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**My child has a disability: An IPA
study and Meta-Synthesis exploring
the experience of parents**

By

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This thesis is submitted in partial fulfillment of the requirements for
the degree of Doctorate in Clinical Psychology

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List of Abbreviations

ASD	Autistic Spectrum Disorder
BPS	British Psychological Society
CAMHS	Child and Adolescent Mental Health Services
CHD	Congenital Heart Disease
CINAHL	Cumulative Index to Nursing and Allied Health Literature
HLHS	Hypoplastic Left Heart Syndrome
IPA	Interpretative Phenomenological Analysis
NHS	National Health Service
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analysis
QA	Quality Assessment
UK	United Kingdom
USA	United States of America

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Declaration

This thesis has not been submitted to any other institution. It has been conducted under the clinical and academic supervision of Jacky Knibbs (Clinical Psychologist and Clinical Tutor, Coventry University) and Dr Carolyn Gordon (Clinical Psychologist and Academic Tutor, Coventry University). Apart from the collaborations stated, all the material presented in this thesis is my own work. It is intended that chapter one is submitted to the Journal of Pediatric Psychology, and chapter two to the Journal of Autism and Developmental Disorders.

Summary

Raising a child is not easy for any parent, however for those whose child also has a disability, the process is even more complex. The papers presented here explore the experiences of parents who have a child with a disability. From understanding parents' experiences in more details, it is hoped that support can be tailored to serve the needs of parents better and improve the outcomes for children.

Chapter one details a meta-synthesis, reviewing qualitative articles which address the experience of parents' with a child with congenital heart disease. Twelve overarching themes are presented, capturing parents' responses, the parent-child attachment and parental resilience. Recommendations are made for how to support parents and areas of development for healthcare professionals are identified.

Chapter two details a qualitative study examining the experiences of eight fathers of children with autism. Interpretative Phenomenological Analysis is used to provide an in-depth account of their lived experiences and three superordinate themes are presented. The results identify resilience and challenges fathers experience, both within themselves and within their relationships. Clinical implications and future directions are discussed.

Chapter three provides a reflective account of the research process. It addresses the issue of reflexivity, considering how the researcher's position may have influenced the research and how the process of undertaking the research influenced the researcher.

Overall word count: 19914

CHAPTER 1: LITERATURE REVIEW

Parents' experiences of having a child with Congenital Heart Disease: A meta-synthesis of the qualitative literature from Western cultures

In preparation for submission to *Journal of Pediatric
Psychology* (See Appendix A for Author Guidelines)

Overall chapter word count: 8463
(Exclusive of figures, tables, footnotes and references)

1.1 Abstract

This paper reports the findings of a meta-synthesis reviewing parents' experiences of having a child with congenital heart disease. Particular consideration is given to parental responses, the parent-child relationship and parental coping. Fifteen original studies were identified that met the author designed inclusion criteria and were rated against a quality assessment framework. Noblit and Hares' (1988) meta-ethnography approach was used to synthesise the findings and twelve sub-themes were identified within three main meta-themes. These highlight firstly parental responses: 'An Emotional Rollercoaster', 'Not Knowing', 'Disempowerment', 'Trusting Others' and 'Lives Changed'. Secondly, factors related to the parent-child attachment: 'Not their Parent', 'Caution in Attachment' and 'Protection', and finally, the discovery of resilience: 'Normalising', 'Finding a Role', 'Support' and 'Finding Meaning'. It is concluded that, experiences underlying high levels of parental distress, and a higher incidence of insecure attachments and behavioural and social problems within this child population, are complex and multifaceted. Supporting parents and encouraging participation in caring for their child is likely to prove beneficial. Additional benefit could also be derived from offering health professionals further training in communication and the role of attachment.

1.2 Introduction

1.2.1 Congenital Heart Disease

Congenital heart disease (CHD) is a heart condition or defect that develops in the womb before a baby is born (British Heart Foundation, 2015). In the UK, it is one of the most common birth defects, affecting one in every 145 births (Petersen, Peto & Rayner, 2003). There are many different types and levels of severity. These range from minor, such as, patent ductus arteriosus, where the pulmonary valve is narrower than normal and is treated with medication, to severe. The latter includes single ventricle defects in which only one heart chamber develops properly; without treatment this is fatal (National Health Service (NHS), 2015). Most cases of CHD will require treatment and this may include one or a combination of: a cardiac catheterisation procedure, open heart surgery and/or medication (National Heart, Lung and Blood Institute, 2011). More than 82% of babies diagnosed with CHD survive their first year of life (Wren & O'Sullivan, 2001), and with advances in treatment more than eight out of ten children become adults (British Heart Foundation, 2015). Sixty percent of cases are diagnosed within the first year (Petersen et al., 2003); whilst 15% are diagnosed prenatally during routine pregnancy scans (Ailes et al., 2014).

1.2.2 The child and their attachment relationship

The prevalence of neurodevelopmental impairment for children with CHD is variable. However, within mild CHD, 10% may experience problems whilst of those with severe CHD, two thirds may have impairments (Wernovsky, 2006). In addition, children are at greater risk of other heart conditions (NHS, 2015),

are more likely to have behavioural and social adjustment problems (Popelová, Slavík & Škovránek, 2001; Utens et al., 1994), and are over twice as likely to have clinically significant levels of psychopathology compared to their healthy peers (Bellinger & Newburger, 2010). Growing up, children report feeling different; struggling to be seen as normal as they live with physical restrictions and visible signs of their condition (Claessens et al., 2005).

A secure attachment is characterised by warmth, sensitivity and responsiveness (Bowlby, 1958) and is critical for cognitive and emotional development (Emde & Spicer, 2000). Parent-child relationships are influenced by many factors, including a child's health status and the onset and progression of their illness (Kazak, 1989). An insecure attachment develops when caregivers are unable to be consistently responsive (Bowlby, 1958); this can have lifelong effects, including impacting physical improvements in children with CHD (Goldberg, Simmons, Newman, Campbell & Fowler, 1991). Parents of children with CHD are responding to an unexpected challenge, in addition to their expected transition to parenthood (Messias, Gilliss, Sparacino, Tong & Foote, 1995). They face numerous obstacles, such as reduced parent-child interaction, feeding problems, separation, disappointments in their pre-birth expectations, and grief for the loss of their aspirations and ideals (Mintzer, Als, Tronick & Brazelton, 1984).

Children with CHD are less likely to have secure attachments compared to their healthy peers (Goldberg et al., 1991) and are more likely to show disturbed parent-child interactions (Gardner, Freeman, Black & Angelini, 1996). In the early days, risk to a child's life and parent-infant separation, due to hospital treatment, may interfere with the development of a secure attachment

(Feldman, Weller, Leckman, Kuint & Eidelman, 1999). Furthermore, psychological distress in mothers increases the chances of an insecure attachment developing (Van Ijzendoorn, Goldberg, Kroonenberg & Frenkel, 1992). The use of experiential avoidance as a coping strategy is significantly related to poor parental attachment and responsiveness, as well as further deterioration in parents' mental health and children's emotional wellbeing (Berant, Mikulincer & Shaver, 2008; Evans, Whittingham & Boyd, 2012).

1.2.3 The parents

Twenty percent of parents of children with CHD experience levels of distress within or above the norms for psychiatric outpatients (Lawoko & Soares, 2002) and have a higher prevalence of anger, anxiety, stress and depression than parents of healthy children (Jackson, Frydenberg, Liang, Higgins & Murphy, 2015; Lawoko, 2007; Soulvie, Desai, White & Sullivan, 2012). Additionally, a significant proportion also show signs of post-traumatic stress disorder (Franich-Ray et al., 2013; Helfricht, Latal, Fischer, Tomaske & Landolt, 2008). Drotar, Baskiewicz, Irvin, Kennell and Klaus (1975) proposed five stages of psychological response to having a child with a congenital disability: shock, denial, sadness and anger, adaptation and reorganisation. However, it seems that for many of these parents increased level of psychological stress persists, with 20% reporting clinical levels of stress at 2-12 years after their child's diagnosis (Uzark & Jones, 2003). The determinants of parental distress appear to be individual and family factors rather than the severity of their child's CHD (Jackson et al., 2015; Lawoko, 2007; Young, Shyr & Schork, 1994). Soulvie et al., (2012) found stressors related to: receiving an unexpected diagnosis,

invasiveness of treatment, parenting styles and the impact of CHD on family relationships, including the parent-child relationship. Use of different coping strategies also appears to be a factor. For example, emotion-focused, avoidance and self-blame were found to increase stress, whilst problem-focused, cognitive restructuring, seeking information and social support appear to decrease stress (Davis, Brown, Bakeman & Campbell, 1998).

Lower educational attainment and delayed development in healthy children is associated with parental distress (Mensah & Kiernan, 2010). Similarly for children with CHD, behavioural and social outcomes appear to be significantly related to parental adjustment in terms of psychological distress, coping and parenting style (Davis et al., 1998; DeMaso, Beardsle, Silbert & Fyler, 1990; McCusker et al., 2007; McCusker et al., 2012). Parents of children with CHD may be more permissive in their parenting style (Brosig, Mussatto, Kuhn & Tweddell, 2007), and overprotective parenting appears to significantly contribute to long-term problems with heart-focused anxiety (Ong, Nolan, Irvine & Kovacs, 2011) and motor development within this child population (Bjarnason-Wehrens, Schmitz & Dordel, 2008).

1.2.4 Rationale for this literature review

Gaining an in-depth understanding of parents' experiences may better equip health professionals to support parents and prevent some of the long term psychological and developmental implications for their children. Whilst there have been several reviews looking at the prevalence of psychological distress and identifying stressors (e.g. Soulvie et al., 2012; Jackson et al 2015; Lawoko, 2007), these have mainly focused on the quantitative literature. To date, the

qualitative research exploring experiences of parents of children with CHD has not been reviewed.

The process of how and whether different qualitative studies can be synthesised is contested (Britten et al., 2002; Campbell et al., 2003). Synthesising different studies makes the epistemological assumption that findings from one study are transferable across contexts and settings. Although other epistemological positions argue that knowledge cannot be generalised, for the full contribution of qualitative research to be realised, findings need to be synthesised (Britten et al., 2002). Bringing together qualitative outcomes offers the opportunity of gaining a more complete understanding of the processes and influences underlying phenomena, which in turn can help to inform policy and practice (Campbell et al., 2011; Green & Britten, 1998).

The purpose of a meta-synthesis is to gain an in-depth understanding beyond the outcomes of the individual studies (Campbell et al., 2003). The aim of this review is to synthesise findings from research exploring parental experiences of having a child with CHD with particular consideration of their responses, the parent-child relationship and how they have coped.

1.3 Methodology

1.3.1 Literature search

A systematic search of the literature for qualitative studies investigating parents' experiences of having a child with CHD, was carried out between October 2015 and January 2016. The search was carried out within the most relevant databases for psychology and nursing¹. Additional searches for online literature were carried out using Google Scholar. Lastly, reference lists and citations of all identified articles were manually searched.

The key search terms are presented in Table 1.1. Three main concepts were used to define the area of interest: Parents, Congenital Heart Disease and Experience. Synonyms, abbreviations and linking terms were identified for each main concept. Where possible, search terms were mapped to database headings. Searching for qualitative literature is complex and it is recommended terms describing different methodological approaches are used (Evans, 2002). These terms were incorporated within the main concept of experience, in addition to a broad range of synonyms, to increase the chance of a thorough search. Key search terms could be located in any area of the article. Boolean operators were utilised for the search strategy². Due to the number of search results found through Web of Science the results were limited to the paediatrics category for this database only.

¹ The searched databases were: PsychINFO, CINAHL, Medline Ovid and Web of Science

² Each main concept and the linking synonyms were combined using OR and then combined with the other main concepts and their synonyms using AND. For example (parents (OR synonyms)) AND (Congenital Heart Disease (OR synonyms)) AND (experience (OR synonyms)). The * operator was used for terms with multiple alternative endings to ensure their inclusion within the search results.

Table 1.1 *Key Search Terms*

Main Concept	Synonyms	Location
Parent*	Parent*	Title
	Parenting	Abstract
	Parent child relations*	Main text
	Single parent	
	Mother	
	Father	
Congenital Heart Disease	Congenital Heart Disease	Title
	Congenital disorders	Abstract
	Heart disorders	Main text
	conHD	
	CHD	
Experience	Experience*	Title
	Emotional response	Abstract
	Attitude	Main text
	Adjust*	
	Adapt*	
	Resilience	
	Post-traumatic growth	
	Coping	
	Attachment	
	Phenomenology	
	Narrative	
	Grounded theory	
	Thematic	

1.3.2 Inclusion and exclusion criteria

The results from all databases were compiled and, after removing duplicates, all article titles and abstracts were screened and retained if they were: (a) written in the English language; (b) in peer reviewed journals; (c) empirical studies including qualitative methodology; (d) participants included parents whose

children had a diagnosis of CHD and (e) the full text was available. Following this initial screening, the full text for the remaining studies were obtained and read in detail. Papers were kept that adhered to the specific inclusion and exclusion criteria, as detailed in Table 1.2. This resulted in a total of 15 articles. Studies exploring experiences of parents in non-Western cultures were excluded. It was felt contextual differences in healthcare access and provision and cultural differences relating to health concerns were too great and would impinge on the credibility of the synthesis and transferability of findings.

Table 1.2 *Inclusion and exclusion criteria*

Criteria	Include	Exclude
Participants	Mothers and/or fathers Child diagnosed with CHD prenatally or postnatally	Parents of children older than 5 years old
Methodology	Qualitative methodology Current and retrospective accounts	Insufficient qualitative data
Parents' Experience	Experience of diagnosis and treatment, parenting and/or parent-child relationship	Experience of older children or adolescents Experience of specific factors e.g. associated costs or parent targeted interventions Non-Western cultures

1.3.3 Classification of studies

In total 1887 articles were retrieved from the database searches and an additional four articles were found through manual searches. Following the removal of 164 duplicates, 1723 articles remained and the titles and abstracts were screened against the inclusion and exclusion criteria, 1693 were removed

as not relevant. Full texts were read for the remaining 30 articles, from which 15 were found to satisfy the inclusion criteria and are included for this meta-synthesis. Figure 1.1 provides an overview of the study selection process using the PRISMA³ flow diagram.

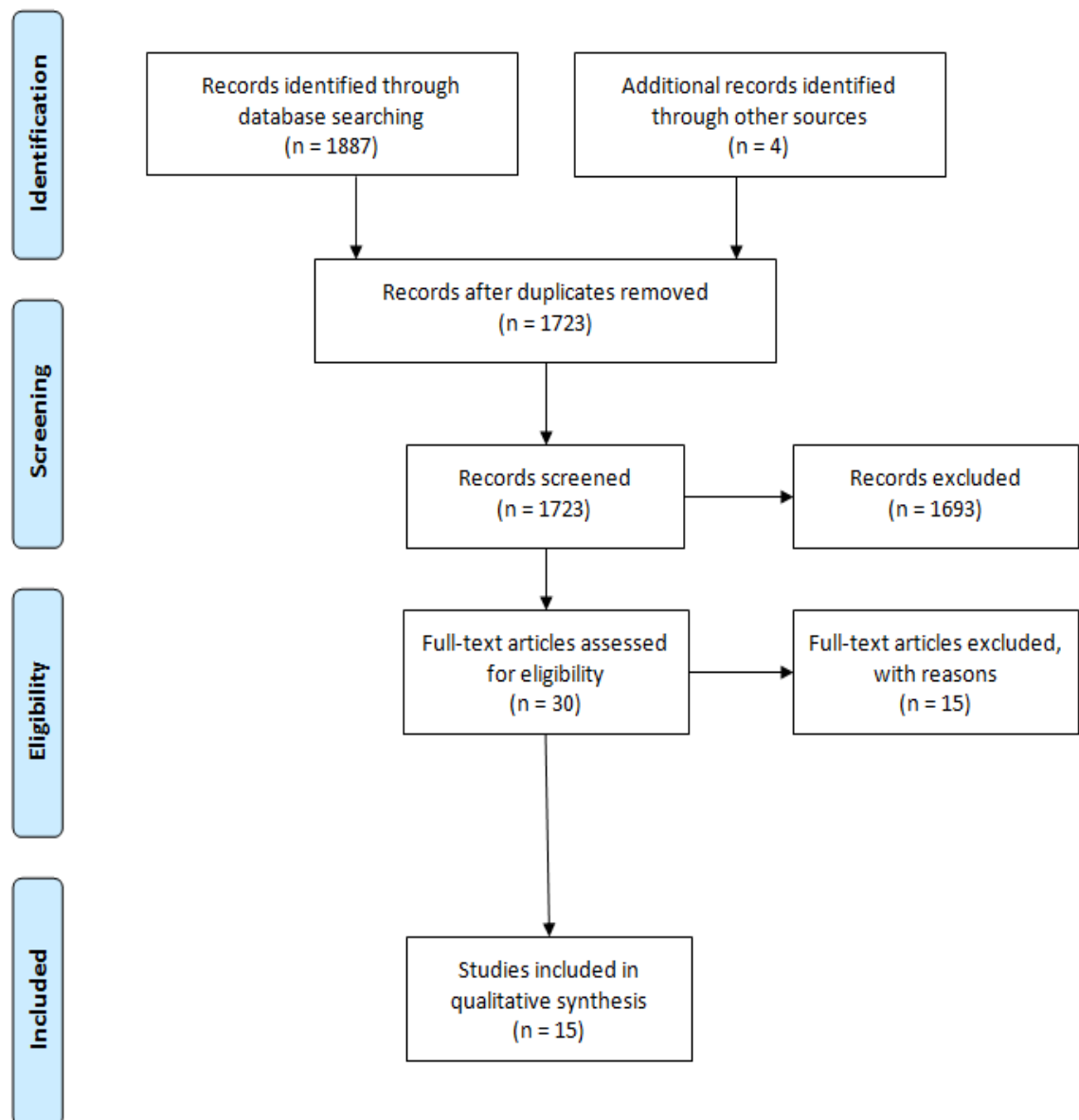


Figure 1.1 PRISMA flow diagram of the study selection process (Moher, Liberati, Tetzlaff & Altman, 2009).

³ PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analysis)

1.3.4 Quality Assessment

1.3.4.1 Conducting the Quality Assessment

Within the qualitative research community, the use of quality assessment (QA) is contested (Walsh & Downe, 2005); with some authors regarding QA as an inappropriate application of quantitative processes (Chapple & Rogers, 1998). However, qualitative research offers valuable insights in to the complexity of individual experience and in order for these findings to inform practice, articles need to be appraised and outcomes brought together (Campbell et al., 2003; Walsh & Downe, 2006).

There is no one appraisal tool agreed as superior. Walsh and Downe (2006) critically reviewed and mapped together eight existing quality frameworks and checklists to produce a summary framework. This eight item framework has been used by several other meta-synthesis studies (i.e. Reid, Sinclair, Barr, Dobbs & Crealey, 2009; Smith, Fox & Trayner, 2015) and is employed here to assess the quality of identified articles (Appendix B). It is argued that checklists should be applied flexibly rather than prescriptively, as findings may still be meaningful, despite inappropriate terminology and probable editing for publication (Barbour, 2001; Sandelowski & Barroso, 2008). It is suggested the assessing of quality should be “an interpretive act” requiring “informed reflective thought” (Kuper, Lingard & Levinson, 2008 p. 687). With this in mind, the current review seeks to use the criteria to identify strengths and weaknesses. Downe, Simpson and Trafford (2007) developed their checklist to include a rating system which applies a hierarchy of quality from ‘A’ to ‘D’. Table 1.3 provides details for these ratings. Each study was rated according to these

criteria. To increase reliability of the quality assessment, a second researcher rated two of the included articles; producing complimentary ratings.

Table 1.3 *Rating system*

Rating	Description
A	Studies with no or few flaws suggesting the study credibility, transferability, dependability, and confirmability is high
B	Studies with some flaws which are unlikely to affect the credibility, transferability, dependability, and/or confirmability of the study
C	Studies with some flaws which may affect the credibility, transferability, dependability, and/or confirmability of the study
D	Studies with significant flaws which are very likely to affect the credibility, transferability, dependability, and/or confirmability of the study

1.3.4.2 Outcome of the Quality Assessment

The QA identified seven papers rated 'A', four rated 'B' and four rated 'C', see Table 1.4. It was decided that all papers offered valuable insights and were included in the review. Particular areas of strength across all papers were: the scope and purpose of the studies, the provision of details for the sampling strategy, consideration of ethical concerns and discussion of relevance and transferability of their findings. All studies described their design choice, although only six (Fernandes, 2005; Harvey, Kovalesky, Woods & Loan, 2013; Re, Dean & Menahem, 2013; Rempel & Harrison 2007; Rempel, Harrison & Williamson, 2009; Rempel, Ravindran, Rogers & Magill-Evans, 2013), provided a more detailed rationale for their choice of methodology. Most gave sufficient detail of their data collection strategy. In four studies (Cantwell-Bartl & Tibballs, 2014; Carey, Nicholson & Fox, 2002; Fernandes, 2005; Jordan et al., 2015), the interview questions were either limited or unreported, and may have impacted

the chances of capturing the complexity of the participants experience. In terms of the data analysis, most gave an explicit account of the steps taken to reach their findings. However, two (Carey et al., 2002; Fernandes, 2005) provided minimal information, and one (Cantwell-Bartl & Tibballs, 2014) provided no information beyond the chosen methodology, impacting transparency and credibility. The interpretation category of the QA had mixed results. The majority of studies evidenced consideration of the data and used sufficient data to support their interpretations. However, three studies (Carey et al., 2002; Jordan et al., 2015; Sikora & Janusz, 2014) provided minimal information to illustrate outcomes were grounded in participants' experiences, impacting confirmability and dependability. The only consistent area of weakness across the studies was the exclusion of information, demonstrating researcher reflexivity and therefore acknowledging researchers influence on data interpretation (Yardley, 2000). It is possible authors compromised on the inclusion of detail for publication (Sandelowski & Barroso, 2008). There were three exceptions to this; two studies (Rempel & Harrison, 2007; Re et al., 2013) which evidenced an active approach to addressing researcher influence and one study which acknowledged the role of influence (Jordan et al., 2015).

1.3.5 Characteristics of studies

Table 1.4 provides a summary of the key characteristics of the 15 studies included in this review. Studies are ordered by the author's quality rating, descending from 'A', the most credible studies, to 'C', studies with some flaws that may affect overall credibility. Within the aims of the studies, nine included a focus on the experience of diagnosis and treatment, eight included parenting

and five considered the parent-child relationship. Seven studies used thematic analysis, four used content analysis, three used grounded theory and one used phenomenological analysis. It is of note that five studies involved Associate Professor Rempel and colleagues at the University of Alberta, Canada, potentially resulting in the dominance of one perspective within the included articles. However, all articles involving Rempel were rated 'A', thus reliability and transferability of these studies is high. Further information on study location, current versus retrospective accounts, sample size, participant details and CHD diagnosis and severity can be found in Table 1.4.

1.3.6 Analysis

There is no one agreed method for synthesising qualitative research. Noblit and Hares' (1988) meta-ethnography is the most well developed and well rooted within the interpretivist nature of qualitative research (Britten et al., 2002). Meta-ethnography offers an explicit process of comparison that includes understanding differences between findings as well as similarities. Noblit and Hare (1988) identified three ways that studies may relate: they are directly comparable as 'reciprocal translations', they conflict as 'refutational translations' or they complement and together 'represent a line of argument'. Although ethnography has a constructivist underpinning informing theory, further interpretation of findings can be made to inform policy and practice (Barnett-Page & Thomas 2009).

The steps outlined by Britten et al. (2002) will be followed here. The first step is to compare and contrast the included studies and identify key themes. The second step is to establish which themes are comparable, complementary or

conflicting. The final step of the analysis is to synthesise the findings in to core themes. This stage needs to clearly illustrate how the whole in terms of the meta-synthesis has greater explanatory power than its parts (Barnett-Page & Thomas, 2009).

Table 1.4 *Characteristics of the reviewed studies*

Article: author, date and geographical location	Quality Rating	Research aims and areas covered	Recruitment: sample size, recruitment strategy	Data collection: method, location, timing, researcher information Analysis: methodological approach, credibility checks	Perspective: age, ethnicity, family details: number of children, marital status, child's age and diagnosis	Summary of key findings
Harvey, Kovalesky, Woods & Loan (2013) USA	A	Aim: Explore the lived and recalled experience of mothers of infants with CHD. Aim to inform support interventions for other families. Areas covered: Mothers' experiences before during and after surgery and what advice would give others.	8 mothers (plus 7 mothers for validation and advice for others) Convenience sampling Recruited through a tertiary urban paediatric medical centre. Those meeting inclusion criteria were contacted directly	Journal entries for three time points: before, during and after surgery Collected over 6 months Both were paediatric nurses one with a clinical role in the research area, the other a qualitative researcher Colaizzi's phenomenological analysis and content analysis for question around advice for other mothers 7 mothers from a regional parent support group who met inclusion criteria completed an email validation survey	Mothers Aged 27–39 5 White, 2 African-American and 1 Pacific Islander 1 only child, 1 one other child, 3 had 2 other children, 1 had 3 other children and 2 had 4 other children 6 married, 2 divorced Child aged 1 week – 4 years old Diagnosis of moderate to severe CHD of 5 different types	Six major themes were identified: 1. <i>Feeling intense fluctuating emotion: a rollercoaster of feelings from helpless and fragile to crying with joy</i> 2. <i>Navigating the medical world: unfamiliar people, speaking an unfamiliar language, responsibility for decisions and trusting others</i> 3. <i>Dealing with the unknown: trying to make sense of why, unknown future and outcomes</i> 4. <i>Facing the possibility of my baby dying</i> 5. <i>Finding meaning and spiritual connection: believe what was supposed to happen would happen, finding benefits and blessings afterwards</i> 6. <i>Mothering through it all: finding normalcy, needing closeness but handing them over, finding support through others</i>
Lee & Rempel (2011) Canada	A	Aim: Describe the relationship between the parental processes of perceiving their child as vulnerable and normalizing their child's	16 parents (16 for first interview and 14 for second) Maximum variation sampling Recruited through a	Two semi-structured interviews with each parent Telephone or face to face at participants home 1-2 hours in length	7 fathers, 9 mothers Mean age 35.2 (range 22-50) No information for ethnicity or family details	Three main themes with subthemes 1. <i>Parental perception as child as vulnerable</i> - Fear and distrust - Precariousness of survival - Vulnerability to illness or injury

		outcomes. Areas covered: What has been the most challenging thing and what has been the most rewarding thing about parenting your child.	tertiary referral centre	No researcher information provided Content analysis informed by grounded theory for secondary analysis of data Findings were presented to paediatric cardiology nurses and parents of children with CHD to check credibility	Child aged 2 months - 5 years Diagnosis of HLHS	- Discipline 2. <i>Normalisation</i> - Cognitive process - Behavioural process - Balancing act 3. <i>Optimistic appraisal</i> - Celebrating survival - Positive appraisal
Meakins, Ray, Hegadoren, Rogers & Rempel (2015) Canada	A	Aim: Differentiate the varying intensities of vigilant parental action. Areas covered: Existence of exaggerated vigilant parental action and how this influences parental response, parental health and well-being, overall family developmental health and parent-professional relations.	41 parents Maximum variation sampling Recruited through a tertiary referral centre	Semi-structured interview (55 interviews in total, 14 parents interviewed twice) Telephone or face to face Location unknown 1-2 hours in length No researcher information provided Directed secondary thematic content analysis of data using sensitising concepts Credibility checks included: triangulation of data, analysis conducted by two authors, bias monitored by other authors	24 mothers, 17 fathers (24 families) Mean age 33.2 (range 22-50) 40 White, 1 Metis No information for family details Child aged 2 months - 5 years Diagnosis of HLHS	Two interrelated concepts were developed, within each were further themes. 1. <i>Context of caring for their child: Out of our hands</i> - Uncertainty: about child's survival over time, risk of death at surgery and child emotional state - Support: that is inadequate, inconsistent and wanes over time 2. <i>Response to caring for their child: In our hands</i> - Protect child (e.g. infection) - Master complex care (e.g. medication, feeds, oxygen) - Monitor child (e.g. medication effects, growth and weight gain)
Re, Dean & Menahem (2013) Australia	A	Aim: Explore the experiences of mothers of infants with CHD to inform psychological support. Areas covered: Mother's experiences of	26 mothers Convenience sampling Recruited on admission to the surgical centre. Initially approached by	Semi-structured interview Face to face No information on interview location or timings Interviewer was an experienced child psychotherapist skilled in personal reflection. A	26 mothers No information for age, ethnicity or family details. Infants aged 2 months Diagnosis of serious CHD, 14 different	Three main themes emerged: 1. <i>Diagnosis</i> : acute stress, dissociation and helplessness 2. <i>Traumatic separation</i> : risk infant won't survive, wanting to escape, help felt as harm 3. <i>Experiences of intensive care unit</i> : horror, seeing the heart

		motherhood, her perceived infants experience, the diagnosis and treatment for her and her infant and her participation in the research.	the cardiologist those interested were contacted by the researcher.	reflective diary was kept to enhance transparency and included in discussions with others. Thematic content analysis Emerging themes and transcripts were discussed with co-authors	types	
Rempel & Harrison (2007) Canada	A	Aim: Describe the process of parenting a child whose treatment has included high-risk heart surgery. Areas covered: Mothers' and fathers' experience parenting a child who has survived Norwood surgical procedure.	16 parents (interviewed twice) Maximum variation sampling and theoretical sampling Recruited through a tertiary referral centre via clinical nurse specialists	Unstructured interviews 18 face to face and 12 telephone No interview timings or location given Advanced paediatric nurse in paediatric cardiology Constructivist grounded theory Credibility of emerging themes was checked with participants and mutual construction encouraged	7 fathers, 9 mothers (9 families) Mean age 35.2 (range 22-50) 15 White, 1 Metis 15 married, 1 divorced 2 first born, 5 second child, 1 third born, 1 sixth born Child aged 2 months - 5 years Diagnosis of HLHS	Two theories were developed with linked themes 1. Safeguarding precarious survival (of child – both ensuring weight gain and shielding from infection) - <i>Taking charge</i> : “I just have to do what I have to do” - <i>Struggling with balance</i> : “Are we being overly paranoid?” - <i>Involving others</i> : We’re extremely lucky to have a great family 2. Safeguarding survival of self (against worry and couple (against strain) - <i>Directing their minds</i> : “Don’t go there” - <i>Normalising</i> : “She’s been like the normal kid” - <i>Trusting</i> : “It’s out of my hands” - <i>Buffering severity</i> : “I mostly only told her the good things” - <i>Staying on the same page</i> : “Who’s going to do what and when?”
Rempel, Harrison & Williamson (2009) Canada	A	Aim: How parents manage their worry associated with uncertain outcomes for	16 parents (interviewed twice over 13 months) Maximum variation	30 semi-structured interviews 18 face to face, 12 telephone No information on interview	16 parents (7 fathers, 9 mothers) Aged 22-50 All White	Four main themes were identified: 1. <i>New survivors with uncertain futures</i> : “a constant source of worry” 2. <i>Normalising life</i> : “Just treat him like a

		their child? Areas covered: Medical events related to diagnosis and treatment, daily life with their child.	sampling Recruited through tertiary referral centre. Nurse identified interested participants.	location or timings No researcher information provided Constructivist grounded theory No information on credibility checks	No information for family details Child aged 2 months – 5 years Diagnosis of HLHS	<i>normal child</i> 3. <i>Delayed growth</i> : “He’s on his own growth curve”. Attributing growth to other factors rather than cardiac problems 4. <i>Delayed development</i> : “She does it at her own stage”: No attribution of delays to effects of cardiac problems
Rempel, Ravindran, Rogers & Magill-Evans (2013) Canada	A	Aim: Gain understanding of the process of parenting from diagnosis through treatment to inform clinical practice. Areas covered: From diagnosis through survival of the first two surgeries and anticipation of the third.	15 families, 53 participants Purposive sampling Parents recruited by a nurse in a tertiary paediatric cardiac surgery programme over 22 month period, parents then recruited grandparents	Semi-structured interview Face to face and telephone No researcher information provided Constructivist grounded theory Verification strategies were employed and co-authors met to discuss interviews.	15 mothers, 10 fathers, 17 grandmothers and 11 grandfathers Parents mean age 32, grandparents mean age 58.7 No information for ethnicity or family details 15 children aged 6 months to 4.5 years Diagnosis of HLHS	Parenting under pressure characterised the inter-relationships between family circumstance and parenting behaviours and interactions with their child. This iterative social process involved four phases with further sub-processes: 1. <i>Realising and adjusting to the inconceivable</i> : “You kept on going” - Realising the precariousness of survival - Adjusting expectations 2. <i>Growing increasingly attached</i> : “I actually held her” - Seeing the baby as their child - Imagining the future for their child 3. <i>Watching for and accommodating to the unexpected</i> : “You keep your guard up” 4. <i>Encountering new challenges</i> : “This next handoff is going to be a nightmare”
Clark & Miles (1999) USA	B	Aim: Explore the experience of fathers of infants newly diagnosed with severe CHD during the infants’ initial hospitalisation and treatment.	8 fathers for first interview, 6 for second interview Purposive sampling Sample was from a larger study, in which all receiving care at	Two Semi-structured interviews, one during initial hospital stay and one at 12 months old Face to face Private location at home or in the hospital No interview timings given	8 fathers Aged 23-40 years (mean 28 years) 6 White, 1 Asian, 1 African American 6 first child, 2 second child 7 married	Four main themes were found 1. <i>The joy and sadness of becoming a father</i> : the initial excitement at birth tempered or lost by intense distress over loss of the expected normal child 2. <i>Becoming attached while dealing with fears about the infant’s outcome</i> :

		Areas covered: The first interview focused on diagnosis, and treatment, parenting their infant and views of the hospital and staff. The second interview focused on their retrospective hospital experience.	a South-Eastern university medical centre meeting inclusion criteria were invited to participate.	No researcher information provided Content analysis The first and second interviews were read and analysed together as a unit Multiple authors involved in generation of themes	Child aged < 10 weeks at first interview and 12months at second interview All severe CHD of varying diagnoses (7 types)	Perception of shared attachment alongside fear and anxiety of their infants outcome and getting too close 3. <i>Trying to maintain control while losing control</i> : A need to maintain areas of control such as work, response, self-care, whilst unable to help infant 4. <i>Providing strength while hiding emotions</i> : Feeling responsible for remaining strong to be caretaker and hide their own distress and related needs
Fernandes (2005) USA	B	Aim: What it is like, as the parent of a newborn infant, to be faced with the diagnosis of CHD? Areas covered: The parent experience of the birth of the child, the needs of parents' and impact of the diagnosis on the family.	10 parents (5 couples) Purposive sampling Recruited from records of parents who had given birth to an infant with CHD between 1994-1997	Unstructured interviews Face to face except one which was over the phone Conducted at the participants home No interview timings given No researcher information provided Thematic analysis informed by van Manen (1990) approach to phenomenological analysis No information on credibility checks	5 mothers and 5 fathers No information for participant age, ethnicity or family details Child aged < 3 years old Diagnosis of CHD	Fifteen themes were identified 1. <i>A mother intuition: "something's just not right"</i> 2. <i>Is it a dream</i> 3. <i>Shock, disbelief, lives shattered</i> 4. <i>Time stops</i> 5. <i>The last kiss</i> 6. <i>Word, words, beeps and buzzers, nothing makes sense</i> 7. <i>Lack of information versus too much information</i> 8. <i>Trust</i> 9. <i>Loss of control</i> 10. <i>The baby's experience</i> 11. <i>Parental perception</i> 12. <i>The closing of the curtain</i> 13. <i>The emotional roller coaster</i> 14. <i>Just wait until this time tomorrow</i> 15. <i>The memory doesn't fade</i>
Kosta et al., (2015) Australia	B	Aim: From parents' experiences of hospitalisation identify factors that could be targeted to alleviate distress.	154 parents Consecutive sampling Recruited by medical team at a tertiary paediatric	Structured interviews Face to face or telephone No information on location or length No researcher information provided	91 mothers, 63 fathers Mean age of mothers 32, mean age of fathers 35 No information for	Six categories were identified: 1. <i>Baby</i> : the uncertain and unfolding nature of the diagnosis 2. <i>Context</i> : ward environment and facilities, and negotiating the interactions and transitions between

		Areas covered: Parents' perceptions of what they find difficult, what they would like to be different and what they have found helpful.	hospital	Thematic and frequency analysis Co-author discussion during interpretation phase	ethnicity 63 first child, 52, second child, 37 later born 150 married, 1 separated, 3 single Child age < 3 months Diagnosis of CHD (11 types)	hospital and 'regular' lives 3. <i>Relationships</i> : advice, support and challenges with communication 4. <i>Information</i> : on condition, orientation and entitlements 5. <i>Waiting</i> : for surgery, during surgery and for recovery 6. <i>Individual coping strategies</i> : cognitive, behavioural and emotional
Messias, Gilliss, Sparacino, Tong & Foote (1995) USA	B	Aim: Increase awareness and understanding of the impact of the diagnosis of CHD on parents and family dynamics. Areas covered: Recollected experience of child's diagnosis of CHD and impact on the family.	8 parents Purposive sampling Recruited through the physician practice of paediatric cardiology service	Semi-structured interview Face to face at participants home or in hospital 1 hour in length No researcher information provided Secondary thematic analysis informed by grounded theory techniques No information on credibility checks	7 mothers, 1 father All White No information for age or family details Children aged 13-25 years at time of interview Diagnosis of CHD	Six themes were identified: 1. <i>Something wrong</i> : The process of discovering through events 2. <i>The illusiveness of normality</i> : a normal pregnancy, birth and no obvious signs of a problem accentuating the unexpectedness 3. <i>The rude awakening</i> : the realising of the seriousness of the situation 4. <i>Managing uncertainty</i> : waiting to see if your child lived 5. <i>New meanings</i> : finding ways to accept, adjust and live with it 6. <i>Taking stock</i> : recognising and responding to the emotional, personal and practical implications
Cantwell-Bartl & Tibballs (2014) Australia	C	Aim: To evaluate the psychosocial status of parents in response to their infants' diagnosis, a retrospective account. Areas covered: Response to diagnosis and prenatal compared to postnatal, experience of doctor	29 parents Purposive sampling Identified from 21 years of paediatric intensive care unit records and invited by letter	Semi-structured interview Face to face Location of participants choice No information on length No researcher information provided Thematic analysis No information on credibility checks	16 mothers, 13 fathers No information for age, ethnicity, family details or child's age. Diagnosis of HLHS	Themes were found within the areas covered: 1. <i>Psychosocial response to diagnosis</i> : 83% recalled it as the worst event that had ever happened to them and as traumatic 2. <i>Perceptions of how the doctor delivered the news</i> : the importance of empathy, kindness and clear communication and the distress when it wasn't 3. <i>Differences in psychosocial response</i>

		and decision making process for treatment.				<p><i>when diagnosis delivered prenatally or postnatally</i>: prenatal diagnosis reported: decisions about termination, stress, waiting, confusion when baby seemed robust, and loss when separated. Postnatal diagnosis reported: feeling unprepared, intense reactions “ripped apart”, juxtaposition of hope and despair, finding help in own strategies, and trust in God.</p> <p>4. <i>Decision-making process</i>: for some an immediate decision linked to doing everything they could, being a good parent and trusting in greater forces. Others were initially unsure due to worries of effect on child.</p>
Carey, Nicholson & Fox (2002) USA	C	<p>Aim: Compare the early child-rearing practices between mothers of young children with CHD and mothers of healthy children.</p> <p>Areas covered: How parenting is different to what expected, how sort help for behaviour and amount of social support.</p>	<p>30 mothers Purposive sampling Recruited through paediatric cardiology clinic</p>	<p>Structured interview in addition to quantitative data collection Face to face at participants home No information on length No researcher information provided</p> <p>Exploratory content analysis Two independent reviewers provided content validation</p>	<p>30 Mothers of children with CHD and 30 mothers of healthy children Mean age 33.5 25 White, 4 African American, 1 Biracial Average of 2.03 children in family 25 married, 5 not married Child aged 2-5 years Diagnosis of moderate to severe CHD (various types)</p>	<p>Six themes were identified for mothers of children with CHD:</p> <ol style="list-style-type: none"> 1. <i>The unexpected</i> 2. <i>Vigilance</i> 3. <i>Uncertainty</i> 4. <i>Positive outlook</i> 5. <i>Normalisation</i> 6. <i>Stress</i>
Jordan et al. (2015) Australia	C	<p>Aim: Explore mothers' experience of their relationship with their infant after hospital</p>	<p>91 mothers Purposive sampling All infants undergoing</p>	<p>Structured interviews 64 over telephone, 27 face to face in hospital No interview timings given</p>	<p>Mothers Mean age: 32.9 No information for ethnicity</p>	<p>Four main themes were identified:</p> <ol style="list-style-type: none"> 1. <i>The emotional tie</i>: precious, protective, “more thankful to have her”

		discharge following surgery. Areas covered: In what ways surgery, illness and hospitalisation has impacted the mother/infant relationship.	surgery during a 19 month period were considered and those eligible approached by the research assistant.	Paediatric clinicians working with infant mental health and attachment theory Inductive thematic analysis Two authors jointly developed a coding template to reduce bias	37 only child 67 married, 21 de facto relationship Child mean age: 109 days All had CHD, 12 different types	2. <i>Bonding difficulties</i> : “she wasn’t mine” “just another nurse”, separation, intrusion, fragility, lack of opportunity, sharing the care 3. <i>Anxiety and worry about the infant</i> 4. <i>Caregiving behaviours towards the infant</i> : more responsive, protective
Sikora & Janusz (2014) Poland	C	Aim: To understand mothers’ experiences of caring for their child in a hospital setting. Areas covered: Caregiving behaviour and experience of bonding with their child during their hospital stay.	4 mothers Purposive sampling Recruited through cardiac surgery ward while children in postoperative rehabilitation period. Aim and nature of study presented	Semi structured interview Face to face in hospital No information on length No researcher information provided Thematic analysis No information on credibility checks	4 mothers Aged 21-30 years No information for ethnicity All married All first child Child aged 5 weeks – 15 months Diagnosis: 4 HLHS, 1 also atrioventricular canal defect	Five main categories with 34 subcategories are presented: 1. <i>From diagnosis</i> : torn between hope and fear 2. <i>Launching mothers’ defence mechanisms</i> : Between cutting oneself off and task orientation 3. <i>We and they</i> : Community and identity 4. <i>From intermittent contact with infant and weakened bond to loss of sense of control and competence</i> 5. <i>Between dependency and anger towards medical staff</i>

KEY: CHD: Congenital Heart Disease; HLHS: Hypoplastic Left Heart Syndrome

1.4 Results

The core themes fall within three main areas: 'Parental Response', 'Parent-Child Relationship' and 'Resilience'. Several meta-themes within each section have been identified; Table 1.5 provides an overview.

Table 1.5 *Meta-themes*

Meta-themes	Sub-themes
Parental Response	An Emotional Rollercoaster Not Knowing Disempowerment Trusting Others Lives Changed
Parent-Child Relationship	Not their Parent Caution in Attachment Protection
Discovering Resilience	Normalising Finding a Role Support Finding Meaning

Within each meta-theme, the shared and overlapping themes of the included articles are discussed and where there are linked conflicting themes, these are identified. Some themes within the included articles overlap with multiple meta-themes. In order to maintain the integrity and transparency of the original articles, Table 1.6 illustrates how the original themes have been synthesised inductively in to the meta-themes.

Table 1.6 *Links between original themes and meta-themes*

Meta-themes	Sub-themes	Linked original themes
Parental Response	An Emotional Rollercoaster	'Psychosocial response to diagnosis' (Cantwell-Bartl & Tibballs, 2014) 'The unexpected' (Carey et al., 2002) 'The joy and sadness of becoming a father' (Clark & Miles, 1999) 'A mothers' intuition', 'Is it a dream', 'Shock, disbelief, lives shattered', 'The emotional rollercoaster' (Fernandes, 2005) 'Feeling intense fluctuating emotion' (Harvey et al., 2013) 'Something wrong', 'The illusiveness of normality', 'The rude Awakening' (Messias et al., 1995) 'Diagnosis', 'Experiences of intensive care unit' (Re et al., 2013) 'Realising and adjusting to the inconceivable' (Rempel et al., 2013) 'Torn between hope and fear' (Sikora & Janusz, 2014)
	Not Knowing	'The last kiss' (Fernandes, 2005) 'Dealing with the unknown', 'Facing the possibility of my baby dying' (Harvey et al., 2013) 'Waiting' (Kosta et al., 2015) 'Out of our hands' (Meakins et al., 2015) 'Managing uncertainty' (Messias et al., 1995) 'Traumatic separations' (Re et al., 2013)
	Disempowerment	'Perceptions of how the doctor delivered the news' (Cantwell-Bartl & Tibballs, 2014) 'Trying to maintain control while losing control' (Clark & Miles, 1999) 'Word, words, beeps and buzzers, nothing makes sense', 'Lack of information versus too much information', 'Loss of control', 'The closing of the curtain' (Fernandes, 2005) 'Navigating the medical world' (Harvey et al., 2013) 'Context', 'Information' (Kosta et al., 2015) 'Out of our hands' (Meakins et al., 2015)
	Trusting Others	'Decision-making process' (Cantwell-Bartl & Tibballs, 2014) 'Trying to maintain control while losing control' (Clark & Miles, 1999) 'Trust' (Fernandes, 2005) 'Mothering through it all' (Harvey et al., 2013) 'Trusting' (Rempel & Harrison, 2007) 'Between dependency and anger towards medical staff' (Sikora & Janusz, 2014) 'Traumatic separations' (Re et al., 2013)
	Lives Changed	'Vigilance', 'Uncertainty', 'Stress' (Carey et al., 2002) 'The joy and sadness of becoming a father' (Clark & Miles, 1999) 'Time stops', 'The memory doesn't fade' (Fernandes, 2005) 'Mothering through it all' (Harvey et al., 2013) 'Anxiety and worry about the infant' (Jordan et al., 2015) 'Baby' (Kosta et al., 2015) 'Taking stock' (Messias et al., 1995) 'New survivors with uncertain futures' (Rempel et al., 2009) 'Encountering new challenges' (Rempel et al., 2013)

Parent-Child Relationship	Not Their Parent	<p>'Loss of control', 'The baby's experience', 'The closing of the curtain' (Fernandes, 2005)</p> <p>'Bonding difficulties' (Jordan et al., 2015)</p> <p>'Growing increasingly attached' (Rempel et al., 2013)</p> <p>'From intermittent contact with infant and weakened bond to loss of sense of control and competence' (Sikora & Janusz, 2014)</p>
	Cautious Attachment	<p>'Becoming attached while dealing with fears about the infant's outcome' (Clark & Miles, 1999)</p> <p>'Parental perception' (Fernandes, 2005)</p> <p>'New meanings' (Messias et al., 1995)</p> <p>'Growing increasingly attached' (Rempel et al., 2013)</p>
	Protection	<p>'The emotional tie', 'Caregiving behaviours towards the infant' (Jordan et al., 2015)</p> <p>'Parental perception as child as vulnerable' (Lee & Rempel, 2011)</p> <p>'Struggling with balance' (Rempel & Harrison, 2007)</p> <p>'Growing increasingly attached' (Rempel et al., 2013)</p>
Resilience	Normalising	<p>'Normalisation' (Carey et al., 2002)</p> <p>'Normalisation' (Lee & Rempel, 2011)</p> <p>'Normalising' (Rempel & Harrison, 2007)</p> <p>'Normalising life' (Rempel et al., 2009)</p>
	Finding a Role	<p>'Trying to maintain control while losing control' (Clark & Miles, 1999)</p> <p>'Mothering through it all' (Harvey et al., 2013)</p> <p>'Individual coping strategies' (Kosta et al., 2015)</p> <p>'In our hands' (Meakins et al., 2015)</p> <p>'Taking charge' (Rempel & Harrison, 2007)</p> <p>'Watching for and accommodating to the unexpected' (Rempel et al., 2013)</p>
	Support	<p>'Providing strength while hiding emotions' (Clark & Miles, 1999)</p> <p>'Mothering through it all' (Harvey et al., 2013)</p> <p>'Relationships' (Kosta et al., 2015)</p> <p>'New meanings' (Messias et al., 1995)</p> <p>'Involving others', 'Directing their minds', 'Buffering severity', 'Staying on the same page' (Rempel & Harrison, 2007)</p> <p>'Launching mothers' defence mechanisms', 'We and they' (Sikora & Janusz, 2014)</p>
	Finding Meaning	<p>'Differences in psychosocial response when diagnosis delivered prenatally or postnatally' (Cantwell-Bartl & Tibballs, 2014)</p> <p>'Positive outlook' (Carey et al., 2002)</p> <p>'Just wait until this time tomorrow' (Fernandes, 2005)</p> <p>'Finding meaning and spiritual connection' (Harvey et al., 2013)</p> <p>'Optimistic appraisal' (Lee & Rempel, 2011)</p> <p>'New meanings' (Messias et al., 1995)</p>

1.4.1 Parental Response

Parental response includes five meta-themes: 'An Emotional Rollercoaster', 'Not Knowing', 'Disempowerment', 'Trusting Others' and 'Lives Changed'. What the articles report in terms of: parents' responses to receiving the diagnosis of CHD, undergoing treatment and the impact of CHD, are captured within these meta-themes. All studies reported some aspect of parental response, with the exception of two studies that focused on the parenting process (Lee & Rempel, 2011; Rempel & Harrison; 2007).

1.4.1.1 An Emotional Rollercoaster.

'An Emotional Rollercoaster' captures the unrelenting emotional distress experienced by parents. Nine articles identified themes explicitly linked to this concept (Cantwell-Bartl & Tibballs, 2014; Carey et al., 2002; Clark & Miles, 1999; Fernandes, 2005; Harvey et al., 2013; Messias et al., 1995; Re et al., 2013; Sikora & Janusz, 2014). The articles portrayed the devastation and fear parents experienced on diagnosis and through treatment. The distress described by the different articles reported different stages of the ongoing emotional process.

Parents expressed the realisation of what the diagnosis of CHD meant for their child and the shift from the elation of birth, to the intense distress that took its place. Several articles captured an initial sense of unreality, shock and confusion expressed by the parents (Fernandes, 2005; Re et al., 2013). Expectations were described as leaping from a normal pregnancy and birth and ideas of a healthy child to the reality of an internal life-threatening diagnosis happening within their baby's heart.

“But she looked great. There was never any signs of distress. This was why it was always so confusing” (Messias et al., 1995, p. 370).

As realisation dawned and parents recognised the life shattering threat of losing their child, intense feelings were expressed. Messias et al., (1995) termed this ‘The Rude Awakening’ and others found evidence of acute stress (Re et al., 2013) as parents’ adjusted to the possibility of their child dying.

“I screamed, my husband cried. I hit the wall, and stomped my feet, my husband did the same. My sister and my mom just hugged us.”

(Fernandes, 2005, p. 322).

“I was torn inside because I was scared for my son’s life.”

(Harvey et al., 2013, p. 402).

Within the experience of realisation, Cantwell-Bartl & Tibballs (2014) compared the experiences of mothers who were given a prenatal diagnosis and those given a postnatal diagnosis. They found that both experienced loss when their child was taken away for treatment, but parents given the diagnosis after birth were less prepared and described a more intense response. This was not captured by other articles with the same mixed participant group. Another conflicting theme was within Fernandes (2005) who reported a sense of a mother’s intuition, mothers knowing something was wrong before the medical teams. Although this may be the case for some mothers, the larger number of parents reported significant emotional distress often proceeded by a sense of numbness and shock.

Several papers used the word rollercoaster to capture the ongoing and changing nature of parents’ emotional landscape (Harvey et al., 2013). The

articles convey a sense of parents' emotions oscillating and being torn from hope to fear (Sikora & Janusz, 2014), along with the exhaustion and emotional and physical stress. For some it was hard to articulate the emotional process they had experienced.

"To describe in words the emotions, questions, uncertainty, emptiness and broken heart that I carried with me through the situation is impossible."

(Harvey et al., 2013, p. 401).

The rollercoaster captured the contrasting feelings of parents'. For example the horror on seeing their baby's heart following surgery whilst also feeling relieved their baby had survived.

"I think seeing [him] after the procedure with his chest open and the heart beating, that was probably the hardest part of the intensive care experience. I think because it was kind of right there, there's his heart, and it's so fragile."

(Re et al., 2013, p. 280).

1.4.1.2 Not Knowing.

This meta-theme captures parents' responses to not knowing whether their child will survive. Six of the 15 articles reported themes linked to parents not knowing whether their child would die and waiting to find out (Fernandes, 2005; Harvey et al., 2013; Kosta et al., 2015; Messias et al., 1995; Meakins et al., 2015; Re et al., 2013). Feelings of uncertainty were expressed for either the immediate future, whether their child would survive surgery, or the longer term future, what their child's future would be like.

“Today we will know something about how our lives are going to proceed. Without our son or with him.”

(Harvey et al., 2013, p. 402)

The distress around waiting to see if their child survived is captured by several articles. Parents wished they didn't have to experience the ongoing nature of waiting whether for surgery, during surgery or for recovery (Kosta et al., 2015).

“Any time he went through surgery or anything like that, it was just hell. Wait and see if he was alive, that seems like the whole thing. The emphasis was we were waiting for this kid to die ... I always told myself life was a bed of roses as long as I'm not waiting in that waiting room, waiting to hear if [my son] made it or not.”

(Messias et al., 1995, p. 372).

Within research where parents were interviewed several years after the diagnosis, the experience of not knowing whether each moment was the last, endured.

“It was hard, any time I left the room; you always think could this be the last kiss? And even now, could this be the last Christmas? Could this be? You know? You can't help to think it, but it's a reality.”

(Fernandes, 2005, p. 323).

1.4.1.3 Disempowerment.

Authors described a sense of disempowerment on two interrelated levels; firstly a sense of being out of control in terms of the condition and not being able to help their child, and secondly being excluded by the treatment teams. Six articles included aspects of disempowerment; four reported this within themes linked to the medical context (Cantwell-Bartl & Tibballs, 2014; Fernandes, 2005;

Harvey et al., 2013; Kosta et al., 2015). Clark and Miles (1999), Fernandes (2005) and Meakins et al. (2015) reported parents feeling out of control. A sense of helplessness was conveyed as parents felt excluded by those involved. Meakins et al., (2015) captured this within the theme 'Out of Our Hands' and a participant reported they felt they were "at the mercy of the system" (p. 36).

Several authors reported parents not being able to understand what medical teams were telling them, feeling that they were speaking a foreign or unfamiliar language. A reluctance to ask was also portrayed.

"The doctor explained everything but I couldn't understand a word he was saying because I didn't understand medical words. I thought I would look stupid if I asked."

(Cantwell-Bartl & Tibballs, 2014, p. 1067).

Within several reports, themes were identified highlighting the importance of appropriate and clear information-giving and availability to answer questions (Fernandes, 2005; Kosta et al., 2015). When communication was good, parents reported experiencing understanding, compassion and humanity (Cantwell-Bartl & Tibballs, 2014) thus illustrating the importance of clear communication.

Another example of how a medical setting can disempower parents was reported by Kosta et al. (2015) who found parents reported practical issues and difficulties accessing resources at the hospital, impacting on their comfort and the time they could spend with their child.

1.4.1.4 Trusting Others.

The process of having to trust others to look after and treat their child was reported by seven of the articles (Cantwell-Bartl & Tibballs, 2014; Clark & Miles, 1999; Fernandes, 2005; Harvey et al., 2013; Re et al., 2013; Rempel & Harrison, 2007; Sikora & Janusz, 2014). Parents described the distress they experienced having to trust others, the trauma of being separated and the conflict between holding on to and letting go of their baby, as they saw treatment as helpful but also life-threatening.

“I was not allowed to enter. So I handed my son over to the nurse...I cried, I watched my son go through the door and I just felt like dying. It was the most difficult part of my life entrusting my son to others.”

(Harvey et al., 2013, p. 402).

There were mixed feelings towards medical staff who were necessary to save children but who also represented both the problem and the severity of surgery. This was interpreted by Skiora & Janusz (2014) as a defence mechanism, where mothers displaced the anger and helplessness they felt about the situation towards the medical team.

In contrast to this, however, three studies found parents used the process of putting trust in others as a way to cope with their distress (Cantwell-Bartl & Tibballs, 2014; Clark & Miles, 1999; Rempel & Harrison, 2007).

“It was just basically putting trust in the nurses and the doctors to know what they told me was the way it was.”

(Clark & Miles, 1999, p. 11).

1.4.1.5 Lives Changed.

This concept of lives changed was featured explicitly as themes of six studies (Carey et al., 2002; Fernandes, 2005; Jordan et al., 2015; Kosta et al., 2015; Messias et al., 1995; Rempel et al., 2009). However it was captured within other themes by an additional three studies (Clark & Miles, 1999; Harvey et al., 2013; Rempel et al., 2013). Reference was made to the ongoing nature of anxiety with parents reporting *“I worry all the time”* (Clark & Miles, 1999, p.11). Authors found parents concerned with the precariousness of their child’s survival, the unrelenting and unfolding nature of CHD, and the unpredictable future outcomes (Kosta et al., 2015; Rempel et al., 2009; Rempel et al., 2013). Sikora and Janusz (2014) found frequent reference to worry about becoming pregnant again. Mixed responses indicated that for some parents it was easier to not think about, whilst others experienced daily reminders of the ordeal of treatment.

“I think about it every day, I swear. Every day when I look at him, or give him a bath, or change a diaper, you’d see the scar and you’d think about it.”

(Fernandes, 2005, p. 326).

Within this theme, there is also acknowledgement of the loss of a previous life and the impact of CHD on parents, their families and their lives. Harvey et al., (2013) reported mothers trying to find a balance between their lives and responsibilities for other children outside of hospital, with the demands of CHD. Concern over the impact on other children was included by Messias et al., (1995) and Carey et al., (2002). Messias et al., (1995) identified the theme ‘Taking Stock’ to capture the process of evaluating the impact the diagnosis had on their lives.

“Until Christmas, boy, we were just a regular stereotype family. Go to work, bought a new home, have a car, cut the lawn, and get everything else, and then that problem came along it was just the main focus of the whole family. That was the problem.”

(Messias et al., 1995, p. 373).

1.4.2 Parent-Child Relationship

Within parent-child relationships, three meta-themes are identified: ‘Not their Parent’, ‘Caution in Attachment’ and ‘Protection’. Eight of the included articles reported aspects of the parents’ experience that linked to the parent-child relationship (Clark & Miles, 1999; Fernandes, 2005; Jordan et al., 2015; Lee & Rempel, 2011; Messias et al., 1995; Rempel & Harrison, 2007; Rempel et al., 2013; Sikora & Janusz, 2014).

1.4.2.1 Not their Parent.

Four of the studies identified themes explicitly linked to the loss of parents’ role as the child’s mother or father (Fernandes, 2005; Jordan et al., 2015; Rempel et al., 2013; Sikora & Janusz, 2014). This theme links to attachment theory, as it highlights factors making it harder for parents to bond with their child.

Studies reported separation between parents and their baby and intense feelings of loss and yearning for the missing closeness.

“This terrible time – like we didn’t have a child because they took her away.”

(Rempel et al., 2013, p. 623).

Parents reported a loss of control over parenting choices as they surrendered decisions of who, what, where and when to the medical staff (Fernandes, 2005).

Jordan et al., (2015) found that this lack of involvement impacted on the mothers feeling of competence and the loss of their role.

“I felt a lot like I was overstepping my welcome because I wanted to touch my baby.”

(Fernandes, 2005, p. 324).

1.4.2.2 Caution in Attachment.

‘Caution in Attachment’ links to the previous meta-theme ‘Not their Parent’, highlighting a further obstacle complicating the bonding process between parents and children. Four studies reported parents’ concerns of becoming emotionally close to their babies (Clark & Miles, 1999; Fernandes, 2005; Messias et al., 1995; Rempel et al., 2013). This theme links to not knowing whether their child would survive and reflects how parents responded by distancing themselves as a means of self-protection. The theme echoes a conflict within parents between longing for closeness and for their child’s survival, yet feeling anxious not to become too attached in case their child died.

“It probably was the best thing that I didn’t hold him right then and stuff. ‘Cause maybe I would have gotten more attached than I did.”

(Clark & Miles, 1999, p. 11).

“We didn’t know if she would make it through the first surgery or anything...not to say you’re detached but you’re a bit guarded,...I loved her and I knew that we wanted to keep her but you don’t connect.”

(Rempel et al., 2013, p. 623).

Rempel et al., (2013) also reported a sense of dehumanising the baby, reporting that ‘Growing Increasingly Attached’ described parents seeing their child as their baby and “*not a lump*” (p. 623).

1.4.2.3 Protection.

Three studies (Jordan et al., 2015; Lee & Rempel, 2011; Rempel & Harrison, 2007) reported themes explicitly linked to parenting behaviours; one other study made reference within another theme of ‘Growing Increasingly Attached’ (Rempel et al., 2013). Due to their child’s physical vulnerability parents reported struggling to find the balance between responsive parenting and over-protective parenting, asking “*How much do we protect her and how much do we just let her live life?*” (Rempel & Harrison, 2007, p. 829). Lee and Rempel (2011) reported parents distrust in others to care for their child and an avoidance of discipline to protect their child from distress.

Rempel et al., (2013) and Jordon et al., (2015) found mothers described enhanced closeness towards their baby and more responsive parenting.

“I think we parent very differently to how parented son. We don’t let her cry for extended periods of time because think she could bust her gasket. With son did ‘controlled crying’ at 8 months but not prepared to do that with her.”

(Jordon et al., 2015, p. 643).

1.4.3 Discovering Resilience

Thirteen studies found aspects of the parenting experience that linked to resilience, only two did not report this (Jordan et al., 2015; Re et al., 2013). Four

meta-themes are reported here: 'Normalising', 'Finding a Role', 'Support' and 'Finding Meaning'.

1.4.3.1 Normalising.

Four of the articles explicitly recognise the coping strategy of normalisation within their own themes (Lee & Rempel, 2011; Rempel & Harrison, 2007; Rempel et al., 2009; Carey et al., 2002). Lee and Rempel (2011) found that parents expressed 'normalising' in three different ways: cognitive, behavioural and finding a balance. Behavioural referred to parents engaging in typical family activities, while cognitive referred to seeing their child as *normal* "*She's very normal. She's very typical and she's doing fine ... she's normal, she's fitting in so, so I'm assured that she'll be fine*" (p. 184). Carey et al. (2002) also found normalising within parents' cognitive interpretations and behavioural responses to their child: "*I treat him like a normal kid. He is a normal kid*" (p. 19). Rempel & Harrison (2007) reported cognitive normalisation as a means parents coped with worries about their child.

"It's not so much the challenge that he gives you, it's the challenge you have to do within yourself to forget about the problem and just treat him like a normal child, which he is pretty much."

(Rempel & Harrison, 2007, p. 831)

Expanding on this, Rempel et al. (2009) found parents normalising delayed growth and delayed development, and attributing them to factors unrelated to CHD, "*He doesn't like to eat...just his personality, like he couldn't care less about food*" (p. 140). Parents had prepared for their child to die so each milestone was celebrated, no matter how delayed "*It was just from where she is to where she started out... it makes every little thing a huge celebration*"

(Rempel et al., 2009, p. 140). Rempel et al's., (2009) finding that parents may not seek early intervention for these delays, overlaps with Lee and Rempels' (2011) last subtheme of finding a balance between giving children as typical a life as possible without compromising their health.

1.4.3.2 Finding a Role.

Six studies reported experiences of parents coping linked to finding a role (Clark & Miles, 1999; Harvey et al., 2013; Kosta et al., 2015; Meakins et al, 2015; Rempel & Harrison, 2007; Rempel et al., 2013). Although all reported the experience of finding a role for themselves helpful, what that role was differed between studies. Clark and Miles (1999) reported fathers engaging in areas of their lives outside CHD and this providing them with a sense of control.

"Where if you can... kinda keep control on a lot of things, on your diet and sleep 'n', uh, work and whatever."

(Clark & Miles, 1999, p. 12)

Others were able to engage in some aspect of parenting behaviour, for example, Harvey et al., (2013) described mother's experiencing the benefits of breastfeeding, and Kosta et al., (2015) found parents engaged in parenting behaviours such as reading a book to their baby. Rempel & Harrison (2007), Meakins et al., (2015) and Rempel et al., (2013) all found parents benefitting and gaining a sense of control when they were the ones involved in monitoring, feeding, medicating and caring for their child once they were home.

"I was a fanatic about the medications, you know, that had to be at – the drops at this time and not a minute after."

(Meakins et al., 2015, p. 37).

1.4.3.3 Support.

Within this theme of Support both support received and support given are taken in to consideration. Six of the studies found themes within parents' experiences linked to support (Clark & Miles, 1999; Harvey et al., 2013; Kosta et al., 2015, Messias et al., 1995; Rempel & Harrison, 2007; Sikora & Janusz, 2014). Clark & Miles (1999) and Rempel and Harrison (2007) both found parents sharing experiences and offering support to each other. Clark & Miles (1999), who only interviewed fathers, found they felt responsible for staying strong and hiding their feelings, which the authors linked to their role as caretaker. However Rempel & Harrison (2007), who interviewed mothers and fathers, found this process of trying to protect the partner was not limited to fathers, but that mothers also tried to protect their partners by editing or withholding information.

Most reported that receiving support from others was a positive experience (Harvey et al., 2013; Kosta et al., 2015; Rempel & Harrison, 2007). Helpful support involved wider family members and agreeing roles and tasks, extensive communication and negotiating, "*We're a team*" (Rempel & Harrison, 2007, p. 829).

However, there were also reports of how well-intentioned comments could be unhelpful. Messias et al. (1995) found one mother was told "*there really was not much she could do, and that it would be better if the child died*" (p. 372). Sikora & Janusz (2014) reported times when well-intentioned comments caused further suppression of feelings, "*but do not worry because everything will be alright*", or increased parents anxiety, "*this is the worst possible defect of the heart, it is not always so*" (p. 485). Rempel and Harrison (2007) and Skiora and Janusz (2014) both found that some parents coped through directing their thoughts away from

difficult issues and suppressing their emotions. Sikora and Janusz (2014) framed this within the theme 'Launching the Mothers Defence Mechanisms'. This could explain the times when support is experienced as unhelpful, as it may push parents to think about topics they are not ready to consider. Both Sikora and Janusz (2014) and Kosta et al., (2015) found parents experienced the relating of difficult information to others traumatic and lead to reliving of their experiences.

1.4.3.4 Finding Meaning.

The process of finding meaning as a means of coping was reported by six studies (Cantwell-Bartl & Tibballs, 2014; Carey et al., 2002; Fernandes, 2005; Harvey et al., 2013; Lee & Rempel, 2011; Messias et al., 1995). For some this was a spiritual process, while others it was about personal optimism (Cantwell-Bartl & Tibballs, 2014). Carey et al. (2002) and Lee & Rempel (2011) reported parents taking a positive outlook on life "*we try to live each day fuller now; we don't take a day for granted*" (Carey et al., p. 19), whilst Harvey et al., (2013) reported a more fatalistic understanding "*I had to believe that whatever was supposed to happen would happen*" (p. 402). For many the process of finding meaning seems to enable parents to find some level of acceptance.

"I don't want to be Pollyannish, but to look for the silver lining because you're not going to make it [CHD] go away. And to look for the positive, to look at the value of life and some of the intrinsic things that are coming because of what you have to go through."

(Messias et al., 1995, p. 373)

1.5 Discussion

1.5.1 Significance of the main findings

The aim of this review was to synthesise the experiences of parents of children, five years old and younger, with CHD. Particular consideration was paid to their responses, parent-child relationship and coping. The literature search identified 15 articles that satisfied the inclusion criteria, from which twelve core themes were identified. Although each article addressed different areas of parental experiences there was a high level of consistency within the outcomes.

Previous quantitative research has identified the high prevalence of psychological distress within this population of parents (Jackson et al., 2015; Lawoko, 2007; Soulvie et al., 2012). This was captured within the included articles which illustrated the intense, ongoing and fluctuating nature of parental distress as they encounter different challenges. Various factors appear to underpin the high distress experienced by these parents. The initial emotional process following diagnosis resonated with the five stages: shock, denial, sadness and anger, adaptation and reorganisation, proposed by Drotar et al., (1975) as parents began to adjust their expectations to their new reality. However it seems this process is not linear but ongoing and circular, with parents returning to feelings of sadness, anxiety and anger as different challenges are faced. Additionally parents face ongoing uncertainty regarding their child's treatment and future. Parents' lack of involvement in their child's care and their experience of poor communication appear to increase uncertainty, adding to their sense of disempowerment. Parents of children in paediatric intensive care units have identified communication issues relating to

availability and attentiveness of medical professionals, honesty, comprehensiveness and accessibility of information and the affect and body language of medical professionals (Meert et al., 2008). Communicating serious illness is stressful for medical professionals and even more so when the patient is a child (Harrison & Walling, 2010). The importance of effective communication is evident; however, it is also important to acknowledge the complexity of relationships between patients and healthcare professionals, particularly in a paediatric setting, where each party brings their own agenda, assumptions and experiences to the relationship (Gabe, Olumide & Bury, 2004).

The effect of CHD on other areas of life also appeared to be a significant cause of distress, particularly concerns around the impact on other children in the family. These are valid concerns, as siblings of children with a chronic illness are at risk of negative psychological affect (Sharpe & Rossiter, 2002). There was some evidence parents may cope through distraction and suppression of difficult thoughts and feelings. Mothers of children with CHD who have avoidant attachments themselves, may cope through redirection and suppression of painful thoughts and feelings, leading to deterioration in their own wellbeing (Berant et al., 2008) and their child's wellbeing (Evans et al., 2012; Gardner et al., 1996). There were only two studies that verify this coping mechanism, one quality rated 'A' the other 'C', which may illustrate that it occurs in a minority of parents.

The identification of distress associated with being separated from their infant and not feeling like the parent is in line with outcomes from quantitative studies showing parental role alteration to be the greatest cause of stress for parents

with children in intensive care (Shudy et al., 2006). As separation continues, the natural preoccupation with their infant starts to decrease and parents may show signs of a depressed state characteristic of loss (Feldman et al., 1999). The incidents of parents reporting a sense that they had no child may be indicative of this process. This is of particular concern as this state of loss does not immediately reverse on contact with their infant and has potential implications for the mother-infant attachment (Feldman et al., 1999). This highlights the importance of the coping strategy of finding a role. If that role enables parent-child contact through feeding or other parenting behaviours it breaks the separation. Feeling excluded by treatment teams also has particular significance as this may increase separation. Wigert, Johansson, Berg and Hellström (2006) found when mothers of babies in intensive care felt excluded, they experienced a reduction in maternal feelings, whilst if the mother was encouraged to participate, maternal feelings increased.

Two particular experiences appear to raise psychological tensions for some parents: being involved in treatment decisions and developing a relationship with their infant. Parents reported tension in terms of trusting others for treatment where there was conflict between short term harm and risk, such as surgery, versus long term gains. Emery (1989) acknowledged the enormous burden of trust involved in cardiac surgery with children, where parents know the costs and benefits and feel responsible for negative outcomes. Conflict between developing a bond with their child and protecting themselves from getting too close was also identified. Cognitive dissonance increases distress in parents of children with life-threatening conditions (Rosenberg et al., 2013). The phrase 'embrace of paradox' (Larson, 1998) captures the competing emotional

forces experienced by mothers of disabled children and illustrates the complex emotional position between acceptance and denial, in which a mother accepts their child and incurability of their disability whilst also seeking solutions and remaining hopeful for their future. Normalising and finding meaning may link to this process of 'embracing paradox' by increasing hope, and reducing internal conflict through the realignment of parents' expectations and reality. Normalising is a central process for parents of children with a range of disabilities (Nelson, 2002). Although vigilance is needed to ensure normalising does not prevent access to early intervention (Rempel et al., 2009), it enables hope and care-giving. In addition celebrating milestones could become a family ritual with symbolic meaning for the whole family; this has been shown to improve family cohesion, quality of life and parent-child relations (Santos, Crespo, Canavarro & Kazak, 2015).

Rempel et al., (2013) developed a model to highlight the facets of parenting a child with Hypoplastic Left Heart Syndrome, a severe form of CHD. They identified five areas of parenting: 'Survival Parenting', incorporating accommodating to complex and uncertain circumstances, 'Hands off Parenting', where care of their child is relinquished to medical teams, 'Expert Parenting', where parents take charge of their child's health needs, 'Uncertain Parenting', capturing acceptance of an uncertain future and 'Supported Parenting' where parents accept informal and formal support. The core themes identified in this review overlap with this model illustrating the application of these concepts to other types and severities of CHD. The outcomes of this review also highlights the importance of normalising, finding a role and finding meaning both in

coming to terms with their situation, and developing the parent-child relationship.

1.5.2 Limitations

1.5.2.1 Limitations of this review

The purpose of a meta-synthesis is to go beyond the individual studies, and offer a new understanding (Barnett-Page & Thomas, 2009). This review has synthesised the existing evidence base and identified overarching themes. There were few areas of conflict within the included articles illustrating a consistent understanding of parent's experiences. This supports the epistemological argument that findings are transferable across settings and bringing them together offers opportunity for a more complete understanding (Campbell et al., 2011; Green & Britten, 1998). However, as noted previously, five of the identified articles included the same author, potentially influencing the outcome of this synthesis. Additionally all but one of the articles came from the USA, Canada and Australia. These are all countries with advanced medical care. The authors' decision to exclude non-Western cultures limits the cross-cultural relevance of the findings.

A further limitation of this review is the QA conducted. Steps were taken to increase reliability of the outcome through an impartial researcher rating two of the included articles; although there was concordance with the outcomes, a second rating for all articles would increase reliability further. A further limitation was the decision to include all papers regardless of quality. This could impact on validity of the findings with lower quality studies influencing outcomes to the

same extent as higher quality ones. Consultation with the authors of the original papers to ratify the third order interpretations presented here would further enhance validity. The outcomes of this review link many areas with their own large bodies of literature, within the constraints of this review it is not possible to consider all these areas in depth, instead attachment theory and psychological distress have formed the focus of the discussion.

Researchers' bias can significantly affect the interpretation of qualitative research and as such it is important to acknowledge the assumptions brought by the researcher (Atkins et al., 2008). In acknowledgement of this the author enhanced awareness of personal influence through using a reflective journal. As a psychologist and a parent, the author brought particular values and experiences and was struck by the emotional power of this research. The upheaval for these families and the powerful influences of professionals, institutions and cultural expectations was especially striking.

1.5.2.2 Limitations of reviewed articles

In addition to the limitations discussed within the QA, the existing research has minimal reporting of researcher reflexivity with the potential effect of findings being unknowingly influenced by researchers' biases and assumptions. This may be due to compromises authors' made to meet publication criteria. Due to the lengthy nature of qualitative data it is possible other compromises have been made for publication however these have not been commented on and thus remain unknown. The majority of the included articles considered parental responses and coping, whilst fewer articles investigated the parent-child relationship. This area may need more attention to further understand and evidence the processes and experiences involved.

1.5.3 Implications for policy and practice

The outcomes of this synthesis highlight the importance of parental involvement and communication. Listening to parents concerns, making support available and allowing time to digest the diagnosis are valuable considerations for treatment teams. Rather than labelling parents as experiencing acceptance or denial, an appreciation for the more complex process and emotional paradox parents may experience could further benefit them. Strategies such as Mindfulness and Acceptance Commitment Therapy may prove beneficial to parents overwhelmed by uncertainty, as these are helpful approaches in tolerating anxiety (Hofmann, Sawyer, Witt & Oh, 2010). Additionally, involving the family in the treatment, encouraging them to be present, and have contact with their child, is critical for the development of a secure attachment. Thoughts around death are often a taboo topic as they are emotionally challenging, however this avoidance allows fear and anxiety to grow (Kübler-Ross, 2009). Treatment teams need to allow space for fears to be aired and acknowledged, or offer access to other support networks to enable these conversations. Parents reported feeling the medical staff spoke another language. Healthcare professionals need to be vigilant of the language they use and check understanding. Healthcare professionals can use distancing tactics to avoid emotions in patients and themselves (Maguire, 1985), the use of complex language may increase their emotional distance and, as the idea of a child dying is hugely distressing, it is plausible that this was happening for parents included in these articles. Further training for professionals on how to have difficult conversations with patients may be beneficial, as well as ensuring sufficient support for professionals to avoid compassion fatigue. Supports such

as reflective supervision and advanced communication skills training for staff may help, in addition to workforce development, to learn more about the importance of attachment, parents' experiences and outcomes.

Entrusting the life of their child to a stranger asks a lot of parents. Professionals can build trust by showing willingness to understand and respect the parents' wishes for how to care for their child. This may also help parents to feel connected and not excluded from the relationship with their infant. The importance of attachment, the implications and barriers need to be considered alongside the medical interventions, as this plays a role in the long term outcomes for the child. Current practice and training could be reviewed with this in mind.

1.5.4 Future directions

The studies all focused on the initial responses of parents, and understanding more about the ongoing impact and experience would be valuable to gain a more complete picture of the lasting influence on child development and parental wellbeing. Similarly, understanding more about the young child's perspective may help to gain a more complete picture. Gaining a fuller understanding of the role of parental attachment across all paediatric conditions may provide further insight in to initial responses and long term effects for parents and staff. Additionally, it would be of value to evaluate the impact on parental distress and the parent-child relationship, of different parents coping responses, such as when parents are helped to find a role and stay connected to parenting behaviours when their child's treatment forces separation. Furthermore, conducting and evaluating the impact of offering training in

communication and attachment to healthcare professionals would be interesting.

1.6 Conclusion

The aim of this review was to synthesise the experience of parents of children with CHD with particular consideration paid to their responses, parent-child relationship and coping. The review found that experiences underlying high prevalence of parental distress and a higher incidence of insecure attachments and behavioural and social problems within this child population are complex and multifaceted. The synthesised themes presented, highlight contributing factors to parental distress and identify barriers to forming secure attachments. They illustrate parents' need for support in processing their experiences and encouragement in actively participating in caring and parenting their child within hospital settings. It also highlights the resilience within many parents, identifying how they cope and adjust to their new reality, and offers insight in to the benefits of providing healthcare professions with training in communication development and education in attachment.

1.7 References

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CHAPTER 2: EMPIRICAL PAPER

Love and loss: The lived experience of fathers' of children with autism

In preparation for submission to *Journal of Autism and
Developmental Disorder* (See Appendix C for Author
Guidelines)

Overall chapter word count: 8449
(Exclusive of tables and references)

2.1 Abstract

Aim: Having a child with autism is known to raise many challenges for parents. However the experiences of fathers in their own right, is an area neglected within the research. It is known that there are high levels of stress for parents and this may, in part, be linked to experiences of adjusting to the diagnosis and relationships with partner and child. This study aims to understand fathers' experiences of having a child with autism. Specifically it aims to address the lived experiences of learning about their child's diagnosis of autism, their relationship with their partner in the context of autism and their relationship with their child.

Method: Interpretative Phenomenological Analysis was used to focus on the detailed account of participants lived experiences. Eight participants were recruited and interviewed, the interviews were then analysed.

Results: Three superordinate themes were identified: 'Bittersweet Bond', 'The Price of Emotions' and 'Surviving and Developing'. These are discussed along with the linking subordinate themes.

Conclusion: The commitment of these fathers to their child and the challenges they face are identified, both internally in terms of their own emotional responses, and externally in terms of their relationships with others. Clinical implications and future directions are discussed.

Key phrases: *Phenomenology, autistic spectrum disorder, fathers, children*

2.2 Introduction

2.2.1 Autism and Attachment

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) identifies four diagnostic criteria for Autism Spectrum Disorder (ASD). These are: the person shows persistent deficits in social communication and interaction across contexts, they show at least two examples of restricted and repetitive patterns of behaviour, their symptoms must have been present in early childhood and all their symptoms together limit and impair their everyday functioning (American Psychiatric Association, 2013). The difficulties children with ASD experience, especially in terms of communication, may make it harder for parents to be attuned, empathise and accurately interpret their child's needs and thus develop a secure attachment (van IJzendoorn et al., 2007).

Attachment patterns represent the child's internal representation of their relationship with their caregiver (Ainsworth, Blehar, Waters & Wall, 1978). Patterns of secure attachment represent a parent-child relationship that is responsive and leads to feelings of security. In contrast an insecure attachment represents a parent-child relationship where the child does not experience consistent closeness and security (Howe, 2011). The child's attachment experiences inform their internal working model for self and others, forming a prototype for future relationships (Bowlby, 1969). A secure attachment increases resilience, leads to better relationships with self and others, and enables more effective responses to environmental challenges and emotional processing (Fonagy, Lorenzini, Campbell & Luyten, 2014).

Despite difficulties in social interaction, children with ASD can form attachments and do display attachment behaviour, such as seeking and maintaining caregiver contact, showing preference for their caregiver, and seeking caregiver proximity after separation (Rutgers, Bakermans-Kranenburg, van IJzendoorn & Berckelaer-Onnes, 2004). Secure parent-child attachment is possible in children with a developmental disability, with around 50% classified as securely attached, compared to 65% of children from a non-clinical sample (van IJzendoorn, Goldberg, Kroonenberg, & Frenkl, 1992). There is much research considering what influences attachment in families with a child with ASD. Characteristics of autism play a role, as the severity of impairment in responsiveness and reciprocal social interaction impact the chance of a secure attachment (Rutgers et al., 2004). Additionally factors located within parents appear to influence the child's attachment. These may include: their own working model of attachment (Seskin et al., 2010), parental sensitivity (Capps, Sigman & Mundy, 1994) and the extent to which parents have integrated their experience of the diagnosis into their internal representation of themselves, their child, and their role as a parent (van IJzendoorn & Bakermans-Kranenburg, 1996; Yirmiya, Seidman, Koren-Karie, Oppenheim & Dolev, 2015).

2.2.2 Being a parent of a child with autism

2.2.2.1 Parental stress

Parenting a child with any disability is stressful for both mothers and fathers (Howe, 2011); for parents of children with developmental disabilities it appears to be particularly challenging, with significantly higher levels of psychiatric problems reported (Pottie & Ingram, 2008; Yirmiya & Shaked, 2005). Parents of

children with ASD have described their experience as “living in a world of our own”; feeling stigmatised, disconnected and unsupported (Woodgate, Ateah & Secco, 2008). Although child-related factors such as symptom severity play a role in increasing stress (Tobing & Glenwick, 2002), it seems primary predictors of mental health problems are linked to parental experiences, such as experiences of support, control and parental satisfaction (Falk, Norris & Quinn, 2014). Studies also report gender difference, with some finding fathers more affected by their child’s temperament (Davis & Carter, 2008; Falk et al., 2014; Krauss, 1993), long term implications of the diagnosis (Davis & Carter, 2008) and their relationship with their child, such as feelings of attachment (Keller & Honig, 2004; Krauss, 1993); whereas mothers may be more affected by day to day pressures and demands of their child (Davis & Carter, 2008; Keller & Honig, 2004; Krauss, 1993). Furthermore, different coping strategies may impact stress levels, with parents who use active avoidance reporting greater distress, while those using positive reframing reporting less distress (Hastings et al., 2005b). Gender differences in coping are also reported, with men using more problem-focused coping strategies, and women more emotion-focused coping strategies (Gray, 2003; Rodrigue, Morgan & Geffken, 1992), although in the long term all parents may use strategies focused on managing emotions (Gray, 2006).

2.2.2.2 Parents perceptions of their child

Parents whose children receive a diagnosis of ASD may experience a process similar to the phases of grief proposed by Bowlby (1980) concluding in the reorganisation of their internal working model of themselves and their child (Oppenheim et al., 2007). Greater parental sensitivity has been observed in parents of children with ASD, who have come to terms with their child’s

diagnosis and hold more realistic mental representations of their child (Marvin & Pianta, 1996; Moran, Pederson, Pettit & Krupka, 1992; Oppenheim, Koren-Karie, Dolev & Yirmiya, 2009; Wachtel & Carter, 2008). How a parent sees their child with a developmental disability seems to impact the parent's psychological experience, with parents reporting positive perceptions of their child also reporting less distress (Blacher & Baker, 2007; Hastings, Beck & Hill, 2005a; Neely-Barnes & Dia, 2008). It seems parents' positive perceptions of their child with ASD acts to help families adapt and cope with challenges (Hastings & Taunt, 2002). However, mothers of children with ASD appear to report more positive experiences than fathers (Hastings et al., 2005a; Kayfitz, Gragg, & Orr, 2010), with fathers reporting a more negative effect of having a child with a developmental disability (Rodrigue et al., 1992).

2.2.2.3 The parental relationship

The rate of divorce within families with a child with ASD is nearly twice the rate of other families, with high levels of parenting-demands, stress, and the resulting reduction in attention available to one's spouse, thought to contribute to parental separation (Hartley et al., 2010). Having a child with ASD puts strain on the marital relationship and fathers seem to be particularly affected by increases in family tension (Gray, 2003; Keller & Honig, 2004; Krauss, 1993). Additionally, the nature of the parental relationship influences infant attachment, as strains within the mother-father relationship can impact on parental sensitivity and thus responsiveness to their child (van IJzendoorn & Wolff, 1997). Bowlby (1980) highlighted the importance of parents being in step with one another and proposed that being in synchrony made processing and adapting to losses easier. Indeed, a supportive and positive relationship

between parents has been identified as a key aspect of resilience in families with children with a disability (Heiman, 2002).

2.2.3 Role of fathers

Fathers are increasingly involved in family life and their role now overlaps more with that of mothers (Cabrera, Tamis-LeMonda, Bradley, Hofferth & Lamb, 2000; Lamb, 2010). Fathers make a unique contribution to their child's emotional security, both directly (Grossmann, Grossmann, Fremmer-Bombik, Kindler & Scheuerer-Englisch, 2002) and through a more complex cyclical and cumulative model of different family factors (Ferguson, 2002). Their involvement with their child with autism can positively affect the child, the mother and the family as a whole (Flippin & Crais, 2011). Despite these considerations, research in to families living with disabilities has been dominated by the experience of mothers; the experience of fathers' of children with ASD is a specific area of neglect within research (Emerson, 2003; Hartley, Seltzer, Head & Abbeduto, 2012). The beginning of this work has started to take place (e.g. Boström & Broberg, 2014; Martins, Walker & Fouché, 2013; Vacca, 2013). However there remains a scarcity of research and, to date, no published report on the experiences of fathers' in the UK living with a child with ASD.

2.2.4 Aims of current study

Within the literature, quantitative research has been favoured over qualitative approaches and as mentioned above there are few studies exploring fathers' experiences (MacDonald & Hastings, 2010). Research by both Wachtel and Carter (2008) and Ylven, Bjorck-Akesson and Granlund (2006) recommend that

support offered to parents of children with ASD could be improved if fathers' experiences of their child's diagnosis and the parental and parent-child relationship were better understood. Support tailored to parents' experiences would serve the needs of parents better and could improve the outcomes for children.

This study aims to understand fathers' experiences of living with a child with ASD within a psychological framework. Specifically it aims to address the lived experiences of learning about their child's diagnosis of autism, their relationship with their partner in the context of autism and their relationship with their child.

2.3 Methodology

2.3.1 Design

Focusing on fathers experiences lends itself to a qualitative approach, adding a rich understanding to an area of limited research. The qualitative approach chosen was Interpretative Phenomenological Analysis (IPA) as this focuses on individuals' detailed account of their lived experiences, the meaning they take from this and identification of meaningful points of similarity and difference between participants (Smith & Osborn, 2007). IPA has three main theoretical underpinnings: phenomenology, hermeneutic and idiographic (Smith, Flowers & Larkin, 2009). IPA adopts a phenomenological approach by focusing on the sense an individual makes of their life experiences; it is underpinned by hermeneutics through participants' interpretation of their experience. An idiographic stance is taken to gain detailed understanding of the lived

experiences of a specific participant group through systematic analysis (Smith et al., 2009).

2.3.2 Materials

A semi-structured interview schedule was developed to guide data collection (Appendix D). This was intended to act as a basis for conversation and not override the needs of the interviewee (Biggerstaff & Thompson, 2008). It was developed to adhere to the principles of IPA by using open questions, encouraging expansive answers and avoiding making assumptions or leading participants (Smith et al., 2009). Demographic data was collected through the completion of a brief questionnaire (Appendix E).

2.3.3 Procedure

2.3.3.1 Ethical approval

The research was designed and conducted in line with guidance from the British Psychological Society Code for Human Research Ethics (2010). Ethical approval was granted by Coventry University (Appendix F), local Research and Development Departments (Appendices G, H and I) and the East Midlands National Research Ethics Committee (Appendix J).

2.3.3.2 Recruitment

As IPA focuses on the detailed understanding of participants lived experiences it is preferable to have fewer participants studied in greater depth than more material analysed to a lesser extent (Hefferon & Gil-Rodriguez, 2011). It is recommended that four to ten interviews are conducted for doctoral level

research (Smith et al., 2009). Participants were recruited who met the inclusion criteria as detailed in Table 2.1. In order to make meaningful interpretations of a particular perspective using IPA the participants need to be from a homogenous group (Smith et al., 2009).

Table 2.1. *Participant inclusion and exclusion criteria*

Inclusion criteria	Fathers of a child with a diagnosis of ASD Child is of primary school age (4 - 11 years old) Living in West Midlands The diagnosis was given at least one year ago
Exclusion criteria	Non-English speaking

Recruitment sites included voluntary organisations within the West Midland and NHS Child and Adolescent Mental Health Services (CAMHS). The researcher approached three local voluntary organisations to provide information about the study. These organisations agreed to email their distribution lists with the research information pack (Appendix K) which included an invite letter, participant information sheet and consent form. In addition, the researcher attended support groups run by these organisations and by CAMHS to advertise the research and give out information.

Nine fathers contacted the researcher to express interest. One of these did not meet inclusion criteria as their child exceeded the age identified; the other eight were interviewed about their experiences of having a child with ASD. The participants were self-selecting; six participants came through voluntary organisations, one through CAMHS and one through snowballing effect from

another participant. Interviews were arranged for a time and location most convenient to the participant.

2.3.3.3 Interview Procedure

Participants were interviewed in private; seven in their own homes and one at their workplace, and at one interview the participants' wife was present. They were all interviewed between June and August 2014. Prior to the interview the participant information sheet and consent were reviewed and signed. Demographic data was collected before recording commenced and the interview started. A digital audio recorder was used to record the interviews and these were later transcribed verbatim by the researcher. Interviews lasted between 1 to 2 hours (mean of 85 minutes). On completion of the interview a verbal debrief was given and participants were provided with debrief information providing details of relevant support services (Appendix L). After eight interviews the researcher concluded that a sufficiently rich level of data had been achieved to identify meaningful points of similarity and difference, and recruitment was terminated.

2.3.4 Participants

Demographic data for participants is presented in Table 2.2.

Table 2.2 *Participant demographics*

Participant	Age	Marital status	Child's age and sex	Time since diagnosis	ASD severity (parent rated)	Number of siblings	Sibling with an ASD diagnosis
Harry*	43	Married	6 (F)	2 years	Moderate	3	0
Simon	37	Married	5 (M)	2.5 years	Mild- Moderate	1	0
Daniel	42	Married	7 (M)	4.5 years	Severe	4	0
Henry	49	Long term partner	6 (M)	4 years	Moderate	7	1
Matt	40	Married	9 (M)	3 years	Moderate	1	1
Roger	41	Married	9 (F)	2 years	Severe	None	None
Gary	34	Separated	4 (M)	1 year	Mild	None	None
Will	58	Married	5 (F)	3 years	Mild	None	None

* Pseudonyms have been used to protect participant identity

F = Female, M = Male

2.3.5 Analysis

2.3.5.1 Procedure for analysis

Audio recordings of the interviews were transcribed verbatim by the researcher and identifiable information edited. The steps for IPA analysis outlined by Smith et al., (2009) were then followed (Appendix M). A line by line analysis of each transcript was completed making initial notes; these were then reviewed to identify emergent themes. Appendix N is an excerpt exemplifying this process. Taking one transcript at a time, emergent themes were searched for connections and clustered together under preliminary themes. These were then brought together to identify patterns across participants forming superordinate and subordinate themes. Appendix O provides photos illustrating this process.

2.3.5.2 Credibility of Analysis

In order to improve validity, quality checks were utilised as suggested by Mays and Pope (2000). This included the involvement of a research supervision team who reviewed developing themes and aided reflective practice through discussion of the data. An additional analyst was also used to verify coding. Researcher reflexivity was encouraged through the use of a research diary, peer based IPA support and regular research supervision. Lastly, within word-limit restrictions, themes have been supported by data and areas of convergence and divergence are highlighted.

2.3.5.3 Position of the Researcher

Good quality qualitative research includes transparency of the researcher's values and assumptions brought to the collection, analysis and interpretation of data (Yardley, 2000) Reflexivity is the process of increasing awareness and acknowledging the researchers influence (Ahern, 1999). In addition to keeping a reflective journal, a bracketing interview with a research supervisor was utilised. The aim of bracketing is to objectify and amplify the researcher's awareness of their own assumptions and experiences (Rolls & Relf, 2006). The researcher's own expectations for fathers' involvement in childcare, linking to feminist values were noted and discussed. Additionally, expectations of loss linked to disability were noted. At the time of interview the researcher was employed as a Trainee Clinical Psychologist by Coventry and Warwickshire Partnership Trust, was working at a CAMHS service and was 30 to 38 weeks pregnant. Attachment theory was of particular interest as it applied personally with the imminent arrival of the researcher's own child and as it was directly applicable to the researcher's case load within CAMHS.

2.4 Results

From the results of the analysis three superordinate themes emerged: 'Bittersweet Bond', 'The Price of Emotions' and 'Surviving and Developing'. Subordinate themes are presented in Table 2.3. Each theme is discussed with supporting quotes and areas of convergence and divergence are considered.

Table 2.3 *Overview of themes*

Superordinate themes	Subordinate themes
Bittersweet Bond	Loss and love Protecting from difference
The Price of Emotions	Turmoil and turbulence Hero and victim
Surviving and Developing	People power Going forward

2.4.1 Bittersweet Bond

This theme captures the father-child relationship, the feelings of loss and love, both on realising their child had ASD and what that comes to mean, and in terms of their connection with their child. Their love and fears of how the ASD could lead to their child being different and vulnerable prompted a sense of needing to protect their child from distress and harm. Some fathers focused on preparing their child for the realities of the world and their future.

2.4.1.1 Loss and love

Feelings of loss were pervasive. Their experiences of what they had lost differed; some identified a loss of the life they had planned, others the loss of an

expected child, a relationship or the child they thought they knew. For one father there was a sense of feeling resentful, perhaps because this life was not part of the deal of parenthood.

“We do feel like we’ve been cheated and that we’ve lost, we haven’t lost her because she’s here obviously, but we’ve lost the potential of normality.”

(Roger, lines 527-529)

“I think undoubtedly you have a vision of how perfect and wonderful your family life is going to be, don’t you, and, you know, you think your kids are going to be healthy and happy always and they’re not going to have any difficulties and ... and, you know, your whole life is planned a head of you, and suddenly it’s not going to be like that at all, it’s going to go off in a completely different direction and that’s... that’s a difficult thing to cope with.”

(Simon, lines 465-469)

All fathers expressed feelings of deep and unconditional love for their children. They celebrated their child’s abilities and achievements and accepted and valued their child. Some expressed hope and pride in their child’s unique skills, even seeing them as “*superpowers*” (Gary, line 424). It seems that from an uncertain start, many fathers now welcomed their child as they are.

“Just my little boy really, that makes him special enough to me, he is really good when you watch him in class and he does the maths, you know, he’s really really good at maths, you know, and it makes me feel really proud when he does that.”

(Matt, lines 343-345)

Some fathers were able to hold their feelings of loss and love together, whilst for others it was a more painful and difficult experience. A lack of acceptance of their own response was evident in several who wished they had not felt sad.

“It’s difficult to look back to realising he had autism and seeing that as a grieving process because in hind sight it shouldn’t have been[...] I think I feel bad that I was grieving for something I had lost, when I didn’t lose anything, I just didn’t have what I expected.”

(Simon, lines 522-526)

Feelings of love and loss seemed to extend to most fathers’ experiences of connectedness to their child. This was dispersed within all the fathers’ experiences, although not necessarily spoken about directly; it was conveyed in many different quotes. Fathers’ longed for and found great joy in times of connection with their child and many found this through play. For some there was an additional benefit as play enabled physical contact that their child may not have tolerated otherwise.

“She comes up to me and says is it time for tickling time so I said yep, I think it might be tickling time and I start tickling her and she loved it, under her chin and under her arm, and she puts her arms out to the side, so yeah she has a nice sense of humour and .. so we did that bit, that’s nice because that’s a bit of closeness.”

(Will, lines 329-332)

Moments of connectedness were treasured, but for some were tinged with sadness as they were aware of these moments being fleeting. Perhaps there was a sense of loss for the connection they longed to have with their child.

Some spoke about tough times of not wanting to take any connections for granted, feeling angry or sad on seeing other parents experiencing an easier relationship, or guilt at the pleasure taken in finding an easy connection with another child.

“You get a sense of perhaps I do understand, and then the next day you’ll get a kick in the teeth, but for that day, or that meal, or you know, you get that spark of communication going and you feel that was good, that was good, and like I say making her smile because you understood that’s what she meant when she was doing that, you know, and you, that’s rewarding.”

(Roger, lines 1074-1078)

“I think it makes me feel bad as well, if I find it very easy to have an interaction with another child to have a chat or a game or whatever, and [my child] sees that, I kind of think that’s going to be hard for him, because I think he realises what he finds hard.”

(Simon, lines 236-238)

Times of disconnection highlighted not only the challenge of continuing to care, but the heartbreak of losing a reciprocal relationship, perhaps representing broader disconnection in the fathers’ experience. There is sadness for some who do not know whether their child has been able to internalise their relationship, not knowing if they are loved by their child or remembered. Some participants felt they started their relationship afresh each day, rather than being able to build on their relationship as they might with others, perhaps emphasising further disconnection. Most fathers went to great lengths to develop relationships and find shared pleasures but it was tiring, and there were

moments of disappointment that it couldn't be easier. There was a contrast between continuing to fight for connection and feeling defeated.

"It's like having a fresh start with [our child] every day, you have to start from the beginning [...] that can get a little frustrating sometimes because you want to just get straight in to the fun and the making a memory for him, creating a stronger bond."

(Daniel, lines 591-595)

"I think she has a bit of it, you know, it's coming, I think it's all part of ... me ... because I'm, I haven't got that sense of her wanting to have me in her life I sort of back off aswell, so I become a bit distanced."

(Will, lines 301-303)

2.4.1.2 Protecting from the world

Several fathers spoke about finding a place for their child in the world, being aware of how their child might be different and how this may separate them and cause their child distress. There was a sense of fear that their child may be targeted for their differences and trying to protect their child from this rejection, *"people are very sharp they are very... conniving and I really hope that I can teach him somehow to be able to pick up on these things"* (Gary, lines 288-289). For some there may also be gratitude that the ASD offered some protection from life's pressures.

"Last night I just sat there and looked at him and sometimes I can just cry, because I think, I would swap places with him in a heartbeat for him to have a normal life, and then sometimes I look at him and think, and his got this big smile on his head and his eyes are all lit up, and I think, I would take an hour in his head, do you know what I mean, I would have an hour away from stress"

free, worry free, no commitment nothing, just to have an hour in his head of... happiness."

(Daniel, lines 554-557)

Half of the fathers explicitly talked about preparing their child for the real world, whether through developing their social skills, emotional literacy or physical and intellectual development. Perhaps this emphasis on development was driven by a desire for their child to fit in, to protect them from exclusion. A few fathers acknowledged their role of supporting their child in the future whilst they struggle to find their place.

"Unfortunately he's got to live in the real world and he's got to get somehow from here, the things he can't do, the envelope, to the things he needs to be able to do in the real world. So he needs to experience all these other things. Some of it is going to be fun, some of it's not going to be fun. But he's got to experience all these things so you've got to keep pushing that envelope."

(Henry, lines 223-228)

Several fathers spoke about times when their child's lack of development was a cause of frustration. At times expressing exacerbation that their child's interests were not age appropriate and a desire for their child to develop in line with peers. Perhaps this was underlined by their fear of their child not fitting in or connected to feelings of loss.

"That's not a book for you to read, you read that to a baby, it's fine if you want to read it again as well but if you want to sit and do some reading you should be reading a proper book."

(Matt, lines 298-300)

Fathers of children with severe ASD expressed acute awareness of their child's lifelong need for care. This seemed to bring a desperate fear of their own mortality, linked to their helplessness in protecting their child in the future. These fears appeared to be exacerbated by difficulties linked to trusting others, partly due to an awareness of child protection issues, whether through work or through media reports. For one father these fears appeared to underline experiences of panic attacks and for another had prompted significant lifestyle changes in order to prolong living.

"I'm not scared of anything or anybody, but my one thing that does really really scares me and keeps me awake every day is if something happens to me what's going to happen to her. Do you know what I mean; because I don't want anybody else to look after her...I don't think anybody would ever understand her and her needs."

(Roger, lines 203-207)

2.4.2 The Price of Emotions

This theme captures the sense of turmoil some fathers conveyed as they spoke about realising their child had ASD and the ongoing influence their child had on their home life. Hero and victim, encapsulates fathers' responses to the disruption both within themselves and within their lives.

2.4.2.1 Turmoil and turbulence

On realising their child had ASD, fathers responded differently; some appeared not to be affected, whilst others expressed various emotional responses. Some identified feelings of confusion and anxiety as they saw differences in their child; others identified feelings of shock, anger and denial on learning of the

diagnosis. Several fathers expressed feeling as if someone was *“taking the world from underneath us”* (Roger, line 814).

“I didn’t believe it to begin with and I know a lot of parents say that and it would be easy to say of course I knew it, but despite some ever so slight indicative behaviour, I still didn’t believe it at first.”

(Henry, lines 1160-1162)

In making sense and coping with the news, some fathers found themselves blaming others or themselves. A possible period of turmoil was conveyed, perhaps as they assimilated this new information.

“Then you have that blame yourself as well, well was it something I did, is it, is he that way because I smoked too much or drank too much when I was younger or did I, have I been a bad person and I’m getting punished, I questioned my faith as well [...] then in the end of it you think well what complete nonsense”

(Daniel, lines 531-536)

The turbulence was ongoing as all fathers spoke about home life feeling chaotic at times, and several mentioned work as an escape. For some, exhaustion was evident and the fear of cracking may indicate how close some lived to the edge of coping, *“It’s always there, it’s always there ... that somebody is going to crack at any point, because [my daughter] is very challenging”* (Roger, lines 35-36). The pressure of living with a child with ASD was captured by terms such as *“treading on egg shells”* (Harry, line 28), *“nightmare”* (Matt, line 306) and *“water torture”* (Roger, line 233) bringing to mind tension, torment and strain some of these fathers may experience.

“It’s a constant, not battle, but constant peaks and troughs, I guess that’s kids with autism in general really, or life in general, there’s always going to be ups and downs but it just seems like the ups are really high and the lows are really low.”

(Gary, lines 381-384)

The nature of autism meant that for a lot of fathers, their child’s needs had to come first. Several spoke about the challenge of balancing their child’s needs with the needs of the family and work. Most fathers, whilst acknowledging the challenge, spoke about their willingness to put their own needs to one side, *“I was actually progressing very well at a couple of promotions, I was going really well in the job, you know, I was doing really well but then obviously family had to come first”* (Harry, lines 370-372). Finding the balance with other children seemed to be more difficult.

“I don’t get to do these things anything like, anything as much as I’d like to do because of a combination of work and the fact that the other kids, you know, the demands are required by some of the other kids as well. He’s not the only kid in the, in the family.”

(Henry, lines 249-253)

For some, it seemed the child was in a powerful position within the family. Several fathers felt unable to influence their child’s behaviour or development, or felt excluded; conveying a sense of impotence and helplessness. Many were apprehensive of triggering distress and the linking behavioural challenges.

“I find with myself if I say to her to do something and she doesn’t want to do it she’s not going to do it and I sometimes, more often than perhaps I should, I just

let it go, [...] it can erupt very easily, yeah yeah, and sometimes for no reason at all.”

(Will, lines 611-618)

“No matter what we say it’s not going to make any difference to the way she sees it.”

(Harry, lines 186-187)

2.4.2.2 Hero and victim

Within this area fathers portrayed a sense of stoicism (i.e hero) but also a lack of acknowledgement of the emotional impact on them (i.e. victim). Some fathers spoke about the need to take action and search for solutions (i.e. taking on a hero role). Receiving the diagnosis appeared to open doors to knowledge and perhaps provides a means of coping through problem-solving and a sense of power through action. This position, however, appeared untenable as fathers spoke about realising there were no clear answers, returning to feelings of helplessness and uncertainty (i.e. a victim position). Some participants expressed feelings of frustration, perhaps linking to a process of realising that autism is not solvable.

“Most things in the world you can say I want a manual for well there ‘aint no manual for kids at the best of times, but there is nobody to say, you know this is the definitive thing you’ve got to do, there’s nothing there and I wanted somebody to say to me “go home, do this and he’ll be okay.”

(Daniel, lines 211-215)

Others spoke about realising learning was ongoing and learning to trust their own instincts to parent their child *“I’ve learnt over time I can just do what comes*

naturally and that's alright, it's alright to just kind of, just be a parent and do your own thing your own way" (Simon, lines 354-355). Perhaps this reflects a shift, from needing to solve a problem, to acceptance of the situation.

Despite the obvious practical and emotional pressures, the majority of fathers spoke about the need to keep going, portraying a sense of stoicism and required fortitude (i.e. a further example of a hero role). There was a sense for some, that stopping was not an option, perhaps as this could have offered space to emotions could not be dealt with or felt frightening or overwhelming (i.e. giving a sense of a victim position).

"If I did have one day where I was to let it all go, there would be nine years of holding everything in and I don't know what that would be like"

(Roger, lines 645-647)

Within most of the fathers' accounts there was reference to how they experienced emotions, there was variability both within and between fathers. With times when emotions were more tolerable, to times where there is a sense of dismissing and denying feelings. A hero role is again portrayed with several suggesting there was nothing to be gained from engaging in emotions *"We're not going to cry over it because there's no point in it, we're no further forward if we cry so we'll just get on and do it"* (Matt, line 63-64) and that it is easy and more practical to *"shelve the blame, shelve the anger, just deal with it"* (Daniel, lines 684-685). Some reported using understanding to cope when their child was the cause of frustration, perhaps meaning that the understandable anger was not addressed. The process of dismissing feelings was more overtly acknowledged by three of the fathers.

"[My ex] was actually doing all the right things, she was actually dealing with all the aspects of grief, the anger, the depression, the whatever, denial. Where I was just trying to be, just logical rather than emotional [...] I just blindsided my feelings, totally disregarded them and just went for it."

(Gary, lines 492-498)

Cultural rules around men and emotions were evident; statements such as *"just man up"* (Gary, line 105) are suggestive of expectations of how men should respond. These pressures seemed to influence whether they felt able to express feelings but also the loss of opportunities for their feelings to be considered, again portraying a victim position.

"You have to just carry on, if you don't, if you didn't, if you didn't just... get on with it, you know, it's not going to get done and everybody else would just collapse around you. It makes me sound like I'm a bit of a hero but you know what I mean, I'm not."

(Roger, 166-170)

"I think this, you're the first person I've told this to in terms of how I've felt, just having this aspect where actually my feelings don't matter in this, I've just got to be the stereotypical sort of man."

(Gary, lines 505-507)

2.4.3 Surviving and Developing

For many fathers, finding ways to survive meant relying on support within and outside the family. Relationships were challenged by the presence of ASD, and fathers spoke about how they had survived and developed. Development

extended to changes in perspective, both personally and within their families and allowed several fathers to find meaning within their experiences.

2.4.3.1 People power

The majority of fathers found value in support from family and other parents of children with ASD. Some fathers spoke about feeling safe, respected and understood within these communities, being able to access valuable knowledge and experiences, and talk openly about their own challenges. Talking was not for everyone; one father identified greater isolation due to his own values for privacy. As he was recruited through snowballing, rather than through support services, his views may be representative of other fathers who choose not to access support.

“Getting to know other families with autistic children that has helped a lot, being able to talk to them and understand that you are not on your own, it’s not just you, and it’s not just your children.”

(Harry, lines 492-497)

Within their own marital relationships, most fathers acknowledged how having a child with ASD caused tensions. Some spoke about the reduced opportunity for time together, challenges with communication and lack of energy. Despite these challenges, most fathers conveyed a sense of commitment and determination to make their marital relationship work. The importance of togetherness was evident within most fathers’ accounts; working together towards shared goals and being united as a team. The one separated father shared these sentiments, expressing commitment to his role as a parent regardless of marital status,

“We’re a team, so, okay we’re not... man and wife anymore, but in that sense we, we are his parents and we always will be” (Gary, lines 34-35).

“Both of us are pretty... determined and extremely unwilling to give up on anything, and I think that’s important, really important... I... it kind of sounds very unromantic, I would love to say, yes, it’s because we are so devoted and adoring and all that kind of stuff, yeah that’s helpful, but the reality is you’ve got to stick at it really and I think if you can do that, the other stuff takes care of its self.”

(Simon, lines 483-487)

At times fathers’ expressed feeling let down by society. Some felt disappointed by the lack of support from institutions such as the NHS or schools, and several spoke about their perception of judgment from the wider community. Perhaps feeling ostracised and angered by a lack of understanding. At times these challenges extended to family members, with some fathers feeling judged, criticised or excluded. It seems that when there are different ideas about what is best for their child or how to achieve it, tensions became more apparent within these relationships.

“They used to do drop in sessions, with [NHS], that used to be quite good, where you could go [for support] that seems to have died a death now, that doesn’t go on anymore”

(Matt, lines 660-669)

“As two parents of a lot of children, not as a couple but of two parents of a lot of children, in effect parallel lines I suppose might be a way of putting it. [Our child...] has made that, a bit more difficult, because there’s more things to argue about and because our views are so very different.”

(Henry, lines 861-868)

2.4.3.2 Going forward

With time, thoughts and feelings appeared to evolve for the majority of fathers. Some found meaning within their experience; others noted ways they had personally developed, including greater confidence and empathy, and ways their families had grown stronger and siblings had benefited, *“If anything I guess it’s made us, as a family unit, it’s made us stronger”* (Harry, lines 635-636).

“My own personal realisation that actually autism isn’t an illness it’s just something we haven’t figured out yet, but I believe that god has a bigger better plan and we just can’t see it.”

(Gary, lines 400-402)

One father spoke about a clear progression in his response to others from anger to engagement. Perhaps this adjustment also paralleled development of his own feelings from denial and anger to acceptance and understanding.

“I just go to a point where I realised there was just no point in shouting at people. [...] I did just kind of go [click] that’s the answer, educate the ignorance. But it’s not ignorance, nobody ever comes in to contact with one of them people, or does and doesn’t have an understanding of it, then they’re never going to know, they’ll just continue going through life... tutting, another naughty kid.”

(Daniel, lines 457-463)

From the initial anxiety and fear of an uncertain future and potential hardship, several fathers spoke of hope for their child’s future and even curiosity and excitement for what might come. Although this was not expressed by all fathers,

there was a sense that some had integrated the unexpected experience of having a child with autism into their lives, seeing a new destination rather than a termination of their life journey.

“You’re going to have good times out of this, it’s not, you know, it’s not the end of the world, you haven’t lost a child, you’ve just changed direction a little bit really, that’s, that’s definitely the case, I can’t imagine changing [my child] for a second, there is nothing I would want to change about him.”

(Simon, lines 519-521)

2.5 Discussion

2.5.1 Summary of findings

The aim of this study was to understand fathers’ experiences of living with a child with ASD. Specifically it aimed to consider their experiences of learning about their child’s diagnosis of autism, their relationship with their partner in the context of autism and their relationship with their child. Three superordinate themes were identified: ‘Bittersweet Bond’ identified fathers’ experiences of their relationship and their view of their child, the love and loss experienced within that relationship and their role to protect their child. ‘The Price of Emotions’ captured father’s emotional experiences and responses to discovering their child has ASD and living with their child, whilst ‘Surviving and Developing’ captured fathers’ experiences of relationships with others and the development of their relationship with ASD.

2.5.2 Discussion of results in relation to literature

2.5.2.1 Loss

The experience of loss portrayed by fathers in this study is consistent with research involving fathers and mothers of children with ASD. Research evidences loss of the imagined child and life plans, as well as loss in parents' relationship with their child, who may be physically present but not fully psychologically present (Boström & Broberg, 2014; Myers, Mackintosh & Goin-Kochel, 2009; O'Brien, 2007). O'Brien (2007) suggested mothers' experiences of conflicting feelings regarding loss, could be captured by the concept of ambiguous loss proposed by Boss (2007). Ambiguous loss describes the psychological challenge when loss is not clear-cut. Fathers in this study also portrayed a sense of conflict between love and loss; the concept of ambiguous loss captures the lack of a definite loss, the sense of conflict and confusion, and the fleeting connectedness fathers' experienced.

The lack of connectedness and related distress is consistent with other fathers of children with ASD (Boström & Broberg, 2014; Vacca, 2013) and quantitative studies linking paternal stress to the father-child relationship (Keller & Honig, 2004; Krauss, 1993). However, consistent with Martins et al., (2013), there was variation between participants experience of connectedness to their child. One factor explaining this could be the severity of autism as research indicates the more severe the impairment in reciprocal social interaction the less able parents are to establish a secure attachment with their child (Rutgers et al., 2004). Another factor may be the reorganisation of fathers' internal working models to reflect their new reality (Oppenheim et al., 2007). Some participants conveyed a period of turmoil as they integrated their new experience of their child and life.

The fathers' stage of integration may impact how connected they feel to their child and their level of distress (Boström & Broberg, 2014; Keller & Honig, 2004). A third factor could be the extent participants experienced positive effects of having a child with ASD, as the process of finding meaning and benefits is critical to adjustment post loss (Hall, 2011).

2.5.2.2 Personal growth

Evidence of high levels of stress in this parent group is well documented (Boström & Broberg, 2014, Davis & Carter, 2008; Myers et al., 2009; Vacca, 2013), and the experiences of fathers in this study support these findings. However, substantial evidence for positive emotions such as pride, joy, love and connectedness is also found. Although this cannot be compared to mothers, it shows that fathers' experiences of having a child with autism are both positive and negative. Post traumatic growth, defined as positive changes resulting from life traumas (Tedeschi & Calhoun, 2004), is associated with parents coming to terms with their child's diagnosis (Yirmiya et al., 2015), and decreases in distress (Hastings et al., 2005b). Unlike Martins et al (2013), this study found evidence that fathers had identified meaning and benefits of having a child with ASD. Consistent with other research the experience of positive growth did not appear to be linked to the passing of time (Holland, Currier & Neimeyer, 2006; Yirmiya et al., 2015). Although this needs further investigation, perhaps the explanation lies within personal characteristics such as resilience, access to support and response to emotional pressures.

2.5.2.3 Responding to emotional pressures

In line with other research, fathers in this study appeared to avoid negative feelings (Boström & Broberg, 2014) and favour problem-solving as a means of

coping (Folkman & Lazarus, 1980; Martins et al., 2013). There was an initial sense of relief from engaging in solution finding. However, this was followed by frustration at the lack of answers. Although problem-focused coping is generally associated with decreases in stress (Hastings et al., 2005b), within this father population the impact appeared to be more complex. Findings from coping with chronic illness indicate that problem-solving when there are no clear solutions can be counterproductive and increase distress (Lazarus, 1993) and instead, avoidant coping may be the most effective option (Smith, Seltzer, Tager-Flusberg, Greenberg & Carter, 2008). Some fathers' experiences within this study may reflect this process. The most helpful response may vary over time, between contexts and between individuals (Folkman & Lazarus 1980; Lazarus, 1993), thus it is important to understand individual response to different aspects of an experience.

For some fathers there was a sense of regretting, fearing or being overwhelmed by emotional responses. Although this process may reflect phases of grief proposed by Bowlby (1980) and necessitate the reorganising of their internal working model of their family, fathers' responses may also reflect their relationship with negative emotions. Perhaps within the chaotic and demanding environment they portrayed, fathers do not have the capacity to deal with painful feelings. Another consideration is cultural pressures; similar to Vacca (2013) there was a theme of not stopping and a felt pressure to support others. Cultural norms of masculinity are associated with suppression of emotions (Flynn, Hollenstein & Mackey, 2010) and there was evidence some fathers felt pressured to play a particular role as family carer, putting their own feelings aside. Although fathers role within the family now overlaps more with mothers'

(Lamb, 2010), this study evidences the continued cultural pressures experienced by fathers in how they respond to emotions. It may therefore be more in line with gender differences in parental grief, illustrating reluctance to engage in difficult emotions potentially impacting the longevity of their distress (Schwab, 1996).

2.5.2.4 Relationships

In agreement with other studies, fathers reported having a child with autism put strain on their marital relationship (Myers et al., 2009). Their emphasis on the importance of togetherness lends support to the concept of positive parental relationships being central to resilience within these families (Heiman, 2002). The joint commitment of working together as a team towards the shared goal of their child's happiness seemed to be crucial for most of these fathers. Unlike other studies, indicating fathers experience wider social isolation (Altiere & von Kluge, 2009; Martins et al., 2013; Woodgate et al., 2008), most of the fathers in this study benefitted from support from the wider community, in keeping with research that support is important in managing stress (Falk et al., 2014). There was one exception, who expressed greater isolation as a result of valuing privacy, this was a father recruited through snowballing, and thus the outcome likely reflects the recruitment strategy of targeting support services. However it may also illustrate that, rather than gender differences in not needing or valuing social support (Martins et al., 2013), fathers can benefit from social support when barriers are overcome. Those barriers may include responses to negative feelings and cultural pressures as discussed above, but also the perception of support and its utility, as seeking support happens more in situations where solutions are possible (Carver, Scheier & Weintraub, 1989). Fathers spoke

about the benefit of getting tips from other parents and reassurance and relief from shared experiences, this experience of utility may further incentivise them to pursue support.

2.5.3 Limitations

Due to the lack of research involving fathers, it was anticipated that recruitment would be problematic and thus inclusive criteria were used. This may have impacted on the homogeneity of the participant group and future research could focus on a narrower group. One difference was in the age of the child; although all were of primary school age, the difference between a four and a nine year old may be distinct. Additionally, parental stress appears to vary depending on the age of the child (Orr, Cameron, Dobson & Day, 1993), suggesting there may be different parental experiences. Other elements that may have impacted directly on fathers' experiences were the severity of ASD and the existence of a sibling with ASD. Furthermore, participants were recruited through support services and were self-selecting, potentially biasing the sample towards fathers who have had more challenging experiences and/or have more proactive coping styles.

2.5.4 Clinical implications

Support for parents needs to focus on their experiences and responses to having a child with ASD and not just parenting strategies to deal with their child (Falk et al., 2014). There is a need to normalise and validate feelings of grief and loss within this population; acknowledging loss of expectations and the

difficulty of coming to terms with their new reality. O'Brien (2007) suggests recognising that confusion and distress are located within the inherently ambiguous situation rather than within the parent, allows reorganisation and release from distress. Finding meaning also appears to be helpful for fathers, this is unlikely to be a directive activity that can be endorsed by a third party (Holland et al., 2006), but, as with this study, may elucidate through the opportunity to discuss their experience. Greater integration and identification of positive experiences, may also aid feelings of connectedness within the father-child relationship, and impact on the security of the child's attachment. Additionally, Acceptance Commitment Therapy may prove useful in enabling parents to adjust to the challenges they live with (Blackledge & Hayes, 2006).

For some fathers there was a sense of feeling let down by diagnostic services, portraying a lack of support, direction and advice. Although those services may have a different experience of offering greater support, the evidence is true to fathers' experiences of the situation. As many described denial, devastation and anger at the point of realising their child had ASD, it is possible that fathers are not in a position to absorb any practical information at that point, but could benefit from follow-up support. The participating father's expressed a desire for support but some also spoke of difficulties engaging in support. Support needs and barriers are different for each family and a variety of support options may be required (Clifford & Minnes, 2013). As fathers valued peer support, services could consider developing parent-parent support systems. Additionally, a direct link between diagnostic services and peer support services may help parents navigate the complexities of support for their child, a problem highlighted by several fathers.

Due to the scarcity of fathers included within research it was anticipated that recruitment would be challenging, this was not substantiated. This has research implications for future studies seeking to recruit parents and how fathers can be reached through support services and social networks to be included more equally within future research.

2.5.5 Future directions

This research adds to the small cluster of studies investigating fathers' experiences of having a child with autism. The use of IPA, based in the lived experience of participants, limits the transferability of these findings; however it has highlighted possible challenges faced by fathers. Longitudinal studies investigating changing experiences from diagnosis through different ages would provide further insight into fathers' adaptation and development of the father-child relationship. It would also be of value to more closely explore fathers' experiences of support, and what they find beneficial, in order to inform the development of services.

2.6 Conclusion

Using an IPA approach, the present study has explored in detail the lived experiences of fathers' living with a child with autism, their experiences of their relationship with their child, and with their partner. The commitment of these fathers to their child and the challenges they face both internally, in terms of their own emotional responses, and externally, in terms of their relationships

with others, has been highlighted. The needs of this population may be hidden as they are commonly less involved with services. This study highlights the need to consider fathers at intervals beyond diagnosis, listen to and validate their experiences.

2.7 References

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CHAPTER 3: REFLECTIVE PAPER

**A conversation: A reflective account of the
influences of researcher and research**

Overall chapter word count: 3002

(Exclusive of footnotes and references)

3.1 Introduction

The following chapter is a review of my personal experiences and reflections whilst completing my research. It is informed by the reflective journal I have kept over this period and discussions with my research supervision team. As both my papers have been qualitative, it feels important to acknowledge the two way flow between research and researcher; as such I have developed a structure based on the flow of influence between me and my research, considering areas where I informed the research, but also how my research has informed and affected me. I conclude with my reflections on commencing a career as a qualified psychologist.

3.2 Reflections on the research process

3.2.1 How I reached you: The conception of my research idea

I found the prospect of writing a thesis intimidating and the process of choosing a topic extremely difficult. That period of time is captured within my reflective journey by words such as, “overwhelmed”, “doubting” and “lost”. Turning vague ideas into an interesting, achievable and unique research project was a journey with several false starts, dead ends and diversions. What influences any researcher’s decision to pursue a particular project, and what other experiences they bring, needs to be considered through the practice of reflexivity (Yardley, 2000), as the researcher’s own beliefs and values influence the interpretation of participants’ accounts (Smith, Jarman & Osborne, 1999). Both my literature review and empirical study are qualitative. Qualitative research methods are underpinned by the interpretivist view of knowledge as constructed and

changing (Chapple & Rogers, 1998). This is in line with my own view that we see the world through the glasses of our own experience, values and culture. My chosen topic area brings together several of my core interests: a value for the importance of early years and attachment, an interest in psychological adjustment within disability and a curiosity in what influences parenting. Although it is unrealistic to be fully objective, the purpose of reflexivity is to increase awareness of the researcher's assumptions and experiences (Ahern, 1999). My interest in these areas is informed by both my clinical experiences working in health psychology, child psychology and offering family support, but also my personal experience of the medical world and being a parent myself. To this research I bring myself as a woman, a mother and a psychologist; where relevant I will discuss these influences throughout this paper.

3.2.2 How I heard you: balancing researcher and therapist

An anxiety I experienced before, during and after the interview process was how to balance my researcher self and my therapist self. There were several moments where I pursued a research agenda, feeling the pressure of time and interjecting over a poignant moment, or wanting to ask all my questions and missing an opportunity to uncover further meaning. I found these moments uncomfortable and I was left feeling that I had let the participant down. This dilemma of balancing the research and therapist role is shared by others (Rowling, 1999). At moments when my therapist self was leading, I found myself wanting to formulate participants' experiences, and seeing ways they could benefit from psychological therapy. Standing back, I see how these are my values and beliefs about the benefits of therapy. Participants had not

expressed a desire to pursue therapy, but spoke about psychological challenges and expressed therapeutic benefit from the interview. Men are more reluctant to engage in therapy (Good, Thomson & Brathwaite, 2005) and this caused me to consider what had enabled these men to engage willingly in research about their experiences, but not access therapy. Rowling (1999) proposes that openness within research may be facilitated by the perception of helping others, as opposed to, within therapy, needing help. This chimes with the cultural pressures my participants spoke about; as a father needing to support others and putting their own needs aside. Additionally, my agenda within the research was to listen to and understand my participants' experiences. There was a freedom from pursuing a goal or reducing distress. This highlighted to me my own assumptions of a desire for, and the possibility of, change within therapy. These experiences have prompted me to consider how I could develop my clinical practice, by incorporating time to explore experiences and more overtly, explore assumptions about change.

3.2.3 How you touched me: involvement in my analysis

Despite my experience of working with people's distress, I was not prepared for how powerful and emotional I would find reading the accounts of parents of children with CHD⁴. This may, in part, be due to my initial expectations: seeing my literature review as secondary to my empirical paper and, a misplaced assumption of distance from the participants. It also resonated personally, as I was in a position where I had to spend more time away from my own daughter than I wanted to. Reading about other parents' separations from their child and

⁴ Congenital Heart Disease (CHD)

fears of loss touched the sadness and regret I also carried. I wrote in my reflective journal "I sit alone in a room, away from my precious child, working and reading other parents accounts of their loss and I cry". The emotional impact of qualitative studies is recognised and valued (Dickson-Swift, James, Kippen & Liamputtong, 2007). My experience also demonstrates the power of qualitative studies to touch us and connect with strangers' experiences, even when three times removed. This exemplifies the value of qualitative research within the field of healthcare: it enables a deeper appreciation and connection to people's experience, which can fuel caregiving motivated by compassion and understanding of the complexity behind measured distress.

Transcribing my interviews took me many months. Partly this was procrastination, but I also felt challenged by some of the interviews, as some of the fathers made disparaging remarks about women and emotions; as a woman, a feminist and a psychologist, I found this very difficult to listen to and found myself feeling angry. I began to reflect on my position as a female researcher and discussed my experiences with my research supervision team. Being aware of a possible autism phenotype (see: Dawson et al., 2002), some fathers may experience their own difficulties with emotional processing and this might impact on their perspective and experiences. Alternatively it may have been a way of them dealing with emotions or an understandable defence against painful feelings. Another consideration was how some fathers may have viewed me, an interested woman curious about a man's world, who, at the time, was unmistakably pregnant. As Stanley and Wise (2002) wrote, "*The researched will have feelings about us as much as we will about them, and also feelings (and theories) about the research itself*" p160. It's possible I could have

represented a threat, or perhaps hope for a future they had lost; for one father, who was perhaps more limited in his disclosure, I may have represented fragility as, on listening back, he expressed concern for my wellbeing several times. A further consideration is the impact cultural ideas of masculinity play, the expectation of a man as dominant, stoical and self-reliant can prompt shame when vulnerable and challenge their sense of masculinity (Good et al., 2005). Perhaps disparaging remarks against women reasserted their position within the researcher-participant dynamic which, through empathic enquiry about their experiences, had prompted feelings of vulnerability.

How participants felt about me, remains unknown, however, as I engaged more in my own anger, I saw that I also felt disappointed. I recognised that I had hopes and expectations that men of my generation, or close to it, were living equally and respectfully with women. I felt let down when that was not what was portrayed. To work effectively with any person from a different culture, including gender, it is important to consider stereotypes and values brought by the therapist (Good et al., 2005). My reflections took my memory back to a male client who had taught me about the masculine environment of manufacturing, how strength meant survival and signs of weakness weren't tolerated. I realised there was vulnerability behind my participants' words. Although acknowledging it may be hard for their wives to live with their views, I also felt empathy for them living with the pressures our culture prescribes for men and the stress and loss that may entail. This experience has highlighted to me the importance of understanding and exploring the impact of cultural forces brought by any client. Mahalik, Good and Englar-Carlson (2003) recommend conducting a gender role analysis to formulate the contribution socialisation to gender roles and norms

makes to presenting problems. I wonder if a broader cultural role analysis would be valuable for all clients.

3.2.4 Where you've taken me: the broader influence of research

3.2.4.1 Disability within society

The themes of my research papers have prompted me to reflect on cultural assumptions around disability. Reading parents' experiences moved me to tears, however reading on and hearing their experiences of growth and acceptance, I began to question my own response. Why had I seen it as a loss; whose loss was it, mine, theirs, the child's or society's? Clearly when there is a threat of fatality, there is a threat of loss of the whole child, and my research identified other real, but more ambiguous losses such as loss of expectations of a child or a life. My reflections took me to a paper by Sinclair (1993), an adult with autism, who spoke about the impact of a parent's grief on the child. He asks for the grief for the hoped event or relationship to be separated from the child's autism as the source of grief.

"Grieve if you must, for your own lost dreams. But don't mourn for us. We are alive. We are real. And we're here waiting for you. [...] Yes, there is tragedy that comes with autism: not because of what we are, but because of the things that happen to us. Be sad about that, if you want to be sad about something. Better than being sad about it, though, get mad about it--and then do something about it. The tragedy is not that we're here, but that your world has no place for us to be. How can it be otherwise, as long as our own

parents are still grieving over having brought us into the world?" (Sinclair, 1993)

This view shows the complexity of two experiences, the parents and the child's, and how they may impact on each other. Within my research there was conflict over these same feelings of loss and gain within the fathers. These considerations have highlighted to me the complexity of responses, the importance of considering both the needs of parents and child, and valuing a system approach to therapy.

One father gave me a poem that for him summarised his experience; it is a poem by Kingsley (1987) called *Welcome to Holland* (Appendix P). It captures the adjustment of a parent, who has a child with a disability, through the metaphor of planning to go to Italy and ending up in Holland. Different parents have different views about this poem, some stating that it misses the point, that all parents, no matter whether their child has a disability or not, end up in Italy, but Italy isn't always quite what they expect; the point is that parenthood is unpredictable and unexpected (Dulock, 2014). This echoes work by Stern & Bruschiweiler-Stern (1998) illustrating the disappointments of parenthood; many parents have fantasies about their child but are disappointed, as every child is their own person. I watched a documentary called *Extreme Love: Autism* (Pickup, 2016) that prompted me to think whether, as a society, we see these parents as heroes and martyrs rather than parents, and what the impact of that may be. In part, are some of the challenges they experience a result of society's perception of them and their child as different and suffering? Could it be society that is disabling people (see: Kitchin, 1998)? Interviews with individuals with varying disabilities highlight that their own identity is not based on their

impairment, and how they reject identities of disability asserted by society (Watson, 2002). From my reflections I noticed how I assumed autism equated to a problem, however I learnt that it isn't the autism that is necessarily the problem. For some it might be, for others there may be other factors and for some there may be no problems at all. Perhaps through seeing a problem we create a problem and within autism this makes the child the problem, with consequences for their own identity. In future, I hope to bring greater awareness to my own and others' assumptions linked to a diagnosis, to put these aside and engage in that person's experience of their life. I also hope to be vigilant of language and include a focus on benefits and strengths and to encourage the celebration of difference. I can see value in systemic models as a means of supporting families living with disabilities and I may pursue this in time.

3.2.4.2 The role of diagnosis

Within my research I encountered challenges with the concept of a diagnosis. Being given a diagnosis allows some sense of certainty, providing treatment options, offering a means to target research, and a vehicle for communication (Gutjahr, 2014). Within my own literature searches, I discovered how hard it was to find information without a clear label. Diagnostic labels appear to carry significant power: the diagnosis of congenital heart disease or autism had the power to turn lives upside down but also the power to offer help. I was struck by the enormous influence of a single word, at times wielded with a lack of consideration, or perhaps a fear to consider the impact, and the focus on deficit and problems. Within my participants, diagnosis appeared to prompt containment but also disintegration: the containment of sense making and access to knowledge, but the disintegration of loss, fear and a void of answers.

The way some participants fought for a diagnosis spoke of expectations, and a diagnosis in itself suggests clarity and discontinuous features. However, the reality of many diagnoses is a spectrum of characteristics (Gutjahr, 2014). This can be disappointing and my participants spoke to feelings of disillusionment. However, it seemed that with time, appreciation of nuances and individuality, self-reflection and self-confidence allowed a greater sense of personal integration. This seemed to be linked more to the process of formulation: making sense of an individual's experience, identifying strengths and paths for coping (Johnstone & Dallos, 2006).

I find myself in a position of ambivalence towards diagnosis. Although I appreciate the organisational aspect of a diagnosis, I also think it can be disempowering, stigmatising and symptom-orientated; the individual can become lost within a label. I have not reached a personal resolution about this issue, but as I embark on the path of being a qualified Clinical Psychologist, the need to balance service demands and necessity to measure effectiveness whilst holding on to a value for the individual experience will be challenging. Through supervision and discussions I hope to stay connected to these values.

3.3 The world beyond my research

I was struck by a pattern within both my literature review and my empirical paper of parenting practices being changed in response to the child's diagnosis. The diagnosis appeared to enable parents to be more attuned and responsive, whether through not wanting their child to become too distressed, or through trying to understand behaviour rather than viewing it as naughty. This struck a

chord with the perceived narrative of parenting within Western countries, valuing independence above all and achieving this through behavioural approaches popularised by the media. It has prompted me to consider how well evidenced and accepted theories of attachment and emotional regulation within the world of psychology, have not reached or influenced parenting practice to a greater degree. I feel psychology has a lot to offer society and I was reassured to read an interview with Peter Kinderman, the incoming president of the British Psychological Society (BPS), endorsing the need for the BPS to be substantially more active in promoting psychological science in wider society (Kinderman, 2016). As I hope to soon be included within the clinical psychology community, it will also be my responsibility to promote psychological science. This thought prompts anxiety as I question my own knowledge and credentials, self-doubt I will continue to battle with, but also continue to find ways to overcome.

Being absorbed in getting on to and then through training, I had not previously thought much about qualified life. It was the search for a job that prompted greater consideration and reflection. In part to be considering this must be a positive thing; I am more convinced that I will have a life as a qualified Clinical Psychologist. It also highlights, how, for years I have focused on becoming a Clinical Psychologist, not being a Clinical Psychologist. It's been an aspiration, not a reality. As I anxiously ruminated about finding the perfect job, I realised my anxiety may, in part, be a recognition that the qualified role may not be perfect. I have sacrificed so much and worked so hard how can anything measure up to that? I wonder if the achievement of this longstanding goal will feel deflating; through achieving my aspiration I will also lose an ambition and a drive, I will lose a security, a protection and a community. Like my participants

experiencing loss in their lives, I will find value in the support of shared experiences with other trainees making this same transition, and maintaining those connections will help me as I find my way within the qualified world. My research has helped reaffirm what areas within psychology I am most passionate about, and from this I can establish new goals and ambitions, and find my next path to travel.

3.4 Conclusion

Considering the position of the researcher, their assumptions, values and beliefs is crucial within qualitative research. Through the research process I have recognised the influence I have had on the research, and also how my research has shaped me. It has helped to confirm my values and also raised issues I had not previously considered. Although it started from anxious beginnings and has been stressful and exhausting throughout; ultimately writing this thesis has been very rewarding as it has allowed me to connect to and grow from the experiences of others.

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Appendices

Appendix A

Author instructions for the *Journal of Pediatric Psychology*

Submission Guidelines

The Journal of Pediatric Psychology is an official publication of the Society of Pediatric Psychology, Division 54 of the American Psychological Association. JPP publishes articles related to theory, research, and professional practice in pediatric psychology.

Types of Manuscripts: Original research, including case studies, Review articles, Commentaries

Manuscript preparation

Manuscript Central will guide authors through the submission steps, including: Abstract, Keyword selection, and the Manuscript. The manuscript must contain an Introduction, Methods, Results, Discussion, Acknowledgements and Reference List.

Length of manuscript: Original research articles should not exceed 25 pages, in total, including title page, references, figures, tables, etc. In the case of papers that report on multiple studies or those with methodologies that necessitate detailed explanation, the authors should justify longer manuscript length to the Editor in the cover letter. Case reports should not exceed 20 pages. Review articles should not exceed 30 pages. Commentaries should not exceed 4 pages. The Journal of Pediatric Psychology no longer accepts brief reports but will accept manuscripts that are shorter in length than the 25 page manuscripts.

Manuscripts (text, references, tables, figures, etc.) should be prepared in detailed accord with the Publication Manual of the American Psychological Association (6th ed.). There are two exceptions:

(a) The academic degrees of authors should be placed on the title page following their names, and

(b) a structured abstract of not more than 150 words should be included. The abstract should include the following parts: Objective (brief statement of the purpose of the study), Methods (summary of the participants, design, measures, procedure), Results (the primary findings of this work), and Conclusions (statement of implications of these data).

Key words should be included, consistent with APA style. Submissions should be double-spaced throughout, with margins of at least 1 inch and font size of 12 points (or 26 lines per page, 12-15 characters per inch). Authors should remove all identifying information from the

body of the manuscript so that peer reviewers will be unable to recognize the authors and their affiliations. E-mail addresses, whenever possible, should be included in the author note.

Informed consent and ethical treatment of study participants. Authors should indicate in the Method section of relevant manuscripts how informed consent was obtained and report the approval of the study by the appropriate Institutional Review Board(s). Authors will also be asked to sign a statement, provided by the Editor that they have complied with the American Psychological Association Ethical Principles with regard to the treatment of their sample.

Details of all funding sources for the work in question should be given in a separate section entitled 'Funding'. This should appear before the 'Acknowledgements' section.

Clinical relevance of the research should be incorporated into the manuscripts. There is no special section on clinical implications, but authors should integrate implications for practice, as appropriate, into papers.

Terminology should be sensitive to the individual who has a disease or disability. The Editors endorse the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of children with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

Additional Guidance:

See the following articles for detailed guidance concerning preparation of manuscripts: Editorial: Thoughts in Improving the Quality of Manuscripts Submitted to the Journal of Pediatric Psychology: How to Write a Convincing Introduction; Methods: Editorial: How to Report Methods in the Journal of Pediatric Psychology; Results and Discussion: Editorial: How to Write an Effective Results and Discussion Section for the Journal of Pediatric Psychology.

Appendix B

Quality Assessment

Summary criteria for appraising qualitative research studies
(Walsh & Downe, 2006).

Stages	Essential criteria - Specific prompts	Scoring (Yes = √, Partial = ~, No = X)
Scope and purpose	Clear statement of, and rationale for, research question/aims/purposes - Clarity of focus demonstrated - Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing - Link between research and existing knowledge demonstrated	
	Study thoroughly contextualised by existing literature - Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both	
Design	Method/design apparent, and consistent with research intent - Rationale given for use of qualitative design - Discussion of epistemological/ontological grounding - Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) - Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims - Setting appropriate	
	Data collection strategy apparent and appropriate - Were data collection methods appropriate for type of data required and for specific qualitative method? - Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? - Was triangulation of data sources used if appropriate?	
Sampling strategy	Sample and sampling method appropriate - Selection criteria detailed, and description of how sampling was undertaken - Justification for sampling strategy given - Thickness of description likely to be achieved from sampling - Any disparity between planned and actual sample explained	
Analysis	Analytic approach appropriate - Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory) - Was it appropriate for the qualitative method chosen? - Was data managed by software package or by hand and why? - Discussion of how coding systems/conceptual frameworks evolved - How was context of data retained during analysis - Evidence that the subjective meanings of participants were portrayed - Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance - Did research participants have any involvement in analysis (e.g. member checking) - Evidence provided that data reached saturation or discussion/rationale if it did not - Evidence that deviant data was sought, or discussion/rationale if it was not	

Interpretation	<p>Context described and taken account of in interpretation</p> <ul style="list-style-type: none"> - Description of social/physical and interpersonal contexts of data collection - Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena 	
	<p>Clear audit trail given</p> <ul style="list-style-type: none"> - Sufficient discussion of research processes such that others can follow 'decision trail' 	
	<p>Data used to support interpretation</p> <ul style="list-style-type: none"> - Extensive use of field notes entries/verbatim interview quotes in discussion of findings - Clear exposition of how interpretation led to conclusions 	
Reflexivity	<p>Researcher reflexivity demonstrated</p> <ul style="list-style-type: none"> - Discussion of relationship between researcher and participants during fieldwork - Demonstration of researcher's influence on stages of research process - Evidence of self-awareness/insight - Documentation of effects of the research on researcher - Evidence of how problems/complications met were dealt with 	
Ethical dimensions	<p>Demonstration of sensitivity to ethical concerns</p> <ul style="list-style-type: none"> - Ethical committee approval granted - Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants - Evidence of fair dealing with all research participants - Recording of dilemmas met and how resolved in relation to ethical issues - Documentation of how autonomy, consent, confidentiality, anonymity were managed 	
Relevance and transferability	<p>Relevance and transferability evident</p> <ul style="list-style-type: none"> - Sufficient evidence for typicality specificity to be assessed - Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies - Discussion of how explanatory propositions/emergent theory may fit other contexts - Limitations/weaknesses of study clearly outlined - Clearly resonates with other knowledge and experience - Results/conclusions obviously supported by evidence - Interpretation plausible and 'makes sense' - Provides new insights and increases understanding - Significance for current policy and practice outlined - Assessment of value/empowerment for participants - Outlines further directions for investigation - Comment on whether aims/purposes of research were achieved 	
		Outcome:

Appendix C

Author instructions for the *Journal of Autism and Developmental Disorders*

Submission Guidelines

Manuscript Format

- All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins.
- APA Style
- Text must be double-spaced; APA Publication Manual standards must be followed.
- As of January 20, 2011, the Journal has moved to a double-blind review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:
 - A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
 - The blinded manuscript containing no author information (no name, no affiliation, and so forth).
 - The Author Note

Types of papers and formatting

- Articles, Commentaries Brief Reports, Letters to the Editor
- The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.
- Order of manuscript pages: Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information, Blinded Manuscript without contact information and blinded Abstract, and References, Appendix, Figure Caption Sheet, Figures, Tables, Author Note
- Title page should include: The name(s) of the author(s), a concise and informative title, the affiliation(s) and address(es) of the author(s), the e-mail address, telephone and fax numbers of the corresponding author
- Abstract: 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.
- Keywords: Please provide 4 to 6 keywords which can be used for indexing purposes.
- Text: Manuscripts should be submitted in Word, use a normal, plain font (e.g., 10-point Times Roman) for text, use italics for emphasis, use the automatic page numbering function to number the pages, do not use field functions, use tab stops or other commands for indents, not the space bar, use the table function, not spreadsheets, to make tables, use the equation editor or MathType for equations, save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Manuscript Submission

- Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.
- Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.
- Please follow the hyperlink “Submit online” on the right and upload all of your manuscript files following the instructions given on the screen.
- Submit your material in PDF format; .doc or .ppt files are not suitable for long-term viability.

Ethical Responsibilities of Authors

- The manuscript has not been published previously (partly or in full), unless the new work concerns an expansion of previous work (please provide transparency on the re-use of material to avoid the hint of text-recycling (“self-plagiarism”)).
- A single study is not split up into several parts to increase the quantity of submissions and submitted to various journals or to one journal over time (e.g. “salami-publishing”).
- No data have been fabricated or manipulated (including images) to support your conclusions
- No data, text, or theories by others are presented as if they were the author’s own (“plagiarism”). Proper acknowledgements to other works must be given (this includes material that is closely copied (near verbatim), summarized and/or paraphrased), quotation marks are used for verbatim copying of material, and permissions are secured for material that is copyrighted.
- Consent to submit has been received explicitly from all co-authors, as well as from the responsible authorities - tacitly or explicitly - at the institute/organization where the work has been carried out, **before** the work is submitted. Authors whose names appear on the submission have contributed sufficiently to the scientific work and therefore share collective responsibility and accountability for the results.
- To ensure objectivity and transparency in research and to ensure that accepted principles of ethical and professional conduct have been followed, authors should include information regarding sources of funding, potential conflicts of interest (financial or non-financial), informed consent if the research involved human participants, and a statement on welfare of animals if the research involved animals.

Copyright transfer

- Authors will be asked to transfer copyright of the article to the Publisher (or grant the Publisher exclusive publication and dissemination rights). This will ensure the widest possible protection and dissemination of information under copyright laws.
- Open Choice articles do not require transfer of copyright as the copyright remains with the author. In opting for open access, the author(s) agree to publish the article under the Creative Commons Attribution License.
- Creative Commons Attribution-Non Commercial 4.0 International License

Appendix D

Interview schedule

Interview Schedule

Introduction

The purpose of this interview is to gather information about your experience of having a child with autism. The interview will take about an hour and I will be recording the interview. Please remember that you are free to withdraw your consent to take part in this research at any time. Please be as honest and open as you can but do not share information you do not feel comfortable sharing. *Confidentiality revisited.*

Local safeguarding contact details:

This may feel like a one-sided conversation as I will only be asking you questions. My hope is to reach an understanding of your experience.

Questions

Complete demographic questionnaire

****note name of child***

Prompts will be used for all questions to gain further detail where needed. Examples of these prompts include:

- What has it been like, what was that like for you, what does that mean for you?
- Can you give me an example of that?
- Can you give me an example of something really good/ really tough?
- How did you feel emotionally? What feelings have you had since?
- What thoughts did you have?
- How, if at all, have others responded (family/friends/work/public)?

Experience of child

Tell me about (*name of child*)?

- Prompts: What do they enjoying doing?
- How are they similar or dissimilar to you?
- How do you feel about (*child's name*)?
- Would you say there is anything special about (*child's name*)?
- Since having (*child's name*), how has life been? (In what ways have you and your life changed and stayed the same?)

Experience of receiving diagnosis

- Could you tell me how you received the diagnosis of autism?
- What was it like to receive that diagnosis?

Experience of living with the diagnosis

- How has it been for you since you received the diagnosis?
- Has anything helped or not helped?

Experience of how this has impacted on relationships

- Could you describe your relationship with your partner?
- How, if at all, has (*name of child*) impacted on your relationship?
- Have you faced any challenges? As a family, how did you cope?
- Would you say there is anything special about your relationship?

Thank you for speaking with me about your experience.

Once the research report has been completed would you like to receive a summary of the research findings?

Yes No

To be sent to:

Appendix E

Demographic Questionnaire

Participant pseudonym:

Demographic Information

What is your age?
What is your marital status?
What is the age of your child with autism? Are they male or female?
When was it that you received their diagnosis of autism?
Would you say your child has mild, moderate or severe autism?
Does your child have any mental health problem or diagnosis other than autism? If yes, please could you give details?
How many children do you have in your family (including the above child)?
Do any of your other children have developmental difficulties? (If so please provide details)

Appendix F

Coventry University Ethics Consent

TO WHOM IT MAY CONCERN

QRS/Ethics/Sponsorlet

Wednesday, 26 February
2014

Dear Sir/Madam

Researcher's name: Emma Hampson
Project Reference: P19817
Project Title: How do fathers adapt to a life with autism: A qualitative exploration of fathers' experiences of having a child with autism.

The above named student has successfully completed the Coventry University Ethical Approval process for her project to proceed.

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

With kind regards

Yours faithfully




Professor Ian Marshall
Deputy Vice-Chancellor, Academic

Enc

Appendix G

Worcestershire Health and Care NHS Trust Approval

Worcestershire Health and Care 
NHS Trust

Research & Development
Worcestershire Health and Care NHS Trust
Isaac Maddox House
Shrub Hill Road
Worcester
WR4 9RW

Tel: 01905 681514

Samantha.Whitby@hacw.nhs.uk
www.hacw.nhs.uk

Emma Hampson
Trainee Clinical Psychologist
Coventry and Warwickshire NHS Partnership Trust
Psychology Department, St Michael's Hospital
St Michael's Road
Warwick
CV34 5QW

Our Ref: 14_130_NP

7 July 2014

Dear Emma,

Thank you for your research application entitled **How do fathers adapt to a life with autism: A qualitative exploration of fathers' experiences of having a child with autism.**

I take great pleasure in informing you that your application has been granted approval by the Research and Development Group, on behalf of Worcestershire Health and Care NHS Trust on 30 April 2014.

Please accept this letter as official confirmation of local Trust Approval.

I should like to take this opportunity to wish you well with your research, and look forward to seeing your final report and recommendations.

If I can be of further assistance please do not hesitate to contact me.

Yours sincerely,



Yours sincerely

Sam Whitby
Audit, Research & Clinical Effectiveness Manager

Chairman: Chris Burdon
Chief Executive: Sarah Dugan

The conditions of this approval are as follows:

- 1) You adhere to the approved version of the protocol and notify R&D immediately of any changes to the study, including any new staff working on the project, who may require Trust or Honorary contracts issued.
- 2) You notify R&D immediately of any Serious Adverse Events, including Suspected Unexpected Serious Adverse Reactions (SUSARs)
- 3) You adhere to the requirements of the ethics committee as detailed in their approval letter and standard operating procedures which can be found on www.nres.npsa.nhs.uk
- 4) For CTIMP studies, you adhere to the regulations, including good clinical practice, of The Medicines for Human UK Clinical Regulations (SI 2004/1031; SI 2006/1928; SI 2006/294; SI 2008/941; SI 2009/1164; SI 2009/3063; and SI 2010/1882).
- 5) You notify R&D immediately of any Serious Breaches of GCP or the protocol occurring on this site. This applies to both sponsored and hosted projects. Guidance on Serious Breaches identification & reporting can be found at:
<http://www.mhra.gov.uk/Howweregulate/Medicines/Inspectionandstandards/GoodClinicalPractice/News/CON084915>
- 6) You adhere to the applicable R&D Standard Operating Procedures which can be found on <http://sharepoint/policies/default.aspx> under R&D
- 7) You notify R&D on completion of the project

The duration of this approval extends to the date specified in the IRAS ethics application form, except where action is taken to suspend or terminate the opinion or should your research not begin within 2 years of the approval date.

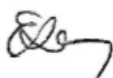
Pharmacy

Should your study require the dispensing of drugs, please do not commence work on the project until pharmacy has issued the green light, as per MHRA requirements (<http://www.mhra.gov.uk/Howweregulate/Medicines/Inspectionandstandards/GoodClinicalPractice/Frequentlyaskedquestions/index.htm>). The green light confirms that pharmacy has all procedures and documentation in place and can comply with the medicines management aspects of the study. The pharmacy team will email you the green light approval once the above is in place.

May I also draw your attention to the Research Governance Framework which can be found on the internet http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962 and remind you that all research within the Trust should be run to the standards as outlined in this document. Guidance and advice is always available from the Department of Research and Development should you require it at any stage of your project.

If you have any queries please do not hesitate to contact me.

Yours sincerely



Liz Adey
Head of Research

Carbon Copy: Emma Hampson-Chief Investigator
Jaqueline Knibbs-Coventry University

Version 10.0 May 2012

Appendix I

West Midlands Comprehensive Local Research Network Ethical Approval



West Midlands (South) Comprehensive Local Research Network
Fourth Floor, West Wing (ACF40002)
University Hospitals Coventry & Warwickshire NHS Trust
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

24th June 2014

Mrs Emma Hampson
Trainee Clinical Psychologist
Coventry and Warwickshire Partnership NHS Trust
Psychology Department
St Michaels Hospital
St Michaels Road
Warwick
CV34 5QW

Dear Mrs Hampson

Project Title: How do fathers adapt to a life with autism: A qualitative exploration of father's experiences of having a child with autism.
R&D Ref: PAR070514
REC Ref: 14/EM/0171

I am pleased to inform you that the R&D review of the above project is complete, and NHS permission has been granted for the study at Coventry and Warwickshire Partnership NHS Trust. The details of your study have now been entered onto the Trust's database.

The permission has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version	Date
Interview Schedule	2.0	26.05.2014
Participant Consent Form	2.0	26.05.2014
Participant Information Sheet	2.0	26.05.2014
Invitation Letter	1.0	03.04.2014
Protocol	1.0	03.04.2014
Questionnaire: Demographic Information	1.0	03.04.2014
Participant Information Sheet:: Debrief Information	1.0	03.04.2014
R and D Form	146715/625750/14/959	15.06.2014
SSi Form	146715/611102/96/643/231996/299953	10.01.2014

All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF), to ICH-GCP

standards (if applicable) and to NHS Trust policies and procedures. Permission is only granted for the activities agreed by the relevant authorities.

All amendments (including changes to the local research team and status of the project) need to be submitted to the REC and the R&D office in accordance with the guidance in IRAS. Any urgent safety measures required to protect research participants against immediate harm can be implemented immediately. You should notify the R&D Office within the same time frame as any other regulatory bodies.

It is your responsibility to keep the R&D Office and Sponsor informed of all Serious Adverse Events. All SAEs must be reported within the timeframes detailed within ICH-GCP statutory instruments and EU directives.

In order to ensure that research is carried out to the highest governance standards, the Trust employs the services of an external monitoring organisation to provide assurance. Your study may be randomly selected for audit at any time, and you must co-operate with the auditors. Action may be taken to suspend Trust approval if the research is not run in accordance with RGF or ICH-GCP standards, or following recommendations from the auditors.

You will be sent an annual progress report which must be completed in order to ensure that the information we hold on our database remains up to date, in line with RGF requirements.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.

Yours sincerely



Natassia Embury
RM&G Facilitator

Cc: Dr Heather Moran, Consultant Clinical Psychologist, CWPT
Ms Jacqueline Knibbs, Academic Supervisor, Coventry University
Ian Marshall, Sponsor Representative, Coventry University

Appendix J

National Research Ethics Service Approval



Health Research Authority

NRES Committee East Midlands - Nottingham 1

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839521

27 May 2014

Mrs Emma Hampson
Trainee Clinical Psychologist
Coventry and Warwickshire NHS Partnership Trust
Psychology Department, St Michael's Hospital
St Michael's Road
Warwick
CV34 5QW

Dear Mrs Hampson

Study title:	How do fathers adapt to a life with autism: A qualitative exploration of fathers' experiences of having a child with autism.
REC reference:	14/EM/0171
Protocol number:	N/A
IRAS project ID:	146715

Thank you for your letter of 27th May 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 22 May 2014

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Other: Interview Schedule	2.0	26 May 2014
Participant Consent Form	2.0	26 May 2014
Participant Information Sheet	2.0	26 May 2014

Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		03 April 2014
REC application	146715/590080/1/526	31 March 2014
Evidence of insurance or indemnity	01.08.13-31.07.14 (Allianz)	01 August 2013

Evidence of insurance or indemnity	01.08.13-31.07.14 (AON Employer's Liability)	01 July 2013
Evidence of insurance or indemnity	01.08.13-31.07.14 (AON Professional Indemnity)	01 July 2013
Letter from Sponsor	Coventry University	26 February 2014
Other: Investigator's CV	Emma Hampson	03 April 2014
Other: Investigator's CV	Jacky Knibbs	14 March 2014
Other: Invitation Letter	1.0	03 April 2014
Other: Interview Schedule	2.0	26 May 2014
Participant Consent Form	2.0	26 May 2014
Participant Information Sheet: Debrief Information	1.0	03 April 2014
Participant Information Sheet	2.0	26 May 2014
Protocol	1.0	03 April 2014
Questionnaire: Demographic Information	1.0	03 April 2014

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/EM/0171	Please quote this number on all correspondence
-------------------	---

Yours sincerely



Miss Vic Strutt
REC Assistant

E-mail: NRESCCommittee.WestMidlands-CoventryandWarwick@nhs.net

Copy to: *Ms Jaqueline Knibbs,*
Miss Natassia Embury,

Appendix K

Participant Information Pack

Invite Letter



Name
Address

Date

Dear ...,

Re: Research about your experience of having a child with autism

I am writing to invite you to take part in a research project hoping to better understand the experience of fathers of children with autism.

The project involves talking with fathers individually about their experiences. Fathers have tended to be neglected in the research in this area and this project hopes to address this gap. The aim of the project is to learn about fathers' experience, from first learning about their child's autism, to how they adapt to their situation and how it affects their lives.

The study is being conducted by Emma Hampson, a trainee Clinical Psychologist as part of her Doctorate in Clinical Psychology at Coventry University. I would be very grateful if you would consider taking part.

Enclosed with this letter are two further documents:

1. a participant information sheet
2. a consent form

Before you decide whether you would like to participate, please read this information, take your time thinking it over and speak with others about it. If you have any questions please contact Emma on the above details or by emailing: hampsone@coventry.ac.uk

If you decide you would like to be involved then please complete the consent form and return it in the enclosed stamp addressed envelope before date/date/date. Emma will then contact you via telephone or email to arrange a time to meet most convenient to you.

Please remember that participation is voluntary and it is entirely your choice. If you chose not to participate or withdraw from the study at any time it will not affect you or your families care in any way. All information will remain confidential.

Thank you for taking the time to read this information.

Yours sincerely,

Clinician name
Job title
Service, Area

Enc: Consent form, Participant Information sheet, stamp addressed envelope

Version 1.0 03/04/14

PARTICIPANT INFORMATION SHEET

Researcher: Emma Hampson

Part 1: Essential Information

Title of study: How do fathers adapt to a life with autism: A qualitative exploration of fathers' experiences of having a child with autism

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please read the following information carefully and discuss it with others if you wish.

What is the purpose of the study? The purpose of this study is to understand more about the experience of fathers who have a child with autism.

Why have I been invited? You have been invited to take part in this research because you have a child with autism. You or your child may be receiving support from an NHS service.

Do I have to take part? No. Your participation in this research is completely voluntary. If you agree to take part we will ask you to sign a consent form. You are free to withdraw from the research study at any point up to 2 weeks after the interview, without giving a reason. Beyond this time it will not be possible to withdraw your data from the study as your interview will already have been written up. This will not affect any support you receive.

What will happen to me if I take part? You will be invited to arrange to meet with the researcher, Emma Hampson. You will meet at a time convenient to you either at your home or, room availability allowing, at an NHS building. An additional option, if it is not workable to meet in person, will be to arrange to meet and speak using Skype. You will meet for approximately an hour to talk about your experiences of being a father of a child with autism. The discussion will be guided by questions already identified by the researcher, these can be provided to you in advance at your request, and will be recorded using an audio recorder. You will also be asked to complete a brief questionnaire asking about demographic details. It is anticipated that you will only meet on one occasion to do this.

What will I have to do? You will be asked to speak with the researcher, Emma Hampson, about your experiences of being a father of a child with autism. The questions will focus on your experiences of finding out about your

child's diagnosis of autism and how this has impacted on you and your life. You will be encouraged to be as honest as you can but you will not be asked to discuss anything you do not feel comfortable sharing.

What are the possible disadvantages and risks of taking part? There are no major risks associated with participating in this research. You will be asked questions about your experiences of being a father of a child with autism. This could feel like disclosing personal information that could elicit unpleasant or pleasant emotions. You have the choice to only disclose what you feel comfortable doing so. There are also details of support networks you can access at the end of this document and the researcher will provide debriefing information after the interview. You can withdraw your consent to participate at any point up to 2 weeks after the interview, without giving a reason. Beyond this time it will not be possible to withdraw your data from the study as your interview will already have been written up.

The interview is anticipated to take approximately an hour which is a commitment of your time. Your interview will be used for transcription, analysis and possible presentation and publication. All data will remain anonymous.

What are the potential benefits? From a personal level, you may find that the interview helps you to reflect on your experiences which could be beneficial and an enjoyable experience. By participating you will also be contributing to our understanding of fathers' experiences, which could help to inform the support offered by services.

What happens when the research study stops? Your involvement in this research will have no impact on the support you receive either from the NHS or any other organisation.

Will my taking part in this study be kept confidential? All information will remain strictly confidential, unless you share information that indicates that you are at serious risk of harming yourself or others; including the neglect or abuse of children. If any issues of this nature are disclosed the researcher is required to share your information with, as appropriate, any clinicians involved in supporting you, safeguarding teams and/or your GP. This may be without your permission. If this happens, where possible, we would discuss it with you first.

Confidentiality will be protected before and after the study by the following methods:

- All your confidential data will be anonymised and will be used under a fictitious name within the research. Any identifiable information will either be omitted or modified.
- Only authorised persons including the researcher, Research and Development staff for audit purposes (to monitor the quality of research) and supervisors will be able to view identifiable data.
- Identifiable information such as consent forms and audio recording will be stored in a lockable cabinet. Electronic data will be kept on password protected computers.
- Once the study has finished, your data will be stored at Coventry University for 5 years on secure university premises in accordance with university policy.

Part 2: Additional Information

What will happen if I don't want to carry on with the study? Your participation in this research is completely voluntary. You are free to withdraw from the research study at any point up to 2 weeks after the interview, without giving a reason. Beyond this time it will not be possible to withdraw your data from the study as your interview will already have been written up.

What if there is a problem? If you have a concern about any aspect of this study, please contact the researcher who will do their best to answer your questions. Alternatively you can contact: Professor Ian Marshall in writing at the following address: AB124, Alan Berry Building, Coventry University, Priory Street, Coventry, CV1 5FB. Professor Marshall is independent of the research team and is responsible for overseeing research reviewed by the Coventry University Ethics Committee.

If you remain unhappy and wish to complain formally, you can contact PALS (Patient Advice and Liaison Service):

PALS (Patient Advice and Liaison Service)
 Telephone: 024 7653 6804
 Text message: 07826 900 926
 Email: pals@covwarkpt.nhs.uk

Involvement of your General Practitioner/Family Doctor (GP). You are asked to provide contact details for your GP this is just in case any information is shared that suggests you or someone else is at risk of harm.

What will happen to the results of the research study? On completion of the interviews, the audio recordings will be transcribed, analysed and written up by the researcher, Emma Hampson. All data used in the study will be anonymised and any identifiable information will either be omitted or modified. On completion, the study will be submitted as part of the researchers' thesis towards completion of the

Doctorate in Clinical Psychology at Coventry University. It is the intention of the research to submit the research study to an academic journal for publication. Summaries of the study will be made available to participants at your request and the whole report will be accessible through Coventry University.

Who is organising and funding the study? The study is being completed as part of a Doctorate in Clinical Psychology at Coventry University. No funding has been provided for this study.

Who has reviewed the study? The study has been reviewed and approved by the department of Clinical Psychology at Coventry University and the Research and Development department at Coventry and Warwickshire Partnership Trust. It has also been granted ethical approval from Coventry University and from the National Research Ethics Service, Nottingham 1 Committee.

Further information and contact details:

- For specific information about this research project please contact the researcher or academic supervisor:

Researcher & Chief Investigator: Emma Hampson
hampson@coventry.ac.uk
02476 887 806

Academic Supervisor: Jacky Knibbs
j.knibbs@coventry.ac.uk
02476 887 806

- Support networks:

Your GP

National Autistic Society
Helpline: 0808 800 4104
Opening times: 10am-4pm, Monday to Friday
Website: www.autism.org.uk

Contact a Family
Helpline: 0808 808 3555
Opening times: 9.30am-5pm, Monday to Friday
Website: www.cafamily.org.uk

Thank you

Participant Identification Number:

CONSENT FORM

Title of Project: **How do fathers adapt to a life with autism: A qualitative exploration of fathers' experiences of having a child with autism**

Name of Researcher: **Emma Hampson**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 26/05/14 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason up to 2 weeks after the interview without my legal rights being affected.
3. I understand the researcher will be recording my interview.
4. I understand that data collected may be published in a write-up of the research, but that my data will be anonymised.
5. I understand that if I disclose information indicating that I am at serious risk of harming myself or another; including the neglect or abuse of children, the researcher will be obliged to report this to any clinicians involved in my support, safeguarding teams and/or my GP.
6. I agree to take part in the above study.

I would prefer you to contact me using my email / telephone number (delete as appropriate) which is:

GPs name and phone number:

Name of Participant

Date

Signature

Name of Researcher
Version 2.0 26/05/14

Date

Signature

Appendix L

Debrief information sheet

Debrief Information

Dear participant,

Firstly I would like to thank you for taking part in this research. The contribution made by each participant is highly valued and without your involvement this research could not take place.

What has happened?

You have just taken part in an interview with Emma Hampson for the purpose of research. The research is looking to understand fathers' experiences of having a child with autism and you spoke with Emma about your own experiences. You also filled in a brief questionnaire collecting demographic details such as the age of your child and how many children are in your family.

What happens next?

There is nothing further you need to do. The interview will be transcribed and analysed by the researcher and written in to a report. If you decide you would like to withdraw your consent to be included in this research, you have up to 2 weeks after this interview conducted on to contact the research team.

If you would like a summary of the research finding please inform Emma of this. On completion of the research the whole report will be accessible through Coventry University.

We have spoken about some personal and sensitive experiences and this can be upsetting. If you would like further support relevant contact details are provided below. For details of who to contact if you would like to make a complaint and for more detailed information about this research please refer to the Participant Information Sheet.

Many thanks,

Emma Hampson

Trainee Clinical Psychologist
Coventry University

Support networks:

- **Your GP**
- **National Autistic Society**
Helpline: 0808 800 4104 Website: www.autism.org.uk
Opening times: 10am-4pm, Monday to Friday
- **Contact a Family**
Helpline: 0808 808 3555 Website: www.cafamily.org.uk
Opening times: 9.30am-5pm, Monday to Friday

Appendix M

Table 2.4 An outline of the IPA analysis (adapted from Smith, Flowers and Larkin, 2009).

Step 1: Reading and re-reading transcripts

The interview was listened to several times, and the transcription read over to enable immersion in the data. The researcher found it helpful to bring to mind the participant and interview setting to connect with the data. Throughout this process, a reflective journal was kept to capture any thoughts and observations.

Step 2: Initial noting

Whilst reading initial notes were made in the right hand margin on the transcript. Anything of interest was noted, along with tentative interpretations and reflections.

Step 3: Developing emergent themes

Working primarily from the initial notes, comments were analysed and interpreted, from which emergent themes were identified. These were recorded in the left hand margin of the transcript.

Step 4: Searching for connections across emergent themes

At this point each participant was assigned a colour. All emergent themes were typed out in that colour and cut up. They were then sorted and resorted in to clusters of related themes, either identifying similar understandings or oppositional positions. Colour coded notes were made on each subtheme and the linking emergent themes were collected in to envelopes.

Step 5: Moving to the next case and repeating

Steps 1-4 were repeated for each interview. Before commencing the next interview, reflective notes were taken to help put aside any previously identified themes.

Step 6: Looking for patterns across cases

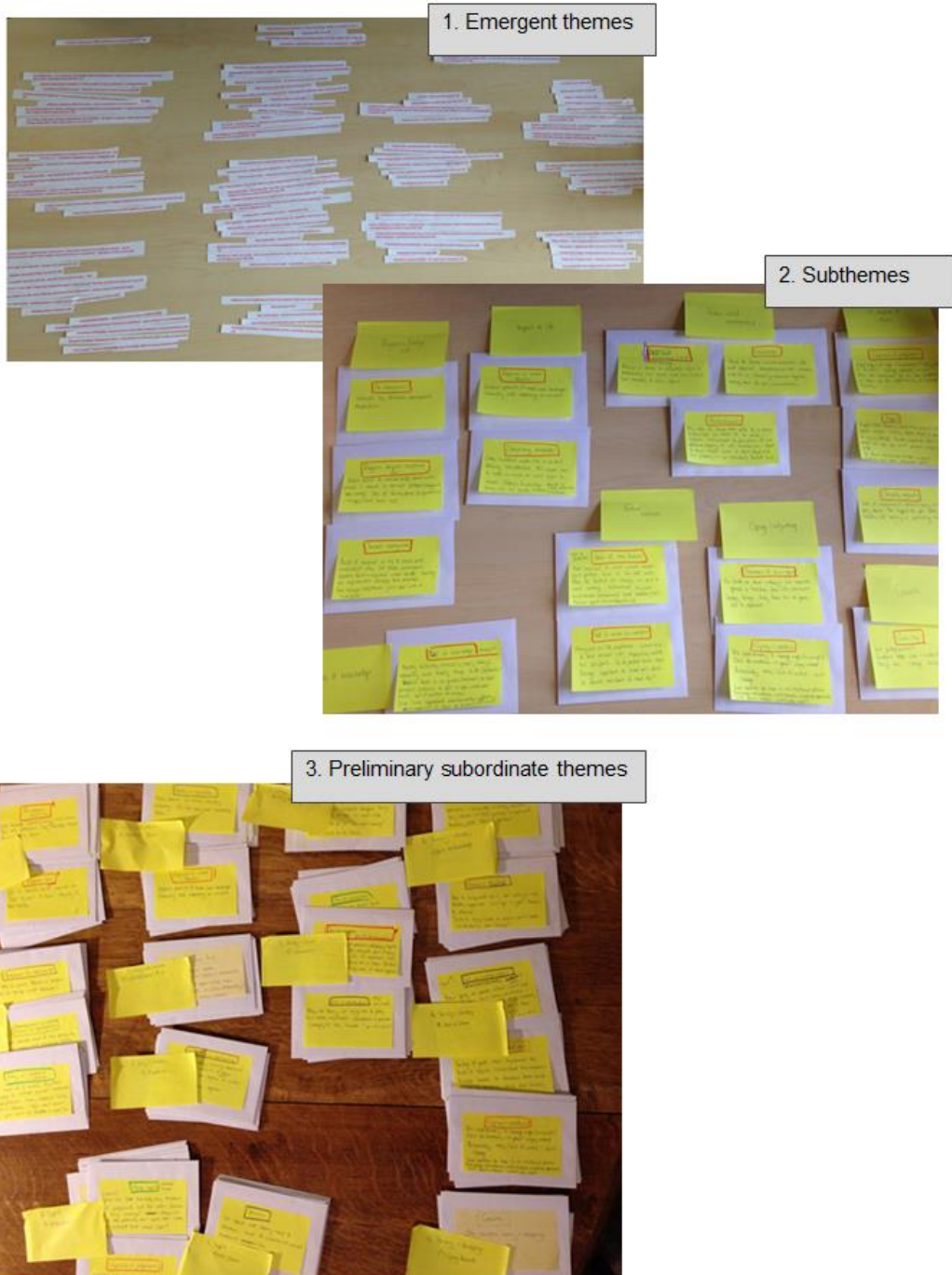
Subthemes were colour coded to represent different participants. They were then organised in to broader categories. Original emergent themes were continually reviewed to check meaning and ensure credibility. From the organisation of subthemes, preliminary themes were identified.

Step 7: Examining and reworking themes to identify superordinate and subordinate

Quotes from the participants were identified and linked to preliminary themes. These were then reworked several times to identify the concluding superordinate and subordinate themes that best captured the data.

Appendix O

Photos illustrating the data analysis process of emergent themes becoming subthemes, and identification of preliminary superordinate and subordinate themes.



Appendix P

WELCOME TO HOLLAND by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability- to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip -to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome _____ to _____ Holland."

" Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ...about Holland.

Emily Perl Kingsley. 1987
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