Her words reflect a deep confidence in parental knowledge, born from experience, and a recognition that professional advice can sometimes overlook the nuances of individual care.

Other parents described encounters where their concerns were brushed aside and information withheld:


Beatrix recalled feeling excluded from her child’s care decisions:

“I never got told anything, […] he (HCP) would just give her ECGs and say ok she fine, then just put us off on our jolly way.”

This lack of communication left Beatrix feeling powerless and uninformed, reinforcing the sense that her voice carried little weight in clinical settings.

Parents also recognised the need to assert themselves more strongly to ensure their child’s needs were acknowledged:


Julie emphasised how the pandemic heightened the need for parents to assert themselves:

“Maybe parents need to be a bit more vigilant now, for the different ones, to really make your voice heard more immediately than it was before, because it's different times.”

Her reflection illustrates how external pressures, such as COVID-19, intensified the responsibility parents felt to protect their children’s health.

This struggle extended into education, where parents often had to challenge institutional resistance:


Veronica shared a powerful account of repeatedly fighting to secure her child’s special educational needs support:

"I said to the school, there's got to be something. They was like no, no, he's absolutely fine […] sometimes I feel like I've got to go in and do their job for them […] this is what you need to do. […] When I fought to get his one plan, they were still adamant after the assessment, no, he doesn't need one. So, I had to say, no, you will listen to me now, I am not asking, I'm telling. This is what we're doing, this is what I want, and this will benefit my child […] and if it doesn't, then we'll do it your way. And really had to sort of put my foot down."

Her determination underscores the emotional labour involved in advocacy and the frustration of repeatedly being dismissed. These battles generated deep frustration and anger, leading her to consider withdrawing her son from school entirely:

"Frustrated, honest to God, there has been so many times that I've wanted to just say, right, he's not coming to school. Like, just sometimes I really feel angry that I'm not being heard."

This highlights the cumulative emotional impact of systemic resistance, and the lengths parents go to protect their child's wellbeing.

Together, these accounts demonstrate how parents draw on their expertise to advocate for their children, often in the face of professional resistance. The repeated need to fight to be heard not only created frustration but also reinforced parents' sense of responsibility to act as protectors and mediators between their children and institutional systems.

7.1.3 Transitioning through education

Parental accounts generated concerns regarding the preparedness of educational staff to support students with clinically complex CHD as contributing to heightened anxiety and uncertainty.

These feelings were particularly pronounced during key educational transitions, from primary to secondary school, through further education (FE), and into HE.

Parents frequently felt that teachers lacked understanding of CHD and its physical implications:

 Veronica voiced this frustration succinctly:

“I don't think schools have got enough information.”

Her comment reflects a broader theme of perceived knowledge gaps, which often left parents feeling they needed to intervene.

To address these gaps, many parents took proactive steps to educate staff:

 Julie explained her approach: *“Have thorough discussions so they properly understand […] I’ve always seen it that he’s our precious gift and we need to do as much as we can, and they are short-staffed, and they are busy […] they haven’t had eleven years to think about this.”*

Julie’s words highlight the emotional weight of these conversations, balancing empathy for staff with the urgency of safeguarding their child.

 Barbara described a similar experience, detailing the practical steps she and her husband took:

“We *sat down […] with one of the ladies in the school to go through like, you know, she’s got this pacemaker […] what you can and cannot do, and the teachers need to be aware, so all the teachers in the school, regardless of whether they teach her or not, are aware that she’s got a pacemaker because the type that she’s got, she can’t be defibrillated on.”*

Barbara defended her decision to personally lead these discussions:

“I’d rather do it myself because then at least I know it’s right. […] You’ve always got that worry that they’re not going to understand or really grasp what’s wrong with them and what they’ve been through.”

Her narrative emphasises the persistent sense of responsibility parents feel to ensure an accurate understanding.

 Beatrix echoed these parental concerns, linking them to repeated health scares:

“I *think if they had that little bit more knowledge, I think they would […] be able to support our cardiac children a lot better. […] we had her back and forth getting her*

checked because five or six times we were getting phone calls from her school, "she's got chest pain."

She also reflected on how staff turnover compounded misunderstandings, leading to harmful assumptions:

"A lot of them never got to know about (*daughter*), *and they put her down as saying she's a lazy child, was she getting enough sleep? I even got asked was she eating enough because* [daughter] *always been slim. […] they're thinking my daughters not fed, they're thinking she not sleeping and actually she's got a congenital heart defect, and it does make our kids tireder."*

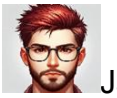
The emotional toll of these judgments was clear to Beatrix:

"It made you feel like a really crappy mum."

Moving from secondary to FE introduced new anxieties, particularly around travel and social dynamics:

 Maria worried about safety during commutes:

"It's going to be more the travel and making sure she's safe till she gets there."

 James expressed deeper fears about his daughter's ability to navigate new environments and relationships. He felt:

"Scared […] there's a lot of new social pressures that she's going to be experiencing […] she goes to an all-girls school, and college is obviously a mixed environment [...] I think my worry is because she's not been in that environment before […] Is she ready for that? […] can she manage her own limitations, or whether she will carry on pushing the boundaries? If she does, then she's going to make herself ill and ultimately end up not going to college."

His account illustrates the intersection of health-related concerns with broader parental fears about adolescence.

The transition to HE was described as a major emotional milestone, compounded by practical challenges and the pandemic:

 Beatrix emphasised the importance of disclosure:

"M*y fear was, you must tell them and the same at Uni, I had to say have you let your mentor know, because at the end of the day if something happened to you, they need to know, like if you're not feeling well."*

 Joan reflected on the enormity of this stage:

"*I've never really planned for my daughter to be going to university. You know, my focus was keeping her alive […] what was important was that she went to a university where perhaps the pastoral care was really good […] I think my worry was at eighteen (years of age), massive health issues, doing a course which has got lots of placement-based work experience, and you're trying to live away from home."*

Collectively, these narratives reveal how educational transitions amplify parental anxieties, driven by gaps in institutional knowledge and the unpredictable nature of adolescence. Parents often assume the role of advocate and educator, striving to balance their child's growing independence with the need for safety and support.

7.1.4 The transition from paediatric to adult CHD services

Although best practice recommends transition planning to adult CHD commencing in early adolescence, parents of older adolescents felt uncertain and unprepared for this, and experienced heightened anxiety about their child's future CHD care.

Poor communication about the transition from CHD HCPs exacerbated these feelings:

 Maria captured this sense of confusion and fear when reflecting on her daughter's experience:

"*It is frightening. We were never told there was a transition at 16 […] we were told we've already started the transition to the other hospital, and I was like what, and that was before she was even sixteen, so we didn't even know what was happening. […] At the moment she is still under (name of hospital), we haven't had any appointments anywhere else, so when that time comes, I think it will be frightening*

[…] they haven't really told us whether there's consultants that do both, that deal with the adult congenital heart patients as well as obviously the child patients as well, we're not really sure how that works […] I don't think we've been kept in the loop with any of transition type things, which is quite scary because I feel like it's a massive change."

Maria's account illustrates how a lack of clear, timely information can leave families feeling unprepared for what should be a carefully supported transition.

 James shared his perspective on the lack of information surrounding the move of his daughters to adult services:

"*In terms of moving forward, in the hospital side of it, the adult side of it, we don't know anything to do with the future."*

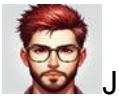
To cope with this ambiguity, James explained that he actively avoids thinking too far ahead:

"It's not something I've thought about to be fair. Because it's not happened, I try not to think about it."

Parents expressed a range of emotions about the quality of care their child might receive within adult CHD services. For some, the anticipated change provoked fear and a sense of loss:

 Maria described her worries about what adulthood might mean for the level of care her daughter receives:

"*My fear is the uncertainty that they have given us. I feel that if it was an adult on an operating table not a child, they would want to take more care of a child. I just don't know what the level of care is going to be. That scares me to be honest, not knowing, everybody loves children, and I just feel like she will become less important as she grows up."*

In contrast,  James viewed aspects of the transition more positively, linking adulthood to increased medical possibilities:

"I think it's good in a way, for the simple fact that the bigger she gets ultimately the easier things are to deal with, because there's a lot more adults in the world in terms of transplants and stuff like that if she does potentially go down that route. So, the chances of any treatment being successful, I would guess, would be a lot higher. […] Medically her percentages are obviously a lot more, it's so much harder operating on a baby than an adult, so from that point of view then it's a really good milestone to reach."

Despite this optimism, James still emphasised his trust in the paediatric team and a reluctance to move on before his daughter's current issues are resolved:

"I've been trying to put it off because at the moment she's got quite a lot of palpitations, so they are just trying to get to the bottom of it and then move her over as late as possible."

 Barbara also highlighted the importance of familiarity and long-standing relationships with her daughters' CHD team:

"*I don't doubt for a second that they'll look after them really well, […] but it's better the devil you know sometimes, isn't it, and we trust [name of paediatric hospital] and we know everybody there. […] It's having that relationship and that rapport, isn't it?"*

She went on to explain that transitioning to a new adult team felt like it would be *"like starting all over again"*, suggesting that unfamiliarity itself may shape how young people and their families experience this transition.

Together, these accounts highlight the complex and often conflicting emotions parents experience as their child approaches adult CHD services. While some recognise potential medical benefits associated with adulthood, the transition is overwhelmingly marked by uncertainty, fear of the unknown, and a sense of losing the trusted relationships built within paediatric care. Ultimately, parents' experiences suggest that without clear communication and meaningful preparation, the transition can feel less like a supported milestone and more like a disruptive shift, one that risks compounding existing anxieties at a critical stage in their child's care journey.

7.1.5 Anticipatory Anxiety

As adolescents begin to assert greater autonomy and engage in social activities beyond the direct supervision of their parents, many parents described a noticeable rise in their own anxiety.

Parents spoke about how even subtle or seemingly unrelated symptoms could trigger immediate fear of cardiac deterioration:

 George illustrated this heightened sensitivity when his daughters became unwell:

"It may not be related to their heart condition, but then as soon as something does, I think your nerves go higher, you panic more […] I definitely find you jump to more or worst-case scenario. […] it makes you think it's something more than what it really is."

 Barbara echoed this pattern of hypervigilance, describing how minor sensations could provoke disproportionate worry:

"Because it's like with any twinges in their chests, and you're like oh my God, are you all right, are you all, right?"

She went on to explain how this anticipatory anxiety extended even to her healthy child, revealing how past experiences shaped her reactions:

"*I think with our son, I definitely find that if he's ill, even if he's just like got a sickness bug, you do think the worst, if you know what I mean. Instead of thinking well, he's just ill, you know, or he's got a headache, it's like it could be something more […] because you've been through so much with them and seen, you know, got through so much, you sort of immediately jump to conclusions, don't you?"*

For some, this anxiety surfaced in everyday encounters, as  Julie described her physiological response when contacted by her son's school:

“When the phone rings and I see the school’s name on the screen, I think ‘oh my god.”

Parents also expressed worry about risks that extended beyond medical symptoms into the broader social environments of adolescence.

 Veronica conveyed an intense fear of physical harm due to her son’s cardiac vulnerability:

“I think my main concerns were, is, oh my God, what if he gets hit, you know, or what if someone hits him in the chest […] because it can happen. What if he falls down the stairs? What if he faints? […] And things like getting run over. Oh my God, if he gets run over it’s going to be worse for him. […] I drove my husband mad, oh my God, what if this happens, what if that happens.”

Her anxiety often translated into explicit instructions aimed at preventing harm, particularly in relation to infection or injury:

“So, I was very much like, you have to keep your hands clean, please don't bite your nails. Going out on his bike, if he falls off, just have your antiseptic wipes, get a plaster, keep it covered.”

For Beatrix  , fears escalated when her daughter was out with friends, leaving her mind “spiralling” through a range of potential dangers:

“I would sit all night thinking, anything could happen, but you worry about her heart, will she drink too much, or, I don’t know, if she gets attacked, […] we’ve got the heart to worry about.”

Some parents recognised that while many anxieties are common to raising adolescents, having a child with CHD magnified these concerns

 George reflected on this overlap:

“And maybe that’s with every parent, I don’t know.”

 Similarly, Veronica noted that although some worries are universal, CHD intensified their impact:

“I think it’s, as they grow up, I think for any parent, with or without, you're going to worry. All of them things that possibly you wouldn't worry about if your child didn't have a congenital, you'd still worry about them being out and all of them sort of things.”

To manage these heightened emotions, some parents adopted proactive strategies to maintain a sense of control:

 Veronica described how cognitive reframing helped her counteract catastrophic thoughts:

“So, like my biggest thing would be he may be getting run over by a car. So instead of thinking that, thinking no, he's going to get to school fine, isn't he, because you've brought him up to ride on the pavement, you've taught him how to cross the road, so he's going to get to school fine. So, I have to just keep doing that in my head.”

She also relied on practical tools to ease her anxiety, even when her son felt these measures infringed on his independence:

“I've got a tracker on his phone which he's not happy about, but I said it’s for your safety […] I'm only tracking to see where you are, making sure you're safe […]. And God forbid, if anything was to happen, I could just look and go that's where he is and get there […]. But I think he thinks I'm doing it to be nosy.”

Collectively, these narratives show how anticipatory anxiety becomes embedded in parents’ daily lives as their adolescents gain independence. Some adopt strategies to manage their concerns, while others normalise their fears by comparing them to parents of typically developing teenagers. These comparisons help them interpret their heightened vigilance as both a response to CHD-related vulnerability and a familiar part of parenting an adolescent

7.1.6 Uncertainty for the future

Parents described considerable uncertainty regarding their child's future health and wellbeing during adolescence, with the unpredictability of CHD contributing to ongoing worry and apprehension. Concerns often centred on the long-term effectiveness of cardiac surgeries or implanted devices, as well as the adequacy and timing of follow-up monitoring.

 Joan illustrated this persistent unease when discussing her daughter's cardiac outlook:

"I do worry because her stent has been in now for seven years so obviously, I worry about that and because of the bicuspid aortic valve, a lot need it replaced when they are in their twenties or thirties […] and of course aneurysms […] and she's already been told she not getting her MRI his year, she gets it every eighteen months so how can they pick up if she's got an aneurysm there?"

This account demonstrates how gaps in surveillance and uncertainty around potential long-term complications compound parental anxiety, reinforcing the sense that the future remains medically unpredictable.

For some parents, this medical uncertainty extended into broader reflections on family life. They questioned whether a sense of "normality" was achievable within the ongoing demands of caring for a child with clinically complex CHD:

 Joan captured this sentiment when she remarked:

"Because of what we've been through, what we live with, maybe we're never going to function fully normal, whatever that is, I don't know".

Her reflection highlights how uncertainty about the child's health permeates the wider family system, reshaping expectations about what everyday life might look like.

 Barbara similarly expressed difficulty imagining or planning for a typical future:

"You can't imagine ever having a normal family life, because one, you don't know what that's like and two, you don't know whether you'll ever get there, because you

don't know, you haven't got a crystal ball […] you just can't think that far ahead, can you?"

Her narrative emphasises how the inability to predict health trajectories restricts long-term planning, leaving families suspended in a state of anticipatory uncertainty. At the same time, she reflected on how her children's condition might shape their future aspirations and opportunities, revealing the ongoing tension between hope and uncertainty.

Barbara's reflection revealed that CHD may limit her child's choices, contributing to a future that feels both unclear and potentially constrained:

"*You're thinking towards the future and what that holds for them, having their heart problems as well and, you know, if that's going to have, like, any impact on what they want to do when they're older."*

For other parents, uncertainty also arose from anticipating the social and behavioural challenges that emerge during adolescence:

 Daniel described the need to remain vigilant as new external risks became more visible:

"It seems that access to sort of drugs seems to be getting easier and kids taking them younger […] and you just have to be on your toes a bit more, just keep yourself aware of the things that are going on and just be sort of streetwise."

Daniel's account suggests that typical developmental risks feel amplified in the context of CHD, prompting parents to monitor their child's social world closely.

Risky behaviours can have more serious consequences for young people with CHD, resulting in parental worry about the influence of peers, and the possibility that social pressures could conflict with medical advice:

 Julie expressed both pride in her son's popularity and concern about how his outgoing nature might interact with peer influence:

"He is that kid that at eighteen you'd want to be at the party with, because he's popular and he's funny and he's all those things. I absolutely worry about that […] He's probably going to get some fool child tell him to get a tattoo."

This tension highlights how social strengths can also generate vulnerability, intensifying uncertainty about the adolescent's future decision-making.


Similarly, Joan hoped her daughter would find supportive and like-minded peers, recognising how social environments could either ease or intensify vulnerability:

"The challenge is for her to meet like-minded individuals who share that love of all the things that she loves."

Joan's hopes reveal how parents see peer relationships as pivotal in shaping adolescents' resilience, identity, and future wellbeing within the context of chronic illness.

Collectively, these accounts illustrate the pervasive and future-oriented uncertainty experienced by parents of adolescents with CHD. Their difficulty envisioning a stable or typical family trajectory reflects the compounded impact of medical unpredictability, social vulnerability, and developmental change. This sense of uncertainty often left parents feeling unable to plan ahead, contributing to sustained worry and emotional fatigue.

7.1.7 Transition from adolescence to adulthood

Parents expressed a range of emotions and concerns when reflecting on their child's transition to adulthood, revealing a mixture of acceptance, uncertainty and anxiety as their child progressed through adolescence:


Julie, whose daughter had recently entered early adolescence, acknowledged the inevitability of change while also anticipating future challenges:

"So, it doesn't fill me with dread, but I know there's a lot of changes that are coming. I don't feel right now that I'm uber concerned about what lies ahead. We just know there's going to be changes and that would be like any kid who's growing up."

This response illustrates how some parents normalised aspects of adolescence, framing upcoming changes as consistent with typical development despite the additional layer of CHD-related concerns.

For some parents, one source of uncertainty was the difficulty distinguishing between behaviours associated with typical adolescent development and those potentially linked to CHD-related symptoms:

 James described this ambiguity when reflecting on his daughter's recent emotional and physical difficulties:

"*She's been difficult in the last 12 months […] and I think it's just a usual teenage behaviour to be fair…whereas with the palpitations and the migraines and the constant tiredness […] it could be just being a teenager because it's goes like that at times, but in terms of the palpitations, you go we'll we need to get this looked at."*

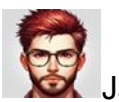
His account highlights the blurred boundary between developmental changes and medical risk, a theme that contributed to ongoing parental vigilance during adolescence.

As their children approached adulthood, some parents expressed heightened concern about the formation of intimate relationships and the associated risk of pregnancy:

 Maria, for example, articulated strong protective feelings and anxiety about her daughter's vulnerability:

"I'm absolutely petrified […] they think everyone's intention is honourable and it's not, so that's one's a bit of a scary one […] more so with her being a girl and the fact that she's got to be more careful, because they did tell us she couldn't have kids."

This fear reflects a broader parental concern that sexual maturity introduces risks that are intensified, rather than eased, by the presence of CHD.

 James shared similar anxieties, particularly as he imagined his daughter entering new educational and social environments involving male peers:

“It’s just the protective dad inside of me that doesn’t want her to be treated in any way less than she deserves […] and I think young boys, especially teenagers, that probably could see her as a target.”

His reflections underscore how emotional vulnerability and shifting social dynamics can heighten parental apprehension during this transitional phase. James explained these worries were heightened by his daughter’s fluctuating mood, fearing that emotional vulnerability might make her more susceptible to manipulation.

Concerns surrounding reproductive health were also prominent, reflecting the medical complexity and potential risks associated with pregnancy in the context of a clinically complex CHD:

 Beatrix described how the transition to adulthood shifted responsibility to her daughter, even as she continued to worry about the unknown:

“I do know she would talk to her cardiologist first, and I do worry about during labour, or would she get a caesarean section, I don’t know. These are obviously questions I can’t ask, (*daughter*) *would have to ask. So yeah, I do worry.”*

Her narrative highlights the tension between parental protectiveness and the young person’s emerging autonomy.

For others, uncertainty stemmed from fears about hereditary transmission and ambiguities in medical guidance:

 George reflected on the possibility of CHD being passed to the next generation:

“Obviously there was more chance that they’ll have a congenital heart defect, but they haven’t really said that they can’t have kids […] it’s just that I think they might have more chance that they’ve got a congenital heart defect.”

This ambiguity reflects the broader difficulty parents face when trying to anticipate long-term implications in the absence of definitive medical information.

 Barbara expressed similar concerns, highlighting how reproductive decision-making would likely require careful consideration in adulthood:

“ We are aware that they (daughters) are going to be high risk, if they do have their own children […] and you know when they’re looking to have families of their own that’ll have to be a consideration that they may have children with heart problems themselves […] it’s always a concern, isn’t it, even though it’s not like in the forefront of your mind all of the time.”

Her account reinforces the ongoing, future-oriented nature of parental anxiety as adolescents prepare for adult life.

Taken together, these narratives highlight the multifaceted challenges parents face when supporting adolescents with CHD through the transition to adulthood. Parents frequently struggled to distinguish between typical developmental changes and symptoms of illness, while also expressing significant concerns about intimate relationships, vulnerability, and reproductive health. These overlapping uncertainties contributed to a desire for clearer information and guidance to help them support their children through this emotionally and medically complex stage.

7.1.8 Navigating through COVID -19

Parents described significant uncertainty when navigating the early stages of the COVID-19 pandemic, largely due to inconsistent guidance around shielding and their child’s level of vulnerability. The absence of clear, unified information left many feeling unprepared to manage emerging health risks and unsure about how to interpret rapidly changing public health advice.

For some, the onset of the pandemic triggered intense fear and a sense of urgency, prompting them to act before official restrictions were announced:


Veronica recalled how escalating news coverage and the unpredictable nature of the virus heightened her anxiety:

“It did really scare me at the start. I was watching the news, like, all the time […] it came to the point that, it was the 23rd of March we went into lockdown […] but before he'd (the prime minister) announced it, I'd said, I'm self-isolating us now. Because I just thought he’s just not going to cope, he's really not going to cope if he catches this virus.”

Her account reflects how, in the absence of specific clinical guidance, parents often relied on their own judgement, sometimes influenced by fear, to determine appropriate protective measures.

Veronica later described how efforts to safeguard her son paradoxically led to further worry, as she questioned whether intensive hygiene routines might weaken his immunity:

"I became more concerned about all the cleaning and handwashing I've made him do, and then their immune system's dropping. So, I was like, oh my God, like you just, you can't win."

This sense of helplessness highlights the emotional conflict parents faced in balancing protection with uncertainty about unintended consequences.

In contrast, other parents felt more reassured about their child's relative risk, drawing on their own interpretations of clinical advice:

 Joan described her position:

"I think she has some vulnerability, but I'd say she's clinically quite well. […] I think she's, for me, she's at the same risk as us. […] she puts herself in that vulnerable group, but she's never been clinically put in that vulnerable group."

Her reasoning demonstrates how parents actively made sense of contradictory information, weighing their child's medical history against evolving public health messages.

Parents reported receiving mixed messages from HCPs and official communication sources. While some were told their child was not at increased risk and could continue normal activities, others received government letters advising shielding, leading to confusion and uncertainty about how best to protect their child:

 . Barbara described this inconsistency:

"*I emailed* (*doctor*) *and asked him about it, and he said I don't think that they're any more at risk than anybody else. Next thing, we get a letter in the post from the government telling us that* (*daughter 2) had to shield. Now,* (*daughter 2) is the less*

*complicated one cardiac wise. We didn't get a letter for (daughter 1) so we were like, well that's weird. And then I thought, why do we need to shield? […] So anyway, then we emailed (*name of doctor*) back, and he's like I don't understand why you got this letter, because as far as I'm concerned, you don't need to shield. So, I was like, well, what do I do? […] so, we'll just err on the side of caution, follow the advice of the letter."*

Barbara's experience illustrates how contradictory messages left parents feeling solely responsible for risk assessment, prompting them to default to caution despite an unclear rationale.

 Veronica encountered similarly inconsistent messages:

"We did get letters, but then when I spoke to the (name of hospital) and went on all the webinars, they were actually saying no, he can carry on as normal, he can still go to school."

Such conflicting advice contributed to a heightened sense of ambiguity, making it difficult for parents to determine which sources should guide their decisions.

Concerns about school attendance intensified this uncertainty, as parents struggled to weigh the benefits of education and social interaction against perceived viral risk:

 Veronica described withdrawing her son from school as a precaution:

"So, with COVID, we didn't send him back to year six."

 Julie similarly described experiencing a heightened emotional response following notification of a positive case within her son's school:

"[…] someone in his year has had a confirmed case. So, I was like, oh my God, so then it's that you want to shield him again. Oh my God, I'm not sending him, I don't want him to go, what if he gets it? […] So, with COVID we didn't send him back to year six, […], and I called (name of hospital) and said 'look what do you guys

reckon? It's 24 days, I know he's okay, but what do you reckon?' So, there's dialogue still."

Her account reflects parents' reliance on ongoing communication with clinical teams to navigate decisions in an environment where official guidance was felt to be insufficient.

For adolescents on the cusp of adulthood, COVID-19 added a further layer of complexity to transitions that were already emotionally charged:

 Joan described the internal conflict she experienced when her daughter left for university:

"I've just sent my eighteen-year-old daughter off to university in the middle of a pandemic. Really, in my heart, I want to keep her at home and keep her safe, as I've done for 18 years, but I can reason that that's not in her best interest and actually that would be depriving her of everything we've worked so hard for […] I'm angry about COVID because it's like, we've done all this and now there's another threat."

Her narrative illustrates the emotional strain of balancing developmental needs with perceived health risks during a period of heightened societal uncertainty.

Overall, parents' experiences during COVID-19 reveal how inconsistent guidance, unclear risk information, and rapidly shifting public messaging intensified existing uncertainties associated with CHD. The pandemic amplified parents' sense of responsibility for risk management, often leaving them to navigate difficult decisions without reliable direction. This created an emotionally charged environment in which fear, caution, and protective instincts frequently conflicted with adolescents' developmental needs and autonomy.

7.2 Theme (b) Conflicts around Control and Responsibility

As adolescents with a clinically complex CHD reach sixteen, parents described navigating a difficult shift in control and responsibility for healthcare management. This transition was marked by conflicting emotions, pride in their child's growing independence, but also fear, frustration, and uncertainty about how much responsibility their adolescent was ready to assume.

7.2.1 Relinquishing control for healthcare management

Parents expressed contrasting views regarding the transition from paediatric to adult CHD care and the expectation that their child would assume greater ownership of their health. For some, transitioning away from paediatric services symbolised progress and closure:

 Joan, for example, described a sense of readiness to move on:

"I want (*daughter*) *out of* (*paediatric hospital). I kind of want to say goodbye to that now, because it's, we've been there, it's happened […] I mean she looks daft, when we go to (paediatric hospital), I mean you've got all these babies and toddlers and an eighteen-year-old grown girl in there […]. It doesn't need to be a big part of our lives anymore. I want her to live alongside it […] I think it's been concluded now, in a way. […] I've advocated for her, but I am aware that it's not my right, for the rest of her life, to sit in every health appointment she has. If she wants me there, I'm supporting her, but I do feel as a young person that she should be doing more of the talking now and that I pull back […] I made that decision not to be part of them, one for my wellbeing and two, because I recognise she needs a level of privacy."*

Joan's account illustrates a deliberate effort to step back, balancing her desire to protect her daughter with an awareness of the developmental need for autonomy.

In contrast, other parents felt the expectation of independence was unrealistic or premature, especially when adolescents lacked the maturity or motivation to manage complex health tasks:

 Maria described the difficulties she faced when HCPs refused to communicate with her:

*"The doctors phoned me with her blood results the other day and wouldn't speak to me because she is sixteen. They are like "sorry I can't give you the results", I was like "are you serious?" and they were like "yeah", so I've had to put [*daughter] *on the phone for her to go "Speak to my mum" […] because she doesn't really have a clue, she's sixteen, she doesn't have a clue and doesn't really care"[…] the lines are blurred between them being a child and adult […] I can't speak to the doctor's past*

sixteen [years] *and so because of things like that, me being not able to put these things in place or putting them in place and having no say over. “*

Her narrative highlights the tension created when legal responsibility shifts before practical readiness, leaving parents feeling excluded yet still accountable for ensuring their child’s safety.


James went on to describe the practical consequences of a premature handover:

“*So, she takes her own tablets of a night and that was like her independence in trying to get herself managed and stuff like that. So, it got to the stage where she was running out and then going “I need tablets” and then the doctors introduced a policy where you put your prescription in and it's seven days later before you get your medication. […] the hospital will phone [daughter] to tell her the dosage and then they’ll go we will test you every four weeks, and it will be five or six weeks later I’ll go “do you need your INR?” and she’ll go “oh yeah its late” or well get a phone call from the hospital saying she not done it, even though we don’t know anything about it because they’ve phoned her and told her […] we find letters, like, randomly around the house at times don’t we, so it’s like, oh, so you’ve missed that appointment now, why didn’t you tell us it was there so we can put it in the diaries? […] it’s a head spin.”*

These examples show how gaps in adolescent responsibility can create additional burden for parents who remain responsible in practice, even when excluded in principle.

For some, the concern centred on the adolescent’s ability to advocate for themselves within healthcare settings:


Beatrix worried that her daughter lacked the confidence needed to communicate her needs effectively:

“I’ll be really worried because I know (*daughter*) *wouldn’t probably speak up and she wouldn’t fight, she’d fight as a person to survive, but she just doesn’t have the […]*

the confidence to sort of say well actually you know what I want, somebody to do this."

This highlights the emotional strain parents feel when imagining their child navigating adult services without their support.

A strong sense of loss was constructed within parents' accounts as they relinquished their long-standing role as the primary point of contact for CHD care. Some described experiencing their involvement as abruptly dismissed, contributing to feelings of emotional disconnection from HCPs:

 Beatrix described this vividly:

"*I felt mad actually, and useless as a parent, because I've protected her for the last sixteen, seventeen, eighteen years and suddenly they think at sixteen they're an adult and then basically your jobs done […] it's just makes you feel like we are not needed […] as parents, are we actually just supposed to stop feeling about our kids because they are now adults? […] and they* (*cardiac nurses) don't like me coming in the rooms with them […] I feel like we've always got to fight for me to be there."*

Her account conveys how service policies can unintentionally invalidate parental expertise, leaving them feeling marginalised and emotionally displaced.

 Maria echoed this frustration, questioning the inconsistency between healthcare and social care expectations:

"I understand the independence and the fact that she is sixteen, but if you're in care, the social services come out and say that your child's your responsibility until they are eighteen years old. So why all of a sudden am I not responsible for certain parts of (*daughter*)*'s life?"*

This reflects a broader tension between legal definitions of adulthood and the practical realities of parenting a medically vulnerable adolescent.

Even parents who supported their child's increasing autonomy, acknowledged how challenging it was to step back while still seeking clarity around medical responsibility:

 Joan discussed:

"*And those are the bits that I think is really hard as a mum, because she would have to drive that and I have to respect that […] it just evolves."*

Her reflection captures the gradual, uncertain nature of this transition, in which control and responsibility shift unevenly over time.

Overall, parents' experiences reveal deep emotional and practical conflicts as responsibility for CHD management shifts from parent to adolescent. While many recognised the importance of fostering independence, they often felt excluded, unprepared, or undermined by rigid service policies that did not align with their child's readiness. These tensions created a sense of loss, frustration, and uncertainty, underscoring the need for more nuanced, supportive approaches to shared responsibility during the transition to adult care.

7.2.2 Striving for independence

Parents reflected on their experiences as their adolescents moved toward greater independence, revealing a spectrum of emotions ranging from relief and renewed personal freedom to frustration and a sense of being held back. Their accounts demonstrate how the transition to adulthood can simultaneously open new possibilities for parents while also exposing the limits of their child's readiness to take on responsibility.

For some parents, their child's increasing independence created space to reclaim aspects of their own lives:

 Joan described a sense of liberation when her daughter left home for university:

"I think it's my time now […] I've always kind of worked my career around the children and things like that, so not having that kind of sense of responsibility day to day, it's quite like she never walked to school, I've always taken her. […] So, it's quite nice at the moment just to kind of […] not have that day-to-day oversight […] So now I think it's about embracing this new chapter […] As (*daughter) started looking around universities and things like that, it kind of ignited something in me a bit more. Spending some time with (other daughter) and kind of focussing on her […]*

I suppose just doing things that everyone takes for granted really. It does feel like the pressure's off a little bit."

Joan's narrative suggests that her daughter's newfound autonomy enabled a shift in parental identity, moving from constant caregiver to someone able to invest in personal goals and relationships that had long been deprioritised.

Other parents similarly anticipated independence as a welcome release from the heavy logistical demands of caregiving:

 Maria expressed eagerness for the freedom she expected driving would bring for both her daughter and the family:

"*it's the countdown to her birthday and then it's everything independence for her, because she can drive herself to college, and it takes the strain of the whole family. […] at least then she'll be able to go and see her mates, she'll be able to whatever, it will just open everything up."*

Yet, Maria also reflected on how her daughter's lack of motivation to learn to drive left her feeling constrained:

"One of my major struggles is I can't be full time as in like work full time because I am just her chauffer, I'm ferrying around, I'm taking her to get her prescriptions and all the independence that we thought she would get from the driving lessons she just not interested in doing, so I feel a bit trapped by it all to be honest".

Her account reveals how parental hopes for increased independence may be disrupted when the adolescent does not take up opportunities to assume responsibility, leaving parents still carrying the practical load.

 A similar sense of frustration was reflected in James's account as he described his daughter's reluctance to complete essential tasks:

"*All she had to do was sign it and send it back […] and then all of a sudden, we got a cheque through the post, it said you've have not filled your provisional (driving licence) in, here's your money back. And no matter how many times you tell her,*

“have you not yet done that yet?”, it's “I’m sorting it, I’m sorting it” […], it’s never like here you go let’s get it fixed, it’s always ‘I’m gonna to, I’m gonna to’.”

This illustrates the emotional and practical strain parents experience when adolescents appear ambivalent or passive about embracing autonomy, reinforcing the tension between wanting independence for them yet still having to take responsibility from behind the scenes.

Other parents framed independence as essential for their child’s development, even if emotionally challenging:


George spoke of the importance of allowing his daughters increasing space to grow:

“Let go of the reins, let them go a little bit more […] Go and experience other things, but they don’t want to go too far from us and that’s why I keep saying to them you know we can’t be here, when you’re in your twenties.”

His reflection highlights the dual responsibility parents feel, protecting their child while also encouraging the distancing necessary for healthy adulthood.

Together, these accounts illustrate the complex and sometimes contradictory emotions parents experience as their adolescents with CHD strive toward independence. While increasing autonomy can offer parents a sense of relief and renewed personal identity, it can also generate frustration, fear, or lingering responsibility when adolescents are not yet ready or willing to manage key aspects of their own lives. This tension emphasises the delicate balance parents must navigate between supporting independence and remaining involved in ways that ensure their child’s safety and wellbeing.

7.3 Theme (c) A sense of Community

Parents of children with moderate or complex CHD often described the importance of having others around them who understood their experiences, noting that connections with people facing similar challenges helped reduce feelings of isolation. Support was drawn from a variety of sources, family, friends, and charitable organisations, but a recurring theme in the data was the centrality of HCPs in parents’ support networks.

This section explores how parents constructed a sense of community through their relationships with HCPs and the emotional significance of these relationships.

7.3.1 The Parent and Healthcare Professional Relationship

Strong and consistent relationships with HCPs were constructed within parent accounts as a cornerstone of support. Many parents spoke about their CHD teams with deep affection and gratitude, frequently positioning them as extensions of the family:

 Daniel emphasised the comfort he gained from continuity of care:

"We've been fortunate that (doctor) has been, they're on the same journey as us, you know,[…] I think it's all part of the reassurance that's he's in good hands, […] it's the familiarity feeling of knowing that the same people are involved, and, you know, they see him grow and you know that's just something that's quite special […] You can't always guarantee that will be that way forever […] I completely understand that, but all I ask is reassurance."

His account highlights how trust is built through shared history and consistent involvement, with reassurance becoming a central emotional need during ongoing care.

For others, accessibility and responsiveness were key features of this supportive relationship:

 Julie described her confidence in reaching out to the team whenever concerns arose:

"When it comes to your child, the bespoke situation you're in, I do not hesitate by picking up the phone and I've always done this."

Julie's experience reflects the value parents place on feeling able to contact professionals without hesitation, reinforcing a sense of safety.

Parents frequently attributed their child's survival and ongoing health to the dedication of the clinical teams, reinforcing the emotional closeness they felt:

 Barbara expressed this deeply held gratitude:

“Because of the staff, and because they saved our girls […] we trust them with their lives […] if it wasn’t for them, they wouldn’t be here […] we owe everything to them.”

Such reflections underscore how lifesaving interventions create bonds that extend beyond typical patient–provider relationships, becoming intertwined with family identity and history.

 George also emphasised how trust was cultivated through shared experiences during critical moments:

“*It’s building up a trust, isn’t it, that’s the thing […] It’s important, we’ve gone through events […] in a sense of what you’ve gone through with the staff, with the doctors, and you’ve learned then to build a relationship up.”*

His account reinforces how enduring emotional connections develop through collaboration during high-stress periods.

Parents described immense pride in the quality of care provided:

 Daniel reflected on his experience:

“I can’t really think of any words to explain how the care was, I mean, amazing is an understatement really […] it was incredible. It made me feel very proud of the NHS, extremely proud.”

This sense of admiration reflects how positive healthcare interactions can contribute to broader feelings of national gratitude and loyalty. For others, trust in the team supported their own emotional wellbeing:

 Joan articulated the stabilising effect of familiar and trusted HCPs:

“*If you ask me what’s really important, it’s all about relationships and I think because these people know us, I trust them […] because we've got a relationship there, I think that helps in terms of perhaps managing my own emotional health and wellbeing.”*

Her account illustrates how relational continuity can buffer parental stress, forming an essential component of their coping strategies.

 Beatrix similarly described profound emotional attachments, rooted in the earliest days of her daughter's life:

"I've got two heroes in my life, (daughter)'s one of them, and the other one, (*doctor), he was the first one to operate on* (*daughter), a tiny 2lb 2-ounce baby."*

This narrative conveys how pivotal interventions can form lifelong bonds between families and HCPs. However, not all experiences were uniformly positive. Some parents acknowledged variability in interpersonal connections:

 George reflected on the natural differences in rapport:

"We had some nurses and doctors, we've had fantastic ones and then some of them, you don't click with […] you just don't get them or, yes, they're not your cup of tea, and that's just life."

This highlights that while relationships can be a source of strength, they are also subject to normal interpersonal differences.

 Barbara also noted that feeling able to ask questions was an important yet sometimes fragile aspect of this relationship:

"Just feeling like you can ask questions, and you don't feel daft for asking questions and somebody that's approachable."

Her account suggests that approachability shapes parents' comfort in seeking information, reinforcing how relational qualities influence their confidence in navigating the care system.

These narratives show that parent–HCP relationships provide vital emotional support for families with CHD. Continuity, trust, and approachability help parents feel secure, especially during uncertainty, while gaps in connection reveal the fragility of these relationships and the need for sensitive, consistent communication.

7.3.2 Parent / Education staff relationship

Supporting adolescents with a clinically complex CHD in education requires close collaboration between parents and school staff, particularly during periods of transition. Parents described a range of experiences in these relationships, from strong partnerships based on trust and clear communication to moments of frustration in which staff appeared unsure about how best to support their child's complex needs.

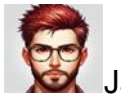
Many parents spoke positively about schools that communicated effectively and implemented appropriate care plans:

 Barbara described feeling reassured by her daughter's school:

"*The school have been really good, […] the communication's always been really good […] there's not much wrong there because the school has a good care plan in place for her."*

Her account shows how clear, proactive planning can foster parents' confidence and reduce anxiety about the child's daily wellbeing.

Trust was also constructed across participant accounts as a central aspect of their experiences:

 James appreciated the school's role in reinforcing safe behaviour:

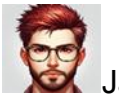
"There's a sense of trust there […] the teachers are there to reinforce any silly behaviour that's going to potentially make her ill. They are there to put an end to that, […] it feels good that she's got the "go to relationship."

This illustrates how parents rely on school staff to act as partners in safeguarding their child's health, particularly when adolescents begin to test boundaries.

 Julie similarly emphasised the importance of trusting relationships with teachers:

"I don't have any lack of faith in the school and the teachers. I probably would have to find another place for him to go to if I did, because I just couldn't imagine feeling that way all the time. [...] so I do trust them."

Her reflection suggests that trust in school staff is not simply beneficial; it is essential for parents managing the dual pressures of health and education. However, some parents described instances where staff were quick to escalate concerns without fully understanding the context of the child's behaviour or symptoms:

 James shared an example relating to his daughter's self-harming:

"I think it just like a scratch to be honest, but then that set the school off, and school was "she's doing this, she's self-harming, she's doing that", and when you spoke about it, she had only done it to fit in."

This highlights how a limited understanding of adolescent behaviour and CHD-related vulnerabilities can lead to misinterpretations, potentially causing unnecessary alarm.

Uncertainty and lack of familiarity with the child were also evident when adolescents moved to new schools:

 Veronica described the frequent phone calls she received as staff tried to assess her son's wellbeing:

"*They don't know (son), so I'm getting phone calls every week. And it's like he's fine, has he got a temperature? No. Okay. You know, he's quite a pale child anyway, but would you say, you know, is he changing colour? No. Okay then. Why are you ringing me then? And they're like, well, he's come, he's saying that he's not feeling very well. Well, what's wrong? […] I suppose, it is a worry to them […] I don't think schools have got enough information."*

Her account reflects the challenges schools face when supporting medically complex children without adequate training or knowledge.

 Julie also felt that greater specialist input could help bridge this knowledge gap:
"*Maybe it's because they haven't got the knowledge […] I do feel that maybe […] a cardiac nurse going into the school with a cardiac child […] would sort of help."*

This points to a need for structured educational support for school staff, enabling them to respond appropriately without overreacting or relying excessively on parents:

 Beatrix echoed this sentiment when recalling repeated calls about chest pain:

"We had her back and forth getting her checked because five or six times we were getting phone calls from her school saying (daughter)'s got chest pain. […] I think if they had that little bit more knowledge, I think they would settle a bit, and they would be able to support our cardiac children a lot better."

Her experience illustrates how a limited understanding can create unnecessary disruption for families and contribute to parental stress.

Overall, parents' experiences highlight the importance of trusting, well-informed partnerships between families and school staff when supporting adolescents with CHD. While many schools provided reassuring communication and effective care plans, gaps in knowledge sometimes led to misinterpretation of symptoms and heightened parental burden.

7.3.3 Supportive networks

Establishing support networks is a vital aspect of managing parents' emotional wellbeing when caring for a child with a clinically complex CHD. While many parents relied on friends, relatives, and other informal supports, the data also revealed moments where these networks fractured, creating emotional strain and contributing to a sense of isolation.

7.3.4 Tensions within the family

Some parents described significant relational strain within extended family networks. These tensions were often rooted in misunderstandings, unequal levels of emotional investment, or relatives' discomfort with the child's condition:

 Maria reflected on the long-standing difficulties within her family:

"*She's (daughter) always been treated differently, […] it causes a massive amount of strain […] so relationship wise between me and my family, it's never been good […] that's caused major arguments within the family over the years […] it feels to me, like they boast about it to other people, whereas I don't tell anyone about it. […] why is that anything to do with anyone else […] So I think the situation has put a strain massively on the whole family."*

Her account suggests that differential treatment and misunderstandings about the child's condition can erode family cohesion, leaving parents feeling judged or unsupported. For others, the loss of family support was even more profound:

 Beatrix described a painful breakdown in her relationship with her daughter's grandmother:

"*I have lost family over it. Her granny […], we actually no longer talk to her […] but the main reason being she actually turned round and said she couldn't love her for fear of her dying […] this was a selfish feeling, and I said to her how do you think we feel, she's our daughter we can't give up now, were terrified every day that she would die,[…] but if she just took time to understand exactly what was happening."*

This account highlights how relatives' inability to cope with the emotional reality of CHD can leave parents feeling abandoned at times when support is most needed. Beatrix further described the loss of her father:

"He was my rock, actually, and I don't have a rock anymore because he's not here."

Her narrative explains the strain within family systems and the grief associated with losing a trusted source of stability and comfort.

CHD can strain extended family relationships, leaving parents feeling emotionally isolated or misunderstood. Such tensions amplify the stress of caregiving and highlight how family support cannot be assumed.

7.3.5 Spousal support

Differences in coping styles between mothers and fathers were also constructed within participant accounts as a significant aspect of experience, at times contributing to tension within couples. Mother's often described themselves as communicators or information-seekers, while perceiving their partners as more avoidant or emotionally withdrawn.

 Beatrix described her husband's tendency to internalise his feelings:

"*he's a very closed book. […] when it comes to anything […] he goes into his own world really […] it's not like he wants to forget about it, […] He doesn't talk about it, I don't know if he pretends it not happening."*

Her account illustrates how contrasting emotional styles can lead to misunderstandings about engagement and concern.

Similarly,  Joan reflected on the differing ways she and her husband processed their daughter's condition:

"He has a very, very different view of it all. […] his way of coping has always been that he'd go to the gym every morning. […] He will deal with now, and he doesn't even want to think too far ahead […] He wouldn't ask questions that I ask. Because if you don't ask the question you don't need to deal with the answer, do you? Whereas I like to know everything and I am the parent in meetings […] he is much more laid back and calm, and that's probably why it works."

Joan's interpretation highlights how different coping strategies can complement one another, even when they create tension.

Other mothers described practical rather than emotional differences:

 Veronica explained how she naturally took the lead with communication:

" I think I'm the better communicator out of the two so it's probably better if I deal with it […] we're both singing from the same book, but nine times out of ten I'll come home and say, right, I've done this, and I've done that, and he'll say ' well, it needs to happen […] tell me what we need to do?'."

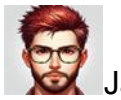
Her account reflects a practical division of tasks, yet one that leaves her carrying most of the emotional and organisational load.

 Maria described moments of friction stemming from "double checking" one another's actions:

"There is tension between us both, because then I'm like "have you asked her if she had a milkshake? […], its double checking each other […] and he's like "for God's sake I've done it all […] but I don't think it affects us in any other way."

Such experiences illustrate the heightened sensitivity and shared responsibility involved in CHD management.

Some fathers also described adopting a protective role, aiming to provide emotional stability for the family:

 James articulated this explicitly:

"It's hard because I try not to let anything affect me, we've got to be strong for the kids and (wife). […] It's always trying to have that positive outlook, what can we do here and now, how can we make things as good as possible."

 George reflected on how the cumulative stress of CHD had shaped his relationship:

"It's definitely a life changing experience, […] it definitely changes you, […] our relationship probably suffered […] for years and it's probably only in the last couple of years we've got things where you feel we're in a good place."

His narrative highlights the long-term emotional impact of chronic illness on couples, but also their resilience in adapting over time.

Caring for a child with CHD places unique pressures on parental relationships. Differences in coping styles, whether emotional, practical, or communicative, can create tensions, yet many couples also described complementary dynamics that supported resilience. Spousal relationships were therefore constructed within participant accounts as both a potential source of strain and an important foundation for navigating the complexities of CHD as a family.

7.3.6 Support from other parents

Parents described the important role of peer support in helping them navigate the emotional demands of caring for a child with a clinically complex CHD. Relationships with other parents, particularly those with lived experience of CHD, provided a unique form of understanding that reduced feelings of isolation and validated their emotional responses.

 Julie reflected on how central these relationships had become to her coping:

“It’s been so fundamentally important that I wouldn’t even question whether or not I should mention something […] I couldn’t imagine doing it any other way than people know that if he needed help, it had to be urgent, and it was very important.”

 Beatrix also described deep reliance on other CHD parents, particularly during stressful periods such as medical check-ups:

“*When* (*daughter*)*’s check-up comes through, I cannot sleep […], and I’ve got the mums that will help support me […] It’s only heart mums that know how it feels to have a heart child […] and who I thought were my friends, they sort of all turned against me, and I was getting Oh well, kids get operations very day, once she gets her op she’ll be fine, that will be her fixed now.”*

Her narrative illustrates the distinct empathy shared among CHD parents, contrasted with the misunderstanding or minimisation she sometimes encountered from others.

For  Veronica, connections with other parents were not only emotionally grounding but also provided valuable opportunities for respite:

“I've made three lots of friends, parent friends, and they've all been amazing, a great support to me as well. […] I tend to text them more than the hospital. […] I'm going out to dinner tomorrow night with my friends […], and I'm actually really looking forward to just having a couple of hours. […] just to sit and have a meal and just chat and relax.”

This demonstrates how shared experience can create strong bonds that extend beyond medical discussions, offering moments of normality and emotional restoration.

These accounts demonstrate how peer relationships offer a vital form of community, validation, and emotional relief. Such support is rooted in shared lived experience, enabling parents to feel understood in ways that general friendship networks may not provide.

7.3.7 Collaborative working to provide support

Beyond peer networks, parents also valued the support from community organisations, charities, and activity leaders knowledgeable about CHD. These trusted

relationships not only provided reassurance but also enabled children to participate safely in enriching experiences that might otherwise have been out of reach.

 Barbara recalled the impact of a charitable holiday programme, highlighting how structured support can alleviate parental fear, allowing children to enjoy independence under safe supervision:

"The experience of a lifetime […] and that's what you want for your kids, isn't it? Having experiences and know that they're safe, even if you're not there […] we knew they'd be well looked after, because there were so many doctors and nurses going with them."

 George similarly emphasised the value of these opportunities for his children:

"You just want them to get as many experiences in life, […] and they'd wanted to see Disney, and so for them to do it […] it definitely was like a lifetime holiday for them."

 Maria reflected on the extent to which charitable organisations had shaped her daughter's life:

"She's been massively lucky in terms of the people who've been there to support her […] she's done some pretty amazing things, and we wouldn't be able to do any of those things without these charities."

These narratives show how such experiences enable families to achieve goals that might otherwise be out of reach due to financial, emotional, or medical constraints, underscoring the vital role of community support in expanding opportunities for young people with CHD.

Parents also drew comfort from collaboration with activity leaders who understood their child's needs:

 Veronica described the ease of communication with her son's sports coach, highlighting the importance of trust and open dialogue in shared-care arrangements:

“I might want to keep an eye out, you know your child, and you might think, oh, he doesn't look a bit right, actually I'm going to ask.”

Others noted improvements in support structures over time:

 Joan reflected on the increasing availability of peer and community resources:

“I think new mums are in a much better position with things like support groups, and that scaffolding, and that kind of lived shared experience.”

 Julie summed up this shared approach clearly, reflecting a holistic understanding of support, extending beyond medical settings into all aspects of the child’s life:

“We work as a team […] the parents, the siblings, the community, the friends, the teachers, the nurses, everything, it all works together. It can’t work separately.”

Collectively, these narratives highlight how collaborative support from charities, community groups, and activity providers enhances both parental confidence and children’s quality of life. Trust, shared understanding and coordinated effort were constructed across participant accounts as important elements in creating supportive environments that enable children with CHD to thrive.

7.4 Summary

This chapter explored parents’ perspectives on caring for adolescents with a clinically complex CHD. Parents described major life events, including surgery, complications, and transition to adult care, as emotionally defining moments in their caregiving journey. Communication with professionals was constructed within participant accounts as a central concern. While some described experiencing supportive dialogue, others recalled dismissive or inconsistent interactions that contributed to diminished trust and feelings of being unprepared for complications.

The communication of risk and diagnosis had lasting emotional impacts. Clinical terminology and public messaging were often experienced as powerful and sometimes distressing, shaping parents’ understanding of their child’s condition and expectations for the future. Many also described the uncertainty between check-ups as “day to day,” with reassurance heavily dependent on medical feedback.

Overall, the findings highlight the ongoing emotional burden parents carry as they balance their child's growing independence with their own advocacy role. Consistent, compassionate communication and better support during transitions were considered essential for reducing uncertainty and improving family wellbeing.

Chapter Eight: Discussion

This study set out to explore the experiences of adolescents living with a clinically complex CHD and their parents, with the aim of understanding how families navigate the practical and emotional realities of long-term cardiac care. The findings from Chapters Six and Seven demonstrated that while adolescents are expected to take increasing responsibility for their condition, this process is often abrupt and poorly supported. Parents, meanwhile, remain central figures in care, balancing advocacy with a gradual shift towards fostering independence. Together, these perspectives highlight transition and communication as the most pressing issues influencing family life with a clinically complex CHD.

The findings also revealed that communication is not only about the transfer of clinical information but about building trust, managing uncertainty and providing relational reassurance. Adolescents often relied on parents to interpret or recall medical advice, while parents sought greater consistency, clarity and compassion from professionals. Language, tone and the framing of risk were shown to have long-lasting effects on both parents and young people. These insights challenge existing assumptions in transition guidelines, which position independence as a straightforward handover at eighteen years, and instead suggest that transition is experienced as a shared family journey shaped by communication, trust and relational support.

8.1 Transition as a Family Process

This study shows that transition was not experienced as an individual milestone but as a shared family process that reshaped autonomy, responsibility and identity. Within Samantha's, Claire's, and Angie's narratives, adolescents were expected to assume greater self-management, while parents were asked to step back, reflecting literature that describes transition as a developmental and relational shift rather than a simple clinical transfer (White and Cooley, 2018; Moons et al., 2021). The loss of long-standing paediatric relationships amplified emotional strain, consistent with existing evidence of parental grief and adolescent anxiety during CHD transition, consistent with existing literature (Bratt et al., 2018; Coyne et al., 2019). Ongoing medical uncertainty further intensified families' need for consistency and support, portrayed in both parental and adolescent narratives.

The collective disruption for adolescents and parents reflected transition patterns in other long-term conditions (LTCs) such as type 1 diabetes (T1D), cystic fibrosis (CF), epilepsy, irritable bowel disease (IBD), and sickle cell disease, where transitions often misalign with developmental readiness (Hansen et al., 2024; Dampier et al., 2019). In patients with a clinically complex CHD, consequences are amplified, as deterioration can occur without obvious symptoms, self-monitoring is absent, and long-standing ties to paediatric cardiology teams make relational breaks particularly destabilising. Without clear cues, adolescents taking responsibility for symptom recognition or risk assessment felt daunting, heightening anxiety and reluctance to take on self-management responsibilities.

Adolescents in this study experienced a transition imposed on them, leaving them unprepared and anxious. Their limited condition knowledge and uncertainty about expectations in adult care heightened the risk of disengagement, supporting previous results (Gray et al, 2018; McLoughlin, Matthews and Hickey, 2018), which in CHD carries serious clinical consequences due to the possibility of asymptomatic deterioration (Ambrosio et al., 2021; Watkins et al., 2023). Missed appointments, delayed detection of change and disruptions in continuity of care may place adolescents at risk of avoidable complications. When transition feels overwhelming or externally imposed, adolescents are more likely to disengage from adult services. Emotional shock reduced parental involvement, and limited preparation can undermine self-management, appointment attendance and medication adherence. Over time, this increases risks to individual health trajectories and places additional pressure on healthcare services.

Parents reported abrupt reductions in their role, generating anxiety and uncertainty about how to support their child. Many feared being sidelined and felt unsafe stepping back, struggling with relinquishing control, consistent with evidence that CHD parents experience worry and role ambiguity when the caregiving role suddenly diminishes (Lykkeberg, Noergaard and Bjerrum, 2025; Bratt et al., 2018). While parents in other LTCs also struggle with reduced involvement (Dampier et al., 2019; Coyne, Hallström, and Söderbäck, 2018), this concern is intensified in CHD. The absence of daily monitoring cues means parents rely on relational knowledge and intuition built over years, and losing access to clinical information undermines their ability to judge risk.

This deepens the emotional burden and intensifies the sense of being forced out before the adolescent is ready.

In this study, adolescents remained practically and emotionally dependent on their parents, creating tension about when and how parents should step back. Premature autonomy increased adolescent anxiety, while parents lacked guidance on how to adjust their role. This reflects broader literature emphasising the need for structured education and clear communication to support parents' shift from primary caregiver to supportive advisor (John et al., 2022; White and Cooley, 2018). Without such support, parents felt marginalised at a time when adolescents still relied on them, increasing the risk of care gaps.

Communication was central to how secure families felt during transition. Adolescents and parents contrasted the relational, consistent communication of paediatric teams with the more task-focused style of adult services, aligning with evidence that empathy, clarity and continuity underpin successful transition (Moons et al., 2021; Pagel et al., 2019). Fragmented or inconsistent communication heightened uncertainty and weakened engagement, mirroring challenges seen across other LTCs (Hansen et al., 2024). These experiences align with evidence that empathy, clarity and relational continuity are core components of effective transition and significantly influence trust, understanding and engagement (Moons et al., 2021; Pagel et al., 2019). Poor communication erodes trust in clinicians and NHS organisations, driving complaints and lowering performance ratings. Declining trust reduces confidence in care, undermines engagement, and widens health inequities, especially for families managing complex, lifelong conditions.

The findings reveal a clear disconnect between the UK transition policy for adolescents with CHD and parents lived experiences. Under the Mental Capacity Act (2005), young people aged sixteen and over are presumed to have the capacity to make autonomous healthcare decisions, and national CHD transition standards position transfer to adult services between sixteen and eighteen (NHS England, 2016). However, the adolescents' experiences in this study show that legal capacity does not equate to developmental readiness. Assumptions that adolescents can manage appointments, medication, clinical communication, and self-care from age sixteen did not align with the experiences of adolescents in this study, a novel contribution to the CHD literature.

Rigid age thresholds risk missed appointments, inconsistent self-management and potential loss to follow-up. Adolescents remained practically and emotionally reliant on parents, creating tension around when and how to step back. Parents remain central agents during transition and require structured guidance to adapt their role, echoing the work of Moons et al. (2021). These study findings have contextualised barriers to transition within UK policy frameworks, and support flexible, readiness-based, family-inclusive approaches that reflect the developmental and clinical realities of growing up with CHD.

8.2 Living with Uncertainty

Uncertainty was constructed within this study as a significant aspect of experience, shaping how adolescents and parents understood symptoms, navigated day-to-day life and imagined the future. Both groups described living with ongoing fears about deterioration, medical procedures, and long-term health, reflecting wider evidence that a clinically complex CHD carries a particularly unpredictable disease trajectory. Unlike many other LTCs, where symptoms or monitoring routines provide clearer cues, the "invisible" nature of a clinically complex CHD risk intensified anxiety and made uncertainty a pervasive part of family life.

Adolescents in this study described significant fear and uncertainty about future health, treatments, disease progression, death, childbearing, and their ability to participate in everyday life, concerns reflected in existing research (Monti, Jackson and Vannatta, 2018; Nakamura et al., 2018; Gibson et al., 2023; Schiele, Emery and Jackson, 2018). In comparison to other LTCs, a clinically complex CHD is distinct in its less foreseeable trajectory, unlike T1D that carries uncertainty regarding glucose control, complications and pregnancy risks (Rasmussen et al., 2013; Ingersgaard et al., 2021), and asthma involving unpredictability that disrupts daily life and future planning (Holmes et al., 2025). This uncertainty imposes a substantial emotional burden, affecting identity development, self-esteem and future planning, and heightens vulnerability to biopsychosocial risk factors for suicide (Iannucci and Nierenburg, 2022; Mayer et al., 2020). Such psychological strain affects wellbeing and increases pressure on healthcare systems, underscoring the need for strengthened multidisciplinary teams, routine mental-health screening within CHD care, and continuity during transition to adult services.

This study showed that adolescents' understanding of their CHD varied widely, with many younger participants demonstrating limited awareness of their anatomy, surgeries, or long-term risks. Such uncertainty reflects developmental factors, parental protection, memory gaps from early interventions, and communication practices that have not always evolved with adolescence. These findings align with literature highlighting low health literacy and knowledge gaps among adolescents with CHD, who often struggle to recall medical information or articulate their diagnosis (Gray et al, 2018; McLoughlin, Matthews and Hickey, 2018). Similar patterns are observed across adolescents with T1D, CF and epilepsy, who frequently have an incomplete understanding of their condition and rely heavily on caregivers to interpret medical information (Hansen et al., 2024). However, because CHD often lacks visible or day-to-day indicators of stability, adolescents struggle to judge when concerns are serious, making uncertainty more emotionally demanding than in many other conditions. As a result, limited knowledge not only undermines confidence but also increases anxiety and makes independent self-management more difficult.

Parents and adolescents in this study experienced the intervals between cardiac reviews as periods of heightened vigilance and anticipatory anxiety. For parents, day-to-day life often involved monitoring subtle changes and feeling unsure when symptoms warranted concern, echoing evidence that uncertainty about complications is a major stressor in a clinically complex CHD (Kolaitis, Meentken and Utens, 2017; Watkins et al., 2023). Years of medical complexity shaped a persistent hypervigilance, with parents relying heavily on clinical reviews to confirm stability (Nayeri et al., 2021). Unlike healthy families, where adolescence reduces parental oversight, these parents felt unable to step back because deterioration can occur without warning (de Maat et al., 2021; McWhorter et al., 2022). Comparisons with other long-term conditions highlight why uncertainty felt particularly intense. Adolescents with T1D, CF, epilepsy or IBD often have more visible or measurable daily indicators of change, via glucose readings, respiratory symptoms, seizure patterns or gastrointestinal flares (Hansen et al., 2024; Dampier et al., 2019). Families use day-to-day cues to judge stability or deterioration, but complex CHD often offers few consistent indicators. As a result, reassurance depends on scheduled clinical reviews rather than everyday observation. This structural difference heightened the emotional burden and uncertainty described by adolescents and parents. Without strategies to bridge this gap, families may face

ongoing stress, delayed help-seeking and periods of disengagement, increasing risks for both adolescents and parents.

Uncertainty in this study extended beyond day-to-day symptom interpretation to wider fears about future complications, survival and long-term health. Adolescents worried about valve failure, further surgeries and unexpected cardiac events, often imagining worst-case scenarios when symptoms changed or test results were delayed. These findings align with existing evidence that more complex forms of CHD are characterised by lifelong clinical uncertainty, with risks such as arrhythmias, heart failure, or thrombotic events that may evolve with limited or non-specific early symptoms (Watkins et al, 2023).

Research indicates that parents of adolescents with CHD often experience anticipatory anxiety rooted in early medical trauma and fears of future crises (Kolaitis, Meentken and Utens, 2017), while adolescents themselves report heightened distress about mortality and long-term health (Gonzalez et al., 2021; Kovacs et al., 2022). Such psychological strain can negatively affect quality of life, social relationships and educational engagement, and may increase vulnerability to depression and anxiety. Difficulties with school participation and concentration could affect educational attainment, in turn limiting future training and employment opportunities. Over time, these challenges may contribute to widening inequalities in health, wellbeing, and socioeconomic outcomes for young people living with clinically complex CHD.

Heightened parental vigilance was a central feature in this study. Although similar patterns appear in other long-term conditions (Hansen et al., 2024), uncertainty appeared particularly acute in more complex forms of CHD, where clinical deterioration may occur with limited or non-specific warning signs. Parents described closely monitoring symptoms, activity, and behaviour, alongside heightened concern about typical adolescent risk-taking, such as alcohol use, substance use, tattoos, and peer influence, because of their perceived potential for serious cardiac consequences. These findings echo previous evidence describing heightened parental vigilance and anxiety in the context of complex CHD (Ciranka and van den Bos, 2021; DiFusco, Schell and Saylor, 2019; Snygg-Martin et al., 2021). As adolescents gained independence, minor symptoms or routine events triggered significant parental fear, reinforced by memories of earlier medical instability. This persistent anxiety often

resulted in over-monitoring and tension around autonomy, increasing emotional strain for both parents and young people.

The findings revealed body image concerns, linked to surgical scars in CHD, reflected the broader uncertainty of living with a visible reminder of illness, similar to muscular dystrophy (MD) patients who feel self-conscious about mobility aids (Birnkrant et al., 2018). Female participants' fears about reduced femininity and rejection were most pronounced in intimate relationships, driven by uncertainty over how partners perceived their scars. Over time, many insecurities eased, highlighting the role of supportive relationships in helping adolescents manage identity and appearance concerns. Some participants adopted a positive outlook, viewing their scars as part of their identity, consistent with previous research (Tylek et al, 2024). These findings echo evidence that visible markers of illness can disrupt self-esteem, identity, and social confidence (Chong et al., 2018; Vankerckhoven et al., 2023). Similar patterns occur in other long-term conditions where treatment effects heighten body-related anxiety, such as insulin pumps or fear of seizures (Hansen et al., 2024). While surgical intervention may also occur in some anatomically simple lesions, moderate and complex CHD are distinct in that visible scarring often reflects early life-saving intervention and ongoing vulnerability, reinforcing uncertainty about the future (Vankerckhoven et al., 2023; Savas et al., 2024). This heightened self-awareness can influence peer relationships, and later decisions around work, intimacy and independence.

Beyond healthcare, everyday communication shaped adolescents' self-perception. Some experienced judgemental comments about body size or scarring, reinforcing feelings of difference. These experiences align with research on altered embodiment in CHD (Chong et al., 2018; Vankerckhoven et al., 2023) and mirror body-related stigma across other LTCs such as CF, IBD and SCD, where appearance-based assumptions create stigma. For adolescents in this study, such comments carried added weight because appearance was often linked to fears about heart health or long-term survival (Gonzalez et al., 2021; Kovacs et al., 2022), reinforcing feelings of difference, diminished confidence and heightened anxiety. Such interactions undermine adolescents' sense of belonging and may heighten self-consciousness or reluctance to participate in social or health-related activities. These experiences

highlight the wider need for public and community awareness about CHD to reduce judgment and support adolescents' confidence and wellbeing.

The COVID-19 pandemic intensified pre-existing uncertainty in moderate and complex CHD by disrupting routine cardiac care, while evolving and inconsistent public health guidance, including shielding recommendations, further contributed to anxiety among adolescents and parents. Appointment cancellations and delays, heightened anxiety among adolescents, align with previous research (Lin et al., 2024) and reflect the importance of regular surveillance for managing uncertainty (Kolaitis, Meentken, and Utens, 2017; Watkins et al., 2023). Likewise, reduced contact with paediatric teams increased parental hypervigilance and shifted responsibility for symptom interpretation to families, whilst adolescents reported less confidence in judging symptoms, echoing evidence of limited health literacy in this group (McLoughlin, Matthews and Hickey, 2018). These disruptions exposed families to increased psychological strain and highlighted vulnerabilities in care continuity for adolescents with moderate and complex CHD. Service disruption and unclear guidance during periods of crisis may heighten stress and uncertainty for adolescents and their families, particularly where regular specialist input is reduced. Diminished clinical contact can undermine confidence in interpreting symptoms and shift complex health-related decision-making onto parents, potentially amplifying stress and contributing to delays in seeking care.

These findings suggest that uncertainty in complex CHD is not just a medical issue, it permeates psychological, developmental, physical, and relational domains. It drives chronic anxiety and emotional fatigue, delays autonomy and identity formation, and can lead to avoidance behaviours that compromise care. At the family level, uncertainty sustains high parental vigilance, which adolescents may perceive as overcontrol, creating friction during a stage when independence is expected.

8.3 Family Roles and Interdependence

This study suggests that growing up with moderate and complex CHD sustains close interdependence between adolescents and parents in managing health risks, interpreting symptoms, and coping with ongoing uncertainty. In contrast to typical developmental trajectories that emphasise increasing independence during adolescence, participants described continued reliance on parents for emotional support, shared decision-making, and practical aspects of care. These findings

highlight how medical complexity can shape family roles and responsibilities alongside, and sometimes in tension with, normative developmental processes.

Across families, moderate and complex CHD appeared to create relational structures in which roles were shared and overlapping, reflecting deeply interdependent patterns consistent with existing CHD research (Hsiao et al, 2024). Parents relied on each other for emotional buffering, adolescents depended on parents for stability, and families negotiated internal tensions shaped by fear, protection and emerging independence. Spousal support played a vital role, with parents describing compensatory dynamics when one partner felt overwhelmed, patterns consistent with family systems research in chronic illness, consistent with research showing that CHD parents often rely on each other to manage emotional strain and uncertainty (Kolaitis, Meentken and Utens, 2017). This study highlighted that families often experienced tensions around risk thresholds, limits, and adolescent readiness. While emotional buffering and spousal support provided stability, these dynamics also revealed strains over autonomy and decision-making.

Parents in this study remained deeply involved in coordinating care, monitoring symptoms, making decisions and managing appointments, reflecting the reality that complex CHD does not lend itself easily to adolescent-led self-management. With limited daily indicators of stability or decline, parents described feeling responsible for detecting subtle changes in their child's condition and determining when medical attention was needed. This supports findings that CHD parents experience enduring vigilance influenced by past instability and anxiety about unexpected deterioration (Kolaitis, Meentken and Utens, 2017; de Maat et al., 2021; Watkins et al., 2023). This not only sustains parental anxiety but also complicates efforts to promote autonomous adolescent self-management, suggesting that transition planning must account for these realities.

Parents acted as advocates across schools, hospitals, and social settings, often correcting misinformation and ensuring appropriate adjustments, reflecting research that CHD is poorly understood outside specialist care (Chong et al., 2018; Vankerckhoven et al., 2023). These responsibilities added emotional strain and reinforced parents' central role in their child's wellbeing, despite transition policies

urging them to step back. Clearer communication and support are needed to ease this burden.

Despite expectations of independence, adolescents remained heavily reliant on parents for practical and emotional support, hindered by limited health literacy and confidence, supporting the works of McLoughlin, Matthews and Hickey (2018). This reliance emphasises the need for targeted interventions to build self-management skills and improve understanding of CHD, ensuring smoother transitions to adult care. This relational dependence also shaped identity development. Adolescents described guilt about causing parental worry, fear of disappointing parents, and reluctance to express symptoms due to concerns about triggering parental anxiety. Such dynamics can hinder autonomous decision-making and increase stress for parents and adolescents, reinforcing the need for clinicians to support realistic, gradual role renegotiation.

Emotional dependence was equally evident. Adolescents expressed anxiety about misinterpreting symptoms and relied on parents to judge whether changes were concerning. This fosters interdependence, contrasting with conditions like T1D or CF, where routine self-monitoring builds autonomy (Hansen et al., 2024). In moderate and complex CHD, the absence of consistent day-to-day health routines may limit opportunities for independent decision-making, reinforcing shared responsibility for health management.

An important contribution of this study is the insight into fathers' experiences, an area under-represented in CHD research (Postavaru, Swaby and Swaby, 2021; Gower, van Meures and Bailey, 2017; Lisanti, 2018; Bruce, Lindh and Sundin, 2016). Fathers reported feeling marginalised in clinical encounters, overshadowed by assumptions that mothers are the primary caregivers, contributing to broader findings that fathers often seek practical information and clarity but receive less targeted support (Postavaru, Swaby and Swaby, 2021; Spurr et al., 2023). Their accounts revealed a desire to be involved but limited opportunities to do so, reflecting systemic biases in healthcare communication, significant because paternal involvement is associated with improved adolescent psychological wellbeing and coping in chronic illness (Woolf-King et al., 2018). Fathers in this study often described providing stability behind the scenes, managing logistics, offering practical reassurance, and supporting partners,

aligning with current literature (Hoffman et al., 2020; Bruce, Lindh and Sundin, 2016), but struggled to voice concerns as readily as mothers. This silent labour represents an overlooked component of family interdependence. The lack of engagement with fathers also risks narrowing the support available to adolescents, particularly those who rely more on paternal than maternal communication styles. Supporting fathers explicitly may therefore enhance whole-family resilience. The experiences discussed here suggest that families living with moderate and complex CHD rely on shared, relational approaches to managing health rather than developing independence in isolation. Adolescents and parents described co-managing symptoms, negotiating meaning and risk together, and providing reciprocal reassurance amid ongoing uncertainty. These patterns indicate that moderate and complex CHD may foster a family model characterised by shared responsibility and mutual reliance as an adaptive response to clinical unpredictability. Rather than following a linear trajectory toward independence, adolescents and parents appeared to maintain interdependence, where uncertainty and medical complexity render individual decision-making potentially risky

8.4 The Role of Communication

This study constructed communication as a central concern within both parent and adolescent accounts, shaping not only understandings of CHD but also experiences of coping with uncertainty. While some families described open and supportive dialogue with professionals, others reported communication that was blunt, inconsistent or poorly framed. Parents in particular highlighted how risk was sometimes conveyed in ways that left them shocked or unprepared, and adolescents often struggled to process complex information without parental support

A key finding of this study is that how information was delivered mattered as much as what was said. Technical or insensitive explanations about surgery, deterioration or prognosis had lasting emotional effects, whereas relational, empathetic communication reduced anxiety and supported engagement. This reinforces evidence that tone, clarity and compassion are fundamental to effective communication (Moons et al., 2021; Pagel et al., 2019). Families consistently valued relational communication for strengthening trust, enhancing emotional security and supporting decision-making, improving emotional wellbeing and long-term health outcomes.

While these findings align with literature showing that poor communication in paediatric cardiology heightens parental stress and erodes trust (Anosova et al., 2025), this study adds that how information is conveyed can be as critical as its content. Insensitive phrasing around surgical risks had long-term emotional consequences for both parents and young people, whereas empathetic and relational dialogue reduced anxiety and supported engagement. Parents recalled moments when risk was conveyed in ways that left them shocked, unprepared, and unsure how to make sense of what they had been told, whilst adolescents frequently struggled to process complex terminology without parental help. Effective communication proved fundamental to fostering a sense of security and engagement. Families contrasted the relational, consistent communication of paediatric teams with the more task-focused style of adult services, aligning with evidence that empathy, clarity and continuity underpin successful transition (Moons et al., 2021; Pagel et al., 2019). Fragmented communication heightened uncertainty and disengagement, similar to other LTCs (Hansen et al., 2024), but with more serious consequences in CHD because misunderstandings may delay help-seeking amid health deterioration. Consistent communication across services is vital for safety and emotional stability. Insensitive delivery can lead adolescents to disengage and parents to lose trust. Clear, compassionate risk communication is essential to maintain parental confidence and prepare adolescents for adult care

Language was constructed as particularly powerful within participant accounts. Parents rejected terms such as disease, fixed or mended, explaining that these misrepresented their children's ongoing health needs and contributed to stigma. This represents a novel contribution to CHD literature, which has largely focused on clinical accuracy rather than the psychosocial impact of language. It also contributes to broader debates on the social construction of illness and the role of language in shaping identity (Bury, 2001; Kelly, 2016). Those communicating with adolescents and families must consider the symbolic and emotional impact of their language to avoid reinforcing fear, shame or misunderstanding.

Feelings of being unheard were constructed as a key aspect of participant experience. Parents felt their concerns were dismissed, which eroded trust and reinforced exclusion. Adolescents reported similar experiences when clinicians either directed information solely to parents or abruptly shifted it to them, leaving them overwhelmed.

This highlights how suboptimal communication can heighten psychological strain and limit adolescents' participation in decision-making, underscoring the need for strategies that promote inclusive, developmentally appropriate dialogue during transition (Bosch et al, 2024)

Communication difficulties also extended into secondary schools, where adolescents and parents described inconsistent understanding and support from teachers and pastoral staff. Many felt that school personnel had limited CHD knowledge, were unsure about safe activity levels, or made assumptions based on appearance. This aligns with CHD literature showing that educator misunderstanding can lead to unnecessary restrictions or, conversely, unsafe expectations (Chong et al., 2018; Vankerckhoven et al., 2023). Parents reported repeatedly explaining the condition and correcting misinformation, adding emotional strain at a time already marked by uncertainty. These experiences mirror patterns across other long-term conditions, including T1D, CF and epilepsy, where school staff often lack adequate training or confidence to support medical needs (Hansen et al., 2024). These gaps in understanding undermined adolescents' sense of safety, reduced their confidence in communicating symptoms, and pushed parents into heightened vigilance or repeated advocacy. Inconsistent knowledge among school staff not only increased emotional strain for families but also led to inappropriate activity restrictions or, at times, unsafe expectations. These patterns point to a broader systemic gap in school-based support for young people with moderate and complex CHD. Strengthening staff awareness and education, promoting active listening, and validating adolescents' concerns may help to enhance emotional security and support safe, inclusive participation in school life.

Families described confusion caused by inconsistent or contradictory messaging between professionals. This aligns with the LTC literature, which shows that communication breakdown contributes to disengagement and reduced adherence (Gerardin et al., 2019; Hansen et al., 2024). Given the potential for deterioration in CHD, such confusion can have significant clinical consequences. Coordinated, coherent communication across teams is essential to preserving trust, promoting engagement and ensuring clinical safety.

The accounts presented here highlight the need for communication training that goes beyond technical explanations to include relational skills such as empathy, continuity and age-appropriate discussion. In practice, this means recognising parents as ongoing advocates and ensuring that adolescents are supported to gradually develop their own voice in consultations. On a broader level, it suggests that clinical services and public health campaigns should work with families in co-design processes to ensure language is accurate, sensitive and supportive

8.5 Contributions to Knowledge and Implications for Practice and Policy

This study contributes new understanding of how adolescents with moderate and complex CHD and their parents experience everyday life and the transition to adult care. By examining both perspectives together, and situating them within communication practices, developmental expectations, and the disruption associated with the COVID-19 pandemic, the study offers insight into the relational, emotional, and structural challenges shaping CHD management. Unlike much existing research that considers parents or adolescents in isolation, these findings highlight the management of moderate and complex CHD as a shared family process. Day-to-day coping, decision-making and emotional regulation are negotiated collectively, with adolescents' emerging autonomy closely linked to parents' ongoing protective and supportive roles. This supports evidence that CHD management is fundamentally relational and developmental rather than based solely on individual responsibility or clinical milestones (White and Cooley, 2018; Moons et al., 2021), underscoring the need for family-inclusive approaches when living with complex CHD.

8.5.1 Contributions to knowledge

The findings extend existing knowledge by demonstrating that communication functions as a form of emotional support, not merely as a clinical explanation. Differences between paediatric and adult services shaped families' sense of safety, trust, and preparedness, highlighting how communication practices can either mitigate or intensify uncertainty, particularly during transitions.

By including fathers' perspectives, the study addresses a significant gap in CHD research. Fathers described feeling marginalised within clinical encounters despite playing key supportive roles at home, revealing gendered assumptions in care practices and communication. This supports research showing that father involvement

benefits adolescent wellbeing (Woolf-King et al., 2018) but is often overlooked (Spurr et al., 2023), highlighting the need for father-inclusive communication and support.

A further contribution is the evidence that current age-based transition policies do not match the developmental readiness of adolescents with complex CHD. The study strengthens the argument that transition should be flexible and readiness-based, especially in CHD, where deterioration may be unnoticed and missed appointments can have serious consequences (Ambrosio et al., 2021; Watkins et al., 2023).

A further contribution is the identification of the psychosocial power of language. Participants' accounts show that clinical terminology shapes identity, stigma and understandings of ongoing risk, extending work on the social framing of illness by demonstrating its emotional and relational impact. Poorly chosen terms can undermine trust and increase anxiety, while sensitive and accurate language can support acceptance and meaning-making. Terminology such as "disease," "fixed," or complex anatomical labels carried emotional weight and were often perceived as minimising ongoing risk. In contrast to research focused on clinical clarity, this study highlights the psychological impact of language in CHD, linking with wider theories on the social meaning of illness (Bury, 2001, Kelly, 2016).

The findings provide condition-specific evidence of how pandemic-related service disruption intensified uncertainty, reduced confidence in symptom monitoring, and placed greater responsibility on families, exacerbating existing vulnerabilities in CHD care and transition.

8.5.2 Implications for Practice and Policy

The findings of this study have important implications for both clinical practice and health policy, highlighting areas where current transition pathways for adolescents with CHD and their families may be insufficiently responsive to lived experience. The following sections outline key practice and policy relevant domains generated through the analysis, with implications for the design, delivery, and communication of services during the transition from paediatric to adult care.

8.5.3 Family- centered models of transition

Abrupt transition to adult care was experienced as unrealistic and distressing. Services should strengthen family-centred, phased transition models that recognise

adolescent–parent interdependence and support the gradual sharing of responsibility, rather than the sudden transfer of responsibility.

8.5.4 Communication

Clear, supportive, and consistent communication from HCPs can improve transition preparation, enhance adolescents' confidence in managing their care, support parents as roles change, and maintain trust in services.

8.5.5 Language and Terminology

The study highlights the psychosocial impact of terminology, with parents rejecting labels such as "disease" or "mended." Clinical teams and public health bodies should use language that reflects the lifelong nature of CHD without reinforcing stigma or unrealistic expectations, ideally co-designed with adolescents and parents.

8.5.6 Ongoing parental involvement

Despite increasing independence, parents remain key advocates and sources of reassurance. Services should facilitate parental involvement when desired, including in adult care, rather than excluding parents solely on the basis of adolescent age.

8.5.7 Psychosocial and educational support

Psychosocial support should be further integrated into routine CHD care to address uncertainty, anxiety and identity challenges. This might include family access to counselling, peer support groups, or specialist psychological services embedded within congenital cardiology teams. In educational settings, a designated contact (e.g., a school nurse or pastoral lead) and basic CHD training for staff, supported by CPD and Personal, Social, Health and Economic (PSHE) health literacy, could improve continuity during transitions.

8.5.8 Contributions and Implications Summary

Taken together, these implications emphasise the importance of CHD services that move beyond a narrow focus on survival and medical management, towards holistic, family-centred care that addresses the relational, emotional and social dimensions of living with clinically complex CHD.

8.6 Methodological Reflections

This study offers several methodological strengths. Using a qualitative, interpretivist approach enabled a nuanced exploration of the relational and emotional experiences of parents of children with complex CHD and adolescents with complex CHD. Open-ended interviewing allowed participants to shape the conversation, yielding richer insights than a more rigid format would have permitted. This depth of understanding was strengthened by reflexive engagement throughout the research process and by peer review of the analysis, enhancing credibility and alignment with wider literature.

The involvement of a YPAG and the use of an animated video to facilitate informed consent further represent ethical and methodological innovations. The YPAG offered invaluable guidance on language, interview structure and accessibility, ensuring that the study was shaped by young people rather than merely about them. The animated consent resource supported comprehension of complex information, reduced reliance on dense written documents, and promoted autonomy by allowing adolescents to review materials at their own pace. These approaches enhanced inclusivity, reduced power imbalances, and empowered adolescents to participate meaningfully in research concerning their lives.

The use of RTA provided a systematic framework for coding and theme development. Nonetheless, as with all qualitative research, interpretation remains influenced by the researcher's position and assumptions. Findings, therefore, represent co-constructed meaning rather than objective truth, a reality intrinsic to interpretivist inquiry

The study also has limitations. The participants consisted entirely of White British nuclear-family households, most of whom were digitally engaged, with parents primarily employed, which limited the representativeness of the findings. Important perspectives, such as those from minority ethnic families, single-parent households, or young people with CHD who have not required surgery, were not captured.

Online video interviews, while convenient and accessible, limited my ability to observe full-body non-verbal cues or the nuances of in-person interaction. Technical issues, variable internet quality and the need for private spaces occasionally disrupted emotional flow or inhibited participants' openness. These factors may have constrained the depth of rapport and the richness of data that might emerge in a face-to-face setting. Online interviews also risked excluding families without reliable internet

access or a safe, uninterrupted place to participate, potentially underrepresenting those with fewer resources or higher levels of social disadvantage in the sample. Although both adolescents and parents were included, parental voices were more numerous, resulting in less depth of adolescent data.

A pilot interview was not conducted due to the small eligible sample, meaning refinements to the interview schedule occurred in real time rather than in advance

These limitations have implications for transferability. Qualitative work provides rich experiential insight but cannot speak to prevalence, generalisability, or policy impact without complementary quantitative data. Future research would benefit from broader, more inclusive sampling strategies, such as stratified or community-engaged recruitment, to capture diverse cultural backgrounds and family structures.

Longitudinal qualitative or mixed-methods designs could examine how uncertainty, communication and family roles evolve over time, particularly across key transition points. Interventional studies evaluating readiness-based or family-inclusive transition models would also help to provide an important next step in translating these experiential findings into practical service improvements.

Evaluating structured interventions, such as personalised readiness assessments, staged skill-building programmes, or models that maintain parental involvement in developmentally appropriate ways, would help determine whether these approaches improve engagement, reduce anxiety, and support safer transfer to adult care.

8.7 Summary

Across the discussion chapters, this study demonstrates how everyday life with moderate and complex CHD is fundamentally shaped by ongoing uncertainty, communication practices, and deeply interdependent family relationships. Adolescents and parents do not experience health management or transition as individual processes; rather, they navigate emotional, developmental, and practical challenges collaboratively, with transition to adult care often perceived as abrupt and destabilising when viewed through the lens of shared family experience. By integrating adolescent and parent perspectives, this study advances understanding of CHD management as a relational process, revealing the psychosocial power of language in shaping meaning, risk appraisal, and reassurance. It makes a distinct contribution by foregrounding fathers' voices and showing how the COVID-19 pandemic intensified

existing vulnerabilities in care continuity, communication, and transition readiness. Methodologically, the study's reflexive qualitative design, inclusion of a YPAG, and use of animated consent improved accessibility and analytic depth. In contrast, limited sample diversity and reliance on online data collection indicate the need for more inclusive, longitudinal research.

Chapter Nine: Conclusion and Recommendations

This thesis set out to explore how adolescents living with moderate and complex CHD and their parents experience everyday life, long-term cardiac care, and the transition toward adult services. Through qualitative enquiry and RTA, the study has shown that adolescence in the context of moderate and complex CHD is shaped by enduring uncertainty, complex communication practices, and deeply interdependent family relationships. These findings demonstrate that the practical, emotional, and developmental challenges faced by families extend beyond individual self-management and are not fully reflected in prevailing healthcare structures or policy assumptions.

By bringing together the perspectives of adolescents and parents, this research shows that living with moderate and complex CHD is best understood as a shared family process rather than an individual journey. Adolescents continued to rely on parents for emotional support, symptom interpretation, and shared decision-making, while parents experienced ongoing difficulty stepping back from roles they viewed as essential to maintaining safety. This sustained interdependence challenges dominant transition narratives that prioritise early autonomy and independence, highlighting a mismatch between policy expectations and the developmental realities of young people living with medically complex and unpredictable conditions.

The findings extend existing CHD literature by demonstrating that transition, communication, and autonomy are fundamentally relational and must be understood in the context of ongoing uncertainty and family interdependence. Novel contributions include highlighting the emotional significance of clinical terminology, foregrounding fathers' experiences within family care, and illustrating how the COVID-19 pandemic intensified existing vulnerabilities in communication, continuity of care, and transition readiness. Together, these insights emphasise the importance of family-centred, developmentally attuned approaches that recognise emotional security, shared decision-making, and preparedness as central to effective care.

Methodologically, this thesis demonstrates the value of reflexive qualitative approaches in capturing the lived complexity of CHD across adolescence and family life. The use of semi-structured interviews enabled rich exploration of identity, uncertainty, and family negotiation, while involvement of a YPAG and the use of

animated consent supported developmentally appropriate and inclusive participation. While the sample size, reliance on online interviewing, and limited diversity are acknowledged constraints, the inclusion of fathers' voices provides important insights into an underrepresented perspective and points to priorities for future research.

Overall, this thesis shows how adolescents and parents make sense of moderate and complex CHD and manage its impact on identity, relationships, and daily life. The themes of interdependence, preparedness, emotional security, and systemic gaps help explain why current policies and services often fall short for this population. By demonstrating that families' needs extend well beyond clinical management alone, this research offers evidence to inform more flexible, relational, and psychologically informed healthcare practice, education, and policy, and provides a foundation for future work aimed at improving quality of life for young people living with moderate and complex CHD and those who care for them

9.1 Research Recommendations

This study highlights several priorities for future research to improve care for adolescents with complex CHD and their families, particularly around transition, psychological wellbeing, education, support networks, and service resilience. Findings suggest a need to develop readiness-based, developmentally appropriate transition models that reflect transition as a shared family process, incorporate family-inclusive approaches, and address anxiety driven by abrupt transfer and inconsistent communication, with attention to adopting more relational, empathic communication in adult services. Research is also needed to address significant psychological burden, including anxiety, uncertainty and hypervigilance, through CHD-specific mental health screening, improved access to support, greater understanding of fathers' distinct experiences and preferences, and exploration of how early medical trauma shapes long-term coping and transition readiness. In education settings, future studies should examine gaps in school staff knowledge, evaluate co-designed educational resources to reduce misunderstanding and family burden, and assess age-appropriate health literacy interventions to support adolescents' understanding of their condition. Given the reported isolation and fragmented support, further research should explore the role of peer networks for adolescents and parents, including father-specific groups, resources for extended family members, and integrated partnerships across the healthcare, education, and charitable sectors. Finally, the disruptions caused by

COVID-19 underline the importance of investigating long-term impacts on mental health, help-seeking and transition preparedness, as well as evaluating hybrid models of CHD care that combine virtual and face-to-face support to enhance resilience during future system pressures or public health crises.

9.2 Summary

This study identifies key priorities for future research to improve care for adolescents with complex CHD and their families. Recommendations emphasise the need for readiness-based, developmentally appropriate transition models that recognise transition as a shared family process and prioritise consistent, empathic communication to reduce anxiety. Further research is needed to address the substantial psychological burden through CHD-specific mental health screening, improved access to support, greater inclusion of fathers' perspectives, and a better understanding of the long-term effects of early medical trauma. Studies should also focus on strengthening support beyond healthcare by addressing gaps in school-based knowledge, evaluating co-designed educational and health literacy interventions, and exploring the role of peer and extended-family support. Finally, research should examine the long-term impact of COVID-19 disruptions and evaluate hybrid care models to support resilience and continuity for families managing complex CHD.

Finally, this thesis concludes with a reflective pitstop, highlighting personal challenges and accomplishments encountered when completing my MPhil research study:

Reflective pitstop

The process of undertaking this master's research study and associated thesis was not without challenges. It had been several years since I had studied research methods or undertaken any formal academic assessment. Despite my academic background and awareness of scholarly expectations, I felt undeserving of this postdoctoral opportunity and experienced impostor syndrome, especially while studying under colleagues who also serve as my supervisors. However, I can now see how I have improved academically, and take joy in the research opportunity, but that feeling of "I could have done better" will probably never leave my thoughts.

The realisation that my writing skills leaned toward description and lacked the critical synthesis required at this level was reinforced by the rigorous feedback from my

supervisory team. This compounded the imposter feeling. How could I be an academic for twenty years plus when I can't master this master's writing? Yet, this realisation became a turning point. By engaging more critically with the literature and allowing myself to sit with discomfort, I began to see writing not as proof of inadequacy but as a process of thinking. Learning to move beyond description has been challenging, but it has deepened both my analytical voice and my confidence as a researcher.

Listening to participants' stories was often emotionally moving, particularly as their experiences resonated with my professional background in nursing. At times, hearing their accounts of vulnerability, resilience, and family relationships evoked feelings of sadness and empathy. However, I consciously adopted my "nursing head" during data collection and analysis, allowing me to acknowledge these emotional responses while maintaining professional boundaries and analytic focus. This balance enabled me to remain present and compassionate without allowing my emotions to overshadow participants' voices or the integrity of the research.

Throughout the process, I encountered significant emotional and mentally demanding life events, which many times made me question my ability to continue, and stepping away seemed the only option. However, key moments reinvigorated my desire to complete. I presented a research study poster at a CHD conference and was shortly after approached by a delegate who had a child with complex CHD. They could relate to the research findings, which underscored both their own journey and that of their child, and were grateful that parental and adolescent voices were being heard. In addition, a clinical CHD specialist reaffirmed the need for awareness of my findings within the clinical field.

These experiences, along with my undying gratitude for the participant's time and stories, made me appreciate the study's value and motivated me to complete it.

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Appendix A: Literature Search Strategy Adolescents

Medline EBSCOhost 1946 – 29th Jan 2025		
S1	(MH “Pediatrics”)	59,350
S2	p?ediatric*	283,904
S3	(MH “Child”)	2,001,647
S4	child*	3,459,219
S5	youth*	137,878
S6	teenager*	26,963
S7	adolescent*	2,456,032
S8	or/1-7	4,737,144
S9	(MH “Heart Defects, Congenital”)	61,923
S10	congenital heart defect*	68,678
S11	congenital heart disease*	76,803
S12	congenital cardiovascular malformation*	408
S13	(MH “Aortic Valve Stenosis”)	34,508
S14	aortic stenosis	46,578
S15	bicuspid aortic valve	6,280
S16	(MH “Aortic Coarctation”)	10,035
S17	coarctation of the aorta	10,558
S18	aortic coarctation	11,737
S19	Complete Atrioventricular Canal defect	177
S20	Complete Atrioventricular septal defect	489
S21	(MH “Heart Block”)	20,416
S22	heart block	29,251
S23	Ebstein's anomaly	2,909
S24	endocardial fibroelastosis	1,419
S25	Eisenmenger's syndrome	1,518
S26	interrupted aortic arch	1,252
S27	isolated non-compaction of left ventricular myocardium	14
S28	(MH “Long QT Syndrome”)	9,193
S29	long qt syndrome	11,894

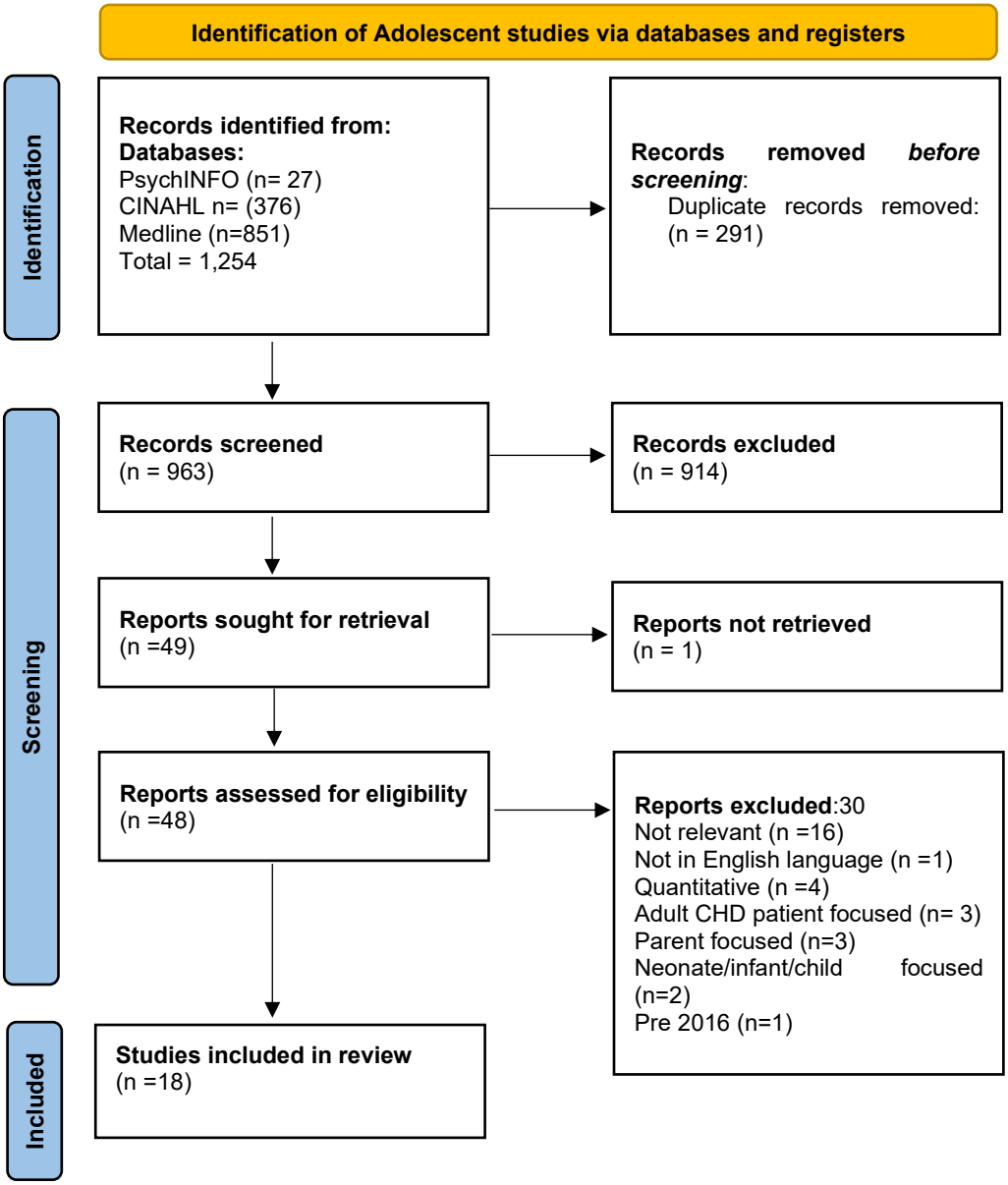
S30	(MH “Mitral Valve”)	35,030
S31	patent ductus arteriosus	14,347
S32	(MH “Pulmonary Valve Stenosis”)	6,476
S33	pulmonary valve stenosis	7,323
S34	(MH “Pulmonary Atresia”)	1,753
S35	pulmonary atresia	4,558
S36	(MH “Heart Septal Defects” OR (MH “Heart Septal Defects, Ventricular”) OR (MH “Heart Septal Defects, Atrial”)	28,587
S37	septal defect*	42,226
S38	hypoplastic left heart syndrome	4,673
S39	tricuspid atresia	1,884
S40	(MH "Tetralogy of Fallot")	10,282
S41	Tetralogy of Fallot	14,303
S42	total anomalous pulmonary venous connection	1,045
S43	(MH "Transposition of Great Vessels”)	7,804
S44	transposition of the great arter*	6,440
S45	(MH “Truncus Arteriosus”)	310
S46	truncus arteriosus	2,181
S47	Ventricular Septal Defect	21,675
S48	Atrial Septal Defect	19,620
S49	OR/S9-S49	274,899
S50	S8 AND S49	97,279
S51	(MH “Qualitative Research”)	97,935
S52	Qualitative Research	130,416
S53	Interview*	528,582
S54	focus group*	87,267
S55	(MH “Focus Group”)	52,380
S56	(thematic* OR theme*)	220,839
S57	Ethnograph*	15,973
S58	Phenomenol*	38,507
S59	symbolic interact*	862

S60	grounded theory	18,803
S61	(MH “Grounded Theory”)	3,162
S62	OR/S51-61	736,837
S63	S50 AND S62	852
CINHALUltimate1980-29/01/2025		
S1	(MH “Pediatrics”)	21,746
S2	p?ediatric*	32,640
S3	(MH “Child”)	544,250
S4	child*	980,560
S5	Youth*	74,062
S6	teenager*	12,274
S7	adolescent*	190,079
S8	OR/S1-S7	1,114,373
S9	(MH “Heart Defects, Congenital”)	13,052
S10	congenital heart defect*	13,910
S11	congenital heart disease*	15,211
S12	congenital cardiovascular malformation*	57
S13	(MH “Aortic Valve Stenosis”)	6,518
S14	aortic stenosis	9,171
S15	bicuspid aortic valve	1,229
S16	(MH “Aortic Coarctation”)	1,131
S17	coarctation of the aorta	1,342
S18	aortic coarctation	1,395
S19	Complete Atrioventricular Canal defect	22
S20	Complete Atrioventricular septal defect,	69
S21	(MH “Heart Block”)	4,229
S22	heart block	5,403
S23	Ebstein's anomaly	555
S24	endocardial fibroelastosis	75
S25	Eisenmenger's syndrome	333
S26	interrupted aortic arch	173

S27	isolated non-compaction of left ventricular myocardium	2
S28	(MH “Long QT Syndrome”)	3,172
S29	long QT syndrome	3,777
S30	(MH “Mitral Valve”)	4,982
S31	patent ductus arteriosus	2,918
S32	(MH “Pulmonary Valve Stenosis”)	369
S33	pulmonary valve stenosis	492
S34	(MH “Pulmonary Atresia”)	231
S35	pulmonary atresia	638
S36	(MH “Heart Septal Defects” OR (MH “Heart Septal Defects, Ventricular”) OR (MH “Heart Septal Defects, Atrial”)	4,765
S37	septal defect*	7,034
S38	hypoplastic left heart syndrome	1,087
S39	tricuspid atresia	228
S40	(MH "Tetralogy of Fallot")	1,459
S41	Tetralogy of Fallot	2,356
S42	total anomalous pulmonary venous connection	231
S43	(MH "Transposition of Great Vessels”)	1,645
S44	transposition of the great arter*	1,565
S45	(MH “Truncus Arteriosus”)	214
S46	truncus arteriosus	213
S47	Ventricular Septal Defect	2,658
S48	Atrial Septal Defect	4,210
S49	OR/S9-S48	53,193
S50	S8 AND S49	12,211
S51	(MH “Qualitative Research”)	853
S52	Qualitative Research	28,790
S53	Interview*	404,814
S54	(MH “Focus Group”)	691
S55	focus group*	69,937

S56	(thematic* OR theme*)	174,417
S57	Ethnograph*	16,198
S58	Phenomenol*	32,324
S59	symbolic interact*	1,216
S60	(MH “Grounded Theory”)	19,252
S61	grounded theory	23,555
S62	OR/S51-S61	518,252
S63	S50 AND S62	379
PSYCHINFO 1806-16th Jan2025		
S1	congenital heart disease*	1145
S2	congenital heart defect*.	822
S3	congenital cardiovascular malformation*	63
S4	congenital heart malformation*	110
S5	congenital heart disorder*	1414
S6	OR/S1-S5	1516
S7	MAINSUBJECT.EXACT("Qualitative Methods")	11810
S8	MAINSUBJECT.EXACT("Interviews")	13350
S9	MAINSUBJECT.EXACT("Focus Group")	868
S10	(Theme* or thematic*)	202939
S11	(narrative* OR discourse*)	161384
S12	OR/S7-S11	171715
S13	S6 AND S12	27

Appendix B: PRISMA: Flowchart of Adolescent study selection



Source: Page MJ, et al. BMJ 2021;372: n71. doi: 10.1136/bmj. n71.

Appendix C: Literature Search Strategy Parents

Medline EBSCOhost 1946 – 29th Jan 2025		
S1	(MH “Parents”)	87,588
S2	(MH “Carer”)	42
S3	carer*	52,364
S4	mother*	354,925
S5	father*	97,212
S6	adolescent*	2,456,032
S7	teenager*	26,963
S8	youth*	137,878
S9	Child*	3,495,219
S10	or/1-10	4,856,826
S11	(MH “Heart Defects, Congenital”)	61,923
S12	congenital heart defect*	68,678
S13	congenital heart disease*	76,803
S14	congenital cardiovascular malformation*	408
S15	(MH “Aortic Valve Stenosis”)	34,508
S16	aortic stenosis	46,578
S17	bicuspid aortic valve	6,280
S18	(MH “Aortic Coarctation”)	10,035
S19	coarctation of the aorta	10,558
S20	aortic coarctation	11,737
S21	Complete Atrioventricular Canal Defect	177
S22	Complete Atrioventricular Septal Defect	489
S23	(MH “Heart Block”)	20,416
S24	heart block	29,251
S25	Ebstein's anomaly	2,909
S26	endocardial fibroelastosis	1,419
S27	Eisenmenger's syndrome	1,518
S28	interrupted aortic arch	1,252
S29	isolated non-compaction of left ventricular myocardium	14

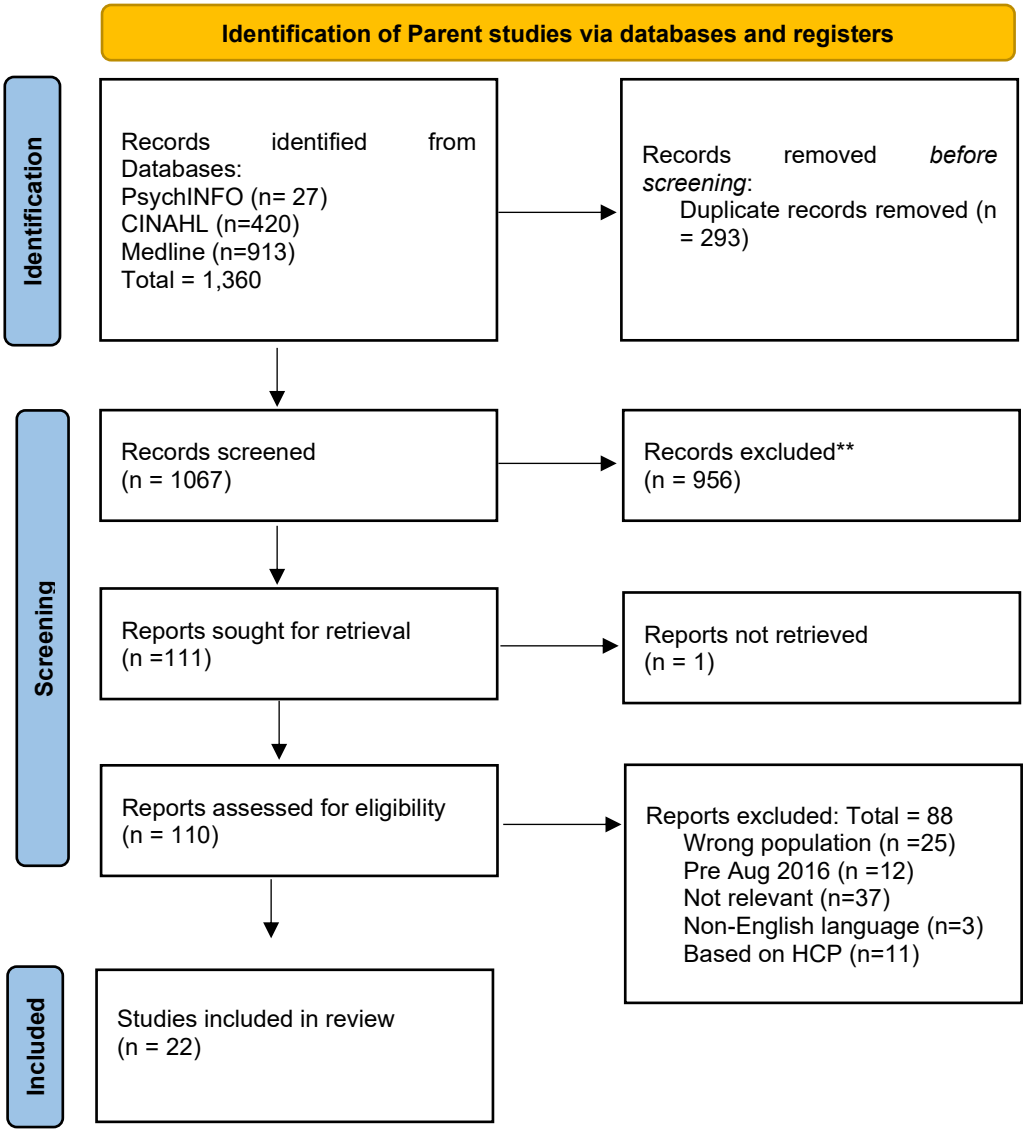
S30	(MH “Long QT Syndrome”)	9,193
S31	long qt syndrome	11,894
S32	(MH “Mitral Valve”)	35,030
S33	patent ductus arteriosus	14,347
S34	(MH “Pulmonary Valve Stenosis”)	6,476
S35	pulmonary valve stenosis	7,323
S36	(MH “Pulmonary Atresia”)	1,753
S37	pulmonary atresia	4,558
S38	(MH “Heart Septal Defects” OR (MH “Heart Septal Defects, Ventricular”) OR (MH “Heart Septal Defects, Atrial”)	28,587
S39	septal defect*	42,226
S40	hypoplastic left heart syndrome	4,673
S41	tricuspid atresia	1,884
S42	(MH "Tetralogy of Fallot")	10,282
S43	Tetralogy of Fallot	14,303
S44	total anomalous pulmonary venous connection	1,045
S45	(MH "Transposition of Great Vessels”)	7,804
S46	transposition of the great arter*	6,440
S47	(MH “Truncus Arteriosus”)	310
S48	truncus arteriosus	2,181
S49	Ventricular Septal Defect	21,675
S50	Atrial Septal Defect	19,620
S51	OR/S12-S52	274,899
S52	S11 AND S52	96,966
S53	(MH “Qualitative Research”)	97,935
S54	Qualitative Research	130,416
S55	Interview*	528,582
S56	focus group*	87,267
S57	(MH “Focus Group”)	52,380
S58	(thematic* OR theme*)	220,839
S59	Ethnograph*	15,973

S60	Phenomenol*	38,507
S61	symbolic interact*	862
S62	grounded theory	18,803
S63	(MH “Grounded Theory”)	3,162
S64	OR/S54-64	736,847
S65	S53 AND S65	913
CINALH Ultimate EBSCOhost 1980-29th January 2025		
S1	(MH “Parents”)	55,213
S2	p?arent*	0
S3	(MH “Carer”)	11
S4	carer*	43,413
S5	mother*	161,020
S6	father*	50,218
S7	(MH “Pediatrics”)	21,746
S8	p?ediatric*	32,640
S9	(MH “Child”)	544,250
S10	child*	980,560
S11	Youth*	74,062
S12	teenager*	1,274
S13	adolescent*	190,079
S14	OR/S1-S13	1,212,843
S15	(MH “Heart Defects, Congenital”)	13,052
S16	congenital heart defect*	13,910
S17	congenital heart disease*	15,211
S18	congenital cardiovascular malformation*	57
S19	(MH “Aortic Valve Stenosis”)	6,518
S20	aortic stenosis	9,171
S21	bicuspid aortic valve	1,229
S22	(MH “Aortic Coarctation”)	1,131
S23	coarctation of the aorta	1,342
S24	aortic coarctation	1,395
S25	Complete Atrioventricular Canal defect	22

S26	Complete Atrioventricular septal defect	69
S27	(MH “Heart Block”)	4,229
S28	heart block	5,403
S29	Ebstein's anomaly	555
S30	endocardial fibroelastosis	75
S31	Eisenmenger's syndrome	333
S32	interrupted aortic arch	173
S33	isolated non-compaction of left ventricular myocardium	2
S34	(MH “Long QT Syndrome”)	3,172
S35	long QT syndrome	3,777
S36	(MH “Mitral Valve”)	4,982
S37	patent ductus arteriosus	2,918
S38	(MH “Pulmonary Valve Stenosis”)	369
S39	pulmonary valve stenosis	492
S40	(MH “Pulmonary Atresia”)	231
S41	pulmonary atresia	638
S42	(MH “Heart Septal Defects” OR (MH “Heart Septal Defects, Ventricular”) OR (MH “Heart Septal Defects, Atrial”)	4,765
S43	septal defect*	7,034
S44	hypoplastic left heart syndrome	1,087
S45	tricuspid atresia	228
S46	(MH "Tetralogy of Fallot")	1,459
S47	Tetralogy of Fallot	2,356
S48	total anomalous pulmonary venous connection	213
S49	(MH "Transposition of Great Vessels”)	1,645
S50	transposition of the great arter*	1,565
S51	(MH “Truncus Arteriosus”)	214
S52	truncus arteriosus	213
S53	Ventricular Septal Defect	2,658
S54	Atrial Septal Defect	4,210

S55	OR/S15-S54	53,191
S56	S14 AND S55	12,788
S57	(MH “Qualitative Research”)	853
S58	Qualitative Research	28,790
S59	Interview*	404,814
S60	(MH “Focus Group”)	691
S61	focus group*	69,937
S62	(thematic* OR theme*)	174,417
S63	Ethnograph*	16,198
S64	Phenomenol*	32,324
S65	symbolic interact*	1,216
S66	(MH “Grounded Theory”)	19,252
S67	grounded theory	23,555
S68	OR/S57-S67	518,259
S69	S56 AND S68	421
PsycINFO to 16th Jan 2025		
S1	congenital heart disease*	1145
S2	congenital heart defect*.	822
S3	congenital cardiovascular malformation*	63
S4	congenital heart malformation*	110
S5	congenital heart disorder*	1414
S6	OR/S1-S5	1516
S7	MAINSUBJECT.EXACT("Qualitative Methods")	11810
S8	MAINSUBJECT.EXACT("Interviews")	13350
S9	MAINSUBJECT.EXACT("Focus Group")	868
S10	(Theme* or thematic*)	202939
S11	(narrative* OR discourse*)	161384
S12	OR/S7-S11	171715
S13	S6 AND S12	27

Appendix D: PRISMA: Flowchart of Parent Study Selection



Source: Page MJ, et al. BMJ 2021;372: n71. doi: 10.1136/bmj. n71.

Appendix E :Adolescent and Parent Participation Information Sheets

I will ask you to sign a form, called an **Assent form**, so I know that you fully understand about the research study and agree to take part.

Can I change my mind?

Yes you can, without telling me the reason why. However, if I have already interviewed you, I will still use the **Research study data** because I may have removed your personal details and it would be difficult to identify your interview

Are there any risks or benefits to taking part?

You may feel that by taking part helps you understand more about your heart condition, and gives you a chance to talk about things that may not normally come up day to day.

Although unlikely, if you felt upset afterwards, you could talk with your parent/carer or Congenital Heart Disease nurse. You can also contact support groups such as the British Heart Foundation, The Somerville Foundation or The Children's Heart Federation.

What will happen to the results of the research study?

The results of this study will be used to educate others about the experiences of adolescents living with Congenital Heart Disease. Results will be published in health related journals, and presented at conferences and teaching sessions.

What will happen next?

I will ask you if I can come back to speak to you in a year's time, as your experiences and feelings may have changed over the year.

LIVERPOOL JOHN MOORES UNIVERSITY

Living with Congenital Heart Disease as an Adolescent.

Participation Information Sheet Phase 1

(10-15 years)

Contact: Laura Kinsey. Registered Nurse, Senior Lecturer.

Tel xxx **Email** xxx

QR CODE HERE

Invitation to take part.

I would like you to take part in a research study. Before you decide if you want to join in, it is important that you understand what it is about, and what it will involve.

I can go through this leaflet with you and answer any questions you might have. You can talk about the study with your parent or carer, and speak with your Congenital Heart Disease nurse if you want to.

What is the study about?

This study wants to find out what it is like be an adolescent who has Congenital Heart Disease. You are called an **adolescent** if you are between **10-19 years.** Adolescence is when you develop from being a child to becoming an adult. During this time, you may experience many changes both emotionally and physically. I want to find out how what experiences you have had or are having, and how this makes you feel.

Why is the study being done?

It is important to understand what it is like for adolescents when they live with Congenital Heart Disease. Others can then be taught how to improve the way they care and support other adolescents.

Why have I been asked to take part?

I have asked you because you are an **adolescent** and have Congenital Heart Disease that has required surgery or other procedure.

What will happen?

If you agree to take part, I will arrange to meet with you, either at your home or the University, for about one hour. I will come on a day and time that suits you best. I will ask you some questions about what it is like at your age to live with Congenital Heart Disease. We will discuss if your parent or carer should be present, or just close by in another room.

You may feel that some of the things you want to tell me are sensitive so we could talk about other ways that you would like to let me know, for example over the telephone or using Skype or FaceTime.

Will taking part in this study be kept private?

Yes. I will record our conversation with an **audio recorder**. I will download this to a secure University computer server.
I will then type up what you have said, but I will remove your personal information such as your name so you can not be identified. Only my research team and I will know your real name

This is called Research study data, and this will be stored in a safe place at Liverpool John Moores University for five years.
I will delete the audio recording when my research team agree.
I will not share what you have said with anyone else without your permission, unless I am worried about your health or safety.

Do I have to take part?

No. It is up to you to decide whether you want to take part.
I need to ask permission from your parents or carers that they are happy that you take part, but I will only interview **you** if you **all** agree

Do I have to take part?

No. **It is up to you to decide whether you wish to take part in the research study.** If you do wish to take part, I will ask you to sign an **Informed Consent Form** to confirm you agree and fully understand the research study.

Can I change my mind?

Yes, you can, up until the point I have analysed the **Research Study Data**. If you change your mind, just let me know.

Are there any risks or benefits to taking part?

You may feel that by taking part in this study helps you understand more about your heart problem, and gives you a chance to talk about things that may not normally come up day to day.

Although unlikely, if you felt it was upsetting, you could talk with your parent/carer, or specialist nurse afterwards. You can also contact support groups such as the British Heart Foundation, The Somerville Foundation or The Children's Heart Federation

What will happen to the results of the research?

The results of this study will be used to educate others about the experiences of adolescents living with a congenital heart condition. I will publish results in health related journals, and present the results at conferences and teaching sessions.

What will happen next?

I will ask you if I can come back to speak to you in a year's time, as your views may have changed over the year.

LIVERPOOL JOHN MOORES UNIVERSITY

Living with Congenital Heart Disease as an Adolescent.

Participation Information Sheet Phase 1

(16-19 years)

Contact: Laura Kinsey. Registered Nurse, Senior Lecturer.

Tel: xxx **Email:** xxx

QR CODE HERE

Invitation to take part.

I would like you to take part in a research study. Before you decide if you want to join in, it is important that you understand what it is about, and what it will involve.

I can go through this leaflet with you and answer any questions you might have. You can talk about the study with your parent or carer, and speak with your Congenital Heart Disease nurse if you want to.

What is the study about?

This study wants to find out what it is like be an adolescent who has Congenital Heart Disease. You are called an **adolescent** if you are between **10-19 years.** Adolescence is when you develop from being a child to becoming an adult. During this time, you may experience many changes both emotionally and physically. I want to find out how what experiences you have, and how this makes you feel.

Why is the study being done?

It is important to understand what it is like for adolescents when they live with Congenital Heart Disease. Others, such as Healthcare Professionals, can then be educated in how to improve the way they care and support other adolescents.

Why have I been asked to take part?

I have asked you because you are an **adolescent** and have Congenital Heart Disease that has required corrective cardiac surgery or other intervention.

If you agree to take part, I will arrange to meet with you face to face, either at your home or the University, for about one hour. I will ask you some questions about what it is like at your age to live with Congenital Heart Disease

We can meet on a day and time that suits you best. I would like to discuss the research study with your parents or carers out of courtesy, especially if you still live with them.

You may feel that some of the things you want to tell me are sensitive so we could talk about other ways that you would like to let me know, for example over the telephone or using Skype or FaceTime.

Will taking part in this study be kept confidential?

Yes. I will record our conversation with an **audio recorder**. I will download this to a secure University computer server.
I will then type up what you have said, but I will remove your personal information such as your name so you can not be identified. Only my research team and I will know your real name

This is called Research study data, and this will be stored in a safe place at Liverpool John Moores University for five years.
I will delete the audio recording when my research team agree.

I will not share what you have said with anyone else without your permission, unless I am worried about your health or safety.

Parent/Carer Participation Information Sheet

Phase 1

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study: Living with Congenital Heart Disease; an exploration of the lived experiences of adolescents, parents and carers.

Name, Contact Details and Status of the Chief Investigator:
Ms Laura Kinsey, PhD Student/Senior Lecturer, Liverpool John Moores University
Email xxxxx Mobile Tel- xxxx Tel xxxx

Name and Contact Details of Supervisor: xxxxx

Invitation to take part.

You are being invited to take part in a research study. It is important for you to understand, why the study is being undertaken, and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish, such as your child's Congenital Heart Disease specialist nurse, or ask me if there is anything that is not clear or if you would like more information.

Thank you for reading this.

Kind regards,

Laura.

1. **What is the purpose of this study (Phase 1)?**
   This study wants to find out parents or carers experiences and feelings when caring for an adolescent (aged 10-19 years) with Congenital Heart Disease (CHD) that has required corrective cardiac surgery or intervention.

   Adolescence is the change from childhood into adulthood. Parents or carers are an essential support for them during this time, so this study will help understand parents and carers needs, and identify areas where their support can be improved for them in the future.

2. **Why have I been invited to participate?**

   You have been invited because you are caring for an adolescent with CHD who has required corrective cardiac surgery or intervention. It's up to you to decide whether or not to take part.

3. **I would like to take part, what happens next?**
   If you have been given this Participant Informaton Sheet from your child's CHD Specialist nurse at Alder Hey Hospital, give permisison for them to pass on your contact details to me, and I will contact you to discuss the study further. You can also contact me directly, by telephone or email.

   If you have found out about this study via The Somerville Foundation, please contact me directly, by telephone or email.

   If you do decide to take part you will be given this information sheet to keep and be asked to sign an Informed Consent Form. This form will be stored at Liverpool John Moores University (LJMU).

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

If you agree to take part, you will meet with me for a face to face interview, on a day and time that suits you best, at either your home, or the University setting. This interview will take about one hour. I want you to tell me about your experiences and feelings when living with an adolescent child who has CHD. This is called Research Study Data.

If meeting face to face is difficult for you, we can discuss other methods of communication between us both, for example, over the telephone, or by internet based methods, such as Skype or FaceTime.

If you are parents or carers that live together and you both agree to take part, if possible, I would like to interview you both seperataly, as I would like to understand the different feelings between male and female parents or carers.

5. **Do I have to take part?**
   No, you do not. It's your choice.

6. **Can I withdraw from this study?**
   Yes, you can also withdraw at any time without giving a reason. This will not affect your rights, or services that you or your child receives. However, any Research Study Data I have gathered may still be used. At this point, all identifiable information will have been removed, so it will be difficult to identify your individual interview.

7. **What are the possible benefits, disadvantages and risks of taking part?**
   Sometimes speaking to an independent person can allow you to make sense of your role as a parent or carer who lives with an adolescent child with congenital heart condition , and gives you an opportunity to discuss topics that may not come up day to day. You may not benefit directly, but it may help to improve support for other parents or carers in the future. You can stop the interview at any point if you feel upset, and afterwards you could contact your child's CHD specialist nurse, to talk about your feelings, or contact a CHD support helpline such as:-

   - The Somerville Foundation xxxxxx
   - The British Heart Foundation xxxxxx
   - Little Heart Matters xxxxxx

8. **Will I be recorded, and how will the recorded media be used?**

   Face to face or telephone interviews will be recorded on a password protected audio recording device. As soon as possible, the recording will be typed up (transcribed) into words, transferred to secure computer storage, and deleted from the recording device.

9. What will happen to the data provided and how will my taking part in this study be kept confidential?

The information you provide as part of the study is the **research study data**. Any research study data from which you can be identified (e.g. from identifiers such as your name, date of birth, audio recordings etc.) is known as **personal data**. . This includes more sensitive categories of personal data (**sensitive data**) such as your race; ethnic origin; politics; religion; trade union membership; genetics; biometrics (where used for ID purposes); health; sex life; or sexual orientation. When you agree to take part in a study, we will use your personal data in the ways needed to conduct and analyse the study and if necessary, to verify and defend, when required, the process and outcomes of the study.

Personal data will be accessible to the study team. In addition, responsible members of Liverpool John Moores University (and the relevant NHS Trust) may be given access to personal data for monitoring and/or audit of the study to ensure that the study is complying with applicable regulations.

When we do not need to use personal data, it will be deleted or identifiers will be removed. Personal data does not include data that cannot be identified to an individual (e.g. data collected anonymously or where identifiers have been removed). However, your consent form, contact details, audio recordings etc. will be retained for 5 years.

Personal data collected from you will be recorded using a linked code. The link from the code to your identity will be stored securely and separately as coded data. All personal identifiers will be removed, e.g. your name and child's name, and dates of birth. We will use pseudonyms in transcripts and reports to help protect the identity of individuals and organisations

10. Limits to confidentiality.

Please note that confidentiality may not be guaranteed; for example, due to the limited size of the participant sample, participants might be indirectly identifiable in transcripts and reports. The investigator will work with the participant in an

attempt to minimise and manage the potential for indirect identification of participants.

In certain exceptional circumstances where you or others may be at significant risk of harm, the investigator may need to report this to an appropriate authority. This would usually be discussed with you first. Examples of those exceptional circumstances when confidential information may have to be disclosed are:

- The investigator believes you are at serious risk of harm, either from yourself or others
- The investigator suspects a child may be at risk of harm
- You pose a serious risk of harm to, or threaten or abuse others
- As a statutory requirement e.g. reporting certain infectious diseases
- Under a court order requiring the University to divulge information
- We are passed information relating to an act of terrorism

11. Data Protection Notice

Liverpool John Moores University is the sponsor for this study based in the United Kingdom. We will be using information from you and in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Liverpool John Moores University will process your personal data for the purpose of research. Research is a task that we perform in the public interest. Liverpool John Moores University will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the study to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting xxxxxxxxxx

12. What if something goes wrong?

If you have a concern about any aspect of this study, please contact the relevant investigator who will do their best to answer your query. The investigator should acknowledge your concern within 10 working days and give you an indication of how they intend to deal with it. If you wish to make a complaint, please contact the chair of the Liverpool John Moores University Research Ethics Committee (xxxxx) and your communication will be re-directed to an independent person as appropriate.

13. What will happen next?

Contact me if you would like to discuss this research study further, or arrange for me to come and gain your consent to participate. My contact details are on the front page.

If you agree to participate, I would like to interview you one year later, as you may have new experiences and feelings that have occurred over the last year. Let me know that you are happy for me to contact you about this.

Thank you for reading this Participant Information Sheet and considering to take part in this study.

Kind regards,
Laura.

Appendix F: Assent and Consent Forms

Young persons: Assent Form 10-15 years:

Participant Identification Number for this study:

Young Persons 10-15 years: Assent Form Phase 1

Title of Project: Living with Congenital Heart Disease; an exploration of the lived experiances of adolescents and their parent/guardians. **Research Team:** Ms. Laura Kinsey	**Please initial box**
I understood the information about the above study. I have had time to think about the information and ask questions. I have understood the answers to my questions.	
I understand that I can choose to take part, and that I can stop taking part until the point that what I have said at the interview is studied. I do not have to give a reason why I want to stop.	
I understand that the interview will be audio recorded. This will then be typed up, and the data used as part of this study. I know that I cannot be identified in any way. I agree for this to happen.	
I understand that the data collected during the interview may be listened to, or read, by other people from Liverpool John Moores University, and I give permission for this.	
I understand that some of the things I say may be used in teaching sessions, conference presentations and publications, but I cannot be identified.	
I agree to take part in the above study.	

Name of Participant		Date:
Signature of participant		
Name of Researcher		
Signature of Researcher		

Young Persons: Consent form 16-19 years:

Participant Identification Number for this study:

Young Persons 16-19 years: Consent Form Phase 1

Title of Project: Living with Congenital Heart Disease; an exploration of the lived experiances of adolescents and their parent/guardians.

Research Team: Ms. Laura Kinsey

	Please initial box
I confirm that I have understood the information about the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.	
I understand that my participation is voluntary, and that I am free to withdraw up until the point of data analysis, without giving reason.	
I understand that the interview discussion will be audio recorded. This will then be typed up, and my words used as part of this study. I know that I can cannot be identified in any way. I agree for this to happen.	
I understand that the data collected during the interview may be looked at by individuals from Liverpool John Moores University, and I give permission for these individuals to have access to this data.	
I understand that some of the things I say may be quoted in teaching sessions, conference presentations and publications, but this will be anonymised.	
I agree to take part in the above study.	

Name of Participant		Date:
Signature of participant		
Name of Researcher		
Signature of Researcher		

Consent Form Parents

Participant Identification Number for this study:

Parent / Guardian: Consent Form Phase 1

Title of Project Living with Congenital Heart Disease; an exploration of the lived experiances of adolescents and their parent/guardians. **Research Team:** Ms. Laura Kinsey	**Please initial box**
I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time up until the point of data analysis, without giving reason.	
I understand that the interview discussion will be audio recorded. This will then be transcribed and will form part of the data collection for this study. I agree for this to happen.	
I understand that the data collected during the interview may be looked at by individuals from Liverpool John Moores University and I give permission for these individuals to have access to this data.	
I understand that some of the things I say may be quoted in teaching sessions, conference presentations and publications, but this will be anonymised.	
I agree to take part in the above study.	

Name of Participant		Date:
Signature of participant		
Name of Researcher		
Signature of Researcher		

Page 1 of 1

Parent/Guardian Agree to Consent (10-15 years):

LIVERPOOL JOHN MOORES UNIVERSITY

Participant Identification Number for this study:

Parent / Guardian: Agree to Consent (10-15 years). Phase 1

Title of Project: Living with Congenital Heart Disease; an exploration of the lived experiances of adolescents and their parent/guardians. **Research Team:** Ms. Laura Kinsey	**Please initial box**
I confirm that I have read and understood the information sheet for the above study about my child. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.	
I understand that my child's participation is voluntary and that they are free to withdraw at any time, up until the point of data analysis, without giving reason	
I understand that the interview discussions will be audio recorded. This will then be transcribed and will form part of the data collection for this study. I agree for this to happen.	
I understand that the data collected during the interview may be looked at by individuals from Liverpool John Moores University and I give permission for these individuals to have access to this data.	
I understand that some of the things my child will say may be quoted in teaching sessions, conference presentations and publications, but their identity cannot be identified.	
I agree for my child to take part in the above study.	

Name of Participant		Date:
Signature of participant		
Name of Researcher		
Signature of Researcher		

Appendix G: Recruiting Poster

Appendix H: RAWSHORT Animation Link

RAWSHORT Video Link:

https://youtu.be/ZAh46QpUp_4

Appendix I: Interview Schedules

Interview Schedule Adolescents 10-15years:

Interview schedule: adolescents 10-15 years	Theme
Have you read the information sheet? Do you understand that you can change your mind about being involved with the project at any time? Do you understand that your parent/carer needs to agree that you take part as well? Are you OK to sign this form to say that you've understood what is going to happen?	CONSENT
Are you happy that your parent/carer doesn't sit in with us when I speak with you? Is it ok if I record the interview? Have you got any questions about the project? If you want to stop the interview, please let me know and we will stop straight away The reason for talking to you today is to find out what it is like for you to live with a Congenital Heart problem at your age.	BEFORE WE START

Can you tell me a bit about yourself Demographics- including age, gender, ethnicity, employment, location School type? (Primary or Secondary) What year of school are you in? What is the matter with your heart? Have you had an operation or some other treatment?	TELL ME A BIT ABOUT YOURSELF
So, you said you are …… years of age. What is it like to be your age and live with your congenital heart problem?	EXPLORATION
Is there anything else you would like to tell me about your experience? What would you like to say to other children your age, who have a congenital heart problem? What would you like to say to parents /carers who live with or care for a child with a congenital heart problem? What would you like to say to nurses or doctors who care for children with congenital heart problems?	ENDINGS

What would you like to say to your school teachers?	
Is that how you felt? Did that happen to you? Let's talk about how you feel. You just said …… what do you mean by this? Can you give me an example of…….. Some children I've spoken to have said……., Why do you think that might be? Can I just make sure that you said…..? You mentioned that …… could you explain why? Can you tell me more about that? Why was that important to you? How did you feel about that? Why does that matter to you? Why does that stand out in your memory? What would you have liked to have happened? You sound upset/angry about that. What made you feel like this?	ADDITIONAL PROMPTS

Interview Schedule Adolescent 16 -19 years:

Interview schedule: adolescents 16-19 years	Theme
Have you read the information sheet?	CONSENT

Do you understand that you can change your mind about being involved with the project at any time? Are you OK to sign this form to say that you've understood what is going to happen?	
Is it ok if I record the interview? Have you got any questions about the project? If you want to stop the interview, please let me know and we will stop straight away The reason for talking to you today is to find out what it is like for you to live with a Congenital Heart problem at your age.	BEFORE WE START
Can you tell me a bit about yourself Demographics- including age, gender, ethnicity, employment, location Are you still studying? If so where? (Secondary/Further Education/Higher education) Do you work? What do you do? What is the name of your congenital heart problem? Did you have heart surgery or some other procedure?	TELL ME A BIT ABOUT YOURSELF

So, you said you are …… years of age. What is it like to be your age and live with your congenital heart problem?	EXPLORATION
Is there anything else you would like to tell me about your experience? What would you like to say to other adolescents your age who have a congenital heart problem? What would you like to day to other parents/carers who live with or care for an adolescent with a congenital heart problem? What would you like to say to nurses or doctors who care for adolescents with congenital heart problems? What would you like to say to your School/Further Education /University teachers? What would you like to say to employers?	ENDINGS
Is that how you felt? Did that happen to you? Let's talk about how you feel.	ADDITIONAL PROMPTS

You just said …… what do you mean by this? Can you give me an example of…….. Some adolescents I've spoken to have said……., Why do you think that might be? Can I just make sure that you said…..? You mentioned that …… could you explain why? Can you tell me more about that? Why was that important to you? How did you feel about that? Why does that matter to you? Why does that stand out in your memory? What would you have liked to have happened? You sound upset/angry about that. What made you feel like this?	

Interview Schedule Parents:

Interview schedule: parents	Theme

Have you read the information sheet? Do you understand that you can change your mind about being involved with the project at any time? Are you OK to sign this form to say that you've understood what is going to happen?	CONSENT
Would you mind if I interview you and your partner separately? Is it ok if I record the interview? Have you got any questions about the project? If you want to stop the interview, please let me know and we will stop straight away The reason for talking to you today is to find out about your experiences of living with an adolescent who has Congenital Heart Disease.	BEFORE WE START
Can you tell me a bit about yourself Demographics- including age, gender, ethnicity, employment, location, marital status, household income Number of children in family	TELL ME A BIT ABOUT YOURSELF
Can you tell me a bit about your child? Current age of child with congenital heart disease Type of Congenital Heart Disease your child has? What type of surgery or intervention has your child had?	TELL ME A BIT ABOUT YOUR CHILD

Your child is now……..years of age. What has it been like for you living with, and caring for, your child who has congenital heart disease?	EXPLORATION
Is there anything else you would like to tell me about your experience? Do you have any messages for other parents/carers in a similar position? What would you like to say to Health Care Professionals who care for adolescents with congenital heart disease?	ENDINGS
Other people have said…… Is that your experience? I'd now like to move on and talk about your experiences …… You just mentioned …… what do you mean by this? Can you give me an example of…….. Some people I've interviewed said ……. why do you think that might be? I just wanted to clarify ….. You mentioned that …… could you explain why?	ADDITIONAL PROMPTS

Can you tell me more about that? Why was that important to you? How did you feel about that? Why does that matter to you? Why does that stand out in your memory? What would you have liked to have happened? Can you say something about why this issue generated so much emotion? What aspects of this issue do you think prompted such strong emotions?	

Appendix J: Participant Demographics and Visual Representation of Participant Relationships

Participant Demographics- Adolescents:

Participant Pseudonym	Age range Yrs	CHD complexity	CHD Type	Stage of CHD Transition	Educational/ Employment Status

	(11-15; 16-19)				
Ted	11-15	Complex	Transposition of the Great Arteries	Pediatric CHD Services	Secondary School
Martin	11-15	Complex	Tetralogy of Fallot	Pediatric CHD Services	Secondary School
Poppy	11-15	Moderate	Interrupted Aortic Arch, Pulmonary Window, Pulmonary Stenosis	Pediatric CHD Services	Secondary School
Becky	11-15	Complex	AVSD Complete interrupted aortic arch pulmonary stenosis	Pediatric CHD Services	Secondary School
Holly	16-19	Complex	Coarctation of the aorta, ventricle septal defect, atrial septal defect, dextrocardia and sinus Invertus	Transition to Adult CHS services	Secondary school
Claire	16-19	Complex	Hypoplastic Right Heart Syndrome underdeveloped right ventricle, large ESD between the 2 ventricles, Straddling tricuspid valve.	Adult CHD Services	Higher Education
Samantha	16-19	Complex	Coarctation of the Aorta, Atrial	Adult CHD Services	Higher Education

			Septal Defect, Bicuspid Aortic Valve, Leaking Pulmonary Valve.		
Angie	16-19	Complex	Shones Complex	Adult CHD Services	Unemployed

Parent Demographics:

Participant Pseudonym	Parent Role	Childs age range Yrs	Child CHD complexity	Employment Status	Ethnicity
Julie	Mother	11-15	Complex	Employed	White British
Veronica	Mother	11-15	Complex	Employed	White British

Barbara	Mother	11-15	Complex and Moderate	Employed	White British
Maria	Mother	16-19	Complex	Unemployed Full time Carer	White British
Joan	Mother	16-19	Complex	Employed	White British
Beatrix	Mother	16-19	Complex	Unknown	White British
Daniel	Father	16-19	Complex	Employed	White British
George	Father	16-19	Complex	Employed	White British
James	Father	16-19	Complex	Employed	White British

Visual Representation of Participant Relationships:

Samantha

Adolescen

Beatrix

Mother

Claire

Adolescent

Joan

Mother

Martin

Adolescent

Veronica

Mother

Family 4 Triad

Ted

Adolescent

Julie

Mother

Daniel

Father

Family 5 Triad

Holly

Adolescent

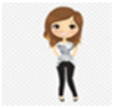
Maria

Mother

James

Father

Family 6 Family Unit



Poppy

Adolescent

Becky

Adolescent

Mother

Barbara

George

Father

Independent Participant

Angie Adolescent

Appendix K: Literature Extraction Table

Author, Year, Country	Aim	Methodology & Data Collection	Sample	Sample Size	Data Analysis	Key Findings	Limitations
Burström et al., 2022, Sweden	Explore reproductive counselling experiences	Quantitative cross sectional design	Adolescents with CHD	202	Multivariable logistic regression	Limited reproductive information leads to uncertainty	Cross-sectional, self-report bias, limited generalisability, selection bias
Cohen & Earing, 2018, USA	Prevalence, impact, and management of cognitive dysfunction in ACHD	Literature review	Adolescents with CHD	No clearly defined sample size	Narrative synthesis	Academic disruption and lack of support	Narrow educational focus
Deng et al., 2019, USA	Explore employment expectations	Quantitative questionnaire	Adolescents/young adults	152	Descriptive and comparative analysis	Anxiety about employability	Cultural context shapes meaning
DiFusco et al., 2019, USA	Explore risk behaviours	Scoping review	Adolescents with CHD	17 studies	Thematic analysis	Limited guidance on lifestyle risks	Self-report may influence disclosure
Gray et al., 2018, USA	Identify barriers to transition	Systematic review	Adolescents with CHD	57 studies	Thematic analysis	The need for early, structured, and coordinated care	Transition barriers are complex and systemic, not just individual
Hansen et al., 2024, Denmark	Explore transition experiences	Systematic review	Adolescents with epilepsy	20 studies	Thematic analysis	Transition is complex, under-supported, and needs better structure	Small sample, heterogeneity, interpretive bias
Killackey et al., 2025, Canada	Explore peer support intervention	Mixed methods design	Adolescents with CHD	34	Thematic / quantitative analysis	Peer support reduces isolation	Intervention-specific context
Lerch & Thrane, 2019, USA	Explore self-management development	Systematic review	Adolescents & parents	9 studies	Thematic analysis	Parental involvement delays independence	Relational data complexity
Lum et al., 2017, Australia	Explore school experiences	Systematic review	Adolescents with CHD	18 studies	Narrative synthesis	Fatigue disrupts education and peer life	School-focused context
McLoughlin et al., 2018, Ireland	Explore understanding of CHD	Qualitative interviews	HCPs involved in CHD care	14	Thematic analysis	Fragmented illness understanding	Recall-based accounts
Miner et al., 2017, USA	Explore reproductive concerns	Quantitative survey	Female adolescents	505	Descriptive analysis	Anxiety around pregnancy risks	Gender-specific sample
Nicolarsen, 2017, USA	Explore transition challenges and improvements	Narrative review	Adolescents with CHD	No defined number	Descriptive analysis	Poor transition, need for structured care	Not systematic, potential bias

Author, Year, Country	Aim	Methodology & Data Collection	Sample	Sample Size	Data Analysis	Key Findings	Limitations
Savaş et al., 2024, Turkey	Explore lived experiences of adolescents with CHD	Qualitative semi-structured interviews	Adolescents with CHD	17	Thematic analysis	Identity impact, emotional challenges, desire for normality	Cultural context
Smith & Kendall, 2018, UK	Explore parents' and HCPs' perspectives on collaboration in managing childhood LTCs	Qualitative interviews	Parents and HCPs	22	Thematic analysis	Communication shapes autonomy	Service-specific
Snygg Martin et al., 2021, Sweden	Understand how common infective endocarditis is in CHD patients and how risk changes over time	Quantitative longitudinal case control	Adult adolescents with CHD	89,541	Statistical analysis	Higher lifelong risk in CHD patients	Registry bias, observational design
Stokes et al., 2023, USA	Explore sexual health communication	Qualitative interviews	Adolescents with CHD	20	Thematic analysis	Gaps in counselling, need for better communication	Sensitive topic limits disclosure
Vankerckhoven et al., 2023, Belgium	Explore how adolescents' identity and body perceptions evolve and interact	Longitudinal questionnaire	Adolescents with CHD	403	Statistical analysis	Identity and body image are closely linked, shaped by stigma	Self-report, generalisability, attrition
Watkins et al., 2023, New Zealand	Explore how CHD is experienced	Systematic literature review	Parents/Children with CHD/HCPs	22 studies	Narrative analysis	Emotional impact, communication gaps	Heterogeneity, no meta-analysis, bias
Author, Year, Country	Aim	Methodology & Data Collection	Sample	Sample Size	Data Analysis	Key Findings	Limitations
Amaro et al., 2025, USA	Explore sibling impact	Mixed methods	Parents of children with CHD	108	Statistical / thematic analysis	Siblings overlooked in care dynamics	Family narratives may privilege parent voice
Bruce et al., 2016, Sweden	Explore fathers' experiences	Qualitative interviews	Fathers	5	Thematic analysis	Importance of inclusion and communication	Context-bound findings
Carlsson, et al 2020, Sweden	Explore how peer support helps parents	Qualitative interviews	Parents	61	Thematic analysis	Peer support key for coping	Access to support varies
Carlsson et al 2022, Sweden	Explore the value and role of peer support	Qualitative interviews	Mothers	10	Qualitative content analysis	Ongoing stress despite adaptation	Gender-specific sample
Cole et al 2024, USA	Explore factors influencing parental wellbeing	Mixed methods	Parents	24 studies	Thematic analysis	Trust and continuity reduce anxiety	Small sample
Delaney et al., 2021, USA	Parental views on entering adulthood	Qualitative literature review	Parents	5	Thematic analysis	Ongoing parental role, concerns about independence	Narrow context

Author, Year, Country	Aim	Methodology & Data Collection	Sample	Sample Size	Data Analysis	Key Findings	Limitations
Dellafiore et al., 2017, Italy	Explore coping strategies	Qualitative meta synthesis	Parents	6	Thematic analysis	Emotional burden, overprotection, need for support	Small evidence base, cultural context
Dorfman et al., 2023, Canada	Explore family experience	Scoping review protocol	Parents/adolescents	N/A	Thematic analysis	Communication central to coping	No results, dependent on future study
Elissa et al., 2018, Palestine	Explore lived experiences	Qualitative interviews	Parents/adolescents	18	Thematic analysis	Major barriers to coping, alongside strong resilience	Small sample
Giroux et al., 2019, Canada	Explore school interactions	Qualitative interviews	Mothers	33	Thematic analysis	Mothers as key coordinators with high burden	Small sample, limited perspective
Gower et al., 2017, UK	Explore fathers' experiences	Qualitative interviews	Fathers	18	Thematic analysis	Fathers feel excluded	Gender-specific sample
Hoffman et al., 2020, USA	Explore coping mechanisms for fathers	Qualitative interviews	Parents	70	Thematic analysis	Information-seeking central to coping	Self-report influence
Javalkar et al., 2017, USA	Explore factors increasing or reducing caregiver burden	Quantitative questionnaires	Parents	150	Descriptive/regression analysis	Mothers carry greater caregiving burden	Gender imbalance
Lappalainen et al., 2021, Finland	Explore emotional experiences	Quantitative questionnaires	Parents	110	Comparative analysis	Acceptance and commitment improves wellbeing and coping	Self-report bias, short follow-up
Liu et al., 2023, Australia	Explore transition experiences	Scoping review	Parents/adolescents	23 studies	Narrative synthesis	Transition is a high-risk period for disengagement	Limited depth
Lumsden et al., 2020, UK	Explore family functioning	Qualitative interviews	Parents	12	IPA	Care demands disrupt family life	Limited diversity
Marino et al., 2023, USA	Explore communication	Mixed methods	Parents/HCPs	32	Descriptive statistics/thematic analysis	Inconsistent messaging increases anxiety	Small sample, short-term
Pagel et al., 2019, UK	Explore communication breakdown	Quantitative survey	Parents	385	Descriptive statistics	Poor communication increases stress	Context-specific, limited depth
Postavaru et al., 2021, UK	Explore gendered caregiving	Meta-ethnography	Fathers	63 studies	Meta-ethnographic synthesis	Unequal emotional labour	Small sample
Spurr et al., 2023, Canada	Explore father involvement	Systematic review	Fathers	10 studies	Thematic analysis	Fathers' needs overlooked	Gender-specific sample
Wei et al., 2017, USA	Explore nurse-parent relationships	Qualitative interviews	Parents	13	Thematic analysis	Nurses provide key support	Context-specific

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Wray et al., 2024, UK	Explore care quality	Qualitative interviews (online)	Parents	343	Thematic analysis	Communication central to satisfaction	Online data limits depth