

**Exploring the experiences of parents caring for their  
infant with Developmental Dysplasia of the Hip (DDH):  
An interpretative phenomenological analysis**

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**Declaration**

I, Claire Poole, declare that this thesis is my own work and that no material contained in it has been submitted for another academic award.

Signed: Claire Poole

Date: 21<sup>st</sup> March 2019

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## **Abstract**

**Background:** Developmental Dysplasia of the Hip (DDH) is a generic term which refers to a developmental bone disorder, in which the femoral head of the femur bone and the acetabulum within the pelvis does not fully develop and dislocates. It is important to diagnose and treat DDH when a child is young, in order to prevent long-term morbidity problems which can present in adulthood, such as a walking disability or chronic back pain. The gold standard treatment for infants under six months old for DDH is the application of a Pavlik harness. Moreover, treatment at this young age gives the infant a positive prognosis. A review of the literature indicated a paucity of research focusing on the in-depth experiences of parents caring for their infant with DDH. More knowledge and understanding is required to inform health professionals how to improve the healthcare experience for parents using DDH outpatient hospital clinics.

**Aim:** To explore the experiences of parents of infants who have been diagnosed with DDH and undergone treatment for the condition.

**Methods:** Nine mothers and nine fathers were recruited to the study through a DDH charity's social media platform. Taking a qualitative approach, using Interpretative Phenomenological Analysis (IPA), data was collected through semi-structured interviews.

**Findings:** From the interviews with mothers, two superordinate themes, 'struggling with empowerment and disempowerment of care over the infant' and 'relationship dynamics' emerged from the data. From the fathers' interviews, there was one superordinate theme, 'Managing the disrupted family'. When the experiences of mothers and fathers caring for their infant with DDH were compared, seven themes encapsulated the phenomenon.

**Conclusions:** This study offers original insight into the lived experience of parents with infant with DDH. It argues that parents psychologically struggled with the diagnosis and initial care of their infant in a Pavlik harness; the paternalistic model of healthcare appears to still exist in DDH outpatient clinics; mothers and fathers have differing carer support needs; fathers needed support and experienced inequality in these DDH clinics. A new conceptual term, 'biographical revision to the new father role' was coined to reflect the experiences of fathers in this study. Also, this study argues that by embedding the principles and practice of family centred care (FCC) could counterbalance any bio-medical power imbalance and any gender power imbalance. Health practitioners were pivotal to the parental experience. Their enhanced interpersonal skills could provide psychological support and empower self-efficacy among parents caring for an infant with DDH. Furthermore, the comparative findings of the parental experience contribute to a theoretical model of parental resilience. Realistic recommendations are offered for multi-disciplinary policy, practice and healthcare education, as well as areas for further research.

## List of abbreviations

ACEs	Adverse Childhood Experiences
ANNP	Advanced Neonatal Nurse Practitioners
CALM	Campaign Against Living Miserably
CASP	Critical Appraisal Skills Programme
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DDH	Developmental Dysplasia of Hip
EPHPP	Effective Public Health Practice Project
GP	General Practitioner
JBI	Joanna Briggs Institute
MeSH	Medical Subject Headings
NHI	Neonatal Hip Instability (mild dysplasia of the hip amongst newborn infants)
NHS	National Health Service
NICE	National Institute for Health Clinical Excellence
NIHR	National Institute for Health Research
NIPE	Newborn and Infant Physical Examination
NHS	National Health Service
PICO	<b>P</b> opulation, <b>P</b> atient/client group or <b>P</b> roblem; <b>I</b> ntervention; <b>C</b> omparison; <b>O</b> utcome
SHO	Senior House Officer (Junior Paediatrician)
UK	United Kingdom
WHO	World Health Organisation

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# Chapter One: Introduction

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## 1.1 Chapter overview

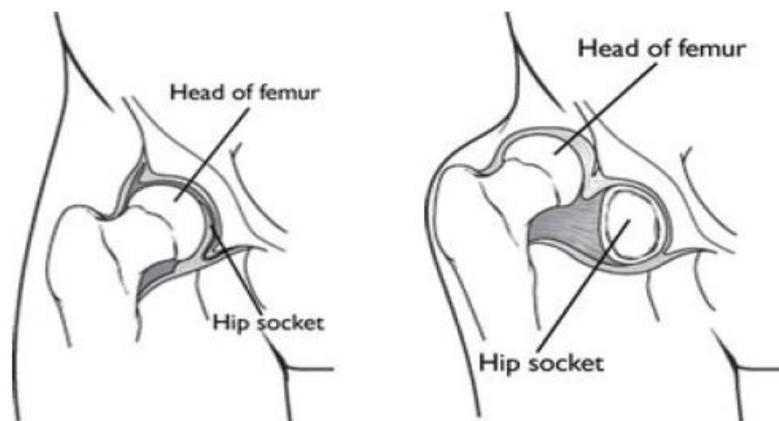
This study investigates the experiences of mothers and fathers as they cared for their infant with Developmental Dysplasia of the Hip (DDH). Although there is a body of research which examines the clinical nature of DDH and limited quantitative research focused on parental engagement with infant DDH health services, there is a clear gap in knowledge about the experiences of mothers and fathers about this phenomenon. It is anticipated that the findings of this study will improve understanding of parental experiences of caring for a DDH baby. This new knowledge and understanding will have implications for: parents/service users; health professionals; healthcare policy and practice; health support charities.

The aim of this chapter is to deliver an overview of DDH and set the context of this thesis. It will feature a background to DDH, including a definition of DDH and the epidemiology of the condition. This is followed by a summary of the care pathway in the United Kingdom (UK), in particular, the use of ultrasonography to examine infant hips and the application of the Pavlik harness in the treatment of DDH (refer to Appendix 3 for diagram of the UK DDH care pathway). This chapter refers to the current health economics associated with DDH diagnosis and treatment. It also presents a personal reflexivity element of my own interest in this research. The chapter concludes with an outline of the structure of this thesis.

## 1.2 Background

### 1.2.1. Definition

DDH is a generic term which refers to a developmental bone disorder in which femoral head (ball) of the femur bone (thighbone) and acetabulum (hip socket) within the pelvis (hip) does not fully develop and becomes dislocated (Dezateux and Rosendahl 2007; Loder and Skopelja 2011). Although DDH most commonly affects one hip, it can be a bi-lateral disorder.



The diagram on the left shows a normal hip. The femoral head fits firmly inside the acetabulum / hip socket.

The diagram on the right shows severe DDH. The femur bone / thighbone is completely out of the acetabulum/ hip socket and it is dislocated.

Figure 1: A diagram shows a normal hip and a hip with severe DDH (American Academy of Orthopaedic Surgeons 2013)

Up until the early 1990s, DDH was known as Congenital Dysplasia of the Hip (CDH). The change in terminology by clinicians aimed to reflect the dynamic nature of the condition which can develop following birth, it can improve or it can become worse as an infant grows (Eastwood 2003; Klisic 1989). At one end of the spectrum of DDH disorders is mild dysplasia; this is when the acetabulum has not formed correctly, but there is a stable pelvis (Sewell et al 2009). Amongst some infants' mild dysplasia can spontaneously resolve itself within a few weeks of birth without any treatment. Some researchers refer to this type of mild dysplasia as Neonatal Hip Instability (NHI) (Eastwood 2003; Elbourne et al 2002; Gardner et al 2005; Paton 2005). Mild dysplasia may not be identified by clinical testing until into adulthood (Dezateux and Rosendahl 2007). However, it is not fully clear why the growth and development of an infant can correct mild dysplasia or which infants' hips will spontaneously correct themselves.

At the other end of the spectrum of DDH disorders is severe dysplasia (refer to Figure 1). Severe dysplasia includes subluxation and dislocation (Sewell et al 2009). Subluxation occurs when the femoral head is partially displaced outside of the acetabulum (Gelfer and Kennedy 2008). Dislocation is when the femoral head is completely outside of the

acetabulum. Subluxation and dislocation are often identified in infancy or early childhood (Dezateux and Rosendahl 2007).

It is important to diagnosis and treat DDH when a child is young in order to prevent long-term morbidity problems associated with the condition which can present later in life. In adulthood, untreated DDH can result in serious disabilities in walking (Dezateux and Rosendahl 2007; Furnes et al 2001; Sewell et al 2009). DDH amongst adults is responsible for chronic hip and back problems as well as the need for early hip replacements (Alsalem et al 2014; Dezateux and Godward 1995; Furnes et al 2001; Sewell et al 2009).

Furthermore, undiagnosed DDH has a long-term morbidity impact with an onset affecting the 30 to 40 age group (Dezateux and Godward 1995). For females, the average age of symptom onset for DDH is 36.6 years old (Dezateux and Godward 1995). For males, the average age of symptom onset is 54 years old (Dezateux and Godward 1995). Research indicates that DDH is responsible for 29% of all primary hip replacements in people aged under 60 years old (Dezateux and Rosendahl 2007; Furnes et al 2001; Gelfer and Kennedy 2008). There tends to be two routes in which children are identified of being at risk of DDH by health professionals and followed by a referral to a hospital to a specialist paediatric clinic. The first route is by the health professionals who are performing the routine physical infant screening programme (refer to Appendix 3 for the UK DDH care pathway). If the health professional finds a positive indication of DDH during the screening or if the child has the risk factors for DDH, then the health professional will make an urgent referral to a paediatric orthopaedic consultant for the child to be closely checked for DDH. The other route is by General Practitioners (GP). If GPs note the signs of DDH in a child, or they note that the child has the risk factors for DDH, or they have been consulted by parents concerned about their child's mobility or physical development, then the GP will make an urgent referral to a paediatric orthopaedic consultant for further investigation for DDH.

### **1.2.2 The aetiology of DDH**

The aetiology of DDH is unknown (Loder and Skopelja 2011; Sewell et al 2009). However, the high risk factors associated with the condition are well documented. These include: breech birth, female gender, a family history, first born infant and positive 'clunking' of hips when clinical physical screening is performed on the infant (Benson and Wainwright 2004; De Hundt et al 2012; Hart et al 2006; Loder and Skopelja 2011; Sewell et al 2009). There are other risk factors associated with DDH such as swaddling infants (Loder and Skopelja

2011). DDH affects girls four times more than boys (Alsaleem et al 2014; Benson and Wainwright 2004; Dezateuz and Rosendahl 2007; Loder and Skopelja 2011; Sewell et al 2009). The disorder commonly affects the left hip three times more than the right hip, though DDH can also be bilateral (Benson and Wainwright 2004). A chromosome has been associated with DDH, 17q21. This chromosome is linked to the cells for the development of joints (Feldman et al 2010; Jiang et al 2003). Although there is a good understanding of the epidemiology and risk factors associated with DDH, the DDH clinical field is continuing to develop.

### **1.2.3 The epidemiology of DDH**

DDH is the most common lower limb problem in childhood (McAllister et al 2018; Woodacre et al 2014). In the United Kingdom (UK), there is some ambiguity about the incidence rate. Public Health England (2015) state that it is between 1-2 per 1000 live births. However, other sources of data suggest that the incidence rate could be between 1-4 per 1000 live births (Loder and Skopelja 2011; Sewell et al 2009; Woodacre et al 2014). Moreover, a study in the South West region of the UK indicates that the current UK incidence rate is much higher than the incidence rate stated by Public England. Woodacre's study showed an incidence rate of approximately 4.8 per 1000 births (Woodacre et al 2014).

The demographic risk factors for DDH are significant. Loder and Skopelja (2011) analysed 422 journal articles in their systematic literature review to record the incidence rates for DDH amongst ethnic groups across the world. The estimated incidence rates per 1000 live births indicated that disorder predominately affects populations of: Native America (76), white Europeans in Eastern Europe (36), Spain and Mediterranean Islands (26), white Australian and New Zealand (7) North West European, such as Scandinavia (4), UK (4) and Ireland (7) (Loder and Skopelja 2011). Although their systematic review provides an important incidence rate of DDH within certain ethnic populations, some caution needs to be exercised with these incidence figures. The vast majority of the 422 journal articles that they examined are over 30 years old and pre-date the medical advancement of ultrasound in detecting DDH in infants. The sensitivity of ultrasound imaging has resulted in a higher incidence rate for DDH (Dezateux and Rosendahl 2007; Sewell et al 2009; Woodacre et al 2014).

## **1.3 The DDH care pathway in the UK**

### **1.3.1. Screening and diagnosis: UK universal infant hip screening programme**

The UK introduced a national infant hip screening programme in 1969. The universal clinical infant hip examination takes part within a wider infant screening programme which includes checks of the eyes, heart, and for male infants, the testes, to screen for any underlying health problems. The aim of this hip screening programme is to detect DDH early to avoid complications associated with late DDH diagnosis, such as avascular necrosis. Avascular necrosis is a complication which is due to the disruption of the blood supply around the femoral head of the femur. It causes deterioration of the bone and the tissues around the bone which causes pain and stiffness in the pelvis (Eastwood 2003).

Neonates (newborn infants up to the age of 4 weeks old) and infants undergo two physical clinical hip examinations which are performed by trained paediatric health professionals. These are known as the Ortolani test and the Barlow test (Public Health England 2015). Neonates are examined within 72 hours of birth by junior paediatric doctors and, occasionally, by midwives (Public Health England 2014). They undergo another examination at 6 - 8 weeks old and this examination tends to be performed by a GP. However, community midwives and health visitors can also perform the examination (Public Health England 2014). The colloquial term for DDH in the UK is 'clicky hip'. This term refers to the nature of the clinical Barlow and Ortolani hip examinations. If a paediatric health professional identifies a palpable or audible 'clunk', in the movement of an infant's femur in the pelvis, then this is considered a positive indication of DDH (Dezateux and Godward 1995). Importantly, a palpable or audible 'click' is not considered a positive indication of DDH.

In the 1980s, the use of ultrasound imaging was an important advancement in the screening, diagnosis and management of orthopaedic conditions in infants, particularly for DDH. It is now regarded as the gold standard for detecting DDH in infants (Woodacre et al 2014). There are many benefits to the use of ultrasound. The sonogram image gives health professionals more information than radiography. Ultrasonography is more accurate than the clinical infant physical examinations and it does not expose infants to the ionising radiation which is emitted from x-ray radiographic imaging (Dezateux and Rosendahl 2007). Since the 1990s, universal ultrasound screening of infants' hips for DDH has been conducted in Austria and Germany (Eastwood 2003; Dezateux and Rosendahl 2007).

Currently, in the UK, there is selective use of ultrasound screening of infants and there are no plans by the UK Government to introduce universal ultrasound screening of infants. Paediatric health professionals use a criterion to assist with the decision to refer an infant for the selective ultrasound screening for DDH. The criterion is:

- a positive indication in the physical hip examination;  
or
- the infant's immediate family has a history of hip problems in childhood;  
or
- the infant was breech in the uterus at or after 36 weeks of pregnancy and this is regardless of the neonate's presentation at delivery or method of delivery;  
or
- the infant was subject to a breech birth before 36 weeks of pregnancy.

(Public Health England 2014)

Identifying DDH early is vital to ensure a successful prognosis and to avoid complications. An infant which meets this selective ultrasound screening criterion are immediately referred to a hospital for an ultrasound scan of their pelvis (Public Health England 2014).

Early diagnosis of DDH is important as there is a small window of opportunity to treat an infant with DDH successfully without subsequent chronic problems in adulthood (Hart et al 2006; Sewell et al 2009). Health professionals refer to diagnoses of DDH as either 'early or 'late' detections of DDH. Early detection of DDH is regarded as being before an infant has reached 12 weeks of age. At this age, the soft tissues are lax, and the infant's pelvis and the femoral heads are cartilaginous (Benson and Wainwright 2004; Dezateux and Godward 1995; Hart et al 2006; Sewell et al 2009). A DDH diagnosis is made by a health professional, such as a specialist nurse or a consultant, on the results of ultrasound imaging and a clinical physical examination of the infants' hips. Early diagnosis and subsequent treatment of an infant of this age can result in the stabilisation of the pelvis and the femoral head, and development of a normal hip joint (Dezateux and Rosendahl 2007; Sewell et al 2009). The effectiveness rate is between 90-95% of cases (Dezateux and Rosendahl 2007). However, beyond this age, the soft tissues contract, develop rapidly and the bones become denser. Late DDH occurs when an infant is diagnosed with the disorder after 12 weeks old (Sewell et al 2009). A late diagnosis is made by a health professional based at the orthopaedic department at a hospital. The diagnosis is made on the results of x-ray images

of the child's pelvis and a clinical physical examination. There is a higher risk of complications with a late diagnosis of DDH with a higher risk of developing avascular necrosis (Dezateux and Rosendahl 2007; Gelfer and Kennedy 2008). Therefore, health professionals aim to detect DDH at an early stage rather than at a later stage because a late diagnosis of DDH involves more complex treatment and increases the risk of complications for the child.

### 1.3.2. Treatment

Early treatment for DDH involves the neonate / infant being placed in an orthosis splint, such as a Pavlik harness and does not involve surgery (Dezateux and Godward 1995) (refer to Figures 2 and 3). The Pavlik harness is regarded as the gold standard in orthosis splints for infants (Gulati et al 2013; Hart et al 2006; Hassan 2009). The orthosis splint is worn every day for several weeks or even months. The infant wears this orthosis splint during feeding, sleeping and nappy changes, though it can be removed for a short time to allow the infant to bathe. Progress in this treatment is monitored by paediatric health professionals through the use of regular ultrasound imaging of the infant's pelvis and by performing the clinical physical examinations on the infant. If this treatment is successful, the child will undergo annual monitoring in the orthopaedic outpatient department of the hospital. This annual monitoring requires health professionals to assess the child's pelvis using x-ray images and a physical examination. This annual monitoring of the child is to prevent the development of any further complications.

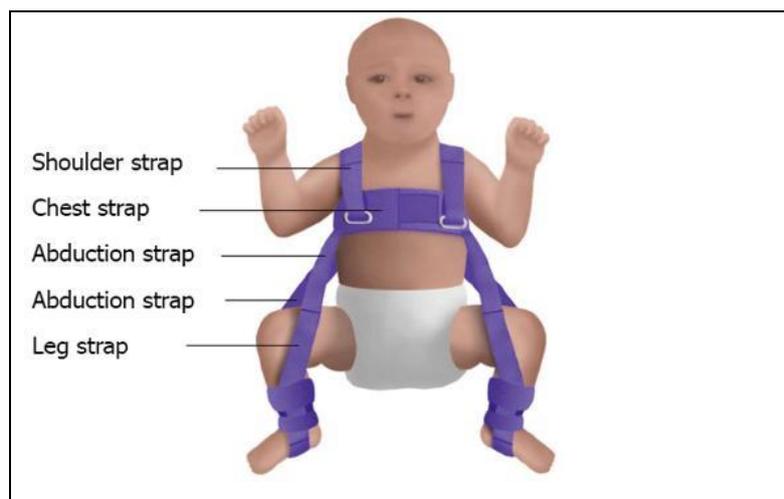


Figure 2: A diagram of an infant wearing a Pavlik harness (Gultai et al 2013)



Figure 3: A photograph of an infant in a Pavlik harness (Steps 2016a)

Delayed treatment for DDH results in an infant undergoing a minimum of two surgical operations and complex post-operative treatment involving the child being set in a spica body cast for approximately 3 months (Chao and Chiang 2003; Newman and Fawcett 1995; Woodacre et al 2014). At the end of open surgery on the child's pelvis, while still under surgical conditions, the child's pelvis and legs are set in a spica body cast (refer to Figure 3). A 'broomstick' is fixed between the ankles of the child to prevent them from dislocating their pelvis while undergoing post-operative treatment in the spica cast. The treatment in a spica cast allows the remodelling of the acetabulum and the femoral head within the pelvis (Hart et al 2006). This treatment can be challenging, and it can be very distressing for parents in terms of day-to-day care for their child (Chao and Chiang 2003; Dezateux and Rosendahi 2007; Eastwood 2003; Gardner et al 2005; Hassan 2003; Sewell et al 2009; Steps 2011). When this treatment comes to a close, the spica cast is removed by health professionals and the child undergoes an x-ray to ascertain the outcome of the operation. Similar to the closure of the early diagnosis and treatment of an infant in an orthosis splint, a child who has been successfully treated for late DDH will be monitored by a health professional in the hospital orthopaedic outpatient unit on an annual basis. The annual monitoring of the child involves the use ultrasound imaging and a physical examination and is used to detect and prevent any further complications.



Figure 4: A photograph of a child in a spica cast with 'broomstick' (Steps 2016a)

### **1.3.3. Prognosis**

There is a positive prognosis for infants who are treated early for DDH, particularly if the infant is treated in a Pavlik harness. With a late diagnosis and treatment of DDH, there is an increased risk of complications.

## **1.4 Other considerations**

### **1.4.1 The health economics of DDH diagnosis and treatment**

The clinical importance of an early diagnosis of DDH compared with a late diagnosis of DDH has been noted; however, there are also important health economic implications for health services which favour an early diagnosis and treatment of DDH. A recent British prospective study examined the costs associated with the late diagnosis of DDH. Woodacre et al (2014) conducted an analysis of 37,000 infant database records spanning 11 years in the South East region of the UK. Within these records, they identified 179 children who were diagnosed with DDH which involved 242 dysplastic hips (some DDH cases will involve one hip and other cases will be bi-lateral DDH). Based on the financial costs for health services during 2008 in this region, Woodacre et al (2014) found that the short-term cost of early DDH treatment in an orthosis splint, specifically a Pavlik harness, was £601 compared with the late detection of DDH which cost £4351. This accounted for a sevenfold increase in the short-term costs of treatment. A limitation of this study is that it only analysed the costs of DDH in the short-term and did not evaluate the costs of DDH treatment in older children and adolescence. However, this study provides a clear and recent economic case for UK health services to diagnosis and treat DDH at an early stage.

#### **1.4.2. Current developments in the UK: Selective infant hip screening programme**

Earlier in this chapter, the UK DDH incidence figure was noted as being estimated to be approximately 1-2% per 1000 live births by Public Health England (2015). However, there is some scepticism about this incidence rate as Public Health England cannot source the basis of this commonly cited UK incidence rate. Furthermore, to date, research indicates that national health organisations in the UK including Public Health England and NHS National Services Scotland do not have access to reliable data relating to DDH diagnoses. DDH data about children is retained on personal patient files and held locally in hospitals and primary care health clinics and is not collated by any central organisation (Public Health England 2014; Alder Hey Children's NHS Foundation Trust 2015). On the other hand, in 2014, Public Health England established a UK neonatal screening database. This was an important step for developing a greater understanding of the prevalence of DDH in the UK amongst newborn infants. This database collates neonate screening data including the results of hip examinations directly from health professionals based in the maternity wards of hospitals. The next development stage of this neonatal screening database is for it to be rolled out to primary care settings for health professionals to note the results of the infant screening examinations when the infants are aged 6 to 8 weeks old. It is anticipated that the availability of accurate DDH data and the analysis of this data about the incidence of DDH in the UK is imminent. However, a limitation of this database is that it will not collate data about the late diagnoses of DDH. However, it is likely that the availability of this data may act as a catalyst for renewed interest by health researchers about the field of DDH amongst children. Therefore, this research study investigating the experiences of parents caring for a child with DDH has the potential to be amongst a new wave of research in the field of DDH in the UK.

### **1.5 Rationale for this research study**

Prior to the literature review, preliminary research of DDH in children suggested a gap in knowledge about the experiences of parents caring for a child with DDH. It was noted that researchers often commented on the challenges of parents caring for a child being treated for DDH, but did not provide evidence for this commentary (Dwan et al 2017; Dezateux and Rosendahl 2007; Hart et al 2006). Also, a survey of UK NHS Acute and Primary Care Trusts by a parent support charity for DDH, 'Steps', highlighted a gap in knowledge about the perspectives of parents and the health professionals (Steps 2009). The survey indicated

that there was very limited awareness and information about DDH for parents, both in terms of the risk factors and the treatment for the disability (Steps 2009). Moreover, they found that there were wide differences in the local health policies which health professionals followed to diagnose and treat the condition, which they argued could potentially create inconsistencies (Steps 2009).

In addition, international and national healthcare organisations champion patient-centred care to deliver health services (Australian Commission on Safety and Quality in Healthcare 2010; NHS England 2015; Picker Institute 2004; World Health Organisation 2016; United States Department of Health and Human Services 2008). Although there is no agreed definition of patient-centred care, there is concurrence on its key principles (Kitson et al 2012; Kuo et al 2012; Pulvirenti et al 2014). Patient-centred care focuses on putting the individual at the centre of the healthcare experience and is underpinned by the principles of: clear communication and shared decision making between the patient and the health practitioner, as well as respect and support for the unique needs and preferences of the individual (Kitson et al 2012; Kuo et al 2012; Pulvirenti et al 2014). Patient-centred care has a philosophical background, but there is strong international empirical evidence which indicates that it improves patient healthcare outcomes, reduced hospital admissions and improved patient satisfaction, which in turn reduces the economic costs of the healthcare services (Stewart et al 1995). Currently, there is a dearth of research understanding the parental experiences of caring for a child diagnosed and treated for DDH in a paediatric outpatient setting. In this setting, it is unclear if parental support needs as a caregiver to their child are being adequately met by health professionals. This gap in the literature has also been identified by other researchers resulting in their call for further research in this field (Gardner et al 2005; Michalopoulou et al 2018). Hence, this was the initial rationale for this research which spurred a detailed, comprehensive review of the literature.

## **1.6 Position of the researcher: Personal reflexivity**

As the researcher of this study, I am conscious of the potential biases, values and experiences that I brought to this study (Creswell 2013). Therefore, I am keen to disclose to my 'position' (Hammersley and Atkinson 1995). I am the mother of two small children who had DDH in infancy. My eldest child, a daughter was diagnosed with DDH as a toddler. She underwent surgery and she was set in a spica cast for three months. My son was diagnosed with bilateral DDH at six weeks old and he was treated in a Pavlik harness for

six months. They were both successfully treated for DDH. Although my children underwent DDH treatment at different times, I still remember it being a challenging time from a practical perspective. I researched DDH and parents' experiences of this phenomenon to increase my own personal understanding of this issue. From my initial research, my interest about this topic intensified and it went on to influence my PhD research proposal. Moreover, I bring to this study, my previous work experience skills and perception, as a trained mixed methods analyst and law enforcement interviewer. During the course of this study, I made notes of my reflections in an electronic journal. From these notes, undoubtedly, I realised that my position as a mother who had experienced caring for small children with DDH sparked the research proposal, but my personal interest in this phenomenon has been overridden by my strong motivation to produce research which is rigorous and credible. Once I had acquired a thorough understanding of the literature about parents caring for an infant with DDH, I became focused on the research of the issue, as opposed to my own biases and values as a parent of children with DDH. Later in Chapter Four, I will discuss the implications of my experience with regards to 'bracketing' and the rigour of this study.

## **1.7 The structure of the thesis**

This introductory chapter has given a background and context to the nature of DDH amongst infants. Chapter Two presents the searches for relevant studies and a critical review of the literature. The rationale for the choice of methodology is discussed in Chapter Three. Chapter Four focuses on the justification the research design and practical application of the research method. Chapters Five presents the findings of the study in relation to the experiences of mothers caring for DDH baby; whereas Chapter Six focuses on the findings of fathers' experiences of caring for a DDH baby. Chapter Seven highlights the similarities and differences in the pertinent findings of the mothers and fathers' experiences of caring for their DDH baby. The discussion of the research findings are presented in Chapter Eight. This chapter explores the key findings of the study in relation to: other research, the strengths and limitations of the study. It also presents the personal reflexivity of the researcher. The final chapter, Chapter Nine, features the final conclusions of the study and recommendations for research and practice.

## **1.8 Chapter summary and the outline of the next chapter**

This chapter has provided a background into DDH in relation to infants and young children. The definition and epidemiology of DDH has been stated and details about the care

pathway of DDH have been presented. Early diagnosis is important for the long-term prognosis of the child and also for health economic reasons. The use of ultrasonography to examine infant hips for DDH is an important technological development and it is used in the UK for selective screening of infants. It is also used for monitoring and managing the condition in infants. Ultrasound is regarded as the gold standard for the monitoring and management of early DDH. Moreover, the Pavlik harness is the gold standard treatment for infants diagnosed with DDH at an early stage. On the other hand, late DDH diagnosis and treatment can result in long term complications. It is fair to state that there is ambiguity about the current incidence rate for DDH in the UK. Furthermore, no single national health organisation has access to this data which is held on patient files at primary and secondary health care levels. However, in the last three years, a new database hosted by NIPE has been implemented in maternity units of hospitals across England, which will offer a reliable DDH incidence rate among infants. It is anticipated that the availability and reliability of this new data will encourage renewed research in the wider field of DDH. In preparation for a research proposal regarding DDH in children, initial scoping searches of the literature suggested a knowledge gap regarding the experiences of parents caring for a child with DDH. Researchers in this field have commented that caring for a child undergoing treatment for DDH is very challenging for parents, but they recognise that there is a lack of knowledge about this subject. Similarly, among non-peer reviewed research by a DDH charity found that the local policies to which health professionals adhered to were inconsistent.

In the next chapter, a detailed search strategy will be presented to identify relevant literature to the research question. This will be followed by a critical analysis of research studies in a literature review.

## Chapter Two: Literature Review

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### 2.1 Chapter overview

This chapter provides a comprehensive search strategy, the details of the review process and an in-depth literature review which focused on the experiences of parents of a child with DDH. The aim of this chapter was to obtain a thorough understanding of the topic and establish a clear focus for the study. The search strategy identified relevant studies. The literature review was structured to follow the UK NHS DDH care pathway (refer to Appendix 3). Since care pathways give health professionals a clear process map to follow with the treatment of a patient with a particular condition, it was logical to follow this care pathway with the review of the literature (De Bleser et al 2006).

Furthermore, in the review of the literature, the studies were synthesised and critically evaluated. It identified gaps in knowledge and understanding about the topic. This chapter concludes with a summary of the key findings of the literature review and the knowledge gaps which justified further research and guided the development of the research question.

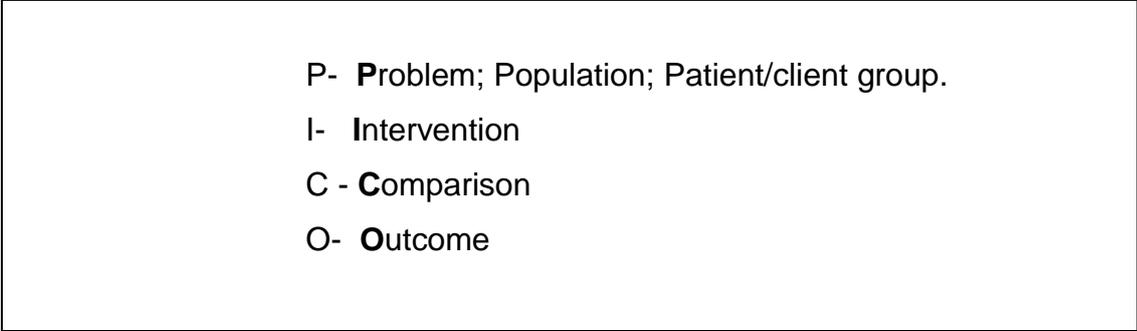
### 2.2 The Search Strategy

The aim of this section is to provide the full details of the search strategy which was used to identify empirical studies in the literature review. It features a discussion about the use of the PICO (**P**opulation, **P**atient/client group or **P**roblem; **I**ntervention; **C**omparison; **O**utcome) model to direct the research question; the inclusion / exclusion criteria of the search strategy; the Medical Subject Headings (MeSH) terms used in the electronic searches of the databases; the rationale for the selection of the databases.

The search strategy utilised a systematic approach to extract and analyse relevant empirical studies. The benefits of this systematic approach is that it is comprehensive, transparent and rigorous, and it identifies quality peer-reviewed empirical research. Moreover, the depth of detail given about the search strategy offers scope for it to be replicated. However, it is important to note that the systematic approach to this literature review differs from a systematic review of literature (Aveyard 2014). Systematic reviews are '*concise summaries of the best available evidence that address sharply defined clinical questions*' (Mulrow et al 1997: 389). A systematic review would involve a team of expert

reviewers, a longer time period would be allocated to perform the review, it would provide greater detail and consequently, it would be highly rigorous (Aveyard 2014). Whereas taking a systematic approach involves only one reviewer, a rigid time limit to conduct it and a less detailed analysis. Notwithstanding, the systematic approach of this search strategy applies the qualities which are inherent in a systematic review and gives a thorough account of the literature review process.

The search strategy began with using the PICO model to focus on the key concepts within the research question (Stone 2002). It is an effective model commonly used in health science research. The focus on the research question allows a precise and accurate search of the literature (McKibbon and Marks 2001). The PICO abbreviation is as follows:



P- **P**roblem; Population; Patient/client group.  
I- **I**ntervention  
C - **C**omparison  
O- **O**utcome

Figure 5: Breakdown of the PICO abbreviation

The aim of this literature review was to explore the views and experiences of parents caring for a child with DDH. Inclusion criteria were developed to ensure that only relevant papers were included in the review. The inclusion criterion was restricted to include studies about children under the age of five years old. The rationale for this specific inclusion criterion in the review was the differences of DDH treatment and the implications of this treatment for five years old children and older children compared with the DDH treatment of younger children. For example, a child aged five years and older will need a wheelchair for mobility and will have begun school. Also, the inclusion criteria included all published research studies about DDH from across the globe.

The PICO model for this research question is shown below (refer to Table 1. Also, further details can be referred to in Appendix 1):

Table 1: The PICO model of key concepts within the research question

<b>Problem or population or patient/client group.</b>	Developmental Dysplasia of the Hip
<b>Intervention</b>	Treatment and care of a child under the age of five years old
<b>Comparison</b>	Not relevant to the research question
<b>Outcome</b>	Views and experience of parents

Using the PICO model to identify the key concepts within the research question facilitated the development of the search terms to search the electronic databases of literature. With the assistance of a specialist librarian, the key search terms were translated into MeSH terms (refer to Table 2). MeSH terms are used to index and catalogue journal articles and books in the health sciences. Using the MeSH terms to search the electronic databases ensures accuracy in the selection of relevant literature. Electronic database limiters were applied to these searches. The databases searches were limited by: English language articles; publications from 1945 to the present day (up to 5<sup>th</sup> July 2018). It is important to note that many electronic databases only collate publications from 1945, hence starting the searches using this year.

Table 2: The MeSH terms used in the searches of the databases

Key MeSH terms	Other related terms
Developmental Dysplasia of the Hip	DDH OR Hip Dislocation OR Congenital
Parents	Parent* OR Family OR families OR Mother OR Father OR Carer* OR caregiver* OR Parent education OR Psychosocial support OR OR Coping OR Patient Acceptance of Health Care OR Patient satisfaction OR Health Knowledge OR Attitudes OR Practice Information Needs.

For the search of relevant literature, five electronic databases of literature were identified, and the search strategy was utilised with each of these databases. These databases were: CINAHL (Cumulative Index to Nursing and Allied Health Literature 1945 - 2018); Cochrane Library (1945 - 2018); MEDLINE (1945 – 2018); PsycINFO (1945 – 2018); PubMed (1945 – 2018). The rationale for searching these particular databases is that they are the key databases which hold millions of records of literature about nursing and allied nursing literature, therefore, they are likely to index literature relevant to the literature search question. CINAHL, MEDLINE and PubMed are comprehensive databases in the field and are prominent databases amongst health researchers and practitioners. Although these databases are vast, the nature of these large databases means that there is much duplication of literature amongst them. PsycINFO specifically indexes literature in the field of psychology including psychological aspects of nursing literature (American Psychological Association 2016). The Cochrane Library databases gather and summarise health evidence about the clinical effectiveness of health care interventions (Cochrane Library 2016). The Cochrane Collaboration is regarded as being independent and highly rigorous. By searching these individual databases and using a clear search strategy, I am confident that a comprehensive search of the literature was achieved. These databases were searched on 5<sup>th</sup> July 2018.

### **2.3 The Review Process**

This section will present the details of the review process. It will feature the steps of the screening and inclusion of relevant empirical studies in the literature review. The initial search of the databases identified 197 journal articles from CINAHL, MEDLINE, PsycINFO and PubMed databases. Furthermore, an electronic search of the Cochrane Library database identified one relevant Cochrane systematic review. Within this systematic review paper, there were five empirical studies. The details of these five studies extracted from the systematic review article and subsequently, the full text articles were sourced from the university electronic library. An overall total number of 202 articles identified in the searches.

These 202 articles were manually screened for duplicates and 118 duplicates were identified and removed. Of the 84 articles remaining, a manual search was conducted on the basis of title, abstract and inclusion criteria. This search excluded 63 articles. These articles were excluded for several reasons: 44 articles were clinical and practical guidance papers aimed at health professionals; 13 articles were non-English language papers; 6

articles related to other subjects. A total of 22 journal articles which were empirical studies remained and were relevant to the literature review. These articles were read multiply times and data was extracted to inform the synthesis and critical appraisal of the studies. Of the 22 empirical studies identified using this search strategy, 19 articles were quantitative studies, two articles were mixed methods studies and one article was a qualitative study. These empirical studies were exported and managed using Mendeley referencing software (Mendeley 2018).

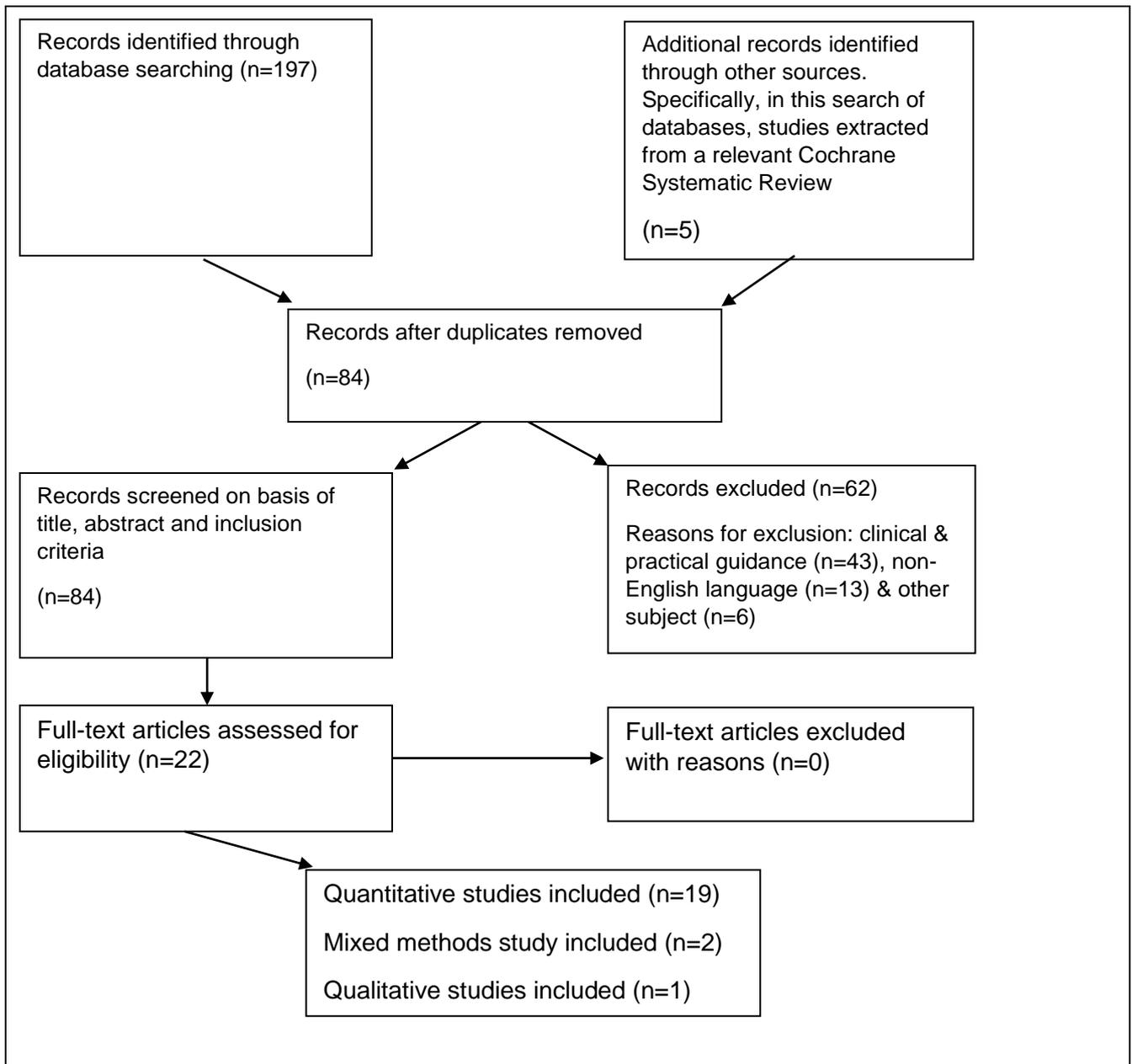


Figure 6: A diagram showing the flow of relevant studies identified through the searches of the electronic databases

## 2.4 Critical Appraisal Tools (CATs)

When the 22 studies were identified from the searches of databases, much consideration was given to the use of critical appraisal tools (CAT) to critique and evaluate the literature in the review. It was anticipated that the use of CATs would further enhance the rigour and transparency of the literature review by providing a structure (Aveyard 2014; Greenhalgh and Brown 2017). There are many CATs available to health researchers, but despite this, there is no single CAT for all study designs (CASP 2013; Greenhalgh and Brown 2017;

Hammersley 2007; Joanna Briggs Institute 2014). I decided to follow the key steps involved in quality assessment offered by Greenhalgh and Brown (2017: 112-122) (refer to Table 3).

Table 3: Key steps in quality assessment (Greenhalgh and Brown 2017)

Step 1	Note the design(s) of your included studies
Step 2	Identify the type(s) of quality assessment tool(s) to suit your review
Step 3	Choose the appropriate quality assessment tool(s)
Step 4	Conduct the quality assessment using the appropriate tool(s)
Step 5	Summarise the results of your quality assessment in a table

Greenhalgh and Brown's (2017) key steps led to my selection of three different CATs. For the quantitative studies, I used a popular CAT known as the 'Quality Assessment Tool for Quantitative Studies' developed by the Effective Public Health Practice Project (EPHPP 1998). For the mixed methods studies, I used the 'Evaluative Tool for Mixed Method Studies' (Long 2005). For the single qualitative study in this review, I chose the 'Critical Appraisal Skills Programme Qualitative Checklist' (2018). I selected these CATs because they are commonly used amongst health and medicine journals. Moreover, I knew from previous CAT research training, that an important principle of the use of CATs is to apply them with consistency to studies. Since I am familiar with using these CATs in other research projects, I felt confident that I could use them with uniformity (WHO 2007).

These CATs guided my critical assessment of each study in terms of its strengths and weaknesses. Moreover, I collated these critical appraisal details in the summary table of empirical studies (refer to Appendix 5). Although the use of CATs by researchers taking a systematic approach to literature reviews is becoming a standard procedure, research studies have been critical of these tools and question their rigour (Crowe and Sheppard 2011; Katrak et al 2004). Katrak et al (2004) analysed 121 CATs used in publications and concluded that there was no gold standard CAT. Moreover, Katrak et al (2004) found that there was no generic CAT which could be applied equally across research designs. Therefore, although the use of a CAT is not an indication of the quality of the literature review, CATs can offer consistency within a review.

In this section, there was an explanation of the reasons for using a CAT in this review of the literature. It also highlighted that there is no gold standard CAT and they do have

weaknesses. The next section presents the literature review of empirical studies which focuses on the experiences of parenting a child with DDH.

## **2.5 Literature Review**

This literature review is a summary of the most pertinent issues in the field of Developmental Dysplasia of the Hip (DDH), with a particular focus on those issues which relate to parents of young children with DDH. This review features 22 empirical studies, of which the majority are quantitative studies, with two mixed methods study and one qualitative study. The structure of this review follows the care pathway for DDH for children aged under five years old. Much consideration was given to selecting either a theme-based or care pathway structure to this review. Initially, the literature review took a theme-based structure. However, it was felt that this structure was disjointed. The decision to structure the literature review by following the care pathway for DDH was preferred as it provided a logical sequence in the literature and it highlighted the gaps in knowledge with clarity. The care pathway structure will feature sections regarding: neonate hip screening for DDH; parental involvement in ultrasonographic infant hip screening for DDH; diagnosis and treatment of mild DDH among neonates; early treatment of moderate / severe DDH amongst infants; late DDH treatment among children. Furthermore, throughout this literature review, references to the wider literature will be made to support points, in particular, relevant systematic reviews, empirical studies and theoretical perspectives.

### **2.5.1 Neonate hip screening for DDH**

There is a consensus among the findings and conclusions of three clinical studies, which identified the key components of a neonatal hip screening programme (Holden et al 2002; Mace and Paton 2015; Rosendahl, Markestad and Lie 1994). Researchers present strong evidence that an effective neonatal hip screening programme for DDH requires a clinical physical hip examination of the neonate; if risk factors for DDH are identified, a further selective based hip examination using ultrasonographic technology (Holden et al 2002; Mace and Paton 2015; Rosendahl et al 1994). A strength of these studies was their longitudinal nature and associated timeframe. Participants were followed up between 27 months and 15 years in order to assess the overall effectiveness of the ultrasonography. A notable strength of the studies by Rosendahl et al (1994) and Holden et al (2002) is that they involved very large samples ( $n=11,925$  and  $n=15,529$  respectively), which enhanced the validity of their results. However, a limitation of all three studies is that they were all

conducted in a single hospital setting. Conducting these studies over multiple settings could have been illuminating in knowledge about the healthcare practices in these differing settings.

The researchers involved in the Norwegian studies argued that the basis for implementing selective use of ultrasonography as opposed to universal ultrasonography, relied on the competency of the health practitioners to perform a satisfactory neonatal physical hip examination (Holden et al 2002; Rosendahl et al 1994). They stated that a competent health practitioner could make an informed decision to refer an infant with suspected DDH for a selective ultrasound (Holden et al 2002; Rosendahl et al 1994). However, in the United Kingdom (UK), there is reduced competency of health practitioners to perform an adequate clinical physical hip examination.

Amongst the wider literature, there is a body of quantitative evidence which indicates that many UK neonatal health practitioners fail to perform the physical examination to a satisfactory level (Bloomfield et al 2003; El-Shazly et al 1994; Lee et al 2001). Research consistently identifies junior paediatricians and midwives as the health professionals who performed inadequate physical hip examinations on infants (Bloomfield et al 2003; El-Shazly et al 1994; Lee et al 2001). Moreover, a recent retrospective multi-centre study conducted in the Republic of Ireland suggests that GPs may also lack the competency to conduct reliable physical hip examinations. Groarke et al's (2017) study found that the clinical signs of DDH identified by GPs during physical hip examination, does not necessarily result in a DDH diagnosis using ultrasonography (Groarke et al 2017). However, Groarke et al's (2017) study was limited by the very small sample size of infants (n=174) and there was no later follow up of the cohort to identify any further hip issues. Interestingly, another recent study showed that when enhanced detection services for DDH are embedded within a local health service, the rate of young children needing corrective surgery was reduced by 50% (McAllister et al 2018). McAllister's et al's (2018) study was a large study involving the examination of 896, 594 children's hospital discharge records in Scotland, UK. They found that when two geographic health service areas established enhanced detection services, the need for hip surgery was halved in these areas compared with the rest of Scotland. The enhanced detection service involved employing a dedicated a DDH specialist to conduct infant hip examinations, train and promote awareness of DDH amongst staff. Notable strengths of this study included the large sample size and the longitudinal cohort follow up to 16 years old. On the other hand, this study was limited by

the lack of randomisation between the intervention and non-intervention groups. The findings and conclusions of McAllister's study offers the potential for the enhanced DDH detection service intervention to be researched in other geographical locations.

The professional competency issue seems to be two-fold. The literature indicates that there is a lack of established best practice procedures for health practitioners to follow when they perform hip examinations on neonates (Bloomfield et al 2003; El-Shazly et al 1994; Public Health England 2008; Wilson and Junger 1968). Secondly, the issue seems to be linked to the need for health practitioners to undergo regular refresher training (Hayes et al 2003; Public Health England 2015). Therefore, there is an element of doubt whether the current UK neonatal hip screening programme based on universal clinical physical hip examinations and the use of selective ultrasonography is effectively achieving its purpose.

Amongst the literature about neonatal hip screening, there is a gap in knowledge and understanding about the experiences of parents as their infant undergoes ultrasonographic screening for DDH. There is an abundance of evidence indicating that the first few weeks and months are critical periods for the development of parental and infant attachment (Bowlby 1988; De Wolff and van Ijzendoorn 1997). Incidence rates show that DDH is the most common lower limb problem in childhood (McAllister et al 2018; Public Health England 2015). Moreover, ultrasonography is an innovative technology for infant screening of DDH which has been used for over 30 years (Elbourne et al 2002). However, to date, research about infant hip ultrasonography has been confined to measuring its clinical effectiveness, as opposed to research about patient and carer experiences of this technology (Wirth, Stratmann and Hinrichs 2004; Woodacre et al 2014).

Drawing on wider literature to gain insight into patient experience of high technology in relation to medical imaging, Munn and Jordan (2011) conducted a meta-synthesis of 15 studies. Their findings indicated that it was common for patients to have a negative experience of medical imaging. This experience was directly linked to certain physical procedural demands put on patients to ensure that the health practitioner produced quality images. Furthermore, many patients undergoing a medical scan expected the identification of a diagnosis or a problem. Another key finding by Munn and Jordan (2011) was that patients sought clear information from health practitioners to give them a sense of control and support in the unfamiliar environment. Notably, within this meta-synthesis, the UK studies were highlighted for a lack of information provision to patients (Munn and Jordan

2011). The role of the health practitioner performing medical scans was pivotal to whether the patient had a positive or negative experience. Clearly, the experience of high technology medical scanning is diverse. However, it appears that health practitioners are potentially making compromises about patient wellbeing, in favour of effectively operating the medical imaging equipment.

Insight into the perceptions of mothers and fathers during obstetric ultrasonography scans is offered by the wider literature. With similarities to Munn and Jordan's (2011) meta-synthesis, Garcia et al (2002) presented a systematic review of women's views of pregnancy ultrasound scans which also identified a lack of information provision to the women about the purpose and limitations of the ultrasound scan. The review revealed the positive implications of these scans: a visual confirmation of the pregnancy; contact with the unborn baby and reassurances about the health of the fetus and the mother. However, when the ultrasonographic scan indicated a problem with the pregnancy and fetus, it is a profound shock and disappointment to the women. Furthermore, there is little research about fathers' experiences of their partner's ultrasound scan. However, some insight is offered in a British ethnographic study of 18 men by Draper (2002). This study had similarities to the study by Garcia et al (2002) which stated that fathers, like mothers, lack awareness of screening and diagnostic importance of the obstetric ultrasonography scan. For fathers, this pregnancy ultrasound scan was regarded as a 'social event' in which the visual presence of their unborn baby was revealed to them (Draper 2002). One important aspect of ultrasound screening in pregnancy identified the need for clear information from health practitioners about the benefits, limitations and possible outcomes of obstetric ultrasonography. While there is good evidence base of knowledge and understanding about both mothers' and fathers' experiences of pregnancy ultrasonography, there is a lack of knowledge about the experiences of parents and the use of ultrasonography on their infants for DDH.

Parents' perceptions of neonatal screening and the use of innovative technology can differ to the opinion of health professionals. Amongst the wider literature, a large American qualitative study conducted by Hasegawa et al (2011) suggested that mothers wanted innovative technology to be used to screen their newborn infants for disorders which could not be treated. This parental perspective is interesting as it challenges the classic screening principles of Wilson and Jungner (1968), who established the benchmark criteria for screening programme policymakers. This includes the principle that: *'There should be an*

*accepted treatment for patients with a recognised disease'* (Wilson and Junger 1968: 26). This study could have added greater value and a deeper understanding to the perspectives of parents and neonatal screening technology, if fathers had been recruited as participants to the study. However, Hasegawa et al's (2011) study highlights the important value of research about parental perceptions to neonatal screening and the deployment of innovative technology.

Medical sociologists argue that technology has reconfigured the nature of the human body with the use of technology by health professionals objectifying the human body (Casper and Morrison 2010; Nettleton 2013; Webster 2002). Consequently, the 'medical gaze' of the body is focussed on understanding it from the inside out, without considering the impact on the emotional human experience of the patient (Foucault 1973). The boundaries of 'normality' and 'abnormality' have become clearly defined through the use of technology, not only at an individual level, but at a national government level in neonatal screening programmes (Webster 2002). Furthermore, the lack of social human interactions between patients and health practitioners at medical imaging consultations concerns medical sociologists (Casper and Morrison 2010; Oakley 1993; Sandelowski 1994). The health practitioner maybe distracted by the technical machinery which objectifies the body and is absorbed by the need to acquire data and clear medical images. The social and emotional interaction between the patient and health practitioner may become lost within the room because the technical machinery is the key focus of the medical encounter.

The development of high technology, specifically, ultrasonography in obstetrics has been extensively explored by medical sociologists over several decades (Oakley 1986; Sandelowski 1994). Oakley (1986) contends that ultrasonography for obstetrics became quickly embedded in clinical practice at a time when healthcare was exclusively overseen by the positivist paradigm. Ultrasonography became a routine technological procedure for mothers in pregnancy and it was conducted by a new professional field of expert diagnostic screeners, such as sonographers (Casper and Morrison 2010). Amongst this feminist perspective, there is a sense that the time to evaluate the human experience was superseded by the quest to utilise this new technology. The views and experiences of women undergoing a pregnancy sonogram and the views of their partners was not considered until more recently. Ultrasonography technology is undoubtedly a core feature of obstetrics today. However, this technology has also become a key feature of other

medical image screenings, including for DDH, with a dearth of knowledge underpinned by evidence-based research.

Professionals in the diagnostic imaging field recognise that their research is dominant by the positivist paradigm (Murphy and Yelder 2010; Ng and White 2005). This field of research focuses on the deductive component of research to confirm the clinical benefits of technology (Murphy and Yelder 2010; Ng and White 2005). In the UK health system, there is increasing importance of patient healthcare experience (Department of Health 2010). Researchers and health professionals in diagnostic imaging, acknowledge a gap in inductive knowledge and the need for qualitative research about the experiences of innovative imaging technology on their patients and their carers (Murphy and Yelder 2010; Ng and White 2005) Therefore, for parents who present their infants for neonatal hip screening using ultrasonographic technology, it is not known how they perceive their experiences and what meanings they attribute to this experience. It is important that given this crucial parent-infant attachment period, that the team of health professionals involved in ultrasonographic screening respond to the support needs of the parents (Bowlby 1988). Medical diagnostic professionals and researchers also recognise the need for this research; they agree that there is a need for understanding of patient and carer experiences during imaging technology screenings, in order to improve the overall patient and carer healthcare experience (Murphy and Yelder 2010; Ng and White 2005). Moreover, the value of qualitative research which addresses this gap in knowledge and understanding about the human experience of DDH can make an original contribution to the wider theoretical fields of medical sociology, in particular that of neonatal technology screening.

### **2.5.2 Parental participation in ultrasonographic infant hip screening for DDH**

Health professionals can influence parental perceptions of ultrasonographic infant hip screening by emphasising its positive aspects. The health behaviours which influence parental participation in infant hip ultrasonographic screening was examined in two Dutch survey studies (Witting et al 2012a; 2013). In a study involving 4150 infant participants, Witting et al (2012a) found that parental participation in the screening was significantly influenced by the positive health outcomes of screening presented in an information booklet, compared with negative health messages conveyed in another information booklet. The study highlighted that the overall participation rate of parents achieved in the screening was 74.3% (Witting et al 2012a). However, the wider literature indicates that Dutch infant

screening parent participation rates are over 90% (International Society for Neonatal Screening 2007). It is clear that Witting et al's (2012a) achieved their key objective to increase parental participation in screenings using health message framed information booklet. Conversely, it is not clear from the study why the participation rate continued to be below the national average in this study. Similarly, Witting et al's (2013) study found that parents with a positive attitude towards the ultrasonographic infant hip screening were significantly more likely to participate. Moreover, there was a significant association between parental participation in the screening, their knowledge of DDH and having a positive attitude. Therefore, an important factor in parental participation in ultrasonographic hip screening is their positive view of the screening.

A criticism of the Witting et al (2012a; 2013) studies is that the researchers utilised different participant recruitment strategies in the two settings which may have skewed the results. Both studies recruited participants from rural and urban settings. In the rural setting, participants were only given the choice to opt-out of the research study. Whereas in the urban setting, participants were offered the choice to opt-in to take part in the study. A consistent participant recruitment strategy in both the rural and urban settings would have enhanced the reliability of these studies. Amongst the wider literature, health studies indicate that participant recruitment strategies which offer potential participants the choice to either opt-in or opt-out, can be pivotal in the successful recruitment of participants to research (Junghans et al 2005; Stanley et al 2003). Notably, an opt-in participant recruitment strategy can significantly lower participant response rates and risks consent bias, as opposed to offering participants the choice to opt-out of the study (Junghans et al 2005; Stanley et al 2003). Although many researchers, particularly those involved in clinical interventions, face the challenges of participant recruitment and who decide to recruit participants using the opt-out recruitment strategy; it could be argued that the opt-in participant recruitment strategy is the most ethical strategy in which the full, clear informed consent from participants is of greater ethical importance.

There are parallels in the factors which influence parental perceptions of ultrasonographic infant hip screening, and these factors impact on parental participation and satisfaction with screening. Studies concur that parental understanding about DDH sonogram screening is facilitated by the verbal and written communication skills of health professionals (Witting et al 2012a; 2012b; 2013). In a survey by Witting et al (2012b) about parents' satisfaction with ultrasonographic hip screening of their infants, showed that satisfaction was significantly

influenced by process factors and not by the structure or outcome (Witting et al 2012b). These process factors included the ability of the screener to answer parents' questions; the perceived competence of the screener; a fluent screening procedure; meeting parental expectations of the screening. On the other hand, amongst the wider literature, empirical studies indicate that those people who participate in screening programmes report very high levels of satisfaction at 90% (Vaile et al 1993; Mazlan et al 2006). A limitation of all three studies is that these surveys were only conducted in the Dutch language. This may have hindered the inclusion of parents who were not fluent in Dutch, particularly in the urban area where the researchers acknowledged that there was a large non-Dutch speaking population. Overall, these studies highlight that positive parental perceptions of infant ultrasonographic hip screening can significantly encourage their attendance to these screenings. Moreover, when parents do participate in these screenings, they are highly likely to be satisfied with the process.

From a quantitative approach, the collective reasons for, predominantly mothers participating and being satisfied with ultrasonographic hip screening is known. However, there is a lack of knowledge about the unique in-depth experiences of mothers' and fathers' of ultrasonographic neonatal hip screening. Moreover, the wider literature highlights that there is a considerable gap in knowledge and understanding in sociology that relates to medical screening (Armstrong and Eborall 2012; Howson 1999). Armstrong and Eborall (2012) argue that elements of sociological enquiry are lacking, notably surrounding medical screening. Furthermore, where those elements about medical screening do exist, they are isolated within sub-disciplines of medical conditions (Armstrong and Eborall 2012). As a result, there are difficulties in extracting and analysing this literature. Armstrong and Eborall (2012) also emphasis the important difference between the sociology of medical screening from the sociology of diagnosis. They clearly state that the sociology of diagnosis relates to a situation in which a person with symptoms consults a health professional, or a person who is under the care of a health professional for a health condition, but tests indicate another health condition. Whereas the sociology of medical screening concerns population-based medical screening, which focuses on a certain target population, such as infant screening programmes.

There is a theoretical body of sociological literature which presents a convincing argument that women's attendance to medical screenings is a form of power by the medical profession, and also a form of wider social control over their bodies. From a feminist social

constructivist perspective, Howson (1999) uses the findings of her phenomenological study with women regarding their experiences of cervical cancer screening to contend that women's attendance at medical screenings is a form of power embedded in their sense of moral responsibility and obligation to behave as a 'good citizen'. There is a female embodiment dimension to participating in medical screening that women feel a moral obligation to attend screening out of respect and care for their bodies (Bush 2000). Similarly, it has been argued that medical screening is not a personal choice, but it is a social norm that there is a social expectation to participate in it (Armstrong and Eborall 2012). However, it is not clear from the wider literature if the moral and social meanings that women place on medical screening applies when their infant undergoes medical screening.

These sociological perspectives about medical screening amongst women could be applied to the pathways of pregnancy, childbirth, neonatal and infant screening in the UK (Armstrong and Eborall 2012; Bush 2000; Howson 1999;). Amongst health sociologists there is criticism of the biomedical focus of pregnancy and childbirth (Nettleton 2013; Oakley 2005). Mothers-to-be participate in a structured clinical antenatal pathway. This involves: consultations with health professionals; screening; blood tests; ultrasonographic scans of the fetus (National Institute for Health Clinical Excellence (NICE) 2015). The mother-to-be, senses the moral responsibility to adhere to the social norms in aspiring to be 'a good mother' to her unborn infant (Armstrong and Eborall 2012). As a pregnant mother she may feel a social responsibility to exert self-discipline over the care of her body and her fetus and as a result, she participates in all stages of the pregnancy antenatal pathway. This leads into the medicalisation of childbirth in the hospital environment (Oakley 2005). Therefore, it could be argued that the consistent dominance of biomedicine, the medical gaze on the woman, the succession of clinics and the influence of normative expectations, over the time during pregnancy and childbirth, continues to embody and influence her participation the neonatal and infant screening programme.

Amongst the literature review, little is known about fathers' experiences of their infant undergoing ultrasonographic screening for DDH. Furthermore, in the wider literature there is very limited research which has explored the experiences of fathers as their child undergoes medical screening (2006). However, a British qualitative study offers some insight into the perceptions of 16 young men as they sought out healthcare advice with their symptoms for testicular cancer (Gascoigne and Whitear 1999). The findings revealed that the men considered their personal health to be a lower priority and only considered

participating in medical screening if the symptoms of a health problem impacted on their day-to-day life, for example, excessive pain (Gascoigne and Whitear 1999). When men participate in medical screening, they reported feeling fear of hearing the results (Gascoigne and Whitear 1999). Interestingly, this study suggests that women play a pivotal role, as partners and as mothers of sons, as they play a key role in observing the health of these men and persuading them to seek out medical attention (Gascoigne and Whitear 1999).

To summarise, there is little known about the experiences and meaning of medical screening, not only for fathers, but for men in general. Clearly, there is a need for more research that explores the deeper meanings of the experiences of fathers when their infant receives ultrasonographic screening for DDH. The implications of this research for health professionals to offer fathers targeted support and assistance with the development of coping strategies, with the overall objective to ensure the successful treatment outcome for their infant with DDH.

Research indicates that fathers are often involved in the medical consultations regarding their child. Mehta and Richards (2002) conducted a quantitative study of 3118 paediatric cardiology clinic referral consultations and it revealed that fathers were present in almost a third of all consultations, often together with the mother of the child. The fathers' attendance at these consultations was found to be significant when the child was aged under four years (Mehta and Richards 2002). Moreover, a North American quantitative study of fathers' caregiving activities which included attending medical appointments, highlighted that those who worked fewer hours were more involved in caregiving to their child (National Institute of Child Health and Human Development 2000). In the UK, there is a shift towards fathers spending more time with their young children. A recent UK Government statistic indicates that 91% of new fathers took time off work to be with their new baby (Department for Business, Innovation and Skills 2014). In the UK workplace, family friendly schemes are common. For example, during 2010-11, approximately 17% of fathers applied for flexible working schemes in their place of employment (Department for Business, Innovation and Skills 2014). These statistics suggest that fathers have some flexibility about accompanying their infant for medical screenings, and in this case, appointments for DDH ultrasonography.

The studies conducted by Witting et al (2012a; 2012b; 2013) are set in the context of the Dutch healthcare system. They take a health psychology perspective and focus on universal ultrasonographic screening for DDH. The findings of these studies are not

relevant to the UK context of infant DDH screening because they were conducted in the Netherlands. To date, little is known about the experiences of both mothers and fathers in terms of selective ultrasonographic screening for DDH in the UK. It is important to have deeper understanding of this healthcare experience to help parents have a more positive experience of the hospital environment and ensure that they are appropriately supported by health professionals and parental support groups. A qualitative study which explores the unique experiences of mothers and fathers taking their infant for selective ultrasonographic screening for DDH in the UK would contribute original knowledge. The findings will have clinical practice implications, as well as contribute to the sub-discipline of medical screening within sociology.

### **2.5.3 Diagnosis and treatment of Neonatal Hip Instability (NHI)**

Neonatal Hip Instability (NHI) is a form of mild DDH amongst neonates (Elbourne et al 2002; Rosendahl et al 2010). From the literature review, researchers who examined the key components of neonatal hip screening programmes concluded that clinical physical hip examination was the appropriate investigation for neonatal population screening, with referrals for selective ultrasonography only in the presence of risk factors (Holden et al 2002; Mace and Paton 2015; Rosendahl et al 1994). However, with regards to the diagnosis, monitoring, management and treatment of NHI, researchers have investigated the use of ultrasonography (Elbourne et al 2002; Gardiner and Dunn 1990; Rosendahl et al 2010). Three similar Randomised Controlled Trial (RCT) studies have examined the effect of immediate treatment of the condition using a hip splint combined with ultrasonographic monitoring compared with a control group who had received ultrasonographic monitoring only. The results of the studies by Gardiner and Dunn (1990), Elbourne et al (2002) and Rosendahl et al (2010) agreed in their conclusions that for those infants diagnosed with NHI; the ultrasonographic monitoring of their hips over a period of time can avoid the unnecessary treatment of using a hip splint. A limitation of these studies is the short follow up time of the cohort of participants which lasted between one and two years. In the clinical research field of DDH, cohort follow up times are much longer to allow for complications to present in children that could influence outcomes and conclusions (Holden et al 2002; Mace and Paton 2015; Rosendahl et al 1994).

The literature regarding the diagnosis and treatment of NHI focuses on clinical outcomes and is dominated by the positivist paradigm. Even amongst the wider literature, there is a

dearth of literature about parental experiences of infants being diagnosed with NHI who were monitored and managed using ultrasonography. By drawing on the wider literature to gain an understanding of parents' experiences of neonatal diagnostic screening, a British qualitative study by Tattersall and Young (2006) offers some insight. The Tattersall and Young (2006) study involved 45 parents who had experienced the diagnostic process which confirmed that their newborn infant was deaf. The findings revealed that a key factor which gave parents a positive experience was adaptability of the interpersonal skills of the health practitioners and their verbal communication skills. Moreover, the findings highlighted that parents reflected on their negative experiences of the hearing screening process with health practitioners and overlooked the positive aspects. A notable strength of this study which is relevant to other qualitative studies in health research is the in-depth detail given to the ethics of the study. Tattersall and Young (2006) adhered to an ethical protocol which sensitively judged the most appropriate time to invite parents to the study. A criticism of this study is the large volume of participants recruited to the study. It is important in qualitative research that the epistemological assumptions which contribute to the formulation of the aims of the study are in synergy with other aspects of the study, which includes sample size. The large number of participants involved in this phenomenological study (n=45) challenged the aim of the study to explore in-depth parental experiences of their infant's diagnosis of deafness. Nonetheless, Tattersall and Young (2006) study highlights the valuable contribution of research which explores the experiences of parents with infants managed for a health condition.

Amongst the wider literature, a phenomenological study by Locock and Alexander (2006) explored the experiences of fathers at antenatal foetal screening and diagnosis consultations. The researchers found that men had inter-linked roles as: fathers; bystanders; protectors/supporters; gatherers of information; guardians of fact; decision-makers. Interestingly, it appeared that these roles were either self-selected or imposed on them by their female partners or health professionals. Locock and Alexander (2006) emphasised the importance of health professionals' role when considering the unique needs of men who attended antenatal fetal screening and diagnosis consultations, as well as the needs of the mother. A limitation of this study was that the vast majority of participants were mothers who presented their perspective of the role of fathers by proxy in these consultations. Future research about parents' experiences should strive to recruit more men as participants to ensure that their thoughts and experiences are represented.

From a theoretical perspective, there is scope to contribute original knowledge and meaning of parental experiences of the diagnosis of their infant with a chronic disability which can be treated, such as DDH, to the emerging field of sociology of diagnosis. Medical sociologists concur that the point of diagnosis, when the medical classification or label of a condition is allocated to the patient, is the pivotal point when a clinical pathway opens up to the structured medical treatment process (Blaxter 1978; Brown 1995; Jutel 2009). In the case of an infant with a diagnosis for DDH, it will result in the immediate management or treatment, follow up hospital visits and the frequent use of medical screening technology, specifically, ultrasonography, to monitor recovery. The diagnosis is the '*voice of medicine*' and the foundation in which '*sense-making and experiences are crafted*' (Jutel and Nettleton 2011: 793). Furthermore, diagnosis can be perceived differently on a cross-national and cross-cultural basis (Jutel and Nettleton 2011). There is a consensus amongst medical sociologists who interpret a transfer of power from the patient to the medical profession when a condition is diagnosed (Brown 1995; Jutel 2015; Jutel and Nettleton 2011;). There is a realignment of the power position, with health practitioners at the top of the power hierarchy and parents below them. However, it is not known if parents regard the DDH diagnosis as a power struggle or even sense a power transfer in terms of decision making and care of their infant. Brown (1995) states that a diagnosis is a point in which the clinical professional has made a decision that deems the patient to be 'abnormal' in the context of their society. It is not clear whether actually parents define their infant as 'normal' or 'abnormal' at the DDH diagnosis stage, or at all.

Little is known about the unique experiences of mothers and fathers at the time before and after the diagnostic event of DDH, and whether or not these events impact on their parental identity (Jutel 2015). For the mother, who had an embodied experience of the infant during pregnancy, it is not known if the mother continues to have an embodied experience after the diagnosis of her infant. There is value for exploring the detailed parental experience of caring for an infant with a diagnosis of DDH. An exploration would provide unique insight into the wider social and structural benefits and constraints of receiving a diagnosis of DDH.

There is a clear gap in knowledge about parental experiences of their infants being diagnosed with DDH and monitored using ultrasonography. This knowledge gap could be addressed through a phenomenological study designed to make an original contribution to the knowledge base about parents' experiences of a DDH diagnosis. A qualitative approach would achieve deeper understanding of parental experiences of the use of ultrasonography

for diagnosis and monitoring of their infant for DDH (Locock and Alexander 2006). The phenomenological methodology of the studies by Howson (1999) and Locock and Alexander (2006) could be replicated to explore the phenomena of mothers and fathers of infants who have undergone ultrasonographic screening and diagnosis for DDH.

To explore the sociology of diagnosis of DDH from the perspective of parents of an infant diagnosed with a chronic disability, a qualitative approach would connect the context of DDH diagnosis, with a broader understanding of the wider social phenomena. These findings could be applied to the clinical healthcare setting, with results encouraging deeper empathy by health professionals of parental perspectives, and in response, offer specific support and assistance.

#### **2.5.4 Early treatment and management of moderate to severe DDH amongst infants**

The literature which reflects parents' experiences of early treatment of their infant for DDH, focuses on the perspective of mothers. There is a breadth of quantitative literature which has identified that some mothers experienced negative psychological consequences in response to the adverse physical demands of caring for their infant in a hip splint (Bergo and Rosendahl 2013; Corbett 1988; Gardner et al 2005; Hassan 2009; Jennings et al 2017; McHale, Major and Corbett 1989). The psychological demands were identified in a RCT which involved 629 participants by Gardner et al (2005), in which the researchers found significant levels of distress, clinical anxiety and worry amongst mothers. Interestingly, mothers continued to experience significant worry when the infant reached one year old, even though these infants had successfully completed their treatment months earlier. The Gardner et al (2005) study was conducted over 33 settings in the UK and the surveys received a high response rate. Beyond the quantitative results of statistical significance, this study lacked an understanding of the perceptions of these mothers as they cared for their infant with moderate to severe DDH. Gardner et al (2005) acknowledged the limitations of their research methodology and recommended further qualitative research.

Two smaller American surveys also found evidence of psychological challenges of mothers who reported feelings of guilt and self-pity as their infant underwent splint treatment (Corbett 1988; McHale, Major and Corbett 1989). The physical demands of managing infants in hip splints has been acknowledged by Bergo and Rosendahl (2013) and Hassan (2009). Researchers also concur that these physical challenges gradually subsided as the mothers adjust to their situation (Bergo and Rosendahl 2013; Hassan 2009). Therefore,

some mothers experience negative psychological issues associated with early treatment and management of an infant with moderate to severe DDH, for a much longer period of time, whereas the physical challenges tend to be short term.

A very recently published survey study by Jennings et al (2017) focused on the experiences of 100 parents attending a DDH clinic in Ireland. This mixed methods study concluded that parents whose child had received an early DDH diagnosis (infant aged under three months old) felt significantly more worry than those parents whose child received a late DDH diagnosis (infant aged over three months old). This finding concurs with the findings of Gardner et al RCT study. Also, Jennings et al (2017) found an association between the diagnosis and treatment of DDH for an infant and the impact of negative psychosocial consequences for the parents. This finding is shared with Corbett (1988) and McHale et al (1989) studies. Although the Jennings et al (2017) study had several strengths: the survey was adapted from other instruments; it had an acceptable level of internal reliability (Cronbach's alpha co-efficient of 0.7); there was pilot study. Nevertheless, the context of this study casts an element of caution over its findings. The title and the aim of the study are completely different. The title of the study refers to exploring parental experiences of DDH. However, in the abstract, the aim of the study is to explore the effectiveness of a DDH clinic. The setting for the completion of the survey was a notable weakness, as participants were asked to complete the survey on their first visit to the clinic. The clinic setting is a vulnerable venue for these parents as they await the outcome of their infant's referral. It is also unclear if participants were asked to complete the survey before or after their clinic appointment, and whether the parents had received a diagnosis for DDH with their infant or not. Both of these factors may have had influenced the outcomes of the survey. Furthermore, the response rate of 100% is a concern. It is based on a 100% return rate. The response rate is not the same as a return rate. Some participants may have chosen not to complete the survey and therefore, they did not return a completed form. In sum, the Jennings et al (2017) study appears to be an evaluation of their experience of DDH clinic service as opposed to a study about the real-life parental experiences caring for their baby with DDH. The qualitative aspect of this study was poor. The research was not embedded in any theoretical perspective or methodology. Moreover, Jennings et al (2017) provided no details about the method of data analysis and the emergence of themes. This study could have been more relevant to the field of DDH and parental caregiving, if the

researchers had conducted a multi-site longitudinal study with a robust qualitative component.

Studies revealed conflicting findings about parental compliance with the hip splint treatment (Corbett 1988; Hassan 2005; McHale, Major and Corbett 1989). In contrast, the results of older studies suggest parental non-compliance, with a more recent study contradicting these findings. Furthermore, the indication that parents are more compliant with hip splint treatment could be explained by the change in the guidance for treatment, which is more flexible to the needs of the infant and parents (Walton et al 2010; Douglas et al 2015).

The literature highlighted the importance of information for mothers of infants being treated at an early stage for DDH (Bergo and Rosendahl 2013; Fabricant et al 2013; Hassan 2009). Although mothers were satisfied with the information provision, they did request information in various formats such as leaflets, which they could use as a reference tool (Fabricant et al 2013; Hassan 2009). An analysis of the quality and accuracy of DDH information offered by the internet found significant differences in the quality, accuracy and readability of the information (Fabricant et al 2013). The websites with the highest quality and accurate information were associated with the search term 'developmental dysplasia of the hip'. Websites that were assessed as having the highest reading attainment level, were the least accurate. A strength of this study is that the level of detail provided in the method section accommodates full replication. On the other hand, one limitation of Fabricant et al's (2013) study is that the results were based on internet search engines performed in North America and only have contextual relevance. Nonetheless, the Fabricant et al (2013) study has important implications for parents and extended family members who seek out reliable information, and also health professionals who refer parents to specific websites.

There is a lack of clarity about the nature of the psychological issues associated with the early treatment of an infant with DDH. For example, maternal clinical anxiety, stress during treatment, and worry prevailing long after treatment has ended (Gardner et al 2005). The gap in knowledge about parents' experiences may be due to the lack of depth provided in the methods used, which were predominately surveys to ascertain knowledge about parents' experiences of DDH. By addressing this gap in knowledge, there is potential to improve the understanding of mothers' experiences, which could lead to improved maternal support by health professionals and parent support organisations. Moreover, there is a clear gap in knowledge about the views and experiences of fathers of infants with DDH in

the literature. In the vast majority of studies regarding early treatment and management of DDH, researchers referred to 'parents', but amongst the detail of these studies these parents were predominately mothers (Corbett 1988; Gardner et al 2005; Hassan 2009; Jennings et al 2017; McHale, Major and Corbett 1989). Clearly, there is scope to explore these gaps to gain insight into the detailed experiences of mothers, fathers and their experiences as co-parents to an infant undergoing early DDH treatment using a qualitative approach. Ultrasonography is a key technology used regularly to monitor the progress of the treatment for early DDH, with an absence of knowledge about parental experiences of management of the condition. There are several gaps in knowledge and understanding about parental experiences of caring for an infant undergoing early treatment for DDH. A qualitative study exploring these gaps in knowledge will add depth to the quantitative results of the current body of research.

### **2.5.5 Late treatment for DDH amongst children**

The literature about parents of children who have undergone late treatment for DDH, is predominately about mothers' experiences of physical, social and psychological problems (Chao and Chiang 2003; Cox and Kernohan 1998; Demir et al 2015; Newman and Fawcett 1995). Interestingly, these findings concur with the literature regarding the experiences of mothers who have infants who have required early DDH treatment (Bergo and Rosendahl 2013; Corbett 1988; Gardner et al 2005; Hassan 2009; McHale, Major and Corbett 1989). Physically, mothers dealt with the mobility challenges of their child in the heavy ridge spica cast (see Figure 4). The mobility problems created complications for mothers in terms of washing, toileting, cast and skin care routines and lifting their infant (Cox and Kernohan 1998; Demir et al 2015; Newman and Fawcett 1995). In a small UK survey of 36 parents, Cox and Kernohan (1998) concluded that the lack of appropriate mobility equipment was the most challenging barrier to parents caring for a child at home who is undergoing late DDH treatment.

Furthermore, mothers experience a major social impact on their lives as they care for their child with late DDH in the home environment (Cox and Kernohan 1998; Demir et al 2015; Newman and Fawcett 1995). Mobility challenges of caring for a child going through late DDH treatment impacted on mothers' occupational commitments and social activities. As a result, mothers become confined to the home and socially isolated (Demir et al 2015; Newman and Fawcett 1995). A North American survey that included 35 mothers with

children who had received late DDH treatment found that as the mother's usual social activities came to a halt, their sense of social isolation precipitated feelings of depression (Newman and Fawcett 1995). Similarly, the findings the Demir et al (2015) Turkish survey of 33 parents found that the challenges of caring for children receiving late DDH treatment resulted in the severe curtailing of the social activities of mothers. In essence, persistent feelings of stress were experienced by parents caring for a child with DDH (Cox and Kernohan 1998; Chao and Chiang 2003; Demir et al 2015; Newman and Fawcett 1995). Of benefit is that some family members provided support and assistance to mothers during this time (Chao and Chiang 2003; Demir et al 2015; Newman and Fawcett 1995). Also, of benefit was fathers providing practical and emotional reassurance to the mother and child (Chao and Chiang 2003; Newman and Fawcett 1995).

A key coping strategy by mothers who were caring for a child being treated for late DDH was their need to seek information and knowledge about the condition (Chao and Chiang 2003; Demir et al 2015). Parents sought this information from many sources, namely, health professionals, the internet and from other parents with children being treated for the same condition. Although mothers were presented with information about their child's condition by health professionals, they often wanted more detailed information (Chao and Chiang 2003; Demir et al 2015).

With a similar aim to other quantitative studies that have investigated parental experiences of caring for a child with late DDH, Chao and Chiang (2003) took a qualitative approach (Cox and Kernohan 1998; Demir et al 2015; Newman and Fawcett 1995). Chao and Chiang's (2003) case study explored the impact and coping strategies of a Chinese mother with a child being treated for late stage DDH. The Chao and Chiang (2003) study revealed that the negative psychological impact on the mother did not solely originate from the demands of DDH treatment of her child. This study provided a candid insight into the pressures and stress created by cultural and social expectations. Chao and Chiang (2005) argue that some Chinese mothers consider giving birth to an abnormal infant as retribution from a previous existence. They contend that in some parts of Chinese culture, society and family circles, mothers feel pressure to give birth to a healthy infant (Chao and Chiang 2005). In keeping with the findings of this study, an awareness of the need for social and cultural sensitivity from health professionals in relation to different cultures. This sensitivity should address stress associated with cultural and social tradition, which may affect a mothers' mental wellbeing and ability to cope and comply with DDH treatment for her child

in her home. Although Chao and Chiang's (2003) study highlighted this issue amongst Chinese culture, researchers acknowledge a wider societal pressure and responsibility placed on all women to produce 'socially defined normal children' (Gregg 1993; Nelson 2002).

The glimpses into the observed perspective of a father caring for a child with DDH suggests that some fathers feel frustrated and isolated by the mother due to a breakdown in communication (Chao and Chiang 2003). The wider literature indicates that the needs of fathers are not being met and they are not receiving adequate support from health professionals (Jacob and Johnson 1997; Spector 2006). In the UK, mental wellbeing is a key problem for men aged 20-44 years old and this is a key life stage for men in terms of employment, relationships and fatherhood (Campaign Against Living Miserably (CALM) 2015). The wider literature also suggests that when an infant is seriously ill and receiving treatment in hospital that the focus of attention and support by the health professionals is on the mother (Hollywood and Hollywood 2011). The fathers' feelings and need for support are often overlooked, which may become a source of frustration (Hollywood and Hollywood 2011). The implications for health professionals is the need for an empathetic understanding of the perspectives of fathers caring for a child with DDH. This deeper understanding of fathers' perspectives may be an efficient, cost effective method of assessing their coping ability, assuring quality of care provision, and an opportunity to enhance the relationships between health professional and father. Researching the experiences of fathers caring for a child with DDH will make an original contribution to the evidence base and may have important implications for clinical practice.

It is apparent from the literature that parents value the importance of information provision by health professionals. However, sometimes these needs are not met. Parents want detailed information booklets about DDH, treatment and care of their child, whilst receiving treatment (Fabricant et al 2013; Hassan 2005). To obtain this essential information, parents are searching the internet (Chao and Chiang 2005; Fabricant et al 2013; Nettleton 2004). Systematic reviews amongst the wider literature acknowledge that parents often receive insufficient information about their child's medical condition (Fisher 2001; Lewis et al 2010; Trim et al 2011). For example, in qualitative studies, Hummelinck and Pollock (2006) explored parental information needs about the treatment of their chronically ill child. They found that parents wanted explanations of their child's diagnosis, treatment and prognosis, to help them to psychologically and practically care for their child. Most parents felt that

accessibility to information was a positive coping strategy, which gave them reassurance as they came to terms with the child's diagnosis. Overall, Hummelinck and Pollock (2006) found that adequate parental information provision is a decision on the part of the health professional. This judgement is based on the interpersonal skills of the health professional to correctly identify the information needs of the parents. Therefore, in relation to this study about the views and experiences of parents of a child with DDH, there is a gap in knowledge and understanding to their information needs. Moreover, the literature does not indicate if mothers and fathers have differing information needs.

From the literature about parental experiences of caring for a child with a late diagnosis for DDH, we know that mothers experience physical, social and psychological challenges (Cox and Kernohan 1998; Chao and Chiang 2003; Demir et al 2015; Newman and Fawcett 1995). These indications that caring for a child with late DDH is challenging suggests that for mothers and possibly, for fathers, caring for an infant who has undergone ultrasonographic screening, diagnosis, monitoring and treatment for DDH face unique psychological and physical challenges. However, currently there is little evidence about these experiences. It also appears that parents seek further information about the condition as a coping strategy (Fabricant et al 2013). Other gaps in knowledge include understanding the role of caring for a child with DDH. Furthermore, we do not understand the fathers' perspective of the situation, which are often conveyed by the mothers by proxy. Little is known about the fathers as reported directly by themselves. There is also a gap in knowledge about parental information needs about DDH. With the exception of Chao and Chiang's (2003) study, a criticism of the remainder of the studies regarding late DDH diagnosis and treatment were very small quantitative survey studies (Cox and Kernohan 1998; Demir et al 2015; Newman and Fawcett 1995). Due to the small response rates in these surveys, it is difficult to extrapolate these survey results to reflect the opinions of the wider population of parents in this situation. On the other hand, Chao and Chiang's (2003) study indicates that a qualitative approach of inquiry can achieve an in-depth understanding and meaning of the experiences of mothers and fathers. This knowledge can contribute to enhancing the healthcare experiences of parents caring for an infant with DDH and fully prepare them for the home treatment phase of their infant's care.

### **2.5.6 Conclusion to the literature review**

This literature review has revealed an absence of literature regarding parental experiences of the use of ultrasonography to screen, diagnose, monitor and manage neonates and infants with DDH. The current body of literature is focused on the clinical aspects of DDH and service user satisfaction. As discussed in Section 1.5 - 'Rationale for the research study', the healthcare service is focused on patient-centred care. However, there is a clear gap in the experiences of parents caring for an infant with DDH. Understanding the perspective of parents could have the potential to improve the quality of the DDH healthcare service, as well as identifying the needs and the support of the caregivers. The wider literature suggests that parental perceptions of general infant screening differs from the perceptions of health professionals (Hasegawa et al 2011). Mindful that DDH treatment takes place in the home, and when unsuccessful can result in mobility problems in adulthood, it is important that the parental experiences are fully understood to ensure that the infant has a successful prognosis. Parents also need to receive appropriate support from health professionals and parental support charities to perform the appropriate care for the infant at home.

The wider literature suggests scope to contribute to the field of health sociology, in particular, sociology of medical screening, use of innovative technology and diagnosis in relation to the experiences of mothers' and fathers' (Armstrong and Eborall 2012; Howson 1999; Jutel and Nettleton 2011; Nettleton 2013). The nature of parental experiences can offer new insight and meaning experiences. The in-depth nature of qualitative study would facilitate this contribution of original knowledge to new areas of sociological enquiry.

Mothers of infants with DDH were the main focus of the majority of research about caring for a child with DDH with a clear gap in knowledge about fathers' perspectives. Quantitative studies have indicated that caring for a child with an early diagnosis for DDH and treatment for DDH had a psychological and physical impact on the mothers (Bergo and Rosendahl 2013; Corbett 1988; Gardner et al 2005; Hassan 2009; Jennings et al 2017; McHale, Major and Corbett 1989). Moreover, the literature regarding late diagnosis and treatment of a child with DDH indicated that some mothers experience physical, social and psychological issues in response to caring (Cox and Kernohan 1998; Chao and Chiang 2003; Demir et al 2015; Newman and Fawcett 1995). To date, there is absence in evidence surrounding experiences of both mothers and fathers caring for an infant who has undergone

ultrasonography for diagnosis, monitoring and management of an infant with DDH. Several studies made recommendations for in-depth qualitative research (Gardner et al 2005; Newman and Fawcett 1995; Rosendahl et al 2010).

Of all the studies in this review, the study identified as offering the greatest depth and meaning was by Chao and Chiang (2003). Although a weakness of this study is that it focused on the experiences of just one mother and her child, it is argued that it the only study which offers in-depth understanding of the mothers' experiences caring for a child with DDH. Moreover, this study provides glimpses into the experiences of the father, even though it is by proxy via the mother. The wider literature which has explored gender and medical screening took a qualitative approach, using phenomenology methodology (Howson 1999; Locock and Alexander 2006). This suggests that a qualitative approach to understanding the experiences of mothers and fathers of an infant who has undergone ultrasonography, received a diagnosis and undergone treatment for DDH, would make an original contribution to the evidence base. The implications of this research could potentially improve the specific care support and information needs of mothers and fathers by health professionals and DDH charities to achieve a successful prognosis of a child with DDH. Improved support has the potential for averting negative mental wellbeing issues, which could impact on the family as well as health services, in terms of support provision. While there has been substantive quantitative research about parenting a child with DDH, there is a paucity of research which focus on qualitative research. Therefore, this study explores the experiences of parents caring for a child with DDH.

## **2.6 Chapter summary**

This chapter has delivered a comprehensive search strategy, review process and a literature review of studies that have provided deeper understanding and knowledge of the nature of parenting a child with DDH. Key findings have helped identify important gaps in knowledge to direct the research design of the study. The justification for the methodology proposed in the next chapter.

## Chapter Three: Methodology

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### 3.1 Chapter overview

This chapter discusses the rationale for the selection of methodology for this study. Firstly, it will present the aim and research questions of the study. Secondly, it will discuss how philosophical assumptions as well as my ontological and epistemological perspective led to the choice of methodology. Thirdly, it will critically discuss Interpretative Phenomenological Analysis (IPA) and provide the rationale for selecting this methodology.

### 3.2 Research aim and research questions

The aim of this study was to explore the experiences of parents of infants who have been diagnosed with DDH and undergone treatment for the condition.

This study specifically investigated the following research questions:

1. What are the mothers' experiences of their infant being diagnosed and treated for DDH?
2. What are the fathers' experiences of their infant being diagnosed and treated for DDH?
3. What are the similarities and differences in the experiences between mothers and fathers caring for an infant with DDH?
4. What are the information needs of mothers and fathers whose infant has been diagnosed and treated for DDH?

### 3.3 Research paradigm

The researcher's philosophical assumptions directly influences their rationale for selecting a paradigm and it also provides a structured research framework. Gray (2014: 687) defines a paradigm as:

*'a perspective or worldview based on a set of values and philosophical assumptions, from which distinctive conceptualisations and explanations of phenomena are proposed.'*

Within paradigms, the researcher's philosophical position with regards to their ontological, epistemological and methodological perspectives are intertwined (Crotty 1998; Gray 2014). These ontological assumptions reflect their understanding of the nature of reality and existence in the social world (Creswell 2013). The researcher's ontological perspective links to their philosophical perspective of epistemology. Although many researchers have beliefs about epistemology and ontology, but they do not have the self-awareness that they have them.

Epistemology asks the researcher to consider how knowledge about the world is acquired. The epistemological perspective of the researcher leads the path to the generation of knowledge and explanations about the social world (Mason 2002). It is important for a researcher to have an awareness of their ontological and epistemological assumptions as these perspectives direct the overall research framework of their study, in particular, the methodology, the nature of gathering data and the implications of the study. Moreover, reflecting and acknowledging these assumptions can direct the researcher's rationale in deciding which research designs are appropriate to answer the research questions (Gray 2014).

What constitutes 'reality' and the acquisition of 'knowledge' are defined by two opposing paradigms: positivism and interpretivism. The positivist paradigm, commonly referred to as the quantitative paradigm, maintains the assumption that: the world is external and objective (ontology); the researcher is independent, and science is value-free (epistemology); the researcher utilises quantitative methods to deductively generalise findings (Creswell 2013). In contrast, the interpretivist paradigm, which is commonly associated with the qualitative paradigm, contends that the social world is subjective (ontology); the researcher interacts with the participants and science is driven by human interests (epistemology); the researcher utilises qualitative methods to inductively generate patterns of meaning (Creswell 2013). The literature review identified a gap and a need to understand the multiple views of parents with infants who have been diagnosed and treated for DDH (ontology). Furthermore, there is a lack of evidence which actively interacts with these parents and explores the essence of their experiences of this phenomena (epistemology). The nature of this research inquiry indicates that the interpretivist paradigm is the most appropriate for this study.

### **3.4 Rationale for adopting a qualitative research approach**

While reflecting on ontological and epistemological perspectives and the conclusions of the literature review which identified an absence in knowledge regarding mothers' and fathers' experiences of their infant being diagnosed and undergoing treatment for DDH, it was clear that there was a need to adopt a qualitative approach in this study. The literature review revealed that the vast majority of studies to date have taken a quantitative approach to investigate experiences of parents who have cared for children with DDH. These studies examined the relationship of variables in an objective, deductive manner using methods such as surveys and RCTs. Amongst these studies, there was a noticeable lack of context about the nature of these parental experiences. Furthermore, the research design of these studies, did not offer the researchers the opportunity to delve deeper to understand the nature and characteristics of parental experiences. However, within the literature review, one study of particular note was a qualitative case study by Chao and Chang (2005) which provided insight into the experiences of a mother of a child with DDH. Chao and Chiang's (2005) study highlighted the value of the qualitative approach to inquiry by presenting the opportunity to convey the voices and understand the parental perspective (Creswell 2013). Moreover, the qualitative paradigm was selected for this study because this approach would reveal the specific nuances of the parental caregiving experience and it would provide the opportunity for different parent perspectives to emerge from the data.

### **3.5 Choosing a research methodology**

Research methodologies are the procedures used in research and they are underpinned by the philosophical assumptions of the researcher (Creswell 2013). The rationale to pursue a qualitative research design, subsequently directed towards the examination of the principles of research methodologies that are congruent with the qualitative approach. Creswell (2013:123) suggests the key question to aid the selection of one research methodology over other methodologies is to ask:

*'What is the methodology attempting to achieve?'*

Furthermore, Creswell (2013:123) encourages researchers to consider:

*'Which methodology can contribute the most to the evidence base in your field?'*

To answer these two questions, there was a critical evaluation of five main research methodologies: ethnography; narrative research; grounded theory; case study; phenomenology.

### Ethnography

In the early stages of this study, a great deal of consideration was given to selecting ethnography as a means to interpreting the shared values and behaviours of the parents' perspectives as they cared for their infant with DDH. However, since the nature of ethnographic inquiry explicitly focuses on the culture of the group, it was felt that this would not achieve the aim of the study with its focus on parental experience of a phenomenon (Denzin 1999). Moreover, since ethnography requires the researcher to undertake direct observations with the participants, this would cause serious timescale challenges with this type of study (Gobo 2008). Consideration was given to the potential settings of an observational research, such as hospitals and the potential barriers that could be encountered in this type of setting. While liaising with an NHS hospital research department and during our discussions, it became apparent that to gain access to healthcare settings would require NHS ethical approval and it was anticipated that this process would take several months to complete. Furthermore, on securing NHS ethical approval, consideration about the timescales of study would be needed in relation to making the organisational arrangements to gathering the data. It was concluded that it was not possible to carry out an ethnographic study within the timeframe allocated to my study. Among researchers, it is widely recognised that obtaining official authorisation to access organisations and the length of time associated with securing access to a setting is a common challenge (Creswell 2013; Gray 2014).

### Narrative research

The potential of narrative research was considered as a means of capturing the detailed individual stories of a small group of parents (Creswell 2013). An autoethnographic paper was written about the researcher's own parental experiences of having children with DDH. However, there were reservations about narrative research being the most appropriate methodology to achieve the aim of the study. Furthermore, consideration was given to the procedural challenges of narrative research to gather multiple sources of information over a period of time and conduct the analysis of this data to be insurmountable within the timeframe of this study (Viney and Bousefield 1990).

### Grounded Theory

Grounded theory methodology develops a theory from data which has been systematically collected and analysed in relation to a phenomenon (Strauss and Corbin 1998).

Furthermore, Grounded theory has been widely adopted in health research (Charmaz 1995). However, grounded theory was inappropriate as a thorough literature review had already been carried out. My extensive knowledge of empirical studies about parental experiences of caring for a child with DDH may have impeded or constrained the development of a theory (Strauss and Corbin 1998).

### Case Study

At first, it seemed that the characteristics of case study methodology appeared to have the potential to achieve aim of the study. Case studies focus on developing in-depth description and analysis of a single case study or several case studies about a particular issue (Creswell 2013). The researcher follows the live progress of the case study or case studies over a period of time (Stake 1995). In case studies, data collection involves drawing on multiple sources of information to establish themes amongst the data. The data can include observations, interviews, documents, photographs and audio-visual recordings. The literature review identified an important study by Chao and Chiang (2005), whose findings greatly influenced the rationale for the research study. This study utilised a case study research design focusing on the experiences of a mother caring for a child with a late diagnosis for DDH. A careful evaluation was given to the prospect of adopting a case study methodology for the study. However, while reflecting on the Creswell's (2013) second question about the importance of selecting a research methodology which can make a valuable contribution to the field of inquiry, it was felt that an alternative methodology, specifically, *phenomenology*, was more advantageous to achieve the aim of the study and add knowledge to the evidence base of health.

## **3.6 Background of IPA**

While considering the contribution and value of various methodologies to the study, phenomenology came to the forefront, as it investigates the essence of the lived experience of a phenomenon by an individual or several individuals (Creswell 2013). This methodology provides the philosophical epistemological context and the methodological framework to understand the lived experience of parents with an infant with DDH. While delving further

amongst the different schools of phenomenology, it was felt that IPA resonated with the researcher's epistemological outlook and the aim of the study. IPA is a popular branch of *interpretive phenomenology* among health research which focuses on the parental experience of caring for a child with a health condition (Jordan et al 2007; Kastel et al 2011; Schweitzer et al 2012; Smith 2011). IPA is led by the philosophical perspective that to understand the meaning of the human lived experience is the need to examine human experiences close up to them (Smith 2011). It also offers a framework which guides the researcher through the data collection and analysis processes, through this is not a '*prescriptive methodology*' and there is scope to be flexible (Smith et al 2009; Smith 2010: 188).

The term IPA encapsulates the main characteristics of the methodology. IPA is *interpretive* because the insight and findings of the study is dependent on the analyst's interpretation of the individual participant's accounts (Smith et al 2009). It is *phenomenological* as it focuses on the individual's lived experience of the phenomena being investigated within the study (Shinebourne 2011; Smith et al 2009). The *analysis* element refers to the distinctive and rigorous form of qualitative analysis (Smith et al 2009). IPA methodology is preoccupied with the participant's individual view and experiences of their world, as opposed to focusing on generalising their individual findings to the entire population (Reid et al 2005; Smith et al 2009). The research procedures in IPA take an inductive approach in which the participants are experts with knowledge and understanding about an experience and who are sharing it with the researcher (Reid et al 2005). This methodology offers the researcher a close insight into the participant's cognition and language (Smith et al 2009). Furthermore, IPA reveals an interplay between how a participant talks about their experience and its connection to their feelings about the experience (Smith et al 2009). The procedures of IPA are iterative and this enables the researcher to gain a deep empathetic understanding of the individual participant's experience (Reid et al 2005; Smith et al 2009).

### **3.6.1 Theoretical foundations of IPA**

During the progress of the study, as the researcher, I developed a deep appreciation, importance and value for researchers to understand the philosophical underpinnings of methodologies. The one of the key pioneers of IPA methodology, Smith et al (2009: 5-6) argues that:

*'Researchers who familiarise themselves with it [the philosophy of IPA] will be able to produce more consistent, sophisticated and nuanced analyses. They will also be able to draw on their understanding of the underlying philosophy to help them to solve unanticipated problems'.*

IPA encompasses the philosophies of key phenomenologists, most notably, the thoughts and work of Husserl, Heidegger and Merleau-Ponty as well as hermeneutics and idiography (Shinebourne et al 2011; Smith et al 2009). IPA is influenced by Husserlian phenomenology which advocates redirecting our everyday gaze of knowledge and understanding of an experience (Smith et al 2009). Husserl calls this our 'natural attitude' (Husserl 1971). Husserl proposed taking a 'phenomenological attitude' by detaching or 'bracketing' ourselves from the subjective knowledge of experience and to make an effort to self-consciously reflect on the specific essence of the experience (Husserl 1971). He argued that we should go '*back to the things themselves*' and suspend our assumptions about the experience and go back and unpick the various elements that make up that particular experience (Smith et al 2009: 12).

IPA is also influenced by Heidegger's interpretivist branch of phenomenology:

*'The meaning of phenomenological description as a method lies in interpretation.'*

(Heidegger 1962: 37)

IPA shares Heidegger's view that human beings, by their very existence of being in the world, are influenced by pre-existence littering of objects, relationships, language, culture and concerns in the world (Smith et al 2009). IPA also acknowledges Heidegger's thoughts that human beings are temporal, perspectival and their meaning making of the world is set in the context of something else, which exists in the world (Smith et al 2009). Merleau-Ponty (1962) thoughts and work contribute to IPA methodology with focus on the centrality of the body and embodiment in nature of our existence and relationship to the world (Smith et al 2009). Furthermore, the rich detailed work of Sartre, emphasises for IPA researchers, the value of human beings as the embodied, interpersonal, affective and moral representation of their experiences in the world (Smith et al 2009).

### 3.6.2 Hermeneutics

A key feature of IPA is phenomenology viewed through hermeneutics. The contributions of hermeneutic theorists, Schleiermacher, Heidegger and Gadamer highlight the role of interpretivism within IPA. The concept that the IPA researcher is engaged 'double hermeneutics' is pivotal to IPA methodology (Smith et al 2004). The researcher and the participant are involved in double hermeneutics in which during a research interview between the participant and the researcher, the participant attempts to make sense and reflect on their experience (Reid et al 2005). Simultaneously, the researcher directs their questioning, reflects on meanings and tries to make their own sense of the participant's experience (Reid et al 2005). As a result, there is a dualism between the participant and the IPA researcher with their contributions to the analysis stage and outcome of IPA research findings (Reid et al 2005). The double hermeneutics of IPA, also known as the 'hermeneutic circle', resonated with me as a researcher. IPA offered an opportunity to me as the researcher, to make an active interpretative contribution to the data and I found this very appealing.

The role of the hermeneutic circle within IPA focuses on the need to consider the relationship between the parts to understand the whole, as well as considering the whole to understand the parts (Smith et al 2009; Smith and Osborn 2003). This analytic process is iterative, going back and forth. Moreover, this process allows the scope for the researcher to develop an 'insider's perspective', a sense of deep empathy and understanding of the participant's unique experience (Reid et al 2005). Smith et al (2009: 37) explain that the value of the theoretical foundations for IPA that:

*'Without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen.'*

### 3.6.3 Idiography

Another important element of IPA methodology is idiography (Shinebourne 2011). IPA engages with the research question at an idiographic level as opposed to the nomothetic level. The idiographic level of IPA requires a focus on the detailed, specific and in-depth nuances of meaning for the participant about their lived experience; whereas the nomothetic level focuses on establishing general laws of human behaviour in a group or population (Larkin et al 2006; Smith et al 2009; Smith 2010). IPA researchers strive to gain an intense level of empathy with the participants about their experiences. Therefore, IPA's commitment

to idiography supports the need for small, purposive sampling of participants and micro-analysis of transcripts to allow for the development of in-depth, empathetic meaning in the data and findings of a study (Smith 2004).

### **3.7 Critiques of IPA**

Much of the research design literature about IPA alludes to its rising popularity amongst researchers in the health field (Hefferon and Gil-Rodriguez 2011; Smith 2004; Smith 2011). Larkin, Watts and Clifton (2006) suggest that the appeal of IPA to researchers is due to the accessibility, flexibility and applicability. A strength of IPA is that there is a wealth of guidance, best practice and strong examples of IPA studies for the researchers. IPA is also attractive to applied health researchers as the nature of IPA research is congruent with the ethos of the NHS, an organisation committed to improving the service user experiences of health care services (Department of Health 2012). Another notable strength of IPA research is that there are clear examples of this research directly influencing UK health policy and practice. For example, Flowers et al (2011) research about human immunodeficiency virus (HIV) has directly influenced sexual health practice and it has challenged biomedical models of HIV testing (Clutterbuck et al 2012; Health Protection Network 2012).

However, it is widely acknowledged that the greatest risk with IPA research is the production of poor descriptive analysis and findings (Brocki and Wearden 2006; Smith 2004; Smith et al 2009). This is a risk shared with all qualitative approaches. Smith (2004) warns researchers that a lack of engagement with the theoretical context of IPA will result in weak descriptive IPA research. Recently, Paley (2017) delivered a tough critique of several phenomenological methodologies including IPA. Using examples from Smith, Flowers and Larkin's (2009) guide to IPA, Paley (2017) argues that there is no method in the IPA framework. Furthermore, he argues there is a lack of a criteria about exactly how to establish meanings from the data (Paley 2017). Paley (2017) takes issue with the concept that meanings 'emerge' from the data. He is adamant that Smith et al (2009) are importing their own theory into the data analysis:

*'It is a consequence of the absence of criteria, leading to a conceptual vacuum, leading to the unconscious intrusion of prior commitments and obsessions'*

(Paley 2017: 164)

Moreover, Paley (2017) is of the opinion that Smith et al (2009), at times, embellish the meanings that participants place on their lived experiences. However, there is a solid quality control process to help IPA researchers enhance the validity and rigour of their studies, while also providing the transparency of verbatim extracts which allows the audiences to assess it for themselves (Elliot, Fischer and Rennie 1999).

### **3.8 Rationale for using IPA**

While reflecting on the strengths and weaknesses of various qualitative methodologies, it became very clear that IPA was the most appropriate methodology for this study. This methodology would achieve the aim of the study with its scope to explore the deeper insights of lived experience of parents with an infant who has been diagnosed with DDH and undergone treatment for the condition. The double hermeneutic element of IPA was interesting, as it allowed the researcher to play an active role in the generation of data and contribute to the findings of the study. Moreover, this methodology gave the opportunity to add original knowledge to the evidence base and has a proven record of delivering research findings which could influence health policy and practice in health settings and by parental support organisations. While being mindful of the timeframe for this research, the application of this methodology was practical and achievable.

### **3.9 Chapter summary**

This chapter addressed the aim of the study: to explore the experiences of parents of infants who have been diagnosed and treated for DDH. As the researcher, my ontological and epistemological perspective together with the gaps in the literature review, have directed and provided the justification for the research design of this study. This study will be a qualitative study using IPA to gain a rich and idiographic understanding of the meanings of the experience of mothers and fathers as they cared for their infant who had been diagnosed with DDH and undergone treatment for the condition. The next chapter, 'Research Design and Methods' discusses the nature and rationale of the methods adopted in this study.

## Chapter Four: Research Design and Methods

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### 4.1 Chapter overview

This chapter will discuss in detail the research design and methods of this study which explores the experiences of mothers and fathers of infants with DDH. It will also provide a rationale and a critical context for the decisions about key elements of the research design, methods and data analysis. It will also address the issues of credibility and rigour.

### 4.2 Sampling

The rationale for the sampling method and the number of participants recruited to the study was informed by the theoretical underpinnings of IPA methodology (Smith et al 2009). To recruit participants to the study using the non-probability sampling method of purposive sampling (Smith et al 2009). As the researcher, purposive sampling offered the scope to identify individuals and/or sites which could purposefully inform our understanding of the central phenomenon or experience within the context of the study (Creswell 2013). The main advantage of purposive sampling in the study was that the sample captured those groups of people who had experienced the phenomenon. In this case, the parents of infants with DDH, rather than other forms of non-probability sampling such as quota sampling or volunteer sampling (Gray 2014).

Eighteen participants were recruited to the study. From this total number of participants, nine participants were mothers and nine participants were fathers of children who had undergone diagnosis and treatment for DDH. The recruitment of participants was open to individual mothers and / or fathers in co-parent relationships and sole parents. Therefore, this study did not aim to exclusively recruit parents in co-parent relationships. The inclusion criteria for participants to join the study required parents with a child diagnosed and treated for DDH.

Prior to recruitment of participants and data collection stages, careful consideration was given for the rationale of the sample size. Marshall et al (2013) suggest a best practice for the justification of sample size in qualitative research. They recommend that researchers should specifically refer to other work of qualitative methodologists and qualitative research within the same field (Marshall et al 2013). The decision about the sampling size for the

study was made at a stage in the research when the researcher was acquiring knowledge and appreciation about IPA methodology as well as becoming familiar with the breath of published IPA health research. The researcher was also mindful of Denzin's (1989: 73) advice to researchers that:

*'All sampling activities are theoretically informed.'*

The sample size was justified on this basis of recommendations by the founders of the IPA methodology, Smith et al (2009) and IPA health research which explored similar phenomena and experiences and which also had similar research designs to the research proposal (Dickson et al, 2008; Harper et al, 2010; Jordan et al, 2007; Marshall et al, 2013). Moreover, the researcher was also aware of the challenges of recruiting men to health research and anticipated that there would be difficulties in the recruitment of fathers to the study (Joseph et al, 2007; Oliffe, 2009; Sherr et al, 2006). Marshall and Rossman (2011) acknowledge that sample sizes are decided before the data collection begins, and researchers need to be flexible about sample sizes. In anticipation that this issue may arise in the research project, the researcher aimed to mitigate it. The sample sizes were decided on the researcher's prior assumption that it would difficult to recruit the number of fathers and afforded the scope to be flexible about the sample sizes. However, the researcher recruited the full sample of mother and father participants to the study without any difficulty. However, on reflection, it was only when the data analysis of the interview transcripts ended, that the full appreciation of the need for smaller sample sizes in IPA research. This was needed to facilitate the micro-analysis of each sentence spoken by the participant and the time dedicated by a sole researcher in this process (Smith et al 2009).

### **4.3 The role of the gatekeeper organisations**

Participants were recruited through two organisations, the Steps DDH charity and Knowsley Children Centres. The Steps charity are a UK wide parent support charity specifically for lower limb conditions including DDH (Steps 2016a). The Knowsley Children's Centres have a public health focus and engage with directly with parents (Knowsley Children's Centres 2016). These gateway organisations were selected because they were considered to be the most effective and rapid sites to recruit the sample of participants to the study (Gray 2014). Moreover, the researcher already had established network links to Knowsley Children's

Centres as a member of their Advisory Board. The management team at Knowsley Children's Centres expressed an interest in the research and unprompted, offered their assistance to help recruit participants to the study.

The initial formal contact with these organisations was by email. This email: introduced the researcher; explained which university was being represented; offered brief details about the research; requested a meeting with the researcher. At the meeting with the gateway organisations, the researcher gave a briefing about the study and clearly communicated exactly how they could assist the study. The researcher was very keen to receive their feedback and thoughts about the study. Specific examples of the areas of the study which required their feedback included, asking them to look through the interview schedule of questions and enquiring their thoughts about giving participants financial incentives. The researcher listened closely and valued their opinions. These organisations played a pivotal role in the study by assisting with the recruitment of participants through use of their internet social media platforms and contributing to the research design.

#### **4.4 Access to participants**

On behalf of the researcher, the gateway organisations circulated an advert to participants through their social media platforms, Facebook and Twitter. Recent studies indicate that these social media platforms are popular amongst parents and they are an effective method of recruiting participants to research (Duggan et al 2015; Quach et al 2013; Thornton et al 2016). Initially, the researcher developed a coherent social media strategy for the recruitment of participants which was justified by non-peer reviewed marketing research (Ellering 2016). This strategy involved asking the gateway organisations to post the participant recruitment advert on their social media platforms at the peak times of the working week when people look at social media. The researcher requested that the gateway organisations to post on their social media platforms twice a day between Monday and Friday at approximately 12.00 hours and 17.00 hours over the course of a fortnight.

However, the gateway organisations contacted the researcher to discuss an alternative social media strategy. The Steps Charity advised that the peak time for traffic on their Facebook page was between 19:00hrs and 20:00hrs. They felt that this peak coincided with sleep times of small children. On the other hand, Knowsley Children's Centres were concerned about 'over-posting' on their social media platforms and they were concerned that parents may become frustrated with viewing repeated posts and 'hide' the Children's

Centres social media pages. Consequently, they risked disengagement with their social media audience. The researcher listened and valued the opinions and experience of the gateway organisations and decided to re-visit the carefully developed social media strategy and adjust it. Accordingly, the researcher negotiated with the gateway organisations to post the advert at 12:00 hours and 19:00 hrs, every other day as opposed to every single day. Arrangements were made for these posts to run for two months. However, the researcher received an overwhelming response. Subsequently, the researcher informed the gateway organisations about the successful response to the posts and asked them to cease putting the posts up on their social media platforms.

Within a fortnight, over 60 emails were received from potential participants who were expressing an interest in taking part in the study. Interestingly, all of these emails were responding to the social media post of the Steps charity. The researcher did not receive any expression of interest emails from any parents responding to the posts from Knowsley Children's Centres. The participants were selected due to their geographical locations and the ease of the researcher to travel to the interview location. The researcher interviewed participants from across England and Scotland and clustered participants who resided in one geographical county area. This afforded the researcher the opportunity to conduct the interviews over the course of a day or two.

The participant recruitment posts on social media featured the researcher's university email address, so that those people who were interested in taking part in the study could make direct contact, without creating an additional workload for the gateway organisations. In addition, by using researcher's university email address as a point of contact, it reduced any potential risks to both the potential participants and the researcher. Furthermore, there was an element of reassurance for potential participants as by contacting the researcher via the university email address indicated that this was a genuine researcher affiliated to the university. When potential participants first contacted the researcher, each participant received a personalised email. In this email, the researcher enquired with the participant about their circumstances to ensure that:

- a) They met the participant inclusion criteria;
- b) To explain the nature of the study;
- c) To discuss possible dates and meeting room venues near to their home;

- d) To enquire with the potential participant if their child's other parent would be interested in participating in the study.

Once the researcher made these initial contacts with the participants, the researcher would identify a venue and book the meeting room. The researcher strove to book a meeting venue and time which was convenient for the participant. Prior to the interviews, the researcher also emailed the interview schedule of questions to the participants. The researcher did this action to enhance openness and transparency with the participants about the nature of the interviews.

The interview questions were developed from the knowledge gaps in the literature review (Brinkmann and Kvale 2015; Gray 2014) (refer to Appendix 6). The interviews questions focused on the parental experience of the DDH care pathway, specifically, their experience of: the DDH ultrasonographic screening scan; diagnosis; follow up outpatient appointments; acquiring information. These interview questions were used in the pilot study and they worked well, therefore, they remained unchanged in the main interviews.

#### **4.5 Data collection**

The decision to select the method of semi-structured interviews with participants was informed by the researcher's philosophical assumptions and choice of IPA methodology. The idiographic nature of semi-structured interviews in IPA are the best method to elicit the views, feelings, interpretations and experiences of mothers and fathers who have experienced and cared for their infant with DDH (Smith et al 2009). They give participants the opportunity to have their voices heard, and to speak freely and reflectively. Moreover, they are a common method of data collection in IPA (Smith 2011). However, Smith et al (2009) also offer a word of caution that a poor IPA interview produces data that is too thin for analysis. The qualities of a good IPA interview require the researcher: to deeply engage with the views and experiences of the participant; to listen carefully to the participant; to sufficiently probe the participant for further details (Smith et al 2009). This IPA method allows the participant to reflect on their experience and in turn, the researcher can gain a deeper understanding of the participant's reflections and comments. The literature review revealed that surveys were the dominant research method. A notable strength of semi-structured interviews is that they can achieve a level of depth that is not possible in surveys (Gray 2014).

The semi-structured interviews took approximately 45 minutes and they took place in a meeting room of a public library meeting or a university. Verbal interview data was collected using audio-recording equipment. During research interviews, I always use two audio recordings devices. This is to allow for any technical issues which may emerge after the interview, such as battery failure in the audio-recording device. Following on from the participant interviews, the data was transcribed verbatim and analysed. All of the data was anonymised to ensure that no recordings or documents or computer files reveal the identity of a participant.

#### **4.6 Pilot interviews**

The researcher gave much consideration to carrying out a pilot study. Furthermore, the researcher fully appreciated the many benefits of conducting a pilot study (Silverman 2013). For the study, the advantages of a pilot study centred on the process of the interview, the interview questions and the accuracy of my data analysis. However, during the early stages of my study, the researcher was concerned that if there were difficulties in the recruitment of the full sample size of participants for the study and proceeded with a pilot study, that there would be much fewer participants in the study. Nevertheless, the researcher successfully recruited participants to the study, without any difficulties. Therefore, the pilot study of interviews with a mother and a father could proceed. In the pilot study, the researcher also wanted to ensure that a robust data analysis of these two transcripts using IPA had been conducted. The researcher asked an experienced IPA methodologist within the university, Dr Zoe Chouliara, to conduct data analysis of the two transcripts. Independently, both researchers coded the data and identified themes within the pilot study transcripts. Later, the researchers shared the data analysis and the emerging themes. They found that the data analysis and themes corroborated. Consequently, the researcher was given solid reassurance that the data was rich and illuminating and the themes were appropriate. Specifically, the pilot study ensured that the interview questions were clear and appropriate; the data collected from participants achieved the aim of the study; to identify any problems with the study (Marshall and Rossman 2011).

#### **4.7 Transcription**

Due to the tight timescale for the completion of the study, the researcher arranged for the interview data to be professionally transcribed by a company affiliated to the university. Although Brinkmann and Kvale (2015) argued that a researcher can learn a great deal

about their interviewing style from transcribing the interview themselves, such as the emotional and social context of the interview; the meaning of what was said by the participant; the interviewing craftsmanship. However, it can be counter-argued that since the researcher was the sole researcher who conducted these interviews, the opportunity to obtain a solid understanding the emotional and social context for these participants had been achieved. Furthermore, the detailed nature of the microanalysis of the interview data facilitated by the IPA methodology allowed the researcher, as the sole analyst, the scope to obtain deep conceptual meanings to these interviews (Smith et al 2009). The researcher listened to the digital interview recording again and followed the interview conversation through the transcriptions, and always found the interviews to be accurately transcribed. On reflection, as the researcher, I feel that arranging the transcription of 18 interviews, plus the two pilot interviews, on this occasion, was a sound decision.

#### **4.8 Data Analysis using IPA**

Before embarking on the data analysis stage of the study, the researcher consciously made an effort to put aside their own parental experiences. In phenomenological studies, this action is referred to as 'bracketing' (Creswell 2013). During the data analysis process, the researcher aimed to reveal the lived experiences of the parent participants in the study. To ensure that the analysis of IPA was in accordance with the framework, the researcher participated in an IPA training course hosted by one of the pioneers of IPA, Professor Paul Flowers. Undoubtedly, this opportunity greatly enhanced the researcher's understanding of IPA and developed confidence to perform the analysis aspect of IPA. Smith et al (2009) offer the novice IPA analyst six steps to perform IPA. Although the researcher used these steps as a guide, while also being mindful of Smith et al's (2009) advice that IPA is not a rigid methodology, but a dynamic and evolving methodology. Table 4 summarises the steps taken with the data analysis using IPA.

Table 4: The steps of analysis using IPA (Smith, Flowers and Larkin 2009)

Step number	IPA action
1	Reading and re-reading
2	Initial noting
3	Developing emergent themes
4	Searching for connections across emergent themes
5	Moving to the next case
6	Looking for patterns across cases

### Step 1: Reading and re-reading

This focus of this step requires the analyst to ‘slow down’; absorb the overall context of the interview data; follow the participant’s idiographic narrative of the phenomenon (Smith et al 2009: 82). The researcher conducted all of the participant interviews and therefore, found that she could immerse herself back into the moments of the interviews as she read and re-read the transcripts (Pietkiewicz and Smith 2014). In the text of the transcripts, the researcher could vividly hear again each individual participant’s voice, the idiographic nuances of their feelings and thoughts of this experience in their lives as they cared for their infant with DDH.

### Step 2: Initial noting

This is the exploratory coding stage. It is recognised as being time consuming and it generates a great deal more detailed data (Reid et al 2005; Smith et al 2009). The researcher/analyst spent several weeks exploring and analysing the data within this stage. While applying an open mind, the analyst followed the interview transcript line-by-line noting anything of interest. Smith et al (2009) state that there is no fixed technique to exploratory coding. However, they do suggest three layers to this aspect of the analysis: description and content; language use; conceptual and interrogative coding (Smith et al 2009). Within the description and content layer, the analyst highlighted events, processes and places. Within the linguistic layer, the focus was on the language used by the participants, such as metaphors, similes, repetition or emphasis on words. The conceptual and interrogative

coding is the most important layer as this is the interpretative aspect of IPA. It is acknowledged that this can be a very challenging time for IPA analysts with the deeper level engagement in the hermeneutic circle and contributing our own data to the corpus of participant interview data (Hefferon and Gil-Rodriguez 2011; Smith et al 2009). IPA analysts need to be confident to reflect and use their own life experiences as a benchmark to understand the meaning of participant's experiences of the phenomenon (Hefferon and Gil-Rodriguez 2011; Smith et al 2009).

To illustrate this step, a sample of an annotated interview transcript can be referred to in Appendix 7. In the right-hand column of the transcript, the analyst has presented the three layers of analysis. Moreover, it is anticipated that the inclusion of an annotated transcript will support the credibility, trustworthiness and rigour of this analysis (Elliot, Fischer and Rennie (1999).

### Step 3: Developing emergent themes

Since the initial note step, the corpus of data has substantially grown with the collation of transcript codes and exploratory codes. It is recognised that for the analyst, managing this volume of data can feel overwhelming (Smith et al 2009). However, the focus of the developing emergent themes step is to bring all the codes together to capture and reflect their understanding of the experience. This step is about coding the codes, while maintaining the complexity of the data (Smith et al 2009). The analyst developed the emergent themes by mapping the connections, patterns and relationships from the initial notes. These themes reflected the participants' original words and thoughts, but also the analyst's conceptual interpretations. These emergent themes are a joint product of both the participant and the analyst (Smith et al 2009). Again, this step is illustrated in the annotated interview extract (refer to Appendix 7) and the emergent themes are shown in the left-hand column.

### Step 4: Searching for connections across emergent themes

This step requires the analyst to map the emergent themes. It also acts as a structure to writing up the findings of the study. The end product of this step is a map of emergent themes which reflects how the analyst thinks that the participant is thinking about their experience of the phenomenon (Smith et al 2009). Interestingly, within this step, the IPA analytical framework allows the scope to discard some emergent themes (Smith et al 2009). For the qualitative researcher, there are difficulties in relinquishing the interpretative data

which they have actively engaged with for many months. However, some emergent themes were discounted from the analysis.

Within the IPA framework, Smith et al (2009) offer six techniques to identify connections and patterns across the emergent themes. These techniques are abstraction; subsumption; polarisation; contextualisation; functionality; numeration (Smith et al 2009). However, Smith et al (2009) emphasize that IPA is a fluid methodology and there is scope to be innovative with the analysis of the data and emergent themes.

The analyst was interested in the numeration technique as it provided transparency to the findings and it would contribute to the credibility and trustworthiness of the study (Elliot Fischer and Rennie 1999; Miles and Huberman 1994). However, the analyst also applied flexibility to explore any divergence from the themes or deviant participant experiences of the phenomenon. Using numeration techniques within the findings of qualitative studies is controversial. It could be argued that numeration is the antithesis of qualitative research. However, researchers such as Miles and Huberman (1994) concur with the opinion of Smith et al (2009) who justify counting in qualitative data analysis as a means to identify patterns with ease. Marshall and Rossman (2011) also have a favourable view of using numbers to indicate frequency of themes or patterns with the data. Nevertheless, they offer a word of caution to researchers that qualitative research, numbers are used quite differently from the way that numbers are used in quantitative research. Amongst some researchers, there is a body of opinion that numeration of themes can support the credibility and rigour of the findings in qualitative research (Bazeley and Jackson 2013; Silverman 2013). On the other hand, researchers such as Creswell (2013) do not value the use numeration in their own research.

Within this step, the analyst revisited the emergent themes on several occasions and examined them broadly, but also very closely. The analyst renamed some emergent themes, merged others together and split others up. The analyst also considered the relationships between the emergent themes; how the emergent themes clustered and converged together as well as those which diverged (Pietkiewicz and Smith 2014; Pringle et al 2011).

#### Step 5: Moving to the next case

The analyst maintained an idiographic focus on each individual participant's case and their story. Steps 1 to 4 were repeated for each individual case. The analyst was able to bracket

off the emergent themes from one participant interview and moved on to concentrated exclusively on the next case (Smith et al 2009).

#### Step 6: Looking for patterns across cases

The analyst focused on the emergent themes that were recurrent. Recurrent themes were those themes which featured in five or more participant interviews (Smith et al 2009). These recurrent themes contributed towards the development of intermediate themes. Moving on from the intermediate themes, the analyst developed overarching superordinate themes (Pietkiewicz and Smith 2014). On many occasions during the latter stages of the analysis, the analyst revisited and revised the conceptual development of the intermediate and superordinate themes. While using numeration as the basis for the themes, the analyst simultaneously focused on the commonality between the themes as well as the individual, idiographic focus of the participant's voice (Smith et al 2009). Figures 7 and 8 show a diagram of the recurrent themes, the intermediate themes and the superordinate themes from interviews with mothers and fathers about their experiences.

### **4.9 The rationale for the use of qualitative data analysis computer software**

NVivo qualitative analysis software was used to assist with managing the interview transcription data (QSR International 2016). It is important to highlight that although the researcher is managing the data using analytical software, it remains that the researcher is the analytical interpreter of the data (Denzin and Lincoln 2005; Gray 2014). The software does not conduct the analysis. However, the use of computer-based qualitative data analytical software is controversial. Silverman and Seale have long advocated the strengths of analytical software (Seale and Silverman 1997; Silverman 2013). On the other hand, amongst IPA research, there is a dearth of studies that acknowledge the use of qualitative data analysis software in their analysis. This may be due to the stance of IPA pioneers, Smith, Flowers and Larkin (2009: 100) who state that:

*'We would not necessarily recommend this to the novice researcher unless it is very close to one's normal working practices.'*

Conversely, Smith et al (2009) suggest that analysts use Microsoft Word to create an electronic emergent theme document and put all the relevant quotations and extracts in the document (Microsoft 2016). Arguable, this is essentially the facility offered by qualitative

data analysis computer software, with the added benefit of the electronic file being linked up to the original transcripts.

As noted in Chapter One, as a trained analyst, the researcher anticipated the benefits of analytical software as a means of electronically indexing, storing and retrieving data, all within one computer project file (Bazeley and Jackson 2013). Moreover, as she began using the software, she found that the software enhanced her ability to apply IPA to the analysis. It enhanced the analyst's ability to be flexible as she coded the data, it allowed her to be iterative and more creative with the data, rather than grappling to revise the rainbow colour codes on hard copies of transcript data. Using the software, the analyst was able to re-visit the themes; re-code data; merge codes; run queries and explore the data against the emerging interpretations (Richards 2002). Furthermore, the analyst used the coding ('Nodes') functionality of NVivo, and in keeping with the hermeneutic circle of IPA, she had the freedom of the blank word processing space ('Memos') to write the line-by-line interpretative commentary. Gray (2014) and Silverman (2013) argue that this qualitative data analytical software can speed up the handling of large volumes of data. In the experience of the analyst, caution is offered, as that the sheer effort in setting up the qualitative dataset, before embarking on the actual analysis of the data is, arguably, equally time consuming as conducting managing and analysing the data by hand. The strength of this qualitative dataset is that once it is set up after months of coding data, it is a valuable tool for organising the interpretations of the analyst and the themes.

## **4.10 Ethics**

An application for ethical approval for this study was made to Edinburgh Napier Research Ethics and Governance Committee (Project Reference: FHLSS/1654). The gateway organisations which assisted with the recruitment of participants, namely the Steps DDH Charity and Knowsley Local Authority Children Centres, provided letters of authorisation from their Governance Boards to the Edinburgh Napier Research Ethics and Governance Committee to support the ethics application.

### **4.10.1 Informed consent**

An important aspect of the study, in particular, my ethical duty towards the participants was their full informed consent to take part in the research (Creswell 2009; Ryen 2011). When a potential participant initially contacted me by email, I would reply with an email which

featured the research information sheet. Furthermore, at the beginning and the end of the study, I verbally reminded participants that they could withdraw from the study at any time, without providing a reason. Also, the participants written consent forms clearly stated this point. At the beginning of each interview, an information sheet was given to the participant. The participant was given time and space to read the information sheet. All of the participants who were invited to a research interview gave their informed consent. They were also asked to sign two consent forms and I also signed those consent forms. I gave one copy to the participants to take away with them and I kept one copy for my research records. When the interview came to an end, I gave a verbal debriefing to the participant about the study and I explained their important contribution to the study. I also issued the participant with a written debriefing sheet to take with them. After the interview had taken place, if the participant had any questions or queries, the participant could refer to the debriefing sheet which featured my contact details and also the contact details of my Director of Studies.

#### **4.10.2 Risk to participants and interviewer**

Since my study aimed to explore the experiences of parents of an infant with DDH, I anticipated that during the interviews, there was a risk that participants would get upset and feel uncomfortable while talking about their child. This situation did arise on approximately three occasions. I planned for this occurrence in my University ethics application documents. Therefore, when these situations unfolded, I would draw on my interpersonal skills: by gently passing the participant a tissue; by tactfully expressing my sympathy; by taking a short break from the interview. After a brief break from the interview, I discussed with participant the option of moving on to another question or bring the interview to a close. However, all of those participants in this situation, asked me to continue with the interview. At the end of the interview, during my verbal debriefing, I would refer all of the participants to the debriefing form and sign-posted them to the Steps charity for professional advice and support. As a researcher, the wellbeing of the participants is paramount.

As well as considering any risks to the participants, a great deal of consideration and planning was given to my own safety as I travelled across the UK to conduct participant interviews. I developed a 'Duty of Care' plan which was informed by Kenyon and Hawker's (1999) best practice guidelines for researcher safety and the 'Guidance to health and safety in fieldwork' (Universities Safety and Health Association 2011). My duty of care plan detailed my personal

safety measures; the stages during my fieldwork when I would contact my family member; an emergency contact procedure for my family member and myself. The duty of care plan was disseminated to my supervisor and close family member. During my fieldwork, I did not encounter any risks to my personal safety.

#### **4.10.3 Confidentiality and data handling**

Another important aspect of research is the data collection, retention and deletion of participant data. In keeping with the Edinburgh Napier University's Data Protection Code of Practice (2017), all paper copies of data are being held in a locked cupboard, in a locked room within Edinburgh Napier University. All electronic files of data are password protected and held on a computer which is also password protected. I am the only person who has direct access to this data. However, on request, the researcher's supervisory team and examiners can also have access to this data. All the data will be destroyed five years after the date of collection. This date will be 31<sup>st</sup> October 2021.

#### **4.10.4 My role as the researcher during the interviews**

From a reflexivity perspective, I was always mindful that the inherent nature of a participant interview entails an asymmetry power relationship between the interviewer and participant (Brinkmann and Kvale 2015). From my first direct email contact with participants, I always strove to be transparent about who I was and my background interest in my research subject. As well as introducing myself as an Edinburgh Napier University research student, I was always open with participants about my own personal interest in the issue as the mother of two children who were diagnosed and treated for DDH. I was keen to build a rapport with my participants as I was mindful that, for two reasons: I wanted to put them at ease in the interview setting and I wanted the interview to progress as a natural in-depth conversation.

Interviews can be synonymous with a range of different types of interviews, such as employment interviews or law enforcement interviews. I made efforts to differentiate the participant interviews from other types of interviews. For example, I shared the interview questions in advance of the interview date. Moreover, I provided drinks at the interview which I used as a prop to make the interview more informal and encourage the interview to

flow like a friendly conversation between two people. On the other hand, as Brinkmann and Kvale (2015: 6) argue:

*'The research interview is not a conversation between two equal partners, because the researcher defines and controls the situation.'*

While acknowledging Brinkmann and Kvale's (2015) point about the nature of interviewer/researcher role, I was conscious that I was representing my university and the field of academic health researchers. I wanted to engage with participants and make the interviews a warm experience.

#### **4.11 Credibility**

The relevance of applying quantitative concepts of rigour, such as reliability and validity, to qualitative research has been debated for decades (Guba 1981; Guba and Lincoln 1989; Long and Johnson 2000; Seale and Silverman 1997). However, researchers conducting qualitative research tend to focus on applying the concepts of 'credibility' and 'trustworthiness' to assess the rigour of their studies (Elliot, Fischer and Rennie 1999). It is fair to state that the use of critical appraisal tools by researchers which assist with the evaluation of quantitative, qualitative and mixed methods studies is now embedded into our professional practice. However, there are threats to rigour in qualitative research. For example, a lack of understanding about the qualitative paradigm, methodologies and methods by the researcher, can result in a poorly designed study and weak data analysis (Barbour 2001). There are several useful critical appraisal tools for qualitative research, otherwise called 'checklists', available to researchers and reviewers. These qualitative critical appraisal tools include the Critical Appraisal Skills Programme (CASP) Appraisal Checklist and the Joanna Briggs Institute's (JBI) Checklist for Qualitative Research (CASP 2018; JBI 2017). Elliot, Fischer and Rennie (1999) offer guidelines for the publication of qualitative research studies featuring seven specific guidelines which will be used to critical evaluate the research in this thesis (Table 5). Although these guidelines were highly regarded by Reicher (2000), challenges and critiques the notion that these guidelines can be used across the range of qualitative methodologies. Reicher (2000) expresses caution against using these guidelines, uniformly, across methodologies which hold differing

epistemological positions; philosophical backgrounds; theoretical assumptions; research questions and methods of enquiry. However, in counter-defence of Elliot, Fischer and Rennie (2000: 224) these are, '*evolving guidelines*' and they should not be applied as '*a rigid checklist*' to qualitative research. Here I will critical evaluate the credibility and trustworthiness of my research against these seven guidelines.

Table 5: Credibility guidelines for reviewing qualitative research (Elliot, Fischer and Rennie; 1999)

1.	Owning one's perspective
2.	Situating the sample
3.	Grounding in examples
4.	Credibility checks
5.	Coherence
6.	General versus specific tasks
7.	Resonating with readers

#### 4.11.1 Owning one's perspective

In this thesis, I have been transparent and disclosed my personal perspective and experiences of parenting a child with DDH. In Chapter One, in the section titled: 'Position of the researcher', I declared my personal experiences and my previous work experiences. Furthermore, in this chapter, I noted that I briefly shared with participants that I was also a parent of two children who had been diagnosed and treated for DDH. I disclosed this information with participants on two occasions: when I liaised with participants to make interview arrangements and when I met with participants in the interview setting. Moreover, later in this thesis, in Chapter Eight, I reflect in detail about my own perspective as my study came to a close. To show how I have pro-actively owned my personal perspective during this research, I have kept an electronic reflexive journal; made interpretive notes and comments on interview transcriptions; discussed my own assumptions in supervisory meetings. All of these reflexive devices and opportunities have allowed me to explore my own values, assumptions and perceptions, which have helped to enhance my understanding of the phenomenon and may have influenced my interpretations of the interview data.

#### **4.11.2 Situating the sample**

In this chapter, I noted the descriptive characteristics of the participants, in terms of their gender and ethnicity to situate the sample. I did not collate data about the participants which were not relevant to the aim and objectives of this research, such as socio-economic status. The characteristic details of the participants were provided to give context to the findings of this study.

#### **4.11.3 Grounding in examples**

This thesis shows two sets of evidence of 'grounding in examples' of data. This chapter provides the precise details of the analytical process of IPA. Secondly, I have illustrated my analytical interpretations of the data and emerging themes by providing an annotated extract from a participant interview. This extract can be referred to in Appendix 11 of this thesis. By showing these examples of data, it will facilitate the transparency of the interpretations of the data. It also allows readers to critically evaluate these interpretations of the data.

#### **4.11.4 Credibility checks**

Elliot, Fischer and Rennie (1999) offer several methods to check the credibility of themes. Early in this chapter, I highlighted that I conducted a pilot study and this involved the piloting of the interview questions and the IPA analytical technique. An experienced IPA analyst within the University, independently analysed two sets of pilot transcription data; one transcript was from a mother and the other one was from a father. We found that we both had the same emerging themes from the data. Also, the recurrent, intermediate and superordinate themes were discussed in supervisory meetings. This study provided two qualitative perspectives; the perspectives of mothers and fathers. Although IPA methodology focuses on the unique, idiographic perspectives and experiences of participants, in Chapter Seven, I have compared the findings of mothers and fathers, this can provide an additional credibility check (Elliot, Fischer and Rennie 1999; Smith et al 2009). Another example of my efforts to invite scrutiny of this study from other researchers and the wider public, was by registering this study on 'Research Registry' (2018) (Research Registry Unique Identifying Number: researchregistry3623). This is an online, open source which can encourage a critical examination, as well as peer and public engagement, in your research (Research Registry 2018). It is also helpful to register studies on this platform to avoid duplication of research and waste research funding (Research Registry 2018).

#### **4.11.5 Coherence**

Later in this thesis, in the Findings chapters (Chapters Five, Six and Seven), I have presented a coherent summary of the analysis using theme diagrams accompanied by a written narrative. The theme diagrams use boxes and arrows to show the integration of recurrent themes into the intermediate themes, and intermediate themes evolving into superordinate themes. These theme diagrams clearly show the relationships between the themes. Furthermore, the theme diagrams provide a logical structure to the written narrative about parents' experiences of caring for their infant with DDH.

#### **4.11.6 General versus specific tasks**

The aim of this study was to explore the specific experiences of parents caring for an infant with DDH. The philosophical context of IPA methodology requires the researcher to capture the unique, detailed nuances of the lived experience of a phenomenon by a small group of participants (Smith, Flower and Larkin 2009). The specific geographical context of this study focused on Scotland and England only. Moreover, additional descriptive data about the socio-economic status of the participants was not collated as this type of data was not pertinent to the aim and objectives of this study. Therefore, the findings should only be referred in the specific context of understanding the phenomenological experience of parents caring for an infant with a health condition in Scotland and England.

#### **4.11.7 Resonating with readers**

During the course of this research, I have strived to accurately convey the narrative experience of mothers and fathers caring for their infant with DDH, while in keeping with the philosophical and interpretative framework of IPA methodology. However, I am confident that this research will increase the reader's understanding and appreciation of parenting an infant undergoing treatment for DDH. In the Findings chapters, I have used detailed, emotive quotations from parents to reveal their experience. I anticipate that the words of the parents will evoke a deeper empathetic understanding of their experience amongst the readers of this research.

#### **4.12 Chapter summary**

This chapter presented the rationale in the selection of the specific features of the research design, methods and data analysis process in this study. There was a discussion about the

recruitment of the participants and the pivotal role of the gateway organisations in this study. This chapter also considered the delivery of the pilot study; the important contribution it made to the final research design and the analysis of the data for study. The detailed steps of IPA data analysis were presented and there was a critical evaluation of the credibility and trustworthiness of this study. The conduct of the researcher and the delivery of this study, in terms of ethics and informed consent from the participants was discussed. The next three chapters present the research findings of parents caring for the infant with DDH: mothers; fathers; comparing the key findings of mothers and fathers lived experience. The next chapter, Chapter Five, focuses on the lived experience of mothers with infants diagnosed with DDH.

## Chapter Five: Key findings from the interviews with mothers of infants with DDH

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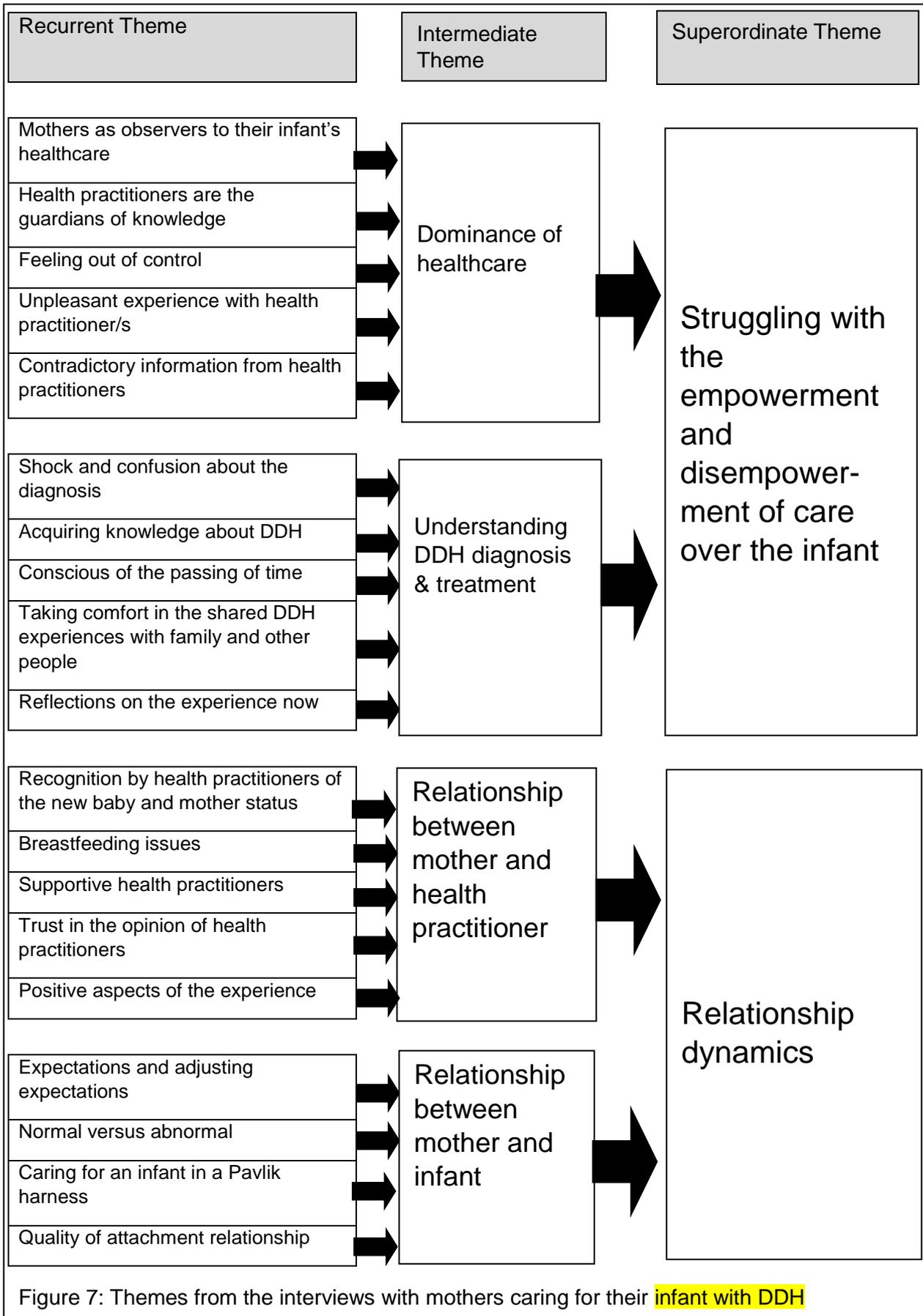
### 5.1 Chapter overview

This chapter presents the findings of the research interviews with mothers of infants that have received a DDH diagnosis and undergone treatment in a Pavlik harness. It will also address the research question about understanding the information needs of mothers of infants with DDH. As noted in Chapter Three, nine mothers participated in the interviews. Due to the idiographic nature of the interviews, the participants were allocated pseudonyms to protect their identity. The analysis of the transcript data was conducted using the methodological framework of IPA (Smith, Flowers and Larkin 2009). In accordance with the IPA theoretical foundations, the interpretative element of this phenomenological study was carried out by the researcher.

Recurrent themes were identified from issues and concepts that emerged in five or more of the participant interviews (Smith, Flowers and Larkin 2009). From 19 recurrent themes, four intermediate themes were developed and contributed to the emergence of two superordinate themes (see Figure 7). The intermediate themes, 'Dominance of healthcare' and 'Understanding the DDH diagnosis and treatment' fed into the superordinate theme, **'Struggling with the empowerment and disempowerment of care over the infant'**. Furthermore, the intermediate themes, 'Relationship between mother and health practitioner' and 'Relationship between mother and infant' contributed to the superordinate theme, **'Relationship dynamics'**. The two superordinate themes which emerged from the interviews with mothers encapsulated their lived experience for caring for their baby with DDH.

In this chapter, each recurrent theme is interpreted using verbatim quotes from the participants. Then there is an explanation of how these feed into intermediate and superordinate themes, as well as a summary of each intermediate and superordinate theme.

## 5.2 Themes



### 5.2.1 Recurrent theme: Mothers as bystanders to their infant's healthcare

The strongest theme to emerge from the interviews with mothers of infants with DDH was about their shared experience of feeling like 'bystanders' as they observed their child's healthcare. These mothers were present in the hospital room with their infant; they watched the health practitioners perform clinical investigations of their infant's hips, but they were not involved in any of the discussions with the health practitioner/s. This theme featured in all nine of the interviews.

It was striking that many mothers highlighted their perception that the ultrasonographic scan of their baby's hips was a routine part of the newborn infant care pathway. Mothers appeared to be accustomed to being part of a system of health screenings and tests throughout the care pathway of pregnancy, birth and postpartum. Their familiarity with health testing seems to continue with their own infants becoming the focus of medical scrutiny with neonatal infant screenings. However, these mothers seemed to have become almost desensitised to the system of clinical screenings without understanding their implications:

*"We went in and we literally thought, 'Oh yes, we're going to be in, she was going to have her hips checked, and then we were going to be off out'."*

(Louise)

During the diagnosis and the application of the Pavlik harness stages of the DDH care pathway, the majority of mothers in the study expressed a strong sense of being 'outsiders' to the unfolding healthcare situation. The health practitioners, as 'insiders', rallied around the infant and dominated the healthcare aspect of the situation:

Jennifer: *"I was just thinking I would be in and out. I think kind of within about three minutes of being in there, I could tell that something wasn't right from the fact that they were kind of...everybody was very quiet. That's kind of how it felt. And then they didn't really give much information, really, other than to say that they needed him [her baby son] to see a consultant today. The sonographer was there. There was a student who was there. I think there was another member of staff as well and they were all kind of conferring and saying, 'Oh you know, that's who we need to refer to', but obviously I wasn't aware of who this person was, why they were referring me, what the problem was? Then when I kind of said 'What's the issue?' They said: 'He's definitely got Developmental Hip Dysplasia.'"*

Interviewer: "So you weren't in the loop with that conversation?"

Jennifer: "No. I kind of felt a little bit on the outskirts of it."

Here in Jennifer's account, she revealed her thoughts of being overwhelmed by the amount of healthcare staff in the room. There is an impression that she felt intimidated by the way the healthcare staff conducted themselves, *"I could tell that something wasn't right...they were kind of...everybody was very quiet"*. The healthcare staff understood the situation and use their own exclusive insider language, nuances and cues to indicate a problem with the infant, but Jennifer did not understand these terms and she felt excluded by them.

Similarly, Nicola, sensed this outsider status with a physiotherapist who led the care on her baby as she was fitted into a harness:

*"The physiotherapist clicked the right one and she said 'No, that one's totally dislocated. It's not in joint at all.' She said 'Yeah, we'll just get you a harness for you then'. Just like that! 'We'll just get a harness for you.' The physio [physiotherapist] was absolutely fantastic, but it was still very much, 'Here's your harness, this is what you do, here's your leaflet, you'll come back in X weeks, blah, blah, off you go.' That was it. But they were nice. It was still very, 'Here you go, go and get on with it.'"*

Nicola's account revealed her perception that the decisions, the actions and therefore, the control were all in the hands of the health professionals. These mothers' feelings of being like a bystander to their infant's healthcare partially emerged from their feeling as outsiders. There is the perception that as outsiders, these mothers felt that they were looking in through a metaphorical window on the care of her baby, as opposed to the health practitioner's insider status as they led the care on their infant as they are fitted into a harness.

These mothers were also made to feel like bystanders due to their physical isolation in an unfamiliar environment. While in the DDH hospital clinic, many mothers repeatedly expressed profound feelings of isolation in this setting. In the following account, Jennifer, vividly recalled the day of her son's diagnosis and his fitting into a harness:

*"They left me in a room on my own with him for a long time just wearing a Pavlik harness because they were seeing so many cases. So I was kind of left in there. They'd put it on for me to measure it up and I didn't know what this device was on my baby other than the fact that he screamed the place down. I wouldn't have known how to have taken it off. I remember, he literally had had it on for about half an hour and he just pooped everywhere. It went everywhere! I just remember thinking what on earth do I do? I've got nobody in here; I don't know how to get this off him; he's absolutely covered in poo. They've told me I'm only allowed one harness and one harness only, and don't wash it, and don't do this... and it was, what am I going to*

*do? I'm the worst mother ever. So I just remember that being incredibly tough; a really, really hard day."*

Jennifer's very poignant account revealed her feelings of abandonment by the health practitioners. Another interpretation of Jennifer's recollections of this episode may be her frustration about her lack of knowledge and feelings of disempowerment. Jennifer was alone, and she was without the facilities to clean and care for her young baby. As a new mother she felt vulnerable. Moreover, as a mother who has just received a diagnosis for a disability to her son's hips, she felt helpless. She wanted to comply with the instructions of the health practitioners and care for her son as he underwent treatment in a harness, but already the harness is damaged and soiled. She lamented, '*They've told me I'm only allowed one harness and one harness only...what am I going to do?*' Through no fault of her own, this hospital situation amplified her self-perceived sense of incompetence. '*What am I going to do? I'm the worse mother ever*'.

The clinical efficiency of health practitioners in the clinic to conduct the hip scan, diagnose DDH and apply the harness to infants was perceived by these mothers as feeling like they were on a metaphorical conveyer belt of carers and patients within the clinic.

*"I didn't really think anything of it. Thinking, 'Oh well, she'll go for an ultrasound and that will be fine'. So we went when she was four weeks old. It hadn't really occurred to me that there might be something here. Basically, she did have the hip dysplasia and he [health practitioner] explained a little bit. He said the treatment is a Pavlik harness which the physiotherapist will put on for you today. Then it has to stay on for, it could be eight weeks, it could be 12 weeks, but I think about 12 weeks because I wouldn't want you to get your hopes up. That was it really. I just then went along to the physio [physiotherapist] room and then she put the harness on her. I was just devastated. I managed to hold it together in the room, but then I went out with my mum and I was just in floods of tears."*

(Sarah)

*"I literally went from ultrasound to waiting to see the consultant, seeing the consultant, having a Pavlik harness fitted, having to have him in the Pavlik harness for an hour whilst they worked out if it was fine, then making plans to see him again. That was a very, very, very distressing kind of time. He was nine weeks old."*  
(Jennifer)

(Jennifer)

From Sarah and Jennifer's extracts, they clearly portrayed their sense of the rapid and functional journey from screening to diagnosis to treatment within a single hospital visit. They went from health practitioner to health practitioner; from one hospital room door to another; while also juggling their new responsibilities with an infant and recovering from childbirth. They were experiencing a major life event. New mothers as carers are busy, sleep deprived and vulnerable.

### **5.2.2 Recurrent theme: Health practitioners do not always share their knowledge**

This recurrent theme, 'Health practitioners do not always share their knowledge' interlinks closely with the previous recurrent theme, 'Mothers as bystanders to their infant's healthcare'. One mother, Jennifer, remembered being told by health practitioners that her baby needed an immediate referral to see a consultant on the same day, but she had not been given any other information by the health practitioners:

*“What is so bad that he has to see a consultant today? What are they going to kind of do? I hadn't done any research into it beforehand; I hadn't thought about what it would be. So then when I was told, I just remember thinking that to me, hip dysplasia is what happens to old dogs. They are crippled and can't walk. I just burst into tears. Looking back it seems almost kind of silly to have thought that, but I had no other knowledge about it.”*

Due to Jennifer's lack of knowledge about the DDH diagnosis for infants, she was very distressed, and she immediately worried about the prognosis for her baby. The health practitioners were knowledgeable about infant DDH, but at this point, they did not share their knowledge. Jennifer was deeply upset as she is consumed by her own thoughts and applies her own knowledge to understand the unfolding situation. On the other hand, it seemed that at this stage, Jennifer, did not initiate any questions or queries with the health practitioners, so it is possible that the health practitioners did not realise the full extent of her psychological state.

Some mothers reported being filled with questions and queries for the clinicians, but they refrained from asking these questions. Interestingly, those mothers who were also employed as health professionals, were more anxious about asking questions to health practitioners. Lisa, who also worked as nurse, felt that she could not query the decision-making of the clinicians:

*“I think for them, they were, sort of like, ‘Well there’s no harm to have her in the harness.’ Whereas I think for me, ‘Well of course I don’t want to have her in it, if she doesn’t have to be’...but I didn’t say. I didn’t say any of that to them because you do, sort of, feel a bit like...I mean, they do know best. That’s their job. I don’t know anything about baby...taking care of babies with hip problems, so I, sort of, wanted to trust them.”*

Lisa’s extract gives a sense of her balancing emotions between her dual roles as a mother and as a health professional. She grapples with understanding her perspective as a mother to a young infant, while also trying to empathise with the opinion of the health professionals, as she is one herself. By the end of this encounter, Lisa recalls conceding to the wisdom and dominance of the health practitioners when she expressed: *“They do know best”*.

Another mother, Emma, was a senior health practitioner. In her first encounter with a sonographer, she chose not to ask any questions because she did not want to irritate the sonographer:

*“You know, she’s looking at the screen the whole time. I know they have to concentrate on that, so I was quite aware not to annoy her, but I also knew that she wasn’t...that she was the sonographer. She’s not an orthopaedic specialist and most of my questions were orthopaedic questions that, although I’m sure she’s very knowledgeable on, she’s probably isn’t in a position to answer them so I, kind of, thought there wasn’t much point in asking her.”*

The next time Emma takes her son for a hip scan, she feels more confident to ask this sonographer questions:

*“Instantly, I just said ‘I don’t know why we are here? I got this letter about needing a review of the images’. I was probably quite questioning the whole time. So I was saying ‘Why? Why?’ I was asking quite a few questions and probably making her think a bit more. But then I obviously, shut up. I was mentioning my son to her at the time in a sort of chatty way and saying ‘Oh, I wonder what his hips would look like on the ultrasound at three months old?’ Not in an accusatory way, but in a chatty way, but trying to maybe show that I wasn’t a 100 percent confident in the diagnosis. Then the nurse, sort of ushered me out of the room and was like ‘Well, that’s us all done here.’ ”*

Mothers, like Emma, explained that they wanted to trust the medical opinion of health practitioners. They wanted health practitioners to deliver the best healthcare and make solid decisions. Mothers do not wish to ask questions about the judgements of health care practitioners as they fear that it will be viewed as a form of mild aggression or challenge their status as a medical authority. In Emma’s words, she feared that it would *‘annoy’* them.

Later, in the DDH care pathway, Emma had a positive and reassuring conversation with the baby's consultant:

*“He’s a very well renowned paediatric orthopaedic surgeon and he’s sort of top of the top, so I was very trusting and confident of his opinion. The fact he’s very nice to chat to and stuff. He was going through all sorts of statistics and facts and figures which I like.”*

Whereas Emma felt uncertainty about the decisions of the other junior health professionals, she felt reassured by the reputation and persona of the consultant. She holds the knowledge of this consultant in higher value compared with the other health practitioners she has met along the care pathway. Idiographically, there is a sense that Emma makes a judgement of the health practitioner opinion in terms of their position in the medical hierarchy. It is likely that this judgement is because Emma is a part of this hierarchy which she respects and holds allegiance. Following the conversation Emma has with the consultant, she accepts and trusts his opinion and the health practitioners.

### **5.2.3 Recurrent theme: Feeling out of control**

Another very strong theme amongst the mothers in this study was their profound sense of being out of control of the situation. The control of the situation appeared to be held by the health practitioners who delivered the diagnosis and gave the treatment of the harness. This theme was highlighted by eight mothers and these feelings tended to peak around the point of diagnosis, application of the harness on the baby and in the first day or two of treatment at home. Kirsty recalled her evocative reaction to her daughter's diagnosis:

*“There’s him [the consultant] and there’s about three or four different medical students all in the room and I was like ‘Ok’. Then he starts asking a lot of questions, like, ‘Do you have a family history?’ ‘No’. ‘Was baby breach?’ ‘No’. You start to...I felt total thrown, totally thrown and then there like we’re putting her in this [a harness]. I remember thinking, ‘This is our baby’. She was getting put in this harness and it was going to be 12 weeks at least because it’s severe and I’m thinking ‘Oh my God!’ I was totally thrown, just totally thrown by it, not expecting it.”*

In this extract, there is a sense of Kirsty trying to understand this moment, even now as she reflected on it in the interview. Here Kirsty repeated the phrase “*totally thrown*” to convey with emphasise, her feelings of shock and out of control. There is a notion that she felt propelled, with force through the air with no idea where she would land. At this time, you also sense from Kirsty that the clinical focus of the health practitioners on the infant has superseded the mother's role as the primary caregiver.

Some mothers found themselves thinking about the worse outcome. For Jennifer, who had a history of mental health issues and who was very vulnerable following the birth of her baby, she felt unable to control the situation:

*“I just remember a blazing feeling of panic thinking that he was never going to walk; it was all my fault.”*

Jennifer’s profound feelings of self-blame and guilt could have placed both mother and baby at risk from harm. Her use of the term ‘*blazing*’ strongly conveys her rampant negative emotions.

Conversely, some mothers attempted to exert their own control from the dominance of the clinical health care of their infant, by shifting the focus the importance on the maternal care of their baby. Several mothers admitted to giving some consideration to not complying with the harness treatment, even though, ultimately, they did conform with the treatment.

Initially, Lisa seemed driven by her deep personal thoughts of injustice:

*“I felt the unfairness of it. Even though I knew we were going to, obviously, do the recommended thing and put it [the harness] on her, I did have those moments of like ‘Well, we could just say that were willing to take the chance’.”*

(Lisa)

While DDH treatment was taking place in the home, many mothers found emotional strength and resilience from the situation:

*“I think it has sort of made me and my partner [infant’s father] stronger people, you know, because if you battle something, you get a bit stronger over it.”*

(Louise)

*“I got into a terrible state and the injustice of it all and how she [her infant] was going to be different. It wasn’t what I’d planned or expected, but I very quickly came to my senses and knew what had to be done to help her out.”*

(Michelle)

Louise’s and Michelle’s extracts revealed that, initially, they felt very negative emotions and it was impacting on their psychological wellbeing. Louise refers to having faced a “*battle*” and consequently, becoming “*stronger*”. Whereas for Michelle, she was in a “*terrible state*” but “*had to help her [daughter] out.*” Mothers felt powerless, in the face of the dominant opinion of the health practitioners. However, in the home environment, mothers developed self-efficacy and resilience as they adapted to the new care needs of their infant with DDH.

Consequently, mothers felt empowered and this enabled them to regain control of their family life with a new baby.

#### **5.2.4 Recurrent theme: Unpleasant experience with health practitioners**

During the DDH pathway, some mothers remembered having unpleasant episodes with health practitioners. There were two striking elements to these unpleasant encounters with health practitioners. Firstly, mothers felt that health practitioners put the importance of the DDH diagnosis and treatment as paramount to the caring needs of a young infant and the feelings of the mother. This element of this recurrent theme interlinks with the earlier recurrent theme regarding 'Mothers as bystanders to their infant's healthcare'. Health practitioners were very effective and efficient with their attention on the clinical needs of the infant. However, some mothers felt that this might be at the detriment of overlooking any interpersonal engagement with the mother as the caregiver. This is shown in Sarah's encounter:

*"The ultrasound man doing it was very matter of fact and I felt like he didn't really explain it. But I wasn't even as if 'Oh this is your brand new baby. Today, this is going to happen...' Then the Physio [Physiotherapist], when I met her I thought 'God, she's awful' Then by the second appointment, I was actually close to getting quite angry with her because I felt like she was being so unsympathetic and just not friendly about it. She went out of the room at one point to get something and I said to my mum, 'If she doesn't start being nice I'm going to...'. Then when she came back, my mum was like, 'I think Sarah's finding this all a bit difficult and so...we just looking for some reassurance'. That was definitely the right thing to say."*

Secondly, most of the mothers found that they were educating community health practitioners about DDH. As a result, the community health practitioners could offer little support to the mothers as they cared for their infant:

*"It sounds bad. I know the health visitors and it was a bit of a...not a novelty...it wasn't a common baby thing they were seeing all the time. There was always three or four them, all speaking to me about what was happening and when it was happening and what the clinic were saying to me? They had no notes. I don't think they were used to the Pavlik harness."*

(Kirsty)

*"My health visitor and midwives, they didn't have a clue. It's not their fault. They didn't have...I don't think they had seen many babies with it, so there wasn't that kind of support. They kind of got their knowledge from me, really."*

(Jennifer)

Kirsty and Jennifer's extracts show that mothers expected community health practitioners to lead and support them with their infants with DDH. However, some mothers found they were taking a dominant role in furthering the community health practitioners' knowledge about DDH. Rather than this being an empowering experience for mothers, they felt despondent. This recurrent theme reveals that for those mothers who had unpleasant experiences with health practitioners, these experiences were characterised by an overwhelming sense of dejection and low expectations of health practitioners.

Although unpleasant experiences with health practitioners was a recurrent theme; later in this Results Chapter, several mothers in this study reflected on their positive encounters with 'Supportive health practitioners'.

### **5.2.5 Recurrent theme: Contradictory information from health practitioners**

This recurrent theme about the contradictory information provided by health practitioners interlinks with the previous recurrent theme, 'Unpleasant experiences with health practitioners'. Five mothers reported that when they were given uncertain and ambiguous DDH care guidance by health practitioners, it accentuated their feelings of despair and confusion as they simultaneously balanced the care of a young infant together with the care of an infant undergoing treatment for DDH. This balance act of caring for a baby in this situation is revealed in Lisa's account:

*"The worst thing that happened is we had to have it [harness] off for two days in the middle of treatment because she got really bad skin...like a bunch of broken skin on her feet. That was probably the worse bit of the whole thing because we'd just got used to it. She'd maybe had it on for three or four weeks. The Physio [Physiotherapist] said, 'You know, taking it off might put it the treatment back by another few weeks.' I was like, 'She might have to have it on for another few weeks! I can't believe that this is going to be what happens!' Then I think that I felt bad because her skin was all broken down because you're trying your best, you know, to clean and dry her and you can hardly even get into those creases. I was like washing in there and bits of skins coming out of it and sort of, smelling. I was like saying 'I don't think it's very good what's going on under there'. Then the Physio just said 'Well, we can put the harness back on, but it's not like...we are probably just better off to let the skin heal."*

In Lisa's account, she recalled trying to care for her baby in the best way. The health practitioner who is a physiotherapist, presented her with a dichotomy. Lisa wanted to

adhere to the clinical treatment instructions for her daughter to constantly wear the hip harness, but her baby also needed the best care to allow her smelly, broken skin to heal. There is a sense of the pulling of maternal responsibilities. Lisa felt confused by the contradictory advice by the physiotherapist, as she expressed that this was “*the worse bit of the whole thing*”. She conveyed a sense of her struggle to make the best decisions for her baby, but either decision has consequences and repercussions. Lisa *‘felt bad’*. She reflected on her feelings of self-blame and she felt sadness. However, the final decision was not the mother’s choice; the judgement was made by the physiotherapist.

Emma expressed despair and confusion due to her perception that she had been given false reassurances from a health practitioner about her young daughter’s hips, and then a few weeks later, she was sent an ambiguous hospital letter:

*“We went for the six-week ultrasound which was literally you just meet the sonographer. So the sonographer did the scan and just said, ‘That’s fine’. So it was literally a five minute scan and I was like ‘Oh, is that it then?’ She said ‘Yes, both hips are fine.’ Then I got a letter, a few weeks later, just saying, ‘On review of the images, we’d like you to bring her [the infant] back in for another scan when she’s three months old’. It was a very short letter. That letter coming through was a little bit of a kick in the gut because it didn’t explain why. I had to wait a good month between that letter coming in and having to go for another ultrasound. I think that sentence went over in my head a lot, ‘In review of the images’ I was like, what does that mean? I think the first thing I said when I came in to the next scan appointment was ‘Oh, I’m not really sure why I’m here?’ It was a bit of stress hanging over me because I was like ‘Oh God, what are we going to have to go through?’ ”*

This situation, as it unfolded here for Emma and her baby has created a deeply unsettling time for her and a great deal of unnecessary rumination. Here we sense Emma grappling to draw her own conclusions from the comments of the sonographer, together with comments from the short, perplexing hospital letter. The perceived vagueness of this letter seems insensitive to the thoughts and feelings of the recipient, specifically a new mother and baby. Emma seems to be trying to make an informed judgement, so that she can psychologically prepare herself for the potential outcomes of her daughter’s next hip scan. When health practitioners communicate with mothers and give contradictory information and behave indecisively, they can create unnecessary stressful time for mothers as they care for young infants.

### 5.2.6 Summary of the intermediate theme: Dominance of healthcare

From these recurrent themes, common perceptions were conveyed by mothers as they followed the DDH care pathway with their infant. An intermediate theme emerged from the recurrent theme about the perception of the dominance of healthcare. The mothers were conscientious caregivers and advocates for their infant. They wanted an inclusive and empowering role in the healthcare of their baby. This inclusivity can be facilitated by the strong interpersonal skills of health practitioners, who should have a heightened sensitivity to this situation. Mothers as carers of a young infant should be acknowledged and supported by health practitioners to enable them to carry out their caring role. Furthermore, health practitioners need to have self-awareness that they have communicated with mothers in a clear manner, shared their knowledge and offer empathetic reassurance.

### 5.2.7 Recurrent theme: Shock and confusion about the diagnosis

At the point of their baby's DDH diagnosis by a health practitioner, the mothers in this study reported feeling shock, coupled with confusion. This was a very strong theme which was highlighted in all of the interviews. This moment also seemed to be a very overwhelming experience for the vast majority of the mothers:

*“The consultant went, ‘Right, she seems to have...’ and he went on and on and on, but I wasn’t listening to a word he was saying. All I was thinking was ‘Oh my God, there’s something wrong with her. He said something about a harness, and I thought he meant put her in, like, a baby carrier and carry her around now and again for a few hours. What he was saying just wasn’t really making any sense to me, but I was like ‘Ok, ok’.”*

(Louise)

*“Totally devastated. Totally devastated. Panicked as well, like, what do we do now? I remember him [consultant] saying to me ‘You know, you didn’t do anything wrong’. I was like, ‘Well, I didn’t think I’d done anything wrong, but it’s obviously just something that has happened, but I’m still totally thrown by it. I didn’t know this was coming.”*

(Kirsty)

Louise's account of feeling shocked when she was informed about her infant's diagnosis also illustrated that mothers' memories of this moment are associated with their lack of knowledge and understanding of DDH amongst infants. The knowledge of DDH and the treatment was held by the health practitioners. Moreover, it is interesting that the focus in Louise and Kirsty's extracts, as well as in the recollections of the other mothers, is the concept of there being something “*wrong*” with their infants. In Louise's account, she is

fixated on her thoughts that *'there's something wrong'* with her baby. The diagnosis is a huge surprise to her and she is caught up in her own feelings and ruminations. Whereas for Kirsty, she had a heightened emotional state. She felt uncontrollable anxiety and sensitivity. She made a passing thought that what is *"wrong"* in this situation, that she is to blame for the problem with her baby's hips.

It is unsurprising that the majority of mothers in this study experienced shock at their infant's diagnosis. However, it is important to highlight that mothers' feelings of shock were felt, simultaneously, with feelings of confusion about the nature of DDH, the prognosis and their own sense that there was something was *"wrong"* with their infant.

### **5.2.8 Recurrent theme: Acquiring knowledge about DDH**

This was another strong theme to emerge from the interviews with mothers caring for their infants with DDH was about acquiring knowledge about DDH. All of the mothers reported seeking information about DDH from the internet. However, the catalyst for mothers seeking information from websites was often due to the poor information provision by health practitioners about how to care for an infant with DDH.

Nicola: *"The nurse gave me a quick run-down of, 'You'll go to the consultant, she'll get put in a Pavlik harness, and then you'll come back a few weeks later and have it taken off.' That's what she said. So I walked out of there. I hadn't even taken in the words she said, so when I came out of there, I was thinking, 'I need to Google this', but I couldn't even remember what she'd said. So I was kind of trying to remember the word. I did find it, obviously."*

Interviewer: *"What word was that?"*

Nicola: *"Pavlik harness, because I'd never heard of it."*

Nicola's extract shows that she was trying to quickly understand the diagnosis and treatment of her baby's condition; a condition that she has never heard of before. She was also simultaneously trying to comprehend the caring needs of her baby with DDH and as a young infant. Nicola was overwhelmed, and to a certain extent, overpowered by the clinical situation. She was given no interpersonal support, she lacked knowledge and therefore, she attempted to empower herself by researching the internet for this information.

*"He [health practitioner] didn't tell me what it was called. I didn't know she had DDH, all I knew was that there was something wrong with the socket. He didn't explain anything like that, or whether he did, I don't know because I tuned him out. My partner was with me and he doesn't remember him really explaining either. So when*

*I got home I went on Google and I researched it all and then I found out it was DDH myself. Then I read all about it and then I got all upset again.”*

(Louise)

Louise, with similarities to Nicola’s earlier extract, and as other mothers have recalled in the interviews that there was a dearth in the information provision about DDH by health practitioners. Consequently, they sought the internet for explanations and guidance.

On the other hand, a note of caution needs to be exercised, as the analysis revealed that when mothers received the DDH diagnosis for their infant, they all had a desire to search the internet for information about DDH, the treatment and experiences of other parents:

*“I must say it’s been really useful for me being able to do a bit more research. I’ve looked at stats [statistics] and watched videos and things, so that was handy to know what to expect.”*

(Laura)

*“I searched extensively through the Steps [a support charity for families with children with lower limb conditions] website and I would say that they were the main source of any information. They referred us to all of their guides. They sent their pack with all the DVDs and leaflets, and information about the types of equipment that families found useful.”*

(Michelle)

Whereas all of the mothers found searching the internet for DDH information helpful, some mothers were cautious about the information which they uncovered from these searches:

*“I did find the information was kind of a bit haphazard.”*

(Jennifer)

*“Sometimes Googling doesn’t really help. You know, it just sort of gives you...but it was good.”*

(Lisa)

All of the mothers felt that searching for information using the internet was an empowering experience for them as carers. It gave them access to the ‘insider’ knowledge and understanding of DDH which until this point was held by the health practitioners. This knowledge and understanding gave mothers reassurance; it gave them the confidence to care for their infant from a practical perspective on a day to day basis; it allowed them to anticipate the likely future DDH outcome with their infant. The information that mothers acquired from their internet research was also empowering at the treatment monitoring appointments at the hospital. When speaking with the health practitioners, mothers

understood the clinical terminology and the importance of the hip measurement angles. It was a means of regaining control for the situation from the health practitioners. For example, when Nicola was informed that the Pavlik harness treatment on her baby had been unsuccessful, the information that she had acquired from the internet helped her to understand and contextualise the situation:

*“By this point, I’d done that much research myself that I knew pretty much what he was telling me anyway. I knew the second he said, ‘It’s not working’.”*

Mothers were empowered by the acquisition of DDH information from the internet. On the other hand, this was often due to the poor information provision by health practitioners. Others consumed the information with an element of apprehension about the reliability of the information.

### **5.2.9 Recurrent theme: Conscious of the passing of time**

Some mothers in this study remembered the stage when their infant was going through the DDH harness treatment as a point in time that they deliberately, consciously, wanted to pass away very quickly. Here Nicola recalled the time her daughter was in a harness:

*“So she had six weeks in it full time. She had no time out at all. She wasn’t allowed out off for a bath or anything. Then we went to a week where she was allowed to come five hours a day. Then she got two weeks when she just wore it at night. Then that is where we’ve just come to now and she got her first night out last night.”*

Five mothers revealed that they counted down the time until their infant no longer had to wear the harness and the DDH treatment stage had come to an end. Interpretatively, the imagery of mothers counting down the time until the treatment was over is synonymous with imagery associated with a prisoner counting down the time until their prison release date. In the experience of these mothers, their infant is like a prisoner confined and trapped in a harness as they count down the days until the harness release date. This image of their infant like a prisoner reflects the mothers’ deep feelings of psychological anguish. In the following account, Jennifer placed the harness treatment timescales of her young son into context with her own maternity leave from work:

*“When they originally told us he would be in it for at least twelve weeks, I just remember thinking that was my maternity leave over because they are so little, you can’t imagine them being five or six months old. So hearing somebody say ‘Oh, you know, he’ll be five months by the time he’s out of it just felt like I was going to have a baby that cried and was unhappy for the whole time that I was off and that time with him was going to be ruined, really. I remember counting down because I think I’d got*

*that in my head and it was like 'Just get to when he's twenty-one weeks or whatever and it will be off.'*”

Mothers were acutely aware of this special time with their new baby. There is an impression that when the mothers counted the harness treatment days away, it was a resilience tactic to gain control, understand and manage this situation. Moreover, when these mothers consciously counted the passage of the treatment time, it gave them hope for a positive end and outcome to their infant's DDH treatment.

#### **5.2.10 Recurrent theme: Taking comfort in the shared DDH experience with family and other people**

There were two elements to this recurrent theme about mothers taking comfort in the shared experience of having an infant with DDH. It was unremarkable that mothers sought comfort and support from their close family at this time. However, it is illuminating to understand the nature of the support that mothers needed from their family. Furthermore, it is interesting that mothers sought information, reassurance and took comfort from an online community of DDH parents.

Many mothers in the study highlighted that they received a great deal of support from family. At the point of diagnosis, several mothers explained that they were stoically composed in the presence of health practitioners. However, once these mothers were amongst their family members, they felt comfortable expressing their 'true face' feelings:

*“The Physio [Physiotherapist] put the harness on her and I was just devastated. I managed to hold it together in the room, but then when I went out with my mum, I was just in floods of tears. So from that day, I went back to my parents' house and I was just a complete wreck.”*

(Sarah)

From an idiographic perspective, Sarah's anguish about the harness is palpable. She did not feel that it was appropriate to reveal her true emotions in the presence of the health practitioner. The place where she took sanctuary and felt most at ease when revealing her negative emotions was amongst her own parents and their home. Similarly, Lisa, also felt an overwhelming need to exhibit her true face and her feelings as she confided in her closest family members, her own mother and sister:

*“I was so upset. I was beside myself. I talked to my sister and mum. I just needed a moan more than anything. I just wanted to talk about the same thing for hours on end. I quite wanted to have a moan and I think it was probably good for me to unleash some of that on my mum and sister as opposed to all on my partner.”*

(Lisa)

In the hospital, Lisa also put on a 'composed face' for the health practitioners, but her psychological feelings were very different: She sought emotional support and reassurance from her closest family. Interpretively, it appears that Lisa wanted to talk at length with her family because she did not get this interpersonal support from the health practitioners in the hospital. As she reflected on this experience, she called this a “moan”, but at this time in her life, the unfolding situation with her young infant is not trivial to this mother. She has received a huge, unexpected shock and she needs the unrestrained freedom to “unleash” her feelings of despair and injustice, as well as enabling her to come to terms with the DDH diagnosis and treatment. However, it seems that this counselling opportunity was lacking in the hospital setting.

Interestingly, several mothers also disclosed that they reached out to connect with other parents who have experienced DDH with infants, by using internet social media platforms such as Facebook and the Steps charity website chat forum. These people were outside of their personal circle of family and friends:

*“The main place I found comfort was to talk to the parents on the groups and stuff, on Facebook. I remember asking for help on my actual Facebook profile to ask if any mums had been through it. I was like ‘Someone please help me!’ I was like, ‘Someone tell me what this is?’ You know, on these pages, people are just so lovely, so nice, so helpful and supportive. You can ask any question and they’ll just be helpful, give advice and friendly. It doesn’t matter what you ask, there’s always someone whose been through it and has got advice. Even if they haven’t been through it, people comment and say, ‘Good luck and ‘I’m here for you’ and stuff.”*

(Louise)

*“There’s a forum network through Steps and I started talking to other people, talking them through the same experiences and emotions. I’ve done it a lot. Loads and loads of talking to other families and being able to provide...reassure people that we’d done it; we’ve survived it; we got over the emotional side and realised that actually, it was a doddle in the grand scheme of things.”*

(Michelle)

In the first instance, it seemed that mothers were motivated to use social media to gather more information, deepen their understanding of DDH and empower themselves. When mothers read forum conversations about DDH and caring for infants with the condition, they gained knowledge, advice and reassurance from people who had experiences with infants diagnosed with DDH. This is exemplified in Michelle's preceding quote. Furthermore, when mothers posted questions on social media and received constructive advice and reassurance from other parents of infants with DDH, it seemed relieved their sense of isolation as a parent with a baby with DDH. It also appeared to give these mothers a feeling of acceptance amongst this online community that having an infant with DDH was not unusual. This is illustrated in Louise's preceding extract. Amongst these online conversations between mothers and other parents of infants with DDH, there is a sense of kinship and identity based on the shared experiences of mothers engaging with other parents in a similar situation. Empowered with this greater knowledge and developing an identity with the DDH parent online community, it seems that these mothers instigated a power shift of infant care from the health practitioners back to themselves. As well as being familiar with DDH and the harness treatment, they had acquired their own 'insider' identity as a mother who also knows how to care for an infant's needs while also wearing a harness.

Towards the closure stages of DDH treatment for their babies, when mothers felt more self-efficacy as they managed their infant in a harness, there is sense of 'parental support reciprocity' to other parents who used social media to communicate with parents of infants with DDH. This parental support reciprocity is shown in Michelle's preceding comment about how she talked to other people through the Steps forum to offer hope and reassurance.

The mothers in this study needed the time and space with their closest family to have the freedom express their true face about their baby's DDH diagnosis. These family members will have experienced highs and lows of the mothers' lives and they have provided a safe and supportive environment around them. As a family, the mothers and their closest family are bound together. Conversely, mothers seemed to hold in higher value, the online interactions with parents who have experienced DDH with their infants. These interactions began as a means of finding out information about DDH and the practical care for a baby in a harness, but they also gave psychological support. These mothers expected family

support, but they did not expect the kinship offered by the faceless strangers engaging in conversations with them via an online community.

#### **5.2.11 Recurrent theme: Reflections on the experience now**

In this study, the mothers of infants with DDH acknowledged that they had completely shifted their perception of the DDH diagnosis and treatment. During the interviews, five mothers reflected on their changing perceptions of DDH harness treatment for infants, hence the recurrent theme 'Reflections on the experience now'. The context of 'now' was during the point of the participants interview. At the point of the infant's diagnosis and application of the harness, the mothers appeared to be very focused on the appearance and management of their infant in the harness:

*"All I was really thinking was about the harness. It wasn't really until...even now, I still think it's slowly sinking in now that thank goodness she had that. I think about the diagnosis more like 'Oh, she had that hip problem, but now it's ok.' "*

(Sarah)

However, during the participant interviews, as these mothers reflected on this time their perception of the diagnosis of DDH had shifted from shock, confusion and distress, and repulsion towards the harness, to feelings of relief that DDH could be resolved in a short amount of time:

*"I'm very positive about the fact that it is eminently a treatable condition, if it's picked up early, the better that you know. It's a shame that it had to happen, and it affected a short period of our lives."*

(Michelle)

With links to an earlier recurrent theme, 'shock and confusion about the diagnosis' in which most mothers revealed their feelings of despair at the DDH diagnosis stage for their infants, the research interviews appeared to have prompted deep reflection amongst mothers. They reflected on their memories, feelings and emotional reactions at the time, and they compared it with hindsight. With retrospect, mothers had a greater understanding of the nature of DDH, they had confidently managed an infant in a harness, together with all the expected needs of a new baby. They had now developed in confidence and felt "very positive" about the diagnosis.

### **5.2.12 Summary of the intermediate theme: Understanding DDH diagnosis and treatment**

The findings of this intermediate theme found that most mothers lacked an awareness of DDH and this caused overwhelming emotional turmoil. When mothers acquired knowledge about infant DDH and its treatment, they felt empowered and it gave them confidence in coping with the caring needs of a young infant, who was fitted into a harness. Mothers ability to manage the experience in relation to time allowed them to contextualise the situation and look forward to the future. When mothers were informed of their infant's DDH diagnosis and the treatment plan by health practitioners, they maintained a composed face. However, amongst close family, mothers revealed their true face, and this enabled them to cope with their feelings, thoughts and apply meaning to their situation. The shared experience with online communities of parents of infants with DDH empowered mothers and greatly enhanced their understanding of caring for an infant with DDH, both as a mother and as a carer. They felt that they had acquired an affinity with these online communities and develop a sense of identity and exclusive insider knowledge and understanding of mothering an infant diagnosed with DDH. This insider knowledge was greater than the knowledge and perceived power of the health practitioners. As a result, the mothers had become insiders with their own unique knowledge of this experience, as opposed to being merely bystanders to the experience. At the point of closure, mothers had developed a lived experience of DDH in infancy and surprisingly, in hindsight, they reflected in a positive manner. When mothers had a good understanding of DDH and its treatment, it improved their mental wellbeing, they developed resilience tactics and self-efficacy to shift the power balance from health practitioners and moved it in their favour as they advocated on behalf of their infant.

### **5.2.13 Summary of the superordinate theme: Struggling with the empowerment and disempowerment of care over the infant**

In the DDH care pathway, at the point in which the infant undergoes a hip screening, the power struggle of care over the infant is balanced in favour of the health practitioners as opposed to the mothers. The health practitioners had the knowledge and experience. However, health practitioners tended to overlook the new mother and baby status, and the needs of this caregiving relationship. They were also focused on the clinical aspects of the care of the infant. The mothers in this study were keen to advocate on behalf of their young infant, but they were excluded and felt isolated in the healthcare setting because of their

lack of understanding about DDH. Due to the poor information provision by the health practitioners, mothers sought knowledge and empowerment. When this has been achieved, the power struggle of care over the infant shifts in favour of the mother; she has the lived experience of both caring for a young infant, as well as caring for a young infant in a hip harness. Moreover, during this short time, the mothers became less vulnerable, and they developed resilience. By the end of the DDH treatment for the infant, the mothers seemed to be empowered by their own unique insider knowledge that could not be challenged or undermined by the health practitioners.

#### **5.2.14 Recurrent theme: Recognition by health practitioners of the special mother and baby status**

The lack of recognition by health practitioners of the special mother and baby status was a strong theme. This theme also interlinks with two other recurrent themes, 'Mothers as bystanders to the care of their infant and 'The challenges of breastfeeding an infant with DDH'. Most mothers recalled being exasperated with the demands of the DDH clinics in hospitals, at a time when they were vulnerable new mothers with young infants. They encountered health practitioners who were very clinical and functional in their approach. For these seven mothers, they felt that health practitioners failed to acknowledge their special new mother and baby status. The mothers wanted health practitioners to respect and apply sensitivity to mothers as caregivers. They wanted health practitioners to be mindful that they were juggling the demands of a young infant baby, as well as recovering from childbirth themselves. The experiences of Jennifer and Kirsty illustrate the protracted disruption that they endured in the first few days and weeks of their infants' lives:

*"I thought that the appointment was going to take about 10 minutes, but it ended up taking about six hours. I literally went from the ultrasound to waiting to see the Consultant; to seeing the Consultant to having a Pavlik harness fitted; to having him [her baby] in the Pavlik harness for an hour whilst they worked out if it was fine; then to making appointments to see him again. That was a very, very, very distressing kind of time. He was nine weeks old; I was feeding on demand. He wasn't breastfeeding very well either."*

(Jennifer)

*"The paediatrician said 'Oh there's an actual hip clinic tomorrow. I'll see if I can get you to the hip clinic while you're still in here'. My daughter was four days old by this point. Well, they [the hospital] were phoning every day at home for me, but I was still in the hospital. So when I got home, the baby was six days old and I phoned them*

*and they said 'You were supposed to be coming in.' And I was like, 'Yes, I was still in the hospital'. They said, 'Can you come into clinic this Friday?' You know, I wasn't feeling my best still, you know the last thing you want to do in January is take a baby...a newborn January baby in the snow to hospital, but we went in again."*

(Kirsty)

Louise had a poor relationship with the health practitioners throughout the DDH care pathway. She perceived that health practitioners were taking the dominant caring role with her baby and they were making the key decisions about her baby's DDH treatment. She felt that the health practitioners were interfering and disrupting her attachment relationship with her baby:

*"I just wanted to bathe her because she enjoyed baths so much and I felt like they [health practitioners] had taken that away from me. That was my thing, as a mum, and you're telling me what to do? I think that was it, I didn't have any control over what was going on. I was, like, I want to bath my child, let me bath my child."*

Louise wanted to embrace her role as a mother to her new baby, especially bath times, but she perceived that the health practitioners were forcefully issuing care instructions to her. This is shown in her confrontational quote: *"You're telling me what to do?"* She was frustrated and angry with them which seems to provoke Louise into challenging these treatment instructions.

On the other hand, Lisa had a mixed DDH healthcare experience. During the DDH diagnosis appointment for her baby, it was quick, but it lacked any meaningful interpersonal engagement with health practitioners. A few days later, when Lisa's daughter was fitted into a harness, she had a positive interpersonal encounter with a physiotherapist who spent time offering her reassurance and empathetic support:

*"There wasn't a lot of time spent with us on that first diagnosis day. I think I was probably in the hospital for 15 minutes. You know, they did the ultrasound and showed me the thing [Pavlik harness]. Then there was the Physio [Physiotherapist] who said, 'Come back on Friday.' But then to be fair, on the Friday, when we saw the physio [physiotherapist], she was great! She obviously knew that we were beside ourselves. She was very good at trying to...almost talk it down, like, saying to us that 'It's going to be fine. It's only going to be eight or 12 weeks. It will go by really fast. It's for her own good. She be so thankful that you did it and she doesn't have hip problems.' "*

(Lisa)

For these mothers, it seemed that when health practitioners provided some time for interpersonal engagement, it gave them reassurance about the diagnosis and treatment for their infant and it was greatly appreciated.

### **5.2.15 Recurrent theme: The challenges of breastfeeding a DDH infant**

Some mothers discussed in the interviews about the challenges they faced as they tried to continue breastfeeding their infant following the application of the Pavlik harness. Six mothers reported that they initially began breastfeeding their infants, but four mothers explained that they stopped breastfeeding once the harness was fitted to their baby. This was for two reasons. Firstly, these mothers lacked the information to achieve a comfortable breastfeeding position due to the rigidity of the infant's harness.

*"I was really worried about carrying on with the breastfeeding. I was like, I don't know how I'm going to be able to feed her if I can't twist her. I was upset about that because I thought that I won't be able to feed her and I might have to stop. Every time I tried to Google 'breastfeeding positions in a Pavlik harness', all it brought back was an Australian factsheet. Every single time, that's all I ever got."*

(Nicola)

*"I have a newborn baby and I'm like trying to breastfeed and I am tired, and I don't want to have to deal with a whole other element that's going to make things more difficult. It's not fair."*

(Lisa)

It seems that the lack of information about breastfeeding an infant in a harness was yet another challenge which faced mothers with young infants. It is interesting that Nicola was not content with the information from an Australian website. She wanted and trusted information from a familiar source. Nicola's account interlinks closely with an earlier recurrent theme, 'Acquiring knowledge about DDH'.

Lisa's preceding extract alludes to her special new mother and baby status. She has handled a series of challenges in a short amount of time. She has given birth, she is caring and breastfeeding a new baby and as a result, she feels exhausted. The application of the harness on her baby is *"a whole other element that is going to make things more difficult"*. However, she explained that she *"figured it out"*. From Lisa, there is a sense of great parent responsibility from which she draws on her own tenacity.

Secondly, mothers explained that they faced pressures from community health practitioners who were promoting direct breastfeeding as opposed to express breastfeeding. This is illustrated in Kirsty's quote of her memories of this experience:

*"I remember being frustrated with health visitors. Every time we went to the health visitor, they knew that I was feeding her myself, albeit I was expressing the milk rather than feeding her and they kept pushing me to try and feed her myself. I kept saying 'No, she's in a harness now, there's no way I can. She's fine, she's still getting breast milk. It doesn't matter. It's not the priority anymore. The priority is her hips.'"*

On the other hand, two mothers did continue to breastfeed their infants. Louise's recollection was very insightful:

*"It was difficult. I don't think it ever got easier, breastfeeding in a harness. It was sort of like just a juggle thing. This position will work today and this one will work tomorrow. It was awkward, and it was upsetting at first."*

These accounts suggest that breastfeeding an infant in a harness could be very challenging. As the mothers faced the challenge of breastfeeding and the pressures of a new baby in the family, the home situation appears to be a chaotic, however, these mothers were continuing to successfully care for their baby. It appears from these mothers accounts that breastfeeding information and interpersonal support was needed by these mothers.

#### **5.2.16 Recurrent theme: Supportive health practitioners**

The mothers appeared to have had a combination of positive and negative experiences with health practitioners. However, during the course of the DDH care pathway, these mothers together with their infants, met with many health practitioners. In the interviews, six mothers highlighted that when health practitioners utilised their interpersonal skills to give them clear explanations, emotional reassurance and practical caring for a DDH baby, in turn they felt empowered and confident in their own parenting skills.

When Kirsty's baby was first diagnosed with DDH, the first consultant stated that he lacked experience with infants. However, when she attended the follow up appointment at the DDH clinic, she met with a consultant who was knowledgeable about infants with DDH. This consultant provided Kirsty with clear clinical explanations and helpful practical caring advice:

*"When we went back, this one was totally different to the first one we met. She was used to dealing with babies. She was another orthopaedic surgeon, but predominantly with babies and she said, so what have you done about washing?"*

*And I went, 'Well, we were told not to and we've been running a baby wipe over the baby for a week'. She was, like, 'Well, we don't want you to take it off, we don't, but ...' Then she told us how to undo the straps and she marked the straps and undo the straps and how you could wash down and do up again, one bit at a time. She told us about she could wear vests underneath it, so that it didn't mark her skin and things. She spoke about her skin and that it might break down and stuff. Things, practical things that I think need discussed with parents, like, particularly with a newborn."*

Some mothers felt apprehensive about caring for their infant in the harness, such as Jennifer. She benefitted from the supportive manner of health practitioners. The nature of this support was both emotional and practical. A dedicated health practitioner spent time with her to explain DDH and the harness; provided practical help about managing and caring for a young infant in a harness; a direct contact telephone number for support. Here Jennifer recalled this experience:

*I remember the first time we took the harness off, I just had that real anxiety of, 'We're not ever going to be able to put it on'. I did book a twenty-four hour kind of follow up with the orthopaedic nurse who fitted our harness, who was wonderful. She was very, very good at that and I felt like I could ring her at any point. So I did and I went to see her within twenty-four hours of him having it fitted, just to check it was fitted ok. To have it all checked and to know that I'd put it on right. All I kept thinking was 'I don't want to get this wrong'. You know, I had a lot of self-doubts and it just took a lot of time and a lot of reassurance that it was fitted properly and he was going to be ok."*

Jennifer felt great responsibility for her son's treatment and prognosis. There was a sense that if the treatment was unsuccessful, she did not want to be the source of any blame: "I don't want to get this wrong".

When health practitioners were supportive towards mothers, it strengthened their relationship. Mothers valued clear communication, quality information provision and psychological reassurance by health practitioners. When mothers had supportive relationships with their health practitioners, it developed their self-efficacy and they felt empowered to care for their infant in a harness.

#### **5.2.17 Recurrent theme: Trust in the opinion of health practitioners**

Some mothers referred to their overwhelming desire to trust the opinion and comments of health practitioners. Here Lisa illustrates this feeling:

*"You do, sort of, feel a bit like...I mean, they do know best. That's their job. I don't know anything about taking care of babies with hip problems, so I sort of wanted to trust them."*

Amongst these five mothers, there was a sense that they felt vulnerable in their position when they were given the opinion of health practitioners. The strength of this relationship dynamic between mother and health practitioner is favourable towards health practitioners. Some mothers did critically consider the reliability of health practitioners' opinion, but they appreciated that they lacked the knowledge and experience. Jennifer appeared to psychologically struggle with her son's diagnosis, and she gave great thought to the opinion and their positive explanation of the benefits of early DDH treatment on her son:

*“So hearing them [the health practitioners] say, ‘There’s something we can do’ that he would never remember. I kind of started to see the real positive side of the diagnosis. It made me realise that it wasn’t the kind of life I wanted him [her baby son] to have. I don’t want him to have medication and be sore; I want him to have as full of life as possible.”*

When health practitioners communicated clearly with the mothers and demonstrated their competence, such as fitting and adjusting harnesses, this seemed to enhance the trust and value in the relationship:

“She was very, very good in terms of fitting the harness and reassuring me.”

(Jennifer)

This notion of trust by the mothers in the decision-making of health practitioners was summed up by Lisa's comment: *“They know best.”*

#### **5.2.18 Recurrent theme: Positive aspects of the experience**

During the participant interviews, as mothers reflected on their experiences of caring for an infant with DDH, five mothers noted the positive aspects. Some mothers highlighted the overall healthcare provision:

*“They provide an amazing service.”*

(Michelle)

*“It’s a fantastic hospital. I feel very confident that we’ve got a great hospital there. It’s such a different environment to the one I was in. It’s so geared up for children. I was on a children’s ward and they weren’t what they are now. They weren’t pleasant experiences”*

(Laura)

Laura, a mother who had recurring problems with DDH throughout her life, felt very apprehensive about the DDH treatment for her baby. She made comparisons to her own negative DDH healthcare experiences. Yet, in the present day in the interview, she felt

positive and confident about the healthcare provision for her daughter and the ability of the health professionals.

With links to earlier recurrent themes about 'Supportive of health practitioners' and 'Trust in the opinion of health practitioners', the mothers specifically identified a positive aspect of the experience being a positive relationship with the health professionals:

*"It was good that the second ultrasonographer, who was...I think she was probably head of department, she was very honest and chatty. She was quite open about saying 'You know what? I'm not sure. Let's go and take these images to the surgeon.' That was quite good."*

(Emma)

This positive experience gave mothers, like Emma, reassurance at a time when they were vulnerable. Emma valued the honest communication and interpersonal skills of the senior sonographer. She felt listened to and respected in terms of her thoughts, worries and concerns.

Also, in hindsight, mothers reflected on this experience in the interviews, they felt confident about caring for their infant undergoing treatment in a harness. They felt that once they got into a daily routine of managing their baby, that it was not particularly onerous, and the treatment took place over a short amount of time:

*"It was the nicest treatment I could think of, because she didn't have to take any medication. The harness wasn't preventing her from walking because...she wasn't walking yet".*

(Lisa)

For Lisa, the treatment was unobtrusive. Interpretatively, Lisa gave the impression that she no longer felt distressed by the nature of the DDH treatment because *"It was the nicest treatment I could think of."* Furthermore, Lisa seemed pleased that she still had the baby experiences that she had anticipated when she explains, *"The harness wasn't preventing her from walking because... she wasn't walking yet."* This is a valid and resonating comment.

The positive features of the lived experience for mothers caring for infants with DDH was underpinned by healthcare encounters with health practitioners. In the relationship between mothers and health practitioner, if the health practitioner expressed empathy and supportive behaviour, then this fostered mutual respect and trust.

### **5.2.19 Summary of the intermediate theme: Relationship between mother and health practitioner**

The nature of the DDH care pathway meant that mothers met many health practitioners. The mothers in this study felt more empowered to care for their baby undergoing treatment in a Pavlik harness when they had a positive supportive relationship with the health practitioners. The positive features of the relationship with health practitioners which were highlighted by mothers were: clear verbal explanations; quality information provision; emotional and practical support; trust in their clinical decisions. Importantly, these mothers wanted health practitioners to recognise their new mother and baby status. Mothers sought acknowledgement and empathy by health practitioners for the duality of their maternal role. As well as managing an infant with DDH, mothers also juggled new infant demands such as breastfeeding. These mothers valued supportive health practitioners who put some time aside and used their interpersonal skills to engage with mothers to offer reassurance and practical advice. When there were positive relationships between the mothers and the health practitioners, health practitioners played a crucial role in developing mothers' sense of emotional and practical self-efficacy to care for their infant undergoing DDH harness treatment.

### **5.2.20 Recurrent theme: Expectations and adjusting expectations**

'Expectations and adjusting expectations' were a strong theme to emerge from the interviews. Eight out of nine mothers in the interviews recollected having expectations of their relationship with a new baby which shifted after receiving the DDH diagnosis for their infant. The mothers felt an overwhelming sense of adjustment in their life and in their relationship with their new baby undergoing DDH treatment. There were overt and covert nuances within this theme.

Notably, two mothers, Lisa and Michelle, expressed overt commentary on their sense of adjustment:

*"It was really that first day because once we'd adjusted after the first few days it was fine. As soon as we, sort of, realised how to use it [the harness] and do her nappy changes and she was feeding fine, I think I almost felt like 'Oh, well, that's fine then'. It was really that first day, the disappointment...of realising that was going to happen. That was really upsetting for us. You know, we kept going to all of our little classes and stuff, besides the swimming, and so we sort of just kept trucking along."*

(Lisa)

*"I'd planned my time off with my little baby, my cute and cuddly baby and suddenly she was going to be... not right. It wasn't what I'd planned or expected, but I very quickly came to my senses and knew what had to be done to help her out. I had to think about my other children too. We all adapted really well. We all got a bit blasé about it really because the kids carry on, so you do, don't you?"*

(Michelle)

For Lisa, she had a very clear idea of the relationship and daily routine she expected with her baby. Her sense of adjustment to caring for an infant undergoing DDH treatment was measured by how much of her original expectations and routine she could maintain with minimal disruption. Similarly, Michelle also had a plan and expectations of life with her new baby. However, her adjustment was facilitated by the needs of her baby and her other children. There was a convergence in the meaning of this experience for Lisa and Michelle which was a sense of continuum:

*"We sort of just kept trucking along."* (Lisa)

*"The kids carry on, so you do."* (Michelle)

Many mothers alluded to feelings of grief and loss for the infant they expected to have and their adjustment. These feelings were very potent for Michelle who very candidly expressed the meaning of this experience for her:

*"I felt like I was grieving for the baby I didn't have, or for the...no, that's not fair... I was grieving for the lifestyle of baby I didn't have."*

(Michelle)

*"We're very outdoor type of people and I had these visions that were going to carry him across hills with the dogs...and obviously that couldn't happen. I couldn't carry him because he didn't fit in the baby carrier because of the harness, so I couldn't do anything like that. I'd looked forward to having this baby and all of a sudden it wasn't going to...It kind of just felt like I'd been cheated and everything I'd wanted wasn't going to happen."*

(Jennifer)

Interpretatively, there is an impression that for the majority of mothers in this study, they had an image of the ideal maternal - infant lifestyle, together with the paraphernalia of baby

life. As Michelle lamented that: *“I was grieving for the lifestyle of the baby I didn’t have.”* The expected lifestyle of a new infant did not materialise for these mothers.

Interestingly, the mothers’ feelings of grief seemed to exhibit itself as a covert psychological response towards their infants clothing:

*“The clothes were an issue because she couldn’t fit into her clothes on anymore [while wearing the harness]. You know what it’s like dressing a little newborn? You’ve got all these gorgeous things. Everyone had given us so many outfits that broke my heart because I was like, oh they’re all in the wardrobe and she’ll never... she didn’t get to wear them. I found that really sad and bad from the people that had given me them because she would never wear them. My partner was like ‘Oh, it’s only clothes, but to me that was a huge part. It was pretty heart breaking which he doesn’t understand.”*

(Sarah)

*“You know, you expect that she’ll wear little baby grows and she’s going to wear little slippers, little shoes. Well, there was none of that, they all went. Newborn socks, well, there was no point in those. Loads of stuff went back. Gifts went back. But the problem is you’ve already done that thing where you’ve bought all these clothes and you’ve washed them and you’ve put them in the drawer. So I just put them into charity. I wasn’t going to look it again.*

(Kirsty)

For mothers, such as Sarah and Kirsty as well as others in this study, the clearing out of the newborn infant clothes appeared to be symbolic of the change in their circumstances. It helped mothers to adjust to the new expectations of her relationship with her infant; the transition to ‘the new normal’ life with an infant. The meaning of the removal of the clothing seemed to be cathartic for these mothers. Other mothers bought special DDH clothes. In the following extract, Nicola, seemed to be trying to maintain some of her expectations of early motherhood:

*“I went and bought the same pack of sleepsuits that she had as a newborn, so that she could wear them over her harness, because I wanted her to still feel like that newborn, and still be in her little clothes. I loved having this tiny little baby and when they put the harness on her, she just felt all big again. I felt like I’d kind of lost my new-born a little bit.”*

Having the same newborn clothing, but in a larger size helped Nicola to adapt, but still retain the emotions and sense of attachment with her baby. Nicola wanted her infant to still feel the same: *“Feel like that new-born”*.

When Lisa’s baby was fitted into a harness, she chose to socially isolate herself as she adapted to a new caring routine for her infant:

*“I felt almost defeated. I felt like ‘I guess we have to do this now’. I think it made a lot of my first-time mum anxieties even more potent because you want to do a good job. The first few days were hard. I felt like with the harness I have to do everything right, but ‘How do I do that? I don’t know?’ I didn’t even do much the first few days because I was trying to get to grips with getting a new routine going. At that age, they’ve got lots of dirty nappies and it was like, I need to clean under the [harness] straps. I guess I was feeling...probably a bit overwhelmed.”*

It appears that Lisa adopted a covert coping behaviour. She needed time to psychologically adjust her expectations, and on a practical level, she needed time to adjust to a new daily infant caring routine, which now involved managing the harness treatment. She disclosed that she felt *“a bit overwhelmed”*, but her account about choosing to socially isolate herself for a few days suggests that she was psychologically and physically exhausted. Lisa needed her own time to adjust to the new situation.

As some mothers reflected on this time with their young infants, they felt that it was not the barrier to motherhood and their relationship with their infant that they feared it would be:

*“I think you do just become used to it as you do anything. It only takes a day or two to get used to carrying them and feeling it. Then all of a sudden, that’s the new normal thing.”*

(Lisa)

Many mothers highlighted that when they were informed of their infant’s diagnosis and the starting of the harness treatment that she felt a need for both adaptation, but also a renewed sense of continuum with family life with a young infant. Many mothers felt grief and loss for the relationship and lifestyle that they expected with their baby. Mothers also cited overt and covert coping behaviours which enabled them to develop resilience.

### **5.2.21 Recurrent theme: Feelings towards the Pavlik harness**

Seven mothers highlighted their feelings and experiences as they viewed a Pavlik harness for the first time. Interestingly, several of these mothers used the specific phrase to

summarise this feeling: *“It looked horrible”*. Three mothers specifically stated that the harness looked like a *“torture contraption”* (Nicola); *“It was like some medieval torture thing”* (Louise); *“It was like a strait jacket for my tiny baby”* (Kirsty).

The harness was often regarded as a *“barrier”* in the relationship between mother and infant. The harness was viewed as an emotional-physical barrier and as a practical-physical barrier in this relationship. As an emotional-physical barrier, it hindered mothers’ ability to form a greater quality of attachment with their baby, in terms of closeness, touch and being able to give cuddles:

*“I think the big one for me was, I couldn’t cuddle her the way I wanted to. I just wanted to cuddle my baby and I think that is what I was really upset about.”*

(Louise)

*“It [the harness] covered up her little skin and I felt like I couldn’t get in for a proper cuddle. I think it just took away the kind of closeness in a way”*

(Sarah)

Moreover, these mothers also considered the harness as a *“barrier”* from a practical-physical perspective. It created additional challenges for the new mothers as they tried to care and clean their infants:

*“I think the most awkward thing was washing her. It was just time consuming. We had a problem at first because they [health practitioners] had tied her harness so tight after it had dislocated that when we went back, the inside of her groin, all of her skin had come off. So I would try and clean it because it was horrible, because it was smelly, it smelled of rotten skin. One of my biggest fears was, I don’t want her to be dirty. I don’t want her to be smelly. I don’t want people to look at her and think ‘Oh what a dirty baby’.”*

(Nicola)

Here Nicola is clear that she did not want *“a dirty baby”*. Conceptually, she wanted a desirable baby and she wanted *“people to look at her [baby]”* and admire her.

Nicola poignantly recalled the occasion when she arrived at the hospital for the appointment in which her baby daughter was going to be being fitted into a harness:

*“So in we brought our shiny newborn to be put in this contraption.”*

Nicola used a very vivid phrase to illustrate the situation she was experiencing with her baby. Nicola viewed the harness as a “*contraption*”, a puzzling device which was strange, ugly and complicated and she has brought her “*shiny newborn*” to be fitted into it. She perceived her “*shiny newborn*” as bright; beautiful; perfect; something or someone to be desired; rather like the imagery of a magpie searching, collecting and treasuring shiny things in its nest. Conceptually, Nicola believes that she is putting someone new, beautiful and desirable into an ugly, strange harness.

Two mothers, Kirsty and Lisa, reflected on the unpleasant moment that they were given a DDH Pavlik harness leaflet by a health practitioner:

*“You know, I felt totally thrown and then they’re [health practitioners] like, ‘We’re putting her in this’ and they put one down [a leaflet]. It was a leaflet and it had a horrible picture of a baby on the front, in a horrible looking Pavlik harness. I remember...this photo...just this terrified looking baby. It wasn’t the greatest [photograph] and I remember thinking ‘They really need to do something about that later on.’ This was our baby and she was getting put in this harness and I’m thinking ‘Oh my God.’ ”*

(Kirsty)

*“The Physio [Physiotherapist] just came and sat next to me in the waiting room and gave me the pamphlet and said, ‘See you next Friday’. The pamphlet was colour and it was about the Pavlik harness. The visual on the pamphlet really bothered me. Like, I think that’s what really sent me into a spiral of crying the whole way home, because I just, sort of, like, went... ‘Oh, so I can’t take it off the whole time?’ Like, all of a sudden, it doesn’t seem very nice anymore because I think I was just trying to say ‘Thank you. That’s sounds good [to the health practitioners]. But actually, I was being, like, ‘No, it doesn’t sound good at all.’ ”*

(Lisa)

It seemed that just as Kirsty and Lisa were coming to terms with the DDH diagnosis for their respective babies, the leaflet they were given which featured an infant wearing a Pavlik harness compounded and accelerated their emotional feelings of distress. In their words, they were being quickly forced into adjusting to their perceived visual “*horror*” of caring for their newborn in a harness. For Lisa, the imagery of her feelings being in a rapid downward “*spiral*” captured her sense of being in a continuous, dramatic decline in her feelings of despair. Lisa wanted to be grateful to the health practitioners for providing treatment for her baby as she projected her ‘composed face’, but she candidly revealed her ‘true face’, that

she was not grateful to them. There is an overwhelming sense that Lisa felt a pull between society's norm and the relationship dynamics between patient/carer and health professionals to express feelings of appreciation towards health practitioners for applying the treatment to her baby. However, she also felt a wave of uncontrollable resentment towards the health practitioners about the disruption to her relationship with her baby, as well as frustration with her own a lack of authority in this situation.

Lisa's account about her feelings towards the harness was very detailed and it uncovered her feelings of dismay, hate and repulsion towards the harness. As she revealed her feelings about the harness, she felt that the harness changed her baby from "*a squishy little baby into a rigid little body*". There is a sense of grief and loss for the new baby that she had before the application of the harness. Once her newborn baby has to wear a harness, she suddenly became "*solid like holding a toddler*". Months later, when the ultrasonography scan confirmed that the harness had been successful in treating her daughter's DDH, the hate that Lisa felt about the harness is palpable: "*I just wanted to burn it in a pile of rubbish somewhere*". However, conversely, once the treatment has come to a successful conclusion, she explained that as she was leaving the hospital and was securing her baby into her car seat:

*"Her legs were still up like a frog because you know, they still sit in that position for a while afterwards. It was so cute. She was just sitting there in the same position in her car seat, so that was really cute.*

Here, Lisa continued to reflect on her memories and the meaning of this occasion at that point in time, and she compared it with her thoughts and meaning of this event in the participant interview:

*"I remember one of the healthcare assistants or someone said to me 'Do you want to keep the harness?' And I said 'No' and she said 'Well, why don't you keep some of it?' And she cut off a little bootie for me, so like, I've still got one tiny shoe. Which is kind of funny. I think at the time I was like 'I never want to see that harness ever again. Just throw it in the bin'. But it's funny now when I see this little tiny shoe."*

On reflection in the interview, Lisa warmly acknowledged her baby daughter's first few months of life and how the harness treatment is now part of her narrative of early memories with her first baby. Mothers noted that when the DDH treatment came to an end that there was another shift in the relationship dynamics with their infant.

There is an overwhelming impression from these mothers' accounts that they were still feeling shock from the DDH diagnosis for their baby, when in turn, these feelings were quickly compounded by their feelings of horror and repulsion towards the Pavlik harness. The physical and emotional barrier of the harness treatment had a negative impact on the relationship between mother and her infant.

#### **5.2.22 Recurrent theme: Normal versus abnormal**

A conceptual understanding of 'normal' and 'abnormal' was another strong theme which featured in the interviews of eight mothers. This concept relates to the normal versus abnormal views of the mothers and their baby, and their view of their own motherhood.

The mothers expressed their view that their baby was no longer 'normal' during the interviews. It was at the point of DDH diagnosis for their infants, that the mothers referred to their infant's as not being "*normal*" (Kirsty; Jennifer; Lisa; Sarah;) and "*not right*" (Michelle). They felt that there was something "*wrong*" their baby (Jennifer; Lisa; Louise). Sarah felt that her baby was "*different*". As the harness treatment progressed, a few mothers aspired for their infant to be "*perfect*" (Kirsty; Lisa; Michelle; Nicola).

This theme also interlinks with the previous theme, 'Expectations and adjusting expectations'. For example, when Lisa remembers the time, she was waiting in the hospital for her daughter to be fitted into a harness:

*"We were in the waiting room and you see other babies in harnesses. So it's a bit like, 'Is that what they're going to look like?' I was sort of looking at her [her own baby] a bit like 'This is the last time I'm ever going to see her normal', which obviously isn't true."*

At this time in the hospital waiting room, there is a notion that Lisa was mourning and feeling a sense of loss for the "*normal*" baby she thought she had, and she remembered the point in time in which she began shifting and adjusting her future expectations with her daughter.

While in public, four mothers felt an element of stigma of their infant and themselves by strangers:

*"I hated the way he looked; I thought he looked awful. I remember feeling almost embarrassed. When I took him out, I felt that people were looking at me. People are wondering what's wrong with my baby."*

(Jennifer)

*“It made me realise how people really look and judge and stare.”*

(Sarah)

From Jennifer and Sarah perspective, they felt that people were judging them, and not necessarily their baby. However, it is possible that Jennifer and Sarah were struggling to accept their infant’s physical appearance in the harness. Maybe Jennifer and Sarah sensed that people were stigmatising them when this was not the case.

On the other hand, other mothers, such as Lisa and Kirsty felt that the public were more curious about the Pavlik harness as opposed to feeling stigma:

*At the baby groups, I felt like...because I was just chatting with the mums anyway, I did feel like I could have some time to say to people, ‘Oh, she’s fine. She’s just in her harness because she had this dodgy hip and hopefully, she will be out of it in few weeks and there’s nothing wrong with her. She’s fine, really’. Then people just, sort of, go, ‘Oh, that’s good’ and then we’d move on.*

(Lisa)

Interpretatively, there is a sense that Lisa embraced these opportunities to inform and convince other people, as well as themselves, that her baby was ‘normal’ and she was ‘normal’. She seemed to be managing the public image of herself as a mother and her infant by repeating the phrase, *“She’s fine”*.

Although initially, many mothers in this study were unfamiliar with DDH, they wanted it to be a common condition as opposed to being unusual. This aspect of the current theme interlinks with an earlier theme, ‘Taking comfort in the shared DDH experience’ with other parents. Several mothers recalled occasions when they encountered other parents with children being treated for DDH. They were very keen to engage with these families and offer mutual reassurance. For example, Louise remembered an occasion when she saw a mother with a DDH baby in a shop:

*“We were going around the supermarket and I saw a baby in a Pavlik harness being carried, so I went over to them to talk to them. I went over and I was like, ‘Your baby is in a Pavlik harness? I think she was a bit took by it and she said ‘Yes’ and I went ‘My baby is too!’ She was like ‘Oh’ and we go chatting. So it was nice to talk.”*

It seems apparent that at the diagnosis stage, some mothers can feel isolated. However, when opportunities arise to connect with other parents who are having the same DDH experience, as illustrated in Louise's account, mothers reported feeling more 'normal' and conceptually, a notion of acceptance within society. This was exemplified in the Louise's preceding quote.

For these mothers, the DDH diagnosis and treatment seemed to have a negative impact on their psychological wellbeing, at least temporarily. In public, mothers projected a 'composed face' and made an effort to appear like a typical mother and infant, but mothers did not necessarily feel this way when they revealed their true face to themselves.

### **5.2.23 Recurrent theme: Quality of attachment relationship**

During the interviews, a strong theme to arise from the lived experience of seven mothers was their overwhelming desire to develop maternal closeness with their infant. They wanted an enhanced quality of attachment relationship with their baby. Mothers had anticipated and wanted to embrace the primary caregiving role as a mother. They reported looking forward to caring for their new infant with great enthusiasm. Specifically, sharing close cuddles and the enjoyment of bath times, but the DDH diagnosis for their infant compromised their expectations. Psychologically, mothers regarded the neonate stage of their infant as a special stage which was defined by time:

*"I feel like I wished away eight weeks of her tiny babyhood and I do feel a bit bad about that because I'll never get...and it remains so that I missed out a bit of her being a baby."*

(Sarah)

*"At the time, sort of feeling, like that was unfair to me. This is my first baby, and this is my own time with her and like, how dare this happen? At the time, it just seems really final."*

(Lisa)

In these accounts, Sarah and Lisa reflected on their emotions and meaning of caring for their infant with DDH as they wanted to enjoy and embrace their new maternal relationship with their infant. Sarah expressed a sense of "*stolen time*"; a unique time with a new baby robbed from her which has gone forever.

With links from an earlier theme, 'Caring for a baby in a Pavlik harness', the mothers conveyed that when their infant was wearing a harness, it acted as a barrier to their infant. The harness interfered with mothers' ability to touch, be close and manoeuvre their infant. The quality of the attachment relationship was at the forefront of Jennifer's initial thoughts when she is informed by the health practitioners that her son will need to wear a harness:

*"I can completely understand why it was, but it was...it was quite hard to hear when you just want to be able to...you know, I was like 'Ok, that's fine, but I still have to mother him and I still have to have this bond with him'."*

In Jennifer's extract, there is a notion that as a new mother, she felt pressure to ensure that she developed a close nurturing relationship with her infant, as she emphasised that: *"I still have to have this bond with him."* She seemed to be trying to come to terms with the responsibilities of caring for a new infant and managing an infant in a harness as well as developing a high-quality attachment relationship between her infant and herself.

The reality for Sarah was that her daughter's harness did hinder their emotional connection:

*"The harness covered up her little skin and I felt like I couldn't get in for a proper cuddle. It just, I think, took away the kind of closeness in a way."*

Bath time was a key activity cited by mothers which helped to cement their sense of maternal connection with their infants. Here Kirsty recalled the point in her daughter's DDH treatment when she only had to wear the harness in the night time:

*"Then the last weeks, it was just at night, and that was brilliant because you could do things like give her a bath!"*

In this extract, the intense happiness and relief that Kirsty exhibits showed that she was finally realising her expectations with her baby. There was also a positive shift in the dynamics of her relationship with her infant.

As mentioned earlier, most mothers in this study were repulsed by the visual appearance of the harness on their infant. One mother, Louise set about making the harness more attractive and this gave her great comfort:

*“I got a bit creative with it and made it...sewed some ribbon on and things. I made it lovely. My mum made a little chest belt, for where it was rubbing her. It was lovely. It was a spongy thing that had all petals on it and stuff.”*

In Louise’s extract, there was an impression of acceptance as she tried to make the best of this time with her young daughter. By making the harness attractive, it assisted Louise to feel comfort and resilience. As she reflected on these memories in the interview setting, she felt a moment of warm nostalgia, *“I made it lovely.”*

The quality of attachment relationship between mothers and their infants was compromised by the DDH Pavlik harness treatment. The mothers tended to develop their own coping strategies and adjust to the situation. Once the harness treatment was completed, mothers felt enormous enthusiasm to embrace the opportunities to care for their infant.

#### **5.2.24 Summary of the intermediate theme: Relationship between the mother and infant**

There was convergence in the perceptions of mothers’ relationship with their infant when they received the DDH diagnosis and harness treatment. Mothers felt confronted with an atypical baby and this challenged their relationship with infant. It seemed to compromise their notion of quality maternal attachment with their baby. However, mothers did develop coping behaviours and resilience tactics. They felt that they had to carefully manage their public ‘composed’ persona, with the reality of their ‘true face’ persona. Undoubtedly, amongst the mothers in this study, the Pavlik harness was viewed as a *“torture contraption”*. They felt it made their baby appear physically abhorrent. In addition, the harness was considered a physical and emotional barrier which interfered in their perceived quality of attachment relationship between mother and infant. However, once the harness treatment came to an end, the negative relationship dynamic between mother and infant shifted in a positive direction.

#### **5.2.25 Summary of the superordinate theme: Relationship dynamics**

The findings revealed that mothers were central to the relationship dynamic with health practitioners and their infant. With supportive, empathetic health practitioners, mothers felt trust in their opinions. Mothers also took comfort in the reassurances of health practitioners that they could adapt their current infant care routine to manage an infant in a Pavlik harness. There is no doubt that mothers were repulsed by the physical appearance of the

harness on their infant. However, positive relationships with health practitioners enabled mothers to develop coping behaviours and a positive mental wellbeing to ensure that their infant's DDH harness treatment was given every opportunity to successfully resolve their infants desolated hip/s.

### **5.3 Chapter summary**

This chapter has presented the analytical findings of the interviews with mothers of an infant with DDH. Nineteen recurrent themes emerged from the data. From these recurrent themes, the intermediate themes: 'Dominance of healthcare' and 'Understanding DDH diagnosis and treatment' developed into the superordinate theme 'Struggling with empowerment and disempowerment of care over the infant'. Similarly, the intermediate themes: 'relationship between mother and health practitioner' and 'relationship between mother and infant' contributed to the development of the superordinate theme about 'Relationship dynamics'. These overarching superordinate themes captured these mothers lived experiences of caring for a DDH baby.

However, it is important to emphasise that even though a robust pilot of this study was conducted, including the analysis of data by an experienced IPA researcher at the University, there is potential that others may have additional thoughts, nuances and perspectives about the meaning of the data. The nature of IPA draws on the active interpretation contribution to the dataset by the analyst and the analyst adheres closely to the words and nuances of the participant. However, the analyst also shapes their worldview interpretations based on their own life experiences.

These findings together with recommendations will be discussed in relation to the current literature in Chapter Eight. The next chapter presents the analytical findings of the interviews with fathers of infants with DDH.

## Chapter Six: Findings from the interviews with fathers caring for an infant with DDH

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### 6.1 Chapter overview

This chapter presents the findings of the nine research interviews with fathers about their lived experiences of caring for their infant with DDH. In addition, it will highlight the information needs of fathers during this time. The interviews with fathers were embedded in the same methodological framework and methods as the interviews with mothers caring for an infant with DDH (see Chapter Five). For ease of comprehension, this chapter, with its focus on fathers' lived experiences of having an infant with DDH, will follow the same structure as the findings of the mothers' lived experiences of caring for their baby with DDH.

From the fathers' interviews, 14 recurrent themes emerged from the data and these recurrent themes contributed to the development of three intermediate themes. These intermediate themes are: 'Trust in the healthcare system'; 'Biographical revision to the new father role'; 'Empowerment through the acquisition of information'. From these intermediate themes, one overarching superordinate theme emerged from the interview data which encapsulated the meaning of these fathers' lived experience. This superordinate theme was, '**Managing the disrupted family**' (see Figure 8).

Within this findings chapter, each recurrent theme emerged from data which featured in five or more fathers' interviews. Also, the individual recurrent themes are supported by verbatim quotes from fathers, using pseudonyms. However, a word of caution; none of the nine fathers concurred on any single recurrent theme.

## 6.2 Themes

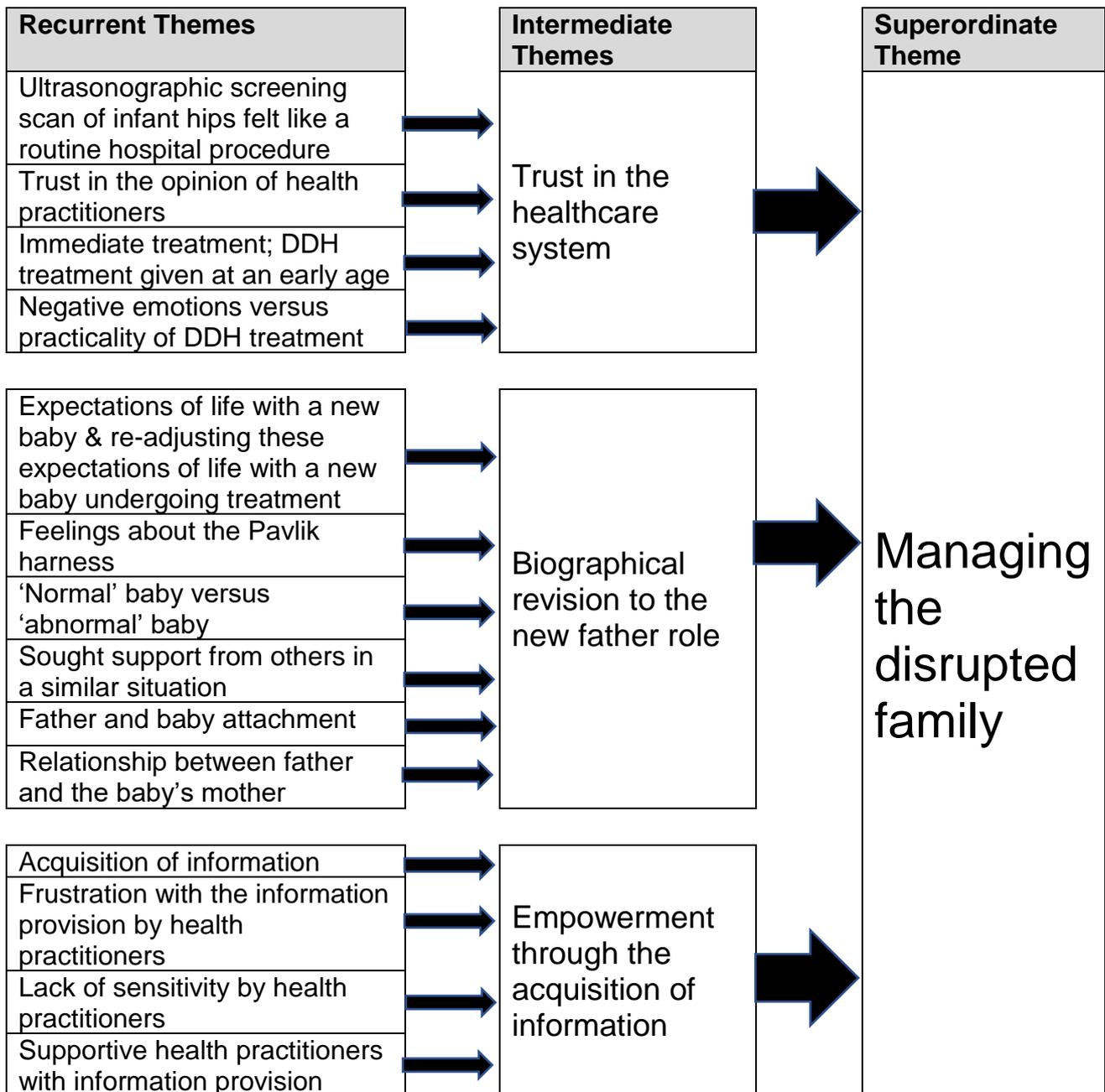


Figure 8: Themes from interviews with fathers caring for their infant with DDH

### **6.2.1 Recurrent theme: Ultrasonographic screening scan of infant hips felt like a routine hospital procedure**

Early in the interviews, fathers were asked about the events that took place which led to their infant's referral for an ultrasonographic hip scan by health practitioners to screen for DDH. Five fathers commented that it was their perception that their baby's hip scan was part of the usual routine series of health checks and tests for new infants:

*"I think I was pretty relaxed going into the appointment, because we...I didn't think there was an issue. I thought it was just a routine thing."*

(John)

*"In my head, I thought it was just a formality, almost to check that there was nothing there."*

(James)

*"We were going in there expecting to be told that everything was ok because that had kind of what had been implied. We didn't really know much about DDH at all."*

(Andrew)

Amongst these fathers, they had no expectation that a diagnosis for the condition was imminent. Their baby was expected to undergo several medical tests and examinations for potential health conditions, but there was no expectation by these fathers that the tests would identify anything untoward. These fathers explained that they were aware of the newborn examinations, but they had no real understanding of the nature and implications of the diagnosis of these conditions.

### **6.2.2 Recurrent theme: Trust in the opinion of health practitioners**

Fathers made clear statements of their complete trust in the opinion of health practitioners. This was a notably strong recurrent theme which emerged from seven interviews.

*"I think I have to take their knowledge at face value and say, you know, ok that's fine, she's [his baby daughter] got this thing [DDH], but if she is treated now, that'll be ok and in the future."*

(James)

*"Who are we to challenge the professionals?"*

(Michael)

Although these fathers expressed their trust in the clinical opinion of health practitioners, conversely, three of these same fathers also gave considerable thought to challenging their opinion and to not proceeding with the treatment. Health practitioners had diagnosed DDH in these infants. However, these fathers felt that there were choices in the decision to proceed with the DDH treatment. What appeared to underpin these fathers' thoughts and considerations was their desire to quickly resume normality in their family life. This sense of wanting family normality is shown in the following extract from David's interview. He appeared to favour what he considered to be the benefits of the short-term disruption of his baby son undergoing an invasive operation, rather than wearing a non-invasive Pavlik harness for several months:

*"If you had said to me, 'It's non-invasive, he can go in a Pavlik harness and that keeps his legs apart or do whatever it does. That will be a slow progress over X amount of months and ultimately, he'll be alright, but it will last this long'. If you give me that option or you're giving me the option where they said, 'You can put him in for an operation. You can cut him open. You can actually do like physically something to him which is like worse, but he goes under general anaesthetic, but he'll be fixed in say half the time'. Well, I would have gone for that option. I was just dead impatient to sort of get it...I just wanted it done as soon as possible so it would mean he was alright. I would have took the choice where it's actually worse for him, just to get it done quicker. So you get to the point when you go, I know he's going to be alright. Time was an issue because I just wanted him to get to that point as quick as possible. It was sort of everything sort of seemed to stop from that point."*

(David)

For David, his idiographic perception seemed to be that DDH treatment brought a halt to family life with a new baby. He felt unsettled and consumed with worry about his baby condition, *"I wanted him to be alright"*. He seemed to be desperate for this feeling to end.

With similarities to David's experience, Michael, also considered refusing DDH treatment for his infant:

*"If it had just been my call, I would have been interested to find out what the options were. Could we have further scans down the line to see if it was getting worse? And honestly, at that point, I probably would have said: 'No', or I would have asked for their professional opinion. But I think if they say this is what we need to do, I think [my partner] was completely right in going for it, because who are we to challenge the professionals?"*

(Michael)

From Michael's extract, his perception of the situation is insightful. It appeared that he felt that it was the mother of his infant's decision to proceed or not proceed with the treatment. Michael also expressed a supportive attitude towards the mother and her decisions.

Although the father felt a sense of trust in the views of the health practitioners, it is not clear exactly why fathers trusted their opinion. It is particularly striking that three fathers stated their trust in the clinical judgements of the health practitioners, but still considered declining the treatment.

### **6.2.3 Recurrent theme: Immediate treatment; DDH treatment given at an early age**

The fathers' highlighted a positive aspect of their lived experience of caring for their infant with DDH. This was a feeling of reassurance that the condition could be resolved at a very early age in their baby's life using a simple device, over a short amount of time. This recurrent theme developed from six fathers' interviews:

*"Well, they picked it up very early on, because of the scan. They had a very simple way of dealing with it which was put this harness on. The harness was there, we had a couple of them. There were regular check-ups and as soon as it was done, it was dusted."*

(Michael)

Michael's reference to, *"it was done, it was dusted"*, gives a sense of full closure to the DDH treatment for his baby and a conceptual closure to his experience as the father of an infant undergoing treatment. This notion was also expressed by Chris:

*"It's fantastic that it was picked up at this stage and that we're doing everything that we can to make getting her back into a better position. We've done everything that we could have possibly done and you couldn't ask for anything more than that. There is nothing more that anybody could have done."*

(Chris)

It was clear from the preceding extract that Chris was pleased with the diagnosis. There is sense that he was at ease with the harness treatment. It also appeared that he felt that both his baby's mother and himself played an active role in the decision making for the treatment and managing the treatment, *"We're doing everything we can...we've done everything that*

*we could have possibly done*". The fathers seemed to take comfort and hope about the diagnosis and treatment.

#### **6.2.4 Recurrent theme: Negative emotions versus practicality of DDH treatment**

Many fathers felt that they were balancing their negative emotions against the practicality of DDH treatment:

*"I felt like that it was maybe going to be awkward and uncomfortable for the time that she was in it, but I thought that, realistically she's never going to remember that in her life, it's just going to be a thing that will be forgotten."*

(James)

As James remembered this episode, on a descriptive level, it seemed that he was referring to the '*awkward and uncomfortable*' practical aspect of the time his baby daughter was in the harness. On the other hand, conceptually, it could be suggested that James interpreted the whole situation as being '*awkward and uncomfortable for the time*' for him which created disruption in his life as he coped and cared for his infant.

During the interview with Steven, he expressed his feelings of anger, frustration and despair with the health practitioners for poor fitting of his baby's harness by the health practitioners which caused his baby pain and distress:

*"You don't like to see your children screaming and crying. I was just coming out of hospital; she's [his partner] in discomfort herself; you're in a bit of a haze; nobody's had a lot of sleep over the last few days; everything's kind of up in the air. You're like what do we do? What do we do? So it is difficult to try and get your head straight and think logically about what needs to be done. It wrenches your heart, and you feel a bit useless because you really don't know what to do."*

Although Steven's memories of this situation seemed to focus on the practical aspect of the DDH treatment and family life, there appeared to a negative psychological element with Steven's perceived sense of powerlessness. Steven conveyed a notion that he was out of control of the situation and that he had to rely on the health practitioners. He appeared to trust and rely on the health practitioners to fit his baby in the harness, but it was not done correctly; it caused physical distress to his baby daughter and psychological distress to the parents. Although he acknowledged that he was distressed and sleep deprived, he also

seemed to be grappling with his negative emotions, while simultaneously, he desperately wanted to provide practical support to his partner and baby.

This recurrent theme interlinks closely with a previous recurrent theme, 'Trust in the opinion of health practitioners. It seemed that fathers trusted the clinical opinion of the health practitioners, however, they did not always trust the ability of the health practitioners to adequately apply the harness to their infant. The poor application of the harness appeared to cause disruption to the family at a time when they seemed most vulnerable.

### **6.2.5 Summary of intermediate theme: Trust in the healthcare system**

For these fathers, it appeared that even before the health practitioners delivered the DDH diagnosis for their infant, there is a sense that they had confidence and trust in the healthcare system. The initial hip ultrasonographic scan felt like a "*routine*" health procedure (John; Michael). Generally, this notion of trust in healthcare continued as fathers reported feeling reassured about the treatment for the condition. They seemed to take comfort that the treatment was immediate, conducted over a relatively short amount of time, carried out early in their infant's life and at a time which their baby would not remember this treatment. Conversely, there were a few fathers who did trust the opinion of the health practitioners, and who considered declining the DDH treatment. However, the decision of the mothers of the infant to proceed with the treatment appeared to supersede any concerns felt by the fathers. For some fathers, it seemed that the treatment did pause and disrupt family life for a time. In a conceptual sense, the treatment appeared to put family life on "*hold*" (David). The consequence of this disrupted family situation seemed to compromise the negative emotional feelings of some fathers as they managed the practical aspect of their baby's treatment in the home environment.

### **6.2.6 Recurrent theme: Expectations of life with a new baby & re-adjusting these expectations of life with a new baby undergoing treatment**

This recurrent theme revealed the tension between the fathers' original expectations of life with a new infant, to their adjustment of their expectation of life with a new baby being treated with DDH. This theme emerged from interviews with six fathers. Moreover, this theme interlinked with the previous recurrent theme of the balancing of 'Negative emotions versus the practicality of DDH treatment'. An example of the inter-relationship between these recurrent themes is shown in Steven's quote about his emotional reaction to his baby daughter being placed in a harness:

*"It's not something that you ever kind of picture having to put your children in, it's that kind of...God!"*

There is a sense that this image, this "picture" of his baby in a harness was shocking. This shock was a reaction to his unexpected image of fatherhood and his life with a new infant. It seemed that Steven had his own expectations and the application of the harness challenged and disrupted his "picture".

Many of the fathers referred to feelings of positivity and sense of looking forward to embarking on a new life with their baby. They had plans, images and expectations of baby centred activities. Four fathers, specifically referred to special baby activities, such as bath time and swimming, being disrupted due to the harness treatment. Their re-adjustment and the need to be patient while they were in this perceived predicament was illustrated by Craig:

*"Then when we got the harness, we were just thinking about what can we do with her, like, while she's in the harness? She couldn't have a bath for ages and, you know, or go swimming with her, so we had to wait ages for her to go swimming and stuff."*

There is a notion of helplessness and despair in Craig's quote. At this point in the situation, he appeared to be struggling to adjust to the new situation, while also searching to maintain some of the expectations that he had of life with his baby. He wanted his new baby to enjoy new activities and he wanted to be a proactive father, but this struggle is captured in the comment when he questions, *"What can we do with her?"*

When placed in a harness, infants need to wear larger clothing to accommodate the harness. Under this recurrent theme, four fathers made specific references to clearing out their baby's wardrobes of newborn clothing which no longer fitted them and giving them to charity:

*"We found it really difficult to start with, what with clothes and stuff. Especially with clothes that people had bought her...because you get a lot of gifts that we couldn't use, so a lot of it went to charity straight away."*

(Andrew)

Andrew's comment and the similar comments by the other fathers including Craig, Scott and James, about clearing out newborn clothing from their home was particularly poignant. There was a deep sense that the act of removing of clothing from the home was

synonymous with change and the past. It seemed to represent a metaphor for the fathers' loss of their expectations of a new baby. For these fathers, the time with their babies being at the newborn stage was severely curtailed by the DDH treatment. There was an unexpected shift in these fathers' assumptions of life with a new baby. The fathers expressed sadness. There was a notion of grief for the loss of this special newborn time. Nevertheless, for Michael, he reconciled that once this feeling subsided, he adapted to the new situation:

*"We'd got used to it; we got used to the routine of it. I think once we realised that it didn't particularly affect him, then that was the bit that I was okay with."*

Michael adapted to the new situation by focusing his attention on the behaviour and mannerisms of his baby, which continued to be like a baby. The fathers' accounts suggested that although they re-adjusted their expectation of life with a new infant, to life with an infant with DDH, once the transition was made, they seemed to cope.

Conversely, during the interviews, there were some comments made by some fathers that appeared to give the impression that their expectations of new baby life and arguably their concept of fatherhood, was put on hold until the harness treatment was over. David alluded to this feeling in the following quote:

*"It was sort of everything sort of seemed to stop from that point. You are just sort of thinking... this is probably the man in me, but you are just sort of thinking, you just want him to get back to normal."*

Steven's baby daughter received harness treatment, but it had been unsuccessful. At the time of the interview, Steven's daughter was about to be fitted into a rigid hip harness. The next quote from Steven has similarities in tone and emotion to David's preceding comment. Here Steven expressed his frustration and a sense that he was trying to do all the baby activities that he expected to do, before his daughter was put into a hip cast:

*"We want to spend as much time with her and do the things that you should do out of the harness. That kind of stuff. It was frustrating when she had the harness and you couldn't give her a bath, it was like...this is one of the things that you, as a little baby, they love and you think...that's frustrating."*

Conceptually, there was a sense of adjustment. These fathers seemed to emphasise the barriers to family life with a baby in a harness, but there was an absence within the interviews about what they could do with their infants, other than maintaining a "routine" (Michael).

### 6.2.7 Recurrent theme: Feelings about the Pavlik harness

Fathers feelings towards the Pavlik harness was a dominant recurrent theme and it featured in eight out of the nine fathers' interviews. This recurrent theme interlinks with an earlier recurrent theme, 'Negative emotions versus practicality of DDH treatment'. Amongst these fathers' accounts, it was notable that they used metaphors to emphasise their negative emotions about the harness. For example, "*a straitjacket*" (Craig and Steven); "*a big huge contraption*" (Chris); "*a thing*" (James). These metaphors are illuminating as they reflected the initial feelings of the fathers and their sense of horror and contempt towards the harness.

Craig's account revealed his feelings of shock when he saw the harness for the first time:

*"When they brought it out, it just looked totally, totally weird. I've never seen anything like it, it was just...at first it was just, like, she'd been strapped up. It was just, like, she's been put in a straitjacket and she's got to stay like that and because I didn't even know nothing about it, so I didn't know what to expect. I didn't know what the harness was going to look like."*

When Craig and his partner were at home with their daughter as she wore the harness, the harness was rubbing on her skin and creating sores. Craig remembers his feelings of desperation to relieve his daughter from painful skins abrasions:

*"I said, maybe a T shirt might help, maybe something underneath so it wouldn't hurt her, because it was hurting us enough anyway that she had to be in a harness."*

Here Craig seemed to be grappling for practical solutions to help his baby, but he also appeared to be overwhelmed by his own negative emotions. The reference to his baby physically "*hurting*" and the reference to Craig and his partner as psychologically "*hurting*" presents a concept that this family unit co-existed as an extension of themselves.

For Andrew, at first, the experience of caring for his baby at home in a harness seemed chaotic and difficult:

*"We just had to muddle through, unfortunately, you know, she had to wear her harness all the time, and we found it really difficult to start with."*

There seemed to be no other option, for Andrew, but to cope and manage the situation. Conversely, during the interview, Andrew also recalled a memory with great fondness about

how towards the end of his daughter's harness treatment when the health practitioner replaced the white Pavlik harness for "*a hot pink harness!*" The fondness that Andrew placed on this memory appeared to underpin the transition of the harness from being a DDH clinical treatment, to becoming a garment which was child-like and fun. Specifically, for Andrew, he gave the impression that the bright pink colour of the harness seemed to enhance his daughter's femininity, and therefore, it gave her own identity as a person.

Three fathers presented another perspective as they reflected on their memories of their infant undergoing DDH treatment in a harness. The view of these fathers was that although the harness was awkward, but it did not impinge on their baby's development. Moreover, they appeared to take comfort that their baby would not remember this time:

*"It meant she was confined in that position, but it wasn't like she was crawling or anything at that stage, so it didn't really stop her doing too much."*

(James)

James had expectations of life with a new baby and to a certain extent, these expectations were being fulfilled for him.

It seemed apparent that for the vast majority of fathers, they felt repelled and emotional turmoil by the appearance of the Pavlik harness on their young infant. By the end of the treatment, a few fathers had some warm memories of this stage in their baby's early life.

### **6.2.8 Recurrent theme: 'Normal' baby versus 'abnormal' baby**

While a DDH diagnosis for the infant was a significant point in the clinical pathway. It was also highlighted by seven fathers as a conceptually significant point in their early fatherhood, as their baby changed from being "*normal*" baby to be a "*different*" baby (David; James). This recurrent theme interlinked with an earlier recurrent theme about fathers 'Expectations of life with a new baby and re-adjusting these expectations of life with a new baby undergoing DDH treatment'.

When James was being shown by the health practitioners how to clean and look after his infant in a harness, he felt a sense of paternal adjustment to the new type of fatherhood that:

*"It was obviously going to be different than having a normal baby"*

Fathers appeared to feel that while their baby was not normal, new baby life was paused in a moment in time. David reflected on his memories of this time:

*“Him being normal, as bad as that sounds, is on hold while he’s got all this on and it was almost like I couldn’t enjoy him, you know, in like a weird way. So I just wanted it boxed off and then he’s born again. I don’t mean born again like that, but you know what I mean. But he’s like...he’s just, you know, he’s alright.”*

David gave the impression that he wanted to have a close paternal relationship with his young infant, but he seemed to feel that the harness treatment had disrupted his ability to have the “*normal*” relationship that he expected to do with his son. James’ comments also seemed to support this concept that this harness treatment time was a time of perseverance until his baby was normal again. James decided to use a time chart to count down the days until his daughter’s harness treatment came to a close:

*Interviewer: “Why did you do the time chart?”*

*James: “I don’t know, like because I thought it was something to look forward to, to see whenever she’d be out of it and back to normal as it were.”*

The use of this time chart is very interesting as it gives a two-fold metaphorical image. Firstly, it offers an image of a prisoner counting the days of a prison sentence until the day of release. It also offers an image of someone who is incarcerated or confined in a space and this image could resonate with the reality of the restricted nature of the harness to allow the baby to move their legs.

It seemed that some fathers perceived their infant as different during the time that their baby was undergoing DDH harness treatment. A few fathers tried to manage this time by using psychological coping mechanisms. However, it is not clear why these fathers viewed their infant as “*different*” (David; James). Did these fathers consider their infant as different because of: the DDH diagnosis; the harness treatment; a change in home routine; the family dynamic?

### **6.2.9 Recurrent theme: Sought support from others in a similar situation**

The desire for fathers to seek support from other people in a similar situation to themselves was another very strong recurrent theme to emerge from eight of the fathers’ interviews. This recurrent theme also interlinks with the previous recurrent theme, ‘Normal baby versus abnormal baby’.

Initially, there is a perception amongst these fathers that they feel like their baby's DDH diagnosis is unusual. Some fathers felt that their baby was atypical or abnormal. However, when these fathers reached out and connected with others, they discovered that there were many parents with children who had DDH and many adults with a family history of DDH:

*"There was a guy on my shift at work who...one of his friend's daughter went through this as well. You know, someone in the local community who's been through it. Then whenever my wife went to the midwife, the midwife had obviously seen a few babies in the harnesses, so...I think, I guess, it's just reassurance that other people have been through it, that it's not an uncommon thing."*

(James)

*"I was talking to a friend, someone at work about it, and I was saying 'Oh my son's, you know, he's got hip dysplasia and he's in a Pavlik harness'. Then someone would go 'Oh my daughter's son had that', or whatever, you know, my grandson had that, or 'Oh yeah, my cousin's kid had that'. And I'm like, pretty much everyone...not everyone, but it seemed like so many people that I talked to had it, and the fact that they were like 'Oh yeah', really put my mind at rest."*

(Michael)

It was important to James that the situation with his daughter being in the harness was not *"uncommon"*. For Michael, the emphasis of normality was that the DDH condition was well known amongst his circle of friends and work colleagues. Michael's mind was not at *"rest"*. He was unsettled and felt anxious about his baby son's condition. Interestingly, from a conceptual perspective, Michael also found his son's DDH diagnosis to be a *"talking point"*. Michael considered it a means of connecting with others about his new baby son's life:

*"There was something almost special"*.

On the other hand, some fathers like Andrew, felt that they had received professional information and guidance from the health practitioners. However, he seemed to want to look beyond his perceived veneer of the professional opinion:

*"It's all very well the Consultant telling you this is what's happening, but for me, personally, I feel it's better if you've got someone who's gone through the experience themselves. You can relate more."*

Andrew wanted to connect with other parents who had been through the experience. He felt that the parental DDH experience conveyed by the health practitioners was a different experience for the parents at home caring for their baby. He considered that other parents were the gatekeepers of other information in which “*you can relate more*”. Andrew gave the impression that, maybe other parents could offer ‘insider’ information that the health professionals are not privy to. Andrew seemed to perceive the Consultant as detached from his family situation, but he appeared to view other parents as more emotionally and practically engaged with the caring of a new baby undergoing treatment for DDH. There is a sense that Andrew trusted and valued the perspective of other parents and he felt that they would tell him the reality of caring for a baby undergoing this type of hip treatment.

The outcomes of the conversations with other people seemed to have helped these fathers normalise their current family situation. Also, possibly, it gave these fathers a sense of hope for their child, and sympathy for other people who have had a similar experience.

Conceptually, it could be suggested that these fathers felt that by reaching out and connecting with others outside of their family circle helped them to re-adjust to the notion that fatherhood can bring unexpected situations.

#### **6.2.10 Recurrent theme: Father and baby attachment relationship**

Another major recurrent theme to emerge from the data focused on ‘father and baby attachment relationship’. This theme featured amongst eight fathers’ interviews. It was characterised by the careful balancing act of fathers’ adhering to the DDH treatment of caring for their baby in the harness, but also their overwhelming desire to form a psychological attachment with their baby. Craig’s emotional recollection revealed the conflict in his parental responsibilities to his baby:

*"We were asking the nurses if we could have another harness, just in case she exploded her nappy all over it [in case baby soiled it]. But they were saying, ‘Just put it in the wash’, but they didn’t want us to take her out the harness, so it was just, like, we can’t win either way. So we can’t take her out, so you want us leave her in it, we can’t bath her, so you want us to leave her in a dirty harness. It’s just a bit weird. Why would I do that? If I got food down my clothes, I’m not going to stay in my clothes with food down it, I’m going to swap it or I’m going to clean it."*

This father referred to the challenges of being a good caring parent, while adhering to the instructions of the health practitioners. There is a sense of conflict and the pulling of parental responsibilities. There is a metaphorical game of ‘Tug Of War’ between the father and the health practitioners, as Craig says: “*We can’t win either way*”. The instructions of

the health practitioner appeared to go against the parental caring norm; the norm of a parent caring for an infant by keeping them clean. Craig viewed the instructions of health practitioners not to take his daughter out of her harness for daily cleaning as “a bit weird”. There is a sense that Craig felt like he wanted to follow the health practitioners’ instructions and maximise the likelihood of successful DDH treatment with the harness. However, simultaneously, he felt like he was neglecting his baby. The depth of Craig’s extract conveyed his real sense of his despair, then he conceded to the instructions of the health practitioners instead of his own parental judgement. He did not explain further why the opinion of the health practitioners overrode his own parental perspective.

Steven also desperately wanted to form a psychological paternal relationship with his new infant. As he cared for her as she underwent treatment, he thought that he could be seen as the “bad guy” by his very young baby daughter:

*I would be the one that would put her in the harness and I’d just put her in, but then I also liked to take her out of it in the morning, so I’m not just the bad guy all the time putting her in the harness. Especially in that last couple of weeks when she’d been out of it all day, and then I’d strap her up in the harness again. It’s like putting her in a straitjacket for the night, you know. I really felt bad for her, but whether she felt that way or not, who knows?*

Even though Steven’s infant would not remember undergoing this treatment, there was a sense of emotional turmoil and struggle for this father. He desperately wanted a positive outcome for his baby in this harness and health practitioners often encourage parents to place their infants constantly during this period of weeks or months in a harness. On the other hand, he wanted an emotional attachment with his baby and did not want her to regard him as the ‘villain’. Steven shared the same sentiments as Craig and other fathers in this study that, ultimately, they wanted the best outcome for the baby.

#### **6.2.11 Recurrent theme: Relationship between father and the baby’s mother**

During the time between DDH diagnosis and the closure of treatment, some fathers revealed an illuminating dynamic relationship between the baby’s mother and themselves. Three fathers stated that they perceived their primary caring role within the family as a supporter and comforter to the infant’s mother and as the facilitator for the continuation of normal family life, as opposed to playing a direct caring role with their baby. John is father

to three young children, and he felt that while his new baby was undergoing harness treatment for DDH, it was his role to ensure that family life for his other two children continued as normal:

*"I guess my role, I think, as it was at the time, was just sort of trying to comfort Sue [his partner/ infant's mother] and be normal, and just you know, carry on with the life with the other kids. If the baby can cope with it, then we've just got to get on with it, and just lead normal lives. Life's too chaotic not to be normal when you've got three kids."*

There is also a sense here that John needed family life to resume to normality. Michael does not hesitate to state that when he went with his partner and baby to the DDH treatment monitoring appointments that:

*"I went for her, not for him...I went for moral support for her."*

Several fathers believed that their baby's DDH diagnosis had the greatest impact on the baby's mother/partner:

*"It definitely affected her more; you know, she was upset by it, but I just kind of, carried on."*

(Scott)

*"I guess she was pretty devastated. I think she was thinking well this is my little baby"*

(John)

However, these fathers do not further expand on why they thought that the baby's DDH diagnosis had a greater impact on the mother.

At times, there is a perception that the fathers were putting on a 'performance' for their partners and families:

*"I think because she was finding it harder, it's that natural thing that you look after them isn't it? Whereas if she'd have been like: 'Meh, it's fine'. I...maybe I would have been the weaker one, and like: 'Oh I'm finding it really difficult.'" But I kind of kept it all internal, a lot of it, until he was okay. Then I kind of expressed how difficult I found seeing it, seeing him in those braces for the first time. But, you know, by the end of it, those ten weeks flew in the end."*

(Michael)

At this point, Michael seemed to perceive roles within his relationship with the baby's mother as having a 'strong' and 'weak' dynamic. Since he viewed the mother as taking up the 'weak' position, he argued that although he felt vulnerable, he had to occupy the 'strong' position. It was only when his son's treatment came to an end that he felt he could reveal his 'weaker' self to his partner. Yet, it is not clear from Michael's account exactly why he chose not to reveal his true feelings about the situation to his partner until the treatment was finished. It is possible that Michael was trying to maintain normality within the family and home environment.

#### **6.2.12 Summary of intermediate theme: Biographical revision to the new father role**

The recurrent themes that emerged from the fathers' interviews revealed that they had clear expectations of early fatherhood and family life with an infant. However, in this study, the vast majority of fathers felt that caring for their baby with DDH was different. Yet, for these fathers, it is not exactly clear why this experience was different. Fathers felt that they had to re-adjust these expectations. Interestingly, many fathers tended to focus on the barriers of fatherhood with an infant with DDH and the importance of maintaining a daily baby routine. Most fathers were repelled by the Pavlik harness, but they managed to cope and adjust to this new family situation. On the other hand, it could be suggested that parenting a young infant is a dynamic situation which brings assumptions, expectations and adjustments to these expectations as reality of parenthood unfolded for these fathers.

It was illuminating that fathers sought support from other people outside of their family and healthcare circles who had DDH experiences. For the fathers in this study, it appeared that knowing about other people's DDH experiences and having the opportunity to share their own experience with other people helped to normalise family life for them. There is a sense that these supportive conversations also seemed to make fathers feel less different to other fathers. Many fathers sensed a dichotomy in their perception of early fatherhood and their relationship with their baby. They felt that they were striving to make a psychological attachment to their baby, while also caring for an infant undergoing DDH treatment. They appeared to struggle to reconcile this perceived dichotomy. Some fathers viewed their principle family role as ensuring the continuation of the family routine and as the comforter to the infant's mother. The conceptual term 'biographical revision to the new father role' sums up the perspective of the lived experience of fathers caring for their DDH baby.

### 6.2.13 Recurrent theme: Acquisition of information

The acquisition of information was a very strong recurrent theme amongst eight of the fathers in this study. It was apparent that the mothers of the infants with DDH were the main conduit for information about DDH from the health practitioners. Receiving information on a 'second hand' basis from the mother of their infant was reported as a source of great frustration for fathers:

*“As a dad you’re left out of that whole process because normally after a couple of weeks you return back to work and your wife’s off, so she’s kind of supported throughout that whole thing. Whereas when you [fathers] get home, you just get information from your wife who you’re then having to support, so it’s difficult because you have to kind of just accept everything that’s being told. You don’t get an opportunity to challenge it in any way.”*

(Steven)

Clearly, Steven vented his frustration as he wanted information to be given to him on a first-hand basis, but he had to hear it on a second-hand basis through his partner. He desperately had questions which he wanted to ask, but he did not have the opportunity to ask them. On one hand, conceptually, it could be viewed that Steven wanted a thorough understanding of the DDH information to allow him to rationalise the situation. Or he might have felt that he wanted to manage the information when he expressed: *“You have to kind of just accept everything that’s being told.”* However, he could have been trying to regain his own control of the situation. For David, he was distraught, and his emotional turmoil seemed to exhibit itself by his overwhelming desire to know more information from his partner about their son’s DDH diagnosis at the hospital:

*“You just sort of want to know more. You want to know everything to the nth degree and like when she told me everything to the nth degree but it’s sort of not enough. You sort of want just more information.”*

There is a sense that David wanted to control the situation for his own sake. He expressed frustration and annoyance that he was not present at the diagnosis where he would have obtained all the information directly rather than receive the information conveyed through his partner. It appeared that he wanted to be included in the care of his baby and be privy to the information first hand. Maybe he felt isolated in the care of his baby because he wanted to be confident in his own infant caring ability.

As well as mothers being the main conduit for information, fathers also utilised the internet as a key source of obtaining information about DDH. Fathers specifically cited the 'Google' search engine as their first point of acquiring information. Others sought information directly from a DDH parents' charity website, Steps:

*"Obviously, I did look stuff up on the internet"*

(James)

James comment raises a number of questions for the health service. It is arguable whether it is "*obvious*" to seek health information on the internet. Should parents as carers be expected to find out health information on their own? Furthermore, in Andrew's experience, he made a conscious decision to devote time to source DDH information from the internet. This was at a stressful time in family life as he was adapting to caring for a new baby, who also had DDH treatment care needs:

*"We kind of made an effort to find out more about it"*

This recurrent theme about the acquisition of information by fathers, especially from the internet, interlinks with the next recurrent theme about 'Frustration with the information provision by the health practitioners. Based on the fathers' experiences highlighted about searching the internet for DDH information, it raised the question whether it is the responsibility of health practitioners to provide accurate, evidence-based information to these parents? It seemed that the infant has received a diagnosis and has been given treatment, but the information support to parents appeared to be lacking. In a sense, who is caring for the carer?

#### **6.2.14 Recurrent theme: Frustration with the information provision by health practitioners**

A notably strong theme to emerge from the interview data focused on seven fathers' feelings of frustration with the information provision by health practitioners. Most notably, Scott's interview was dominated by his own sense of frustration and despair with poor information provision by the health practitioners:

*"I was genuinely quite shocked at how poor the information was in the hospital. I thought the materials that they gave you were pretty diabolical. Like, 1000th photocopy of some tatty old...you know what I mean; you could barely read it."*

He also lamented that *“it was awful”*. He recalled that neither his partner nor himself were given an actual website to research for DDH information:

*“The Physio [physiotherapist] just sort of said ‘Oh yeah, just Google it’.”*

Although Scott perceived that both his partner and himself were given poor information by health practitioners, it could be suggested that this element of his experience of caring for his infant with DDH, conceptually, reflected Scott’s sense of frustration with feelings of disempowerment. His frustration was not about the quality of the information, but more about his own frustration with his lack of empowerment as a father, within the unfolding DDH healthcare situation.

Andrew offered an insightful reflection. He would have preferred more information through the stages of the clinical pathway towards his baby daughter’s diagnosis. Also, he would have preferred greater transparency and sensitivity from health practitioners. Through these stages from routine hip screening to a DDH diagnosis, he needed time to psychologically prepare for any potential diagnosis:

*“Once we got the referral, we were ok; once we had been told that she had DDH and this is what is going to happen. But up until that point we were under the illusion that everything was still perfectly fine. Whereas, if they had made their referral and told us that they thought something was wrong...even some more information between the test and the first meeting would’ve have been better. Just so we knew what we were going in for. It was just wrong to be honest. I was just really disappointing. If they’d said...or maybe just explained it a little bit more, you know, we found this when we were doing our checks and it may relate to something else. They didn’t explain anything. They just said: ‘We’re referring you to a Consultant.’”*

Much to his frustration, Andrew stated that he was under an *“illusion that everything was perfectly fine”*.

Throughout this recurrent theme, the fathers seemed to convey that if they had received a clearer explanation of the situation, they would have felt less frustration. Moreover, it could be suggested that fathers would have felt more empowered to manage the disruption to their family life, had they had more preparation for the role.

### **6.2.15 Recurrent theme: Lack of sensitivity by health practitioners**

In the participant interviews, fathers were asked if there were any prominent positive or negative aspects of their experiences of caring for their infant with DDH. Fathers highlighted both excellent and poor encounters with health practitioners. Five fathers identified a negative aspect of their experience, which was the lack of sensitivity and support from health practitioners, with regard to their plight as parents, as they follow the DDH pathway with their young infant:

*“I remember being particularly annoyed at the absolute lack of sort of empathy for what you were going through. I’m sure it’s all pretty routine to them [health practitioners], but I remember...it is just a dead big deal to you. When it’s your own kid, it’s completely different. It’s like, it’s just magnified.”*

(David)

*“I think any negative news to do with a child, no matter how old they are, I’m sure is horrible, but at that early age...it’s just you need a bit more kind of emotional support. The things that go through your head when you hear that news [DDH diagnosis] are just so dark and horrible.”*

(Michael)

At this time, some fathers felt particularly vulnerable and they looked to health practitioners to provide this emotional support. They also wanted health practitioners to draw on their interpersonal skills to acknowledge and admire the ‘new baby status’ of their patient to the parent of the child.

This recurrent theme, ‘Lack of sensitivity by health practitioners’, captured the negative elements of fathers’ experiences of caring for an infant with DDH. It also interlinks closely with the next recurrent theme, ‘Supportive health practitioners with information provision’, which highlights the most positive aspects of these fathers’ experiences during this time.

### **6.2.16 Recurrent theme: Supportive health practitioners with information provision**

In contrast to the previous theme, there were fathers who had very positive experiences with health practitioners. Six fathers referred to the constructive efforts of health practitioners to clearly explain DDH and the treatment to them. Notably, two fathers

reflected on the occasions when health practitioners used hip scan images and drawings of infants' hips to explain DDH and its treatment:

*"I had a really good sort of understanding of the condition. I totally understood it. Probably the most useful thing that made me understand it was he [consultant] just drew a picture. I remember him drawing a picture going, like her hips here. This is here. What we are going to do is we are going to do this and that. He was just sort of saying like 'This is a bit flat like the socket and, look, this is out here and that should be there and so what we are going to have to do is do this and this.' He made it sound dead matter of fact, which I liked."*

(David)

For James, he appreciated the clarity of the thought processes and decision-making by the midwife who conducted the physical hip examination on his young daughter. He felt reassurance that the referral for an ultrasound hip scan was a "double check" of his daughter's hips:

*"The midwife wasn't sure, so she did the right thing and said 'Well, we need to have a full referral and we'll have a scan of those hips.'"*

It appeared that fathers felt reassured and supported by the health practitioners when they were given a clear, transparent explanations at each stage of the clinical pathway. In a sense, fathers had a more positive lived experience of caring for their baby with DDH when health practitioners empowered them with information.

#### **6.2.14 Summary of intermediate theme: Empowerment through the acquisition of information**

In this study, a key issue for the vast majority of fathers was the acquisition of information about DDH. Furthermore, from the fathers' perspective, it was striking that they had clear thoughts about expectations of the pivotal role they felt health practitioners had in relation to delivery of information. Across the fathers' interviews, during the diagnosis and treatment of their baby with DDH, they had equally positive and negative experiences and encounters with health practitioners. Interestingly, these positive and negative health practitioner experiences were underpinned by quality of the information given to fathers. The majority of fathers expressed frustration with receiving information by proxy through the mother of their baby. They were also frustrated with the general quality of DDH information from health practitioners. Several fathers had positive experiences with the delivery of information. These encounters were characterised by health practitioners taking the time to explain in a clear and constructive manner about the nature of DDH and its associated treatment. At the

diagnosis and early treatment stage, some fathers recalled feeling emotionally vulnerable and looked to health practitioners for acknowledgment, empathy and support with their parental and new baby status. Some fathers consulted the internet to empower themselves with information about DDH. Conceptually, it is possible that these fathers felt isolated and disempowered with the lack of DDH information provided. If empowered with information about the condition, stages of treatment and prognosis, fathers may have felt more empowered to manage the disruption to the family at this time.

#### **6.2.15 Summary of the superordinate theme: Managing the disrupted family**

The three immediate themes, 'Trust in the healthcare system'; 'Biographical revision to the new father role'; 'Empowerment through the acquisition of information', contributed to the development of an overarching superordinate theme, 'Managing the disrupted family'. In this study, most fathers trusted the opinion of health practitioners and during the interviews, they reflected positively on the method of treatment for DDH. It was immediate; non-invasive; and applied at a young age over a short period of time, which minimised any impact on the infant's development. However, some fathers felt that the DDH diagnosis and treatment disrupted their family life.

Fathers revealed that they had to revise their original expectations of early fatherhood and new family life. Even though this was a temporary disruption to family life, these fathers perceived that their DDH baby was different from normal infants. Also, these fathers seemed to rationalise and manage this family situation when it was a shared experience with other people outside of their family circle. When discussing their infant's DDH diagnosis and treatment with work colleagues and friends, there was a sense that these conversations facilitated these fathers' perception that having a baby with DDH was relatively common, which gave them reassurance and helped these fathers to feel more 'normal'.

The fathers expressed self-awareness of the importance of father and infant attachment relationship and appeared to strive to make this psychological connection. Rather than playing a primary carer role to the baby, some fathers perceived their role was to manage and minimise disruption to the family unit by playing the role of an emotional supporter to the mother of the infant, as well as caring for the other children in the family and reducing any disruption or impact upon them.

Fathers expressed frustration at the lack of information about the DDH diagnosis and its associated treatment and they possibly felt disempowered to cope with the unexpected disruption to the family situation. Their lack of knowledge spurred some fathers to research and acquire information about DDH for themselves. By managing the disrupted family, these fathers may have been trying to mitigate the anxieties of the mother and possibly, themselves.

### **6.3 Chapter summary**

This chapter presented the analytical findings of the lived experience of nine fathers, as they cared for their infant with DDH. From the analysis emerged three intermediate themes: Trust in the healthcare system; Biographical revision to the new father role; Empowerment through the acquisition of information. From the intermediate themes developed a superordinate theme, 'Managing the disrupted family'. As mentioned at several stages throughout this study, it is important to highlight that this analysis was conducted using IPA, which involves the active contribution of interpretation by analyst to the dataset (Smith, Flowers and Larkin 2009). Therefore, it is important to note that these analytical interpretations were offered by the analyst. Other commentators may have their own interpretations and nuances about the data.

The findings of the fathers lived experiences of caring for an infant with DDH will be explored in Chapter Eight, the Discussion chapter. The next chapter provides a collective comparative summary of the mothers and fathers findings.

# Chapter Seven: Comparing the lived experiences of mothers and fathers caring for their infant with DDH

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## 7.1 Chapter overview

The last two chapters of this thesis presented the findings of the interviews with mothers (see Chapter Five) and fathers (see Chapter Six). The purpose of the present chapter is to understand the collective lived experience of *parents*, as mothers and fathers caring for the infant with DDH. During process, it will specifically explore the patterns of convergence and divergence across the cases of the mothers and fathers in this study (Eatough and Smith 2017). In addition, it will capture the significant meanings of this experience to these parents (Smith et al 2009). It will also highlight the common themes which emerged during the analysis of the interviews with parents: **the role of the healthcare system; relationship dynamics; acquiring and understanding information about DDH; the application of the Pavlik harness on the infant; adjusting expectations of parenting an infant undergoing DDH treatment; perceptions of 'normal' and 'abnormal' parenthood; the importance of the attachment relationship between parent and infant.** The findings will be supported with both new quotes as well as some of the previous quotes from earlier findings chapters. This is a summary chapter of parental experiences of this phenomenon focusing on the most salient parental perspectives in which mothers and fathers converge and diverge on nuances of their experience.

It is important to address that this is a potentially controversial chapter for purist IPA researchers. Bringing together the findings of the lived experiences of mothers and fathers, which could be argued to be contrary to the primary focus of IPA; to elicit the unique and nuanced experiences of people. The primary focus of this methodology and research question was about exploring the individual lived experience of mothers and fathers caring for a baby with DDH, and this was captured in the earlier findings' chapters (see Chapter Five and Six). It is argued that this chapter should be viewed as the latter analytical stage of IPA; the part of the hermeneutic circle that moves between the understanding the part and the whole of their parental lived experience (Smith et al 2009).

IPA methodology is a dynamic and evolving methodology (Smith et al 2009; Eatough and Smith 2017). There is a clear need for this chapter in this thesis, in terms of understanding this parental experience for the literature base and the implications of the parental findings. An alternative argument is that if this chapter did not exist, and the earlier findings chapters were separate isolated entities, the audience of this thesis would reflect and question: *'What are the similarities and differences between the lived experiences of mothers and fathers as they cared for their DDH baby?'* Therefore, there is a clear justification for this chapter.

## 7.2 Themes

### 7.2.1 The role of the healthcare system

On the theme of the role of the healthcare system, the findings of the parental interviews revealed an element of convergence, and also, surprisingly marked elements of divergence in the lived experiences of this phenomenon. Both mothers and fathers converged on their perception that the ultrasonographic scan of their infants' hips was part of a routine system of health checks for an infant:

*"I think it was made out to be routine, too routine, and it wasn't, you know. Looking back, I was so blind to it, but that's how it was made out to me, so it was a routine thing."*

(Kirsty)

*"In my head, I thought it was just a formality, almost to check that there was nothing there"*

(James)

*"We didn't think he was going to have it at all and normally, I go to appointments, but at this point, I didn't even bother going because I thought it was an absolute formality [routine appointment]."*

(David)

In this study, there seemed to be a sense of frustration by many of the parents with the healthcare system. They seemed to feel frustrated because they perceived that they were made to feel complacent about the ultrasonographic hip scan by the healthcare system. As Kirsty stated above, *"I think it was made out to be routine, too routine, and it wasn't"*.

On the other hand, mothers and fathers held very different perceptions about the role that they played within the healthcare system. All of the mothers stated that they felt like bystanders to their infant's healthcare. As the health practitioners gathered in the clinic room to conduct their clinical investigations, they used exclusive language and cues amongst themselves to convey their suspicions of a DDH diagnosis for the infant. Mothers felt on the "outskirts of it" (Jennifer) isolated in the clinic setting. Their accounts of this time gave a sense that they wanted to be involved in the discussions about their infant. This is illustrated in Jennifer's poignant account:

*"I could tell that something wasn't right from the fact that they were kind of... everybody was very quiet. That's kind of how it felt. And then they didn't really give much information, really, other than to say that they needed him [her baby son] to see a consultant today. The sonographer was there. There was a student who was there. I think there was another member of staff as well and they were all kind of conferring and saying, 'Oh you know, that's who we need to refer to', but obviously I wasn't aware of who this person was, why they were referring me, what the problem was? Then when I kind of said 'What's the issue?' They said: 'He's definitely got Developmental Hip Dysplasia.' "*

Whereas the fathers appeared comfortable with the system of healthcare. They seemed to be content in their perceived role within the healthcare system. In this study, the fathers appeared to express an element of detachment, possibly, a lack of responsibility and accountability, from the clinical investigations:

*"We were already in the system. He was like, high risk. He was automatically, like, just checked."*

(David)

*"I kind of see it as, "Well, it's fine because it's sorted out," You know, better now...better that it gets dealt with. It is dealt with, so it's good that they're dealing with it. I'm pretty much matter of fact about these things."*

(Scott)

David and Scott's comments could imply that they were comfortable with the clinical decision-making remit that was being held by the health practitioners.

Furthermore, the findings of the fathers' interviews indicated their trust in the system of healthcare. Conversely, a few of the same fathers who expressed this trust, also gave consideration to declining the immediate DDH treatment with the application of the harness:

*"If it had just been my call...honestly, at that point, I probably would have said: 'No', or I would have asked their professional opinion. But I think if they say, 'This is what we need to do, I think [my partner] was completely right in going for it, because who are we to challenge the professionals?"*

(Michael)

*The Consultant was very nice about how he said, you know: 'This is the situation guys, both your children have got hip problems, and they both need intervening'. When we [John and his partner] discussed it afterwards, it was like...got no issues with how he'd broken the news to us, but what if we sort of refused? What if we say, 'No, actually, we don't want this?'*

(John)

In the interviews, when these fathers explained that they had given some thought to declining the treatment, their reasoning was due to their perceived disruption to the family and home environment.

### **7.2.2 Relationship dynamics**

Unsurprisingly, the concurring findings from the parental interviews revealed that their relationship with their infant was at the forefront of their primary concerns. The importance of this parent-child relationship is threaded throughout all three findings chapters. Furthermore, for mothers, another key relationship was with the health practitioners. Conversely, for fathers, the relationships which were their priority tended to be his relationship with the mother of his infant and his relationship with his baby.

In this study, mothers experienced both positive and negative relationships with health practitioners. When mothers were asked about any positive aspects to their experience of caring for their infant with DDH, a positive relationship with a health practitioner often defined this part of the experience. This relationship was at its strongest when health practitioners acknowledged and supported them in their maternal role with a young infant; expressed empathy and used their interpersonal skills to convey information, and gave

practical and emotional support. In the following extract, Emma recalls her appointment with an ultrasonographer:

*“The second ultrasonographer...I think she was probably head of department, she was very honest and chatty and quite like, you know, she was quite open about saying: ‘You know what, I’m not sure. Let’s go and take these images to the surgeon’. So that was quite good. It was very positive.”*

(Emma)

This comment made by Emma was one of several quotes by mothers in this study who cited the solid interpersonal and communication skills of a health practitioner as a notably positive aspect of her overall lived experience as she cared for her infant with DDH.

However, a challenge which mothers faced which could have been improved by a supportive health practitioner was breastfeeding a baby in a harness. This issue was raised by several mothers:

*“She [health practitioner] just said, ‘You should be able to breastfeed fine. She said, ‘You do need to make sure that you don’t move it out of position. But she said, you should be able to feed her. That was it, yeah.”*

(Nicola)

Many of the mothers who were breastfeeding their baby before the application of the harness, did not continue with it as they felt that they did not have the appropriate information and support from health practitioners. Considering this was an important issue for the mothers in this study, interestingly, this issue was absent from the fathers’ narratives.

In contrast to the mothers’ experiences, fathers often identified the most negative aspect to their lived experience of this phenomenon was a frustrating relationship with a health practitioner. Furthermore, they were frustrated with health practitioners about the poor information provision, as well as lack of sensitivity towards their unfolding clinical situation with their young infant. This is illustrated in David’s quote with an ultrasonographer:

*“I remember being particularly annoyed at the absolute lack of sort of empathy for what you were going through. I’m sure it’s all pretty routine to them [health practitioners], but I remember...it is just a dead big deal to you. When it’s your own kid, it’s completely different. It’s like, it’s just magnified.”*

(David)

In David's account, he considered the health practitioner to have poor interpersonal skills and that they lacked sensitivity towards the parents who felt vulnerable because of the DDH diagnosis for their baby. The lack of emotional reaction or sympathy by the health practitioner to worried parents was highlighted by several fathers as a negative aspect of this lived experience.

In the findings from the interviews with mothers of infants with DDH that there was a noticeable absence of references to their relationship with the fathers of their baby. Although they mentioned their presence during the span of this experience, the mothers did not mention the impact of their infant's DDH diagnosis and treatment on the fathers. These quotes from the mothers illustrate this point:

*"We both went to the hospital. My partner and I both went 'cause he was still off work at that point."*

(Nicola)

*"My partner was in the car in the hospital car park and I just went in with her [the baby]."*

(Lisa)

During the interviews, without any prompting or queries by the interviewer, fathers emphasised that they felt that the mothers felt the greatest impact of their infant's DDH diagnosis and treatment. They saw their role as supporter and comforter to the mother and the key family member to facilitate the continuation of day-to-day family life:

*"I think, you know, that it really...probably, hit her quite hard at the time, and I was probably a little bit less, you know, bothered by it, 'cause merely just enquiring and understanding what's going on and what was going to happen, I guess. My role, I think, as it was at the time, was just sort of trying to comfort my partner and be normal. Just you know, carry on with the life with our other kids, etcetera."*

(John)

*"You're there having to try and hold the wife who has just had the baby and everything else, so you do feel a little detached from the process, but you're still having to deal with the baby in the harness."*

(Steven)

Similarly, both mothers and fathers highlighted that they sought support from other people. Yet, there was a difference in the type of social circles that parents looked to for this support. Mothers spoke about the psychological support they sought from their immediate family. They also pursued psychological, information and practical support from internet forums with other DDH parents. The following extract exemplifies Louise's experience, as she referred to social media for further information about DDH:

*"You read everybody's stories on the Facebook pages, and you think: 'No, that's not going to happen to us, this [Pavlik harness] is going to work.'"*

Whereas none of the fathers mentioned seeking any support from their families. They just spoke about the psychological support they sought and received from people in their employment and friendship circles. This is shown in the following quote from one father:

*"Someone at work has got it and some of my mates at work's family have had it and they've been telling me about what they've gone through."*

(Craig)

Noticeably, fathers emphasised that they wanted to know about the reality of care for DDH from other people, as opposed to the care of a DDH baby from the perspective of the health practitioners. The following comment from Andrew encapsulates the view of some fathers:

*"It's all very well the consultant telling you this is what's happening, but for me personally I feel it's better if you've got someone who's gone through the experience themselves."*

### **7.2.3 Acquiring and understanding information about DDH**

The findings from both the mothers and fathers' interviews revealed that both groups had the collective impression that there was a lack in information provision by the health practitioners about DDH. Often the poor information provision by health practitioners prompted parents to search the internet for DDH information. Parents highlighted searching 'Google' for information and the Steps charity website:

*"He [health practitioner] didn't tell me what it was called. I didn't know she had DDH, all I knew was that there was something wrong with the socket. He didn't explain anything like that, or whether he did, I don't know because I tuned him out. My partner was with me and he doesn't remember him really explaining either. So when I got home I went on 'Google' and I researched it all and then I found out it was DDH myself. Then I read all about it and then I got all upset again."*

(Louise)

*“We mostly got information from Steps. They were really helpful. Speaking to people on the forums on the website was handy.”*

(Andrew)

*“The booklets are very limited though because they’re all fact based, there’s nothing on experience. I don’t think there’s enough time taken. They kinda give you a quick guide.”*

(Steven)

When health practitioners gave mothers and fathers clear information it was gratefully appreciated and improved their understanding of the condition and the need for treatment:

*So, he showed me, he showed me the position of her hip and things, and he drew it on a paper, and things, really explained it a little bit more to me.*

(Louise)

*I remember the surgeon explaining to me, dead clearly. He showed me and explained things with the actual x-rays on the computer. He was just sort of saying, like, ‘This is a bit flat like the socket and, look, this is out here and that should be there and so what we are going to have to do. This and this and this.’ He made it sound dead matter of fact which I quite liked, so I knew totally.*

(David)

On the other hand, fathers’ experiences about the delivery of information diverge from mothers. It was an interesting key finding that the majority of fathers emphasised their frustration about mothers being the conduit for information.

*“I remember trying to find out exactly what the nurse had said. I remember being told by my wife what it was [a diagnosis for DDH], and you know, you get information second hand. I was saying, ‘What did they say about this and what did they say about that?’ I think it was a bit of a shock when she was told, so maybe she never took everything in as well.”*

(David)

*“For a dad, the whole experience, it’s a little bit second-hand or even third-hand. You’re a little detached from it. You don’t get the first-hand information as frequently or as quickly. Sometimes I thought that if I was there, I would have asked that or challenged that, so it was a little harder.”*

(Steven)

There is a sense from the fathers' accounts that they wanted to be an active caregiver to their young infant and supportive to their baby's mother, but they lacked information to understand the DDH diagnosis and treatment for their infant.

Another aspect in which there was divergence in the experiences between mothers and fathers was that all the mothers appeared to perceive the searching and acquiring information from the internet as an empowering activity. Mothers felt confusion and many lacked information about DDH at the diagnosis stage, but by the time they attended the treatment monitoring appointments in the hospitals, they had a clearer understanding of the condition:

*“By then, obviously, we'd done a little bit of research, so we knew what numbers we were looking at with the angle. When she had the ultrasound, I saw that she wasn't hitting the 60-degree angle.”*

(Laura)

*“By this point, I'd done that much research myself that I knew pretty much what he was telling me anyway. I knew the second he said, 'It's not working'.”*

(Nicola)

There was a notion that the acquisition of information about DDH for mothers was a means of re-gaining control of the healthcare situation about their infant. It also empowered mothers with the knowledge to advocate on behalf of their baby, and challenge health practitioners about the DDH treatment and home caregiving guidance.

#### **7.2.4 The application of the Pavlik harness on the infant**

There were similarities in the vivid language and emotions embroiled with the physical look of the harness expressed by both mothers and fathers. They felt repulsed by the harness:

*“I hated it [Pavlik harness]. I thought it was so brutal looking; the straps on her. It just looked awful, I thought.”*

(Sarah)

*“When they brought it out, it just looked totally, totally weird, like I have never seen anything like it. At first it was just like she's been strapped up and she's got to stay like that, so it was weird.”*

(Craig)

Parents highlighted the struggles at home with the harness. However, as time passed, they felt that they got into a routine of managing and caring for their infant:

*“I think I found it very...the first few days were hard. I think, I just didn’t even do much the first few days, ‘cause I was just...trying to come to grips with how to get a routine and like: How do you change a nappy and do all these things properly with the harness on? I think you do just become used to it, as you do anything. I think it didn’t take long as I probably think it did to just say, ‘Right, ok, well now we’re in the harness and that’s fine. All of a sudden, that’s the new normal thing.”*

(Lisa)

*“We’d got used to it, got used to the routine of it, but at the beginning... I think once we realised that it didn’t actually, particularly affect him, then that was the bit that I was okay with.”*

(Michael)

In this study, it was interesting that both mothers and fathers specifically highlighted an occasion when they removed newborn clothing from the family home. Parents explained that this action was carried out because while their infant wore a harness, the infant had become too large to wear the smaller clothing. From the parental accounts, there was a sense that the act of removing clothing was led by the mothers:

*“Clothes. It was one of the first things I remember doing that weekend; Getting rid of all those clothes. I just thought I can’t look at these beautiful little clothes that she can’t wear, like pyjamas. Well, there’s none of that because the way her legs were in the harness. It was horrible, it was horrible. I remember...I don’t know. I felt really cheated, really cheated.”*

(Kirsty)

*“The baby had to wear her harness all the time, and we found it really difficult to start with, what with clothes and stuff. Especially with clothes that people had...because you get a lot of gifts that we couldn’t use, so a lot of it went to charity straight away.”*

(Andrew)

It seemed apparent from the parental accounts of this occasion, that the removal of the newborn clothing from the home was an equally psychological seismic episode within the parenting unit.

During the treatment, parents referred to use of time charts to count the Pavlik harness treatment time away:

*“When they originally told us he would be in it for at least twelve weeks, I just remember thinking that was my maternity leave over because they are so little, you can’t imagine them being five or six months old. So hearing somebody say ‘Oh, you know, he’ll be five months by the time he’s out of it just felt like I was going to have a baby that cried and was unhappy for the whole time that I was off and that time with him was going to be ruined, really. I remember counting down because I think I’d got that in my head and it was like ‘Just get to when he’s twenty-one weeks or whatever and it will be off.’ ”*

(Jennifer)

James: *“I had made up a chart where we ticked off the days as she was in it.”*

Interviewer: *“Why did you do the chart?”*

James: *“I don’t know, like because I thought it was something to look forward to; to see whenever she’d be out of it and back to normal as it were.”*

It seemed that the use of time charts was a coping mechanism as they looked forward to the end of the treatment, and in the words of James, their baby being *“back to normal”*.

### **7.2.5 Adjusting expectations of parenting an infant undergoing DDH treatment**

Following the DDH diagnosis for their baby, parents referred to their adjustment in expectation for parenthood. Parents wanted to do the fun baby activities, but some of these activities and the associated expectations of these activities were curtailed during the harness treatment:

*Actually, the one thing that did make me sad is that we had signed her up for swimming and she’d went to one swimming lesson. Then she got the harness put on, so we had to cancel them. So I remember that was something that made me...that was one of the other things that made me really upset.*

(Lisa)

In Steven’s recollections of this experience, there is a sense that he had adjusted his expectations of life with new baby, to caregiving a baby undergoing DDH treatment:

*“Then when we got the harness, we were just thinking about what can we do with her, like, while she’s in the harness? She couldn’t have a bath for ages or go swimming, so we had to wait ages for her to go swimming and stuff.”*

James comments seemed to convey the feelings of many of the parents in this study. He expressed a sense of re-aligning his expectations of early parenthood:

*“I felt like that was maybe going to be awkward and uncomfortable for the time that she was in it [the harness], but I thought that, realistically, she’s never going to remember that in her life. It’s just going to be a thing that will be forgotten.”*

At first, it seemed that the father was referring to the “awkward and uncomfortable” time” for his daughter wearing the harness. However, James comments could be interpreted as his perception of the whole situation being “awkward and uncomfortable for the time” for him as he cared for his baby with DDH.

Similarly, for Lisa, she reflected her feelings of not just the adjustment to the routine and the physical nature of the harness, but she was also making psychological maternal adjustments:

*“Once we’d adjusted, after the first few days, it was fine because as soon as we, sort of, realised how to use it and do her nappy changes and she was feeding fine, I think I almost just felt like, ‘Oh, well, that’s fine then, but it was really that first day, sort of, disappointment. I guess, realising what was going to happen. That was really upsetting.”*

(Lisa)

### **7.2.6 Perceptions of ‘normal’ and ‘abnormal’ parenthood**

The concept of ‘normal’ baby versus ‘abnormal’ baby was a strong recurrent theme across the parental accounts of their lived experience caring for an infant with DDH. The terms ‘normal’ and ‘abnormal’ were expressed by both mothers and fathers in interviews. Similarities across the parental interviews highlighted that the point of diagnosis was a pivotal time when many mothers and fathers shifted their perception of their baby from being normal to being “different” (Sarah; David; James).

Interestingly, for those parents who held this notion of having normal/different baby, that it seemed to be linked to their own concept of their parenthood role; they wanted to be ‘normal’ parents with a ‘normal’ baby. This concept is illustrated in the recollections of Lisa and James:

*At the baby groups, I felt like...because I was just chatting with the mums anyway, I did feel like I could have some time to say to people, ‘Oh, she’s fine. She’s just in her harness because she had this dodgy hip and hopefully she will be out of it in few weeks and there’s nothing wrong with her. She’s fine, really’. Then people just, sort of, go, ‘Oh, that’s good’ and then we’d move on.*

(Lisa)

*“It was obviously going to be different than just having a normal baby. She was our first child, so I mean, just adjusting to all, like, the lack of sleep, the feedings, all the nappy changes. This was just like one more thing. The whole thing, at that stage probably felt quite alien, just having a child. So then this other thing on top of it, maybe that was almost normal then for us.”*

(James)

In this study, both mothers and fathers conveyed that they wanted to care and nurture for their baby; however, mothers expressed that they wanted recognition for their special new mother and baby status. Sarah’s recollection of this feeling is shown in the following quote:

*“The ultrasound man who was doing it, was very matter of fact. I felt that he didn’t really...he explained a bit, but it wasn’t even as if...’This is your brand new baby and this is going to happen.’ ”*

(Sarah)

Sarah felt that the sonographer was insensitive to her circumstances as she cared for young baby. Mothers seemed to be acutely aware that their young infant was fragile, vulnerable and dependent on them.

Whereas for fathers, the focus was about maintaining the new baby status only. They wanted to care for their baby as they expected to care for a baby:

*“We got used to it, got used to the routine of it, but at the beginning yeah, and I think once we realised that it didn’t actually, particularly affect him, then that was the bit that I was okay with.”*

(Michael)

### **7.2.7 The importance of the attachment relationship between parent and infant**

The importance of the attachment relationship between parent and infant was a strong recurrent theme for parents in this study. It was striking that this issue was raised by the vast majority of parents in the study. Moreover, this was not an issue which could have been prompted by the interviewer, as it did not feature on the interview questions schedule. Parents wanted to form a secure psychological attachment relationship with their baby. However, mothers and fathers diverged in their perceptions of the barriers to developing this psychological attachment relationship with their infant.

Mothers seemed to view the Pavlik harness as it is worn on their infant's body, as a physical barrier. They felt that it was a physical barrier to the day-to-day care of the infant such as cleaning, bath time and breastfeeding. Mothers also stated that their baby felt different to touch and cuddle, compared to infants without a harness. Their baby felt "solid" and "sturdy" (Kirsty; Lisa). Kirsty's memories of this time are very candid and heartfelt:

*I remember...I felt really cheated. I felt really cheated out of this normal newborn stage with the cuddly baby because I remember immediately feeling, like, she was suddenly this solid, little... I don't know, I can't describe it; this solid little person. I didn't really realise how hard that was until she came out of it. When she came out of it, suddenly, she just went mushy again.*

(Kirsty)

Here Kirsty expresses her sense of injustice about having an infant in a harness. This feeling of injustice and unfairness resonated across several accounts by the mothers in this study.

Fathers also wanted to develop a secure psychological attachment relationship with their baby, but they seemed to place greater focus on the successful DDH treatment and outcome. Here Craig's account sums up the feelings conveyed by many of the fathers in this study:

*"I try and think of the positives rather than the negatives. I'm glad that there's something that can help her. I was happy that we've got a harness. You know, help her out, but it was just trying to work it out around the harness. What was going through my head was, obviously, she's a baby and obviously, like, you know, you just want to feel the baby's skin and stuff, but it was totally different. It was, like, something was in the way of holding my daughter. But, you know, if it's going to help her in the long run, it's going to help her out, that's all you want, isn't it, really."*

In this extract, Craig's expressed mixed emotions about his daughter's harness treatment. He felt positive that there was treatment for the condition, but simultaneously, he wanted his baby to feel like a baby. He appeared to imply that the harness was a physical barrier, but also a psychological barrier to his parental relationship with his baby which disrupted his enjoyment of his new baby.

### **7.3 Chapter summary**

This chapter highlighted the most pertinent comparative aspects of the lived experience of parents caring for an infant with DDH. The similarities and differences between the experiences of mothers and fathers caring for an infant with DDH were presented in relation to the key themes of:

- the role of the healthcare system;
- relationship dynamics;
- acquiring and understanding information about DDH;
- the application of the Pavlik harness on the infant;
- adjusting expectations of parenting an infant undergoing DDH treatment;
- perceptions of 'normal' and 'abnormal' parenthood;
- the importance of the attachment relationship between parent and infant.

In the next chapter, the findings of this chapter and also the findings of the chapters which focused on the specific experiences of mothers (Chapter Five) and fathers (Chapter Six), will be discussed in relation to other research. Furthermore, the Conclusion of this thesis (Chapter Nine) will suggest the potential implications of the findings of this study.

## Chapter Eight: Discussion

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### 8.1 Chapter overview

This chapter will discuss the key findings of the study in relation to the wider body of literature. Since there is a dearth of research about parental experiences of caring for an infant with DDH, the discussion will predominantly draw on the wider literature from other aspects of paediatric, paternal, maternal and postpartum healthcare research. Firstly, the original aim of the study will be reiterated. This will be followed by addressing the key findings of the study with mothers, fathers and the comparative key findings from both the mothers and fathers' interviews.

To orient the audience through this chapter, each section (mothers, fathers, parental comparative section) is uniformly structured for the audience. The section is divided under the identical superordinate and the intermediate themes of the Findings Chapters (see Chapter Five, Six, Seven). The key findings are noted using bold italic font. At regular intervals, references are made to the current study to reorient the audience to the key findings.

Furthermore, in this chapter, the key findings of the mothers' interviews are drawn together and interlinked with the concept of family-centred care (Michalopoulou et al 2018). The key findings from the fathers' interviews are discussed in relation to a newly coined concept of 'biographical revision to the new father role' (Bury 1982). The comparative key findings of the mothers and fathers' interviews are mapped to hypothesised conceptual model of the protective factors of parental resilience (Gavidia-Payne et al 2015).

As this chapter comes to a close, the strengths, limitations and other considerations about the current study will be addressed. My own perceptions and experiences will be reflected on the 'personal reflexivity' section.

### 8.2 Reiterate the aim of this study

The aim of this current study was to explore the experiences of parents of infants who have been diagnosed with DDH and have undergone treatment for the condition. It focused on addressing a gap in knowledge and understanding about the unique lived experiences of

mothers and fathers as they cared for their infant with DDH. This study also compared the unique insights from mothers and fathers accounts of this phenomenon, their shared perceptions of the experience, as well as the aspects that diverge about their experience. Furthermore, the literature review indicated that there were specific nuanced gaps in DDH research about parental perceptions of the diagnosis and management of their infant's DDH condition and a gap about the information needs of these parents. Using IPA methodology and semi-structured interviews with parent participants revealed new and original findings which contributes to the literature in this field. The findings also have implications for further research and practical implications for healthcare.

### **8.3 The lived experience of mothers caring for their infant with DDH**

#### **8.3.1 Superordinate theme: Struggling with the empowerment and disempowerment of care over the infant**

#### **8.3.2 Intermediate theme: Mothers felt the dominance of healthcare**

The most prevailing finding of the lived experience of mothers caring for an infant with DDH was their shared perception of feeling like ***observers to their infant's healthcare***. They were bystanders, as the health practitioners performed the clinical examination of their baby. Mothers identified these encounters as an unpleasant aspect of their experience. During this time, mothers were not part of any discussion with or between the health practitioners. Mothers explained that they were made to feel like 'outsiders' in the hospital setting as the health practitioners, the 'insiders', used exclusive language and cues to communicate the situation with each other. This finding concurs with other recent research about parental experiences of paediatric healthcare settings by Aarthun et al (2017), Hagen et al (2016) and Serlachius et al (2018).

Recent literature suggests that a power imbalance continues to exist in paediatric clinical settings, even when interventions to address this power have been embedded. Serlachius et al (2018) used a mixed methods approach to explore parental experiences of a neonatal intensive care unit in New Zealand. Even though the senior managers and health professionals had spent several years striving to embed a family-centred ethos in the unit, Serlachius et al (2018) highlighted that a power imbalance continued to persist. The study found that parents still felt like 'spectators' and staff were regarded as the 'experts'. However, the researchers felt that this perception by parents was due to ingrained

assumptions about the parent-staff dynamic in the unit. A notable weakness of this study was that it was focused on one neonatal unit in one hospital. The findings of this study could have been more illuminating if it had been a multi-site study.

There are similarities in the findings of Serlachius et al's (2018) study and Hagen et al's (2016) of parental experiences of coping in neonatal intensive care unit, which also revealed that parents felt like outsiders in the healthcare situation, like 'spectators in an audience'. However, both these studies focused on the perspectives of the parents, predominantly mothers, with the noticeable absence of the perspective of health professionals. Nimmon and Stenfors-Hayes (2016) attempted to readdress this gap with their qualitative study of 30 doctors. As they explored the insights of the doctors and role of power during clinical encounters with patients. This study concluded that doctors were not consciously aware of their power role within the doctor-patient relationship. However, in this study, there were some doctors who were aware of their power role. In the case of these doctors, they acknowledged that they would deliberately use their own communication and language strategies to: exert; share; moderate; relinquish power, to direct their clinical opinion in the best interests of the patient (Nimmon and Stenfors-Hayes (2016)).

Another key finding from this current study is that **mothers felt out of control** in the DDH clinic setting. However, there were two sub-contexts to this notion of being out of control. Some mothers perceived the reins of power and control of the unfolding situation to be held by the health practitioners. This finding is consistent with other research by Lawlor and Mattingly (1998); Lupton and Fenwick (2001); Shattnawi (2015). Whereas other mothers felt out of control due to the diagnosis and their perceptions about their baby's prognosis. This was most strongly felt at the diagnosis, application of the harness in the hospital and the first few days in the home. Mothers' sense of being out of control implies they felt psychological distress. This echoes the quantitative findings of the very limited research about DDH and harness treatment amongst young infants (Gardner et al 2005; Jennings et al 2017). Gardner et al's (2005) RCT was an important study in relation to this current study and it was discussed in detail in Chapter Two: Literature Review. Gardner et al (2005) found a significant association between the early harness treatment of a young infant, and maternal worries and anxiety about their infant's hips when their infant was eight weeks old. Moreover, mothers' worries about their infant's hips continued when their infant was one year old, and the treatment had come to a close. Gardner et al's (2005) study could have

been more interesting if the sample included fathers, particularly if the findings had been triangulated between the parent couplings/dyads (Gray 2014).

Some mothers highlighted what they perceived as **unpleasant experiences with health practitioners**. There were two elements of these encounters which were identified by mothers as being unpleasant: the dominating clinical focus of the health practitioners on the baby as opposed to the interpersonal engagement and caregiving needs of the family unit; mothers educating health practitioners about DDH. In this current study, it seemed that the experiences of mothers in the DDH healthcare settings that the biomedical model of health continued to dominate their encounters with health practitioners (Freidson 1975). Wider research indicates that even when paediatric healthcare services are committed to being family-centred focused, the biomedical approach to healthcare still permeates the parent-health practitioner relationship (Michalopoulou et al 2018; Serlachius et al 2018).

Another key finding of the experience of mothers as they cared for their baby with DDH is their perception that they played the dominant role as they educated community health practitioners about the condition. This finding conflicts with the concept of the biomedical power hierarchy with the health practitioner at the top of the hierarchy dominating the healthcare encounter with the patient and carer at the bottom (Freidson 1975). However, Freidson's (1975) classic research is now over 40 years old and it could be argued that healthcare environments are changing and the relationships between health professionals and patients and their carers are becoming more nuanced. In this current study, the finding seems to indicate that the community health practitioners were in a positive sense, applying principles of family-centred care (refer to Table 6) (Michalopoulou et al 2018). Conversely, this finding seems to shift towards a need to raise awareness amongst parents that they can play an active role in healthcare situations. For family-centred care to be successful, Shields et al (2015) warns that there has to be a clear connection between what families want, need and expect from the health service.

### **8.3.3 Intermediate theme: Understanding DDH diagnosis and treatment**

At the stage when mothers were informed of their infant's DDH diagnosis by a health practitioner, they all reported feeling immediate **shock and confusion**. Arguably, mothers' feelings of shock are an unremarkable finding and it is consistent with a large body of previous research (Bingham et al 2012; Coffey 2006; Havermans et al 2015; Pelchat et al 2007). However, the feelings of shock, coupled with the sense of confusion that there was

something “*wrong*” with their baby was a psychological experience which could have been mitigated by health practitioners. This point is supported by the findings of Coffey’s (2006) meta-synthesis of 11 studies about parenting a child with a chronic illness. It identified critical times during this type of parenthood experience. The first major critical stage was around the point of diagnosis and discharge from hospital to home with their child. Parents felt overwhelmed, helpless and confused by their child’s care needs.

In this current study, all of the mothers searched the internet to ***acquire knowledge about DDH***, in particular, they sought explanations and guidance. Often the poor information provision by health practitioners acted as a catalyst for mothers to acquire DDH information. Furthermore, mothers experienced a sense of empowerment as they acquired knowledge about DDH from the internet. Under the circumstances, there was a sense amongst these mothers that the ability to access DDH information using the internet was a positive behavioural response to their infant’s diagnosis. Whereas some mothers were cautious and unsure about the reliability of some of the sources of DDH information; other mothers developed a sense of self-efficacy empowered by advice and empathy offered through online peer-to-peer social media platforms.

It is well recognised in research about the ease of accessing the internet about health information (Amante et al 2015; Armstrong-Heimsoth et al 2017; Fabricant et al 2013; Kraschnewski et al 2014). Quantitative and qualitative research indicates that websites, such as Facebook, and mobile phone applications, otherwise known as ‘apps’, are likely to be used by pregnant women or new mothers with their first infant (Duggan et al 2015; Kraschnewski et al 2014; Lupton 2016). Furthermore, a qualitative study by Kraschnewski et al (2014) suggested that women seek information through the internet because of lack of information or support by health practitioners during healthcare appointments. Interestingly, a study Wallwiener et al (2016) indicated that there were opportunities to positively influence health behaviours through the women’s use of websites and mobile phone apps. The study found a significant correlation between accessing internet-based health information and positive health decision making. Although it is important to be mindful that correlation is not causation (Gray 2014). Also, there could be an underlying variable such as education or social class, that could drive information seeking behaviours and influence positive decision making. Another relevant and insightful study by Lupton (2016) investigated the use and value of digital media for providing information about pregnancy and early motherhood. Thirty-six women took part in the focus group study. The findings of

the Lupton study (2016) suggested that the women valued apps and internet social media platforms for pregnancy and parental information and to establish and maintain social connections with other mothers. A limitation of Lupton's study was that the participants were all highly educated and resided in an urban area. The findings of this study could have been more illuminating if there was data gathered from participants from deprived areas.

However, as indicated by the mothers in this current study, parents tend to access online health information because of the lack of verbal and written information provision provided by the health practitioners. On the other hand, the internet should not be a substitute for the lack of information delivered by health practitioners. Moreover, it is important to note caution that the internet is not the solution for providing all public health information needs. International research indicates that the most vulnerable people in communities are being 'digitally excluded' from the internet (Armstrong-Heimsoth et al 2017; Helsper and Reisdorf 2017; Rowsell et al 2015). Factors which are linked to being digitally excluded are: older age; achieved low education; having a disability; being socially isolated; being unemployed (Armstrong-Heimsoth et al 2017; Helsper and Reisdorf 2017; Rowsell et al 2015). The body of research in this field recommends that internet-based health information needs be accurate and reliable (Amante et al 2015; Armstrong-Heimsoth et al 2017; Fabricant et al 2013; Knapp et al 2011).

Research conducted in the USA has attempted to tackle health literacy using the internet. In a mixed methods study by Armstrong-Heimsoth et al (2017), they developed a health literacy education programme intervention. The intervention consisted of training 30 parent participants to find; understand; critique and retrieve evidence-based healthcare information on the internet. The participants were also asked to complete pre and post intervention surveys to assess their perceived confidence of conducting these searches and critical understanding the information. The study found that following this intervention the participants perceived confidence had significantly improved. There were several limitations to this study. The qualitative part to this study was poor. It was based on direct quotes from open ended questions on the survey. These quotes were not imbedded in any qualitative methodology or methods and there was no data analysis undertaken with these comments (Creswell 2013; Gray 2014). It also questionable whether it is appropriate to train patients/carers to search for evidence-based research using the steps of an electronic academic literature search. On the other hand, this intervention study could have been more interesting and the findings more relevant if the researchers had conducted a

longitudinal study. Although the results of Armstrong-Heimsoth et al (2017) study are positive about the intervention, the practical reality of this intervention is doubtful. Also, the sample size was not large enough to show any statistically significant changes with the use of the intervention.

There is future potential for health practitioners to signpost parents to reliable websites for information, while also warning parents of the inaccurate information and 'scare stories' (Fabricant et al 2013). It is a positive course of action that health practitioners have the potential to empower parents by directing them to reliable websites for DDH information and advice. This could foster positive and engaging discussions between parents and health practitioners at the DDH diagnosis and treatment stage (Michalopoulou et al 2018; Shields et al 2015). However, it could also be argued that this health information requires clarification by a health practitioner who can give an honest view of the information, which could potentially prompt further health inquiries and offer interpersonal support to parents. The findings of the current study and other research suggests that there is an opportunity to provide mothers with a credible app featuring DDH health information, practical advice and a peer-to-peer social connection platform. This study adds to the literature about the information needs of mothers of infants undergoing DDH harness treatment.

### 8.3.4 Superordinate theme: Relationship dynamics

#### 8.3.5 Intermediate theme: Relationship between mother and health practitioner

Mothers wanted health practitioners to ***recognise and acknowledge their new baby and mother status***. They had just given birth. They were caregivers juggling the demands of a new baby, with some mothers breastfeeding. They felt sleep deprived and exhausted. However, mothers felt that health practitioners were very focused on the clinical aspect of their professional role. One mother spent a protracted six hours in the hospital as her baby was screened, diagnosed and treated for DDH. Conversely, another mother had a seemingly efficient 15 minutes appointment in which her baby daughter received a DDH diagnosis. However, both mothers, and the experience of many of the other mothers in this study, reported a lack of supportive interpersonal engagement with a health practitioner. When health practitioners exhibited a supportive attitude towards mothers, gave reassurance and provided good quality information, it seemed to strengthen their relationship with mothers. Furthermore, mothers felt empowered and developed a sense of their own self-efficacy in their caregiving abilities towards their infant in a harness.

The concept of mothers looking to health practitioners to acknowledge their new mother and new baby status is a very nuanced finding in this study. There appears to be a dearth in the wider literature about this concept. However, there is literature which recognises motherhood as a major '*social transition; one source and cause of life change*' (Oakley 2005:117). There is also a body of research which highlights motherhood as time when a women's identity shifts, and it is transformative (Antonucci and Mikus 1988; Barclay et al 1997; Oakley 2005; Smith 1999). Nystrom and Ohrling (2004) conducted a literature review of 33 studies about parenthood experiences during a baby's first year. They found that mothers viewed nurses as a source of strength. Nystrom and Ohrling (2004) argued that the support offered by nurses played a key role empowering in parenthood. A notable strength of this literature review is it draw on both quantitative and qualitative research. On the other hand, it is fair to argue that this literature review is very dated now, as it reviewed research published between 1992-2002. Some of the studies in this review are over 25 years old.

Mothers wanted to engage with **supportive health practitioners** and gain their support. Moreover, mothers appreciated the occasions when health practitioners put some time aside to discuss their queries and health practitioners gave them psychological and practical support to enable them to care for their infant with DDH. This finding concurs with other research about partnerships between parents and health professionals (Michalopoulou et al 2018; Shields et al 2015; Smith et al 2015). According to Rifkin (2006) an enhanced relationship between parents and health practitioners is regarded as an important mutual learning opportunity. Smith et al (2015) develop this argument further by noting that for health professionals, they rely on their relationship with parents to convey knowledge and information about the child and deliver the treatment care in the home.

Mothers wanted to breastfeed their infants while wearing a Pavlik harness. However, they faced **challenges while breastfeeding their infant in a harness** that they faced can be summarised, in terms of a lack of information and support from health practitioners. Mothers had difficulties achieving a comfortable position to breastfeed their infant who was rigid in their harness. Also, mothers felt pressurised by community health practitioners to continue breastfeeding despite having the harness.

The World Health Organisation (WHO) advocates that infants are exclusively breastfeeding up until six months old (WHO 2013a; WHO 2013b). This recommendation is informed by a

solid evidence base of the short and long-term benefits of breastfeeding for infant and mother (WHO 2013a; WHO 2013b). There appears to be a lack of research about breastfeeding an infant undergoing treatment for DDH, particularly with regards to the type of difficulties experienced by mothers and potential solutions to these difficulties. Causon (2010) offers a nurse's commentary guide to supporting parents caring for a child with DDH. This guide mentions the potential challenges of breastfeeding an infant in a harness without any reference to existing literature. Furthermore, recently Dwan et al (2017) published a Cochrane Systematic Review protocol which investigates the role of splinting as an optimal treatment strategy for infants with DDH. One of the secondary outcomes that is anticipated from this systematic review is to identify the obstacles to breastfeeding an infant harnessed in a splinting device. Surprisingly, there is no citation within the protocol to justify investigating the challenges of breastfeeding in these circumstances.

As far as the researcher is aware, this is the first research study which shows that mothers with infants undergoing DDH treatment in a Pavlik harness face challenges to breastfeeding their baby. Therefore, mothers could benefit from improved support and information about breastfeeding their infant in a harness from health practitioners who specialise in DDH in infants.

### **8.3.6 Intermediate theme: Relationship between mother and infant**

For the mothers who recalled their lived experience in this study, the circumstances of the diagnosis and harness treatment for their baby had an initial negative impact on their relationship with their infant. They experienced a noticeable shift in their expectations of early motherhood caring for a young infant and they felt a ***re-adjustment in their new expectations of family life*** with a new baby undergoing DDH treatment in a harness. Many mothers felt that they could adjust to the new situation with their baby if they sensed a continuum in family life, both in terms of the daily care routine for the infant and psychological attachment to their infant. In the key findings of this study, there was certainty that for many of the mothers that the application of the Pavlik harness to treat their baby for DDH challenged their relationship with their infant.

Mothers felt a shift in their expectations about life with their baby, and adjustment to the new expectations of motherhood with an infant undergoing DDH treatment. Some mothers showed their sense of re-adjustment in overt behaviours, whereas others exhibited their re-

adjustment by using covert behaviours. Interestingly, mothers expressed a sense of grief and loss for the expected relationship with their infant.

This finding concurs with quantitative DDH research by McHale, Major and Corbett (1989) (see Chapter Two). In addition, similar findings about parental adjustments to their expectations of family life with children diagnosed with a congenital or chronic illness have been identified in several studies (Dixon-Woods et al 2005; Fonseca et al 2015; Pelchat et al 2007; Schweitzer et al 2012). Research by Jordan et al (2007) echoes the findings of the current study. Jordan et al (2007) highlighted both the shift in parental expectations for their sick child and also, the notion of grief and loss amongst parents of older children with complex chronic pain. The Jordan et al (2007) study was an IPA study involving focus groups with 17 parents. A prominent finding of the Jordan et al (2007) study showed that parents struggled to adapt to the new family life which was different to their expectations and felt grief for their child who had changed from being a happy and healthy child to a child with chronic disabling pain. A notable strength of this study was that the sample was representative of parents; they were a mix of mothers, fathers and a primary caregiving grandmother.

On the other hand, the aspect of the current study's findings about the adjustment in expectations, which revealed the subtle nuances of maternal covert and overt behaviours is an original finding and contributes to the body of literature. This finding seems to suggest that there is an important role for health practitioners to offer specific psychological support, in anticipation of this potential psychological impact on mothers of infants with DDH.

Mothers felt repulsion towards the physical appearance of ***the Pavlik harness on their baby***. It was regarded as a barrier in the relationship between mother and infant; it was a psychological, physical and practical barrier. This finding corroborates with the quantitative results of other research about parental attitudes towards the Pavlik harness (Corbett 1988; Gardner et al 2005; McHale et al 1989; Jennings et al 2017) (see Chapter Two). However, this finding contributes to the literature because it suggests that the abhorrence that mothers felt about the harness was more nuanced. This deeper understanding is helpful to health practitioners who can improve the nature of the support they provide to mothers caring for an infant with DDH in a harness.

The findings of this current study suggest that mothers psychologically and socially struggled to come to terms with their infants DDH diagnosis and treatment in the harness.

There were two aspects to this notion. Many **mothers considered their baby to be 'different'** due to the appearance of the harness on their baby; this infers that they considered their infant to be 'abnormal'. Moreover, the accounts from mothers of this experience, they also felt like a 'different' type of parent. Mothers seemed to convey a notion of 'felt stigma', which refers to the mothers' own sense of shame and fear of rejection by others (Jacoby 1994; Scambler and Hopkins 1986). This is opposed to 'enacted stigma', which is the overt prejudice and discrimination of stigmatised individuals (Gray 2002; Jacoby 1994). In this current study, mothers felt stigma and they pre-empted their own notion of prejudice and discrimination from other people, but these mothers could not recall any incidents of prejudice or discrimination by other people during this experience.

These findings mirror those in the wider paediatric healthcare literature about mothers' views of 'normal' and 'different' parenthood (Gray 2002; Maciver et al 2010; Nelson 2002; Tluczek et al 2011). They also echo the findings of other qualitative research that suggests that mothers have a heightened sensitivity to enacted stigma (Johansson and Ringberg 2004; Klein et al 2006; Nelson 2012). A qualitative study by Maciver et al (2010) explored the impact on parenting a child with chronic pain. Based on interviews with 12 parents, Maciver et al (2010) concluded that parents felt a sense of loss and failure because they perceived that their child had deviated from the normal course of childhood. One weakness of this study was that it was a single site study in the UK. Maciver et al's study could have been more interesting if it had been a multi-site study, particularly if involved a site in another country.

In the current study, it seems that the mothers were influenced by the socially constructed notion of parenthood. They had experienced a dissonance between their expectations of normal parenthood and their perceived lived experience of a different parenthood (Maciver et al 2010). Although there is a large corpus of literature in the field of stigma and health (Bury 1982; Charmaz 1983; Goffman 1963; Scambler 2009; Williams 2009) and it seems that this is a concept, in relation to DDH, has the potential for further research. The finding in this current study makes a new contribution to the literature which investigates parental experiences associated with a chronic physical disability that can be treated, over a short time.

An interesting and important finding of this current study is that **mothers strove to form a high-quality attachment relationship with their infant**, but the Pavlik harness was a

physical barrier in development of this the relationship. Mothers felt that the harness hindered their mothers' ability to touch and closely hold their baby. In addition, mothers felt that the neonate period was the optimum time to form their attachment with their baby. The importance that mothers placed on the quality attachment relationship was focused on their relationship to their baby. This is opposed to this being a mutual attachment relationship. During the harness treatment stage for their baby's DDH condition, mothers developed coping strategies. Once the harness treatment ended, mothers conveyed a sense of an improved attachment relationship with their infant which fulfilled their expectations of early motherhood and infancy. This finding is similar to the findings of other studies which examined the psychological outcomes of parents of an infant being treated for DDH in a harness (Corbett 1988; Gardner et al 2005; McHale et al 1989; Jennings et al 2017) (see Chapter Two). However, these other studies lack detail to pin point the nature of the negative psychological consequences for parents in relation to the harness.

Attachment theory was conceptualised by Bowlby (1969) and it is supported by empirical research using the Strange Situation Classification assessment (Ainsworth and Wittig 1969). The term 'attachment' relates to infants being innately ready to form an attachment relationship with a parent/primary caregiver. The quality of this relationship in which the child feels safe, secure and protected is a core foundation for their future personal development (Bowlby 1969). The child uses a high-quality attachment relationship foundation, to grow into adulthood with confidence and self-esteem. More recently, other researchers, including Redshaw and Martin (2013) have progressed attachment theory further by arguing for the recognition of the subtleties of the concept of 'antenatal and postnatal maternal and paternal attachment' (Bowlby 1969). This concept focuses on the links of parenthood trajectory of: understanding maternal and paternal attitudes during pregnancy; parental adjustment to parenthood and predicting; maternal and paternal attachment at a later stage (Redshaw and Martin 2013). There is also a growing body of research which supports the notion of this concept (Condon et al 1998; Condon et al 2013; Fonagy et al 1991; Laxton-Kane and Slade 2002). Anderzen-Carlsson et al (2014) conducted a meta-synthesis of parental experiences of skin-to-skin care with their infant. From their analysis of 29 international studies, they concluded that when skin-to-skin care is a positive experience for the parents, it can enhance the parental self-esteem and their adjustment to new parenthood. A notable strength of this meta-synthesis is that it involved research published in many non-English languages which provided a holistic international

context to understanding parental experiences of skin-to-skin care with their infant (Anderzen and Carlsson et al 2014). In this current study, the finding about the mothers' perceptions and desire to develop their own sense of a quality attachment relationship adds to the literature in this field.

### **8.3.7 Delivering a holistic family-centred care service for DDH outpatients' clinic**

This study suggests that in the experience of mothers caring for their baby with DDH that the dominance of a paternalistic model of care in UK paediatric settings in the UK continues in the present day. On the other hand, there had been an international movement towards 'family centred care' for decades. The American Academy of Pediatrics, with its international influence, has championed delivering family-centred care in paediatric healthcare settings for over 20 years (Frader et al 1996; Serlachius et al 2018). On the other hand, in the context of the UK healthcare system, they use the relatively new concept of 'patient and family-centred care'. However, patient and family-centred care has a distinctly different focus to the aligned and arguably, more popular concept of 'patient centred care' (NHS England 2015; Kuo et al 2012; The King's Fund and The Health Foundation 2014). Mikkelsen and Frederiksen (2011: 1159) define family-centred is:

*“..... characterized by a relationship between healthcare professionals and the family, in which both parts engage in sharing the responsibility for the child's healthcare. The professional support of the child and the family through a process of involvement and participation, underpinned by empowerment and negotiation’.*

Family centred care is underpinned by the following mutual key principles of health practitioner and family encounters (refer to Table 6) (Michalopoulou et al (2018):

Table 6: The key principles of family-centred care (Michalopoulou et al, 2018)

<b>Information sharing</b>	Open, inclusive communication and sharing of information between family and health professionals.
<b>Respect</b>	Clear communication and listening with a self-awareness of tone and body-language. An understanding of the family dynamics and a non-judgemental attitude.
<b>Family participation</b>	Encouraging opportunities for family engagement to ask questions and bring relevant information to appointments.
<b>Collaboration/Partnership</b>	Collaborative decision making when both parties are fully informed of the circumstances and both parties feel comfortable to raise queries and ask questions.

Researchers argue that family centred care is often championed in paediatric setting all over the world, but few paediatric settings actively implement its principles into practice (Kuo et al 2012; Michalopoulou et al 2018; Shields 2015; Serlachius et al 2018; Smith et al 2015). There is also an on-going debate about the evidence-based effectiveness of family-centred care. Michalopoulou et al (2018) cites a range of positive outcomes of family-centred care from improved health status to reduce hospitalisations and patient satisfaction. Conversely, Shields (2015), a lead author of a Cochrane Review on family-centred care counter-argues this point and states that there is no solid evidence to support the effectiveness of family-centred care (Shields et al 2007; 2012). However, in relation to the findings in the current study about mothers' experiences of caring for an infant diagnosed and treated for DDH, it is clear that the areas of weakness in their lived experience relates to a weakness in the application of the key principles of family-centred care. The poor application to healthcare practice of these principles is threaded throughout the mothers' findings. This current study has identified a potential area for further research; a research focus on family-centred care in outpatient hospital-based speciality clinics such as DDH clinics. The knowledge gap and need for research on this matter concurs with the conclusions of other studies in this field by Harrison (2010) and Michalopoulou et al (2018).

## 8.4 The lived experience of fathers caring for their infant with DDH

### 8.4.1 Superordinate theme: Managing the disrupted family

#### 8.4.2 Intermediate theme: Trust in the healthcare system

A key finding in this study is that fathers expressed their ***trust in the opinion of the health practitioners***. On one hand, they felt reassured and relieved that Pavlik harness treatment for DDH was non-invasive, immediately applied at a very young age, for a short period of time. On the other hand, fathers felt that they were balancing their own negative psychological feelings towards the nature of the harness treatment, against their ***positive psychological feelings about their immediacy and practicality of the treatment***.

The findings of fathers' in this current study echoes the findings of other studies which focused on the concept of high levels of trust by service users of the healthcare system (Legido-Quigley et al 2014; Meyer et al 2012; Croker et al 2013). A study by Croker et al (2013) examined confidence and trust in primary care doctors (known as General Practitioners) in relation to age, gender and ethnicity. By analysing national patient survey data from a sample of 1.5 million adult participants, the researchers found that approximately 73.5% of patients had trust and confidence in the decision making of a doctor. Croker et al (2013) also found a significant correlation between the high-quality interpersonal skills of primary care doctors and patient perceptions of confidence and trust them. When age was factored into the analysis, trust in the doctor increased with age indicating higher rates of trust. A strength of this study was the very large sample of participants. On the other hand, the reporting of the results focused on the data from older participants. There was a gap in the discussion about the reasons why the younger participants in the study were less likely to trust a doctor.

In the current study, findings from the fathers' interviews appeared to reflect the psychological health behaviours depicted in the Health Belief Model (Hochbaum, Rosenstock and Kegels 1952) that fathers will comply with the opinion of health practitioners and comply with the harness treatment for their baby. To give a brief overview, the Health Belief Model is a value-expectancy theory (Clemow 2008). In its most contemporary version, the model is now based on six variables which predict behaviour: perceived susceptibility; perceived severity; perceived benefits; perceived barriers; cues to action; self-efficacy (Clemow 2008). In the context of this current study, the predicted behaviour indicated by the Health Belief Model seems to be reflected in the fathers'

accounts. To illustrate, fathers felt a sense of trust in the health practitioners to conduct an accurate DDH diagnosis using ultrasonography (cues to action; perceived susceptibility; perceived severity). The application of the harness to the infant as DDH treatment was a non-invasive procedure required for a short amount of time at home. Also, this treatment was desired by the mother of the infant (perceived benefits; self-efficacy). However, some fathers conveyed that they were concerned about the disruption to normal family life (perceived barrier).

The finding of this current study contributes to the literature. In this section of the chapter, a summary of the application of the Health Belief Model has made to this theme about fathers' trust in the opinion of health practitioners. However, any further detail is beyond the scope of this study. On the other hand, this finding could suggest further research in relation to the Health Belief Model.

#### **8.4.3 Intermediate theme: Biographical revision to the new father role**

The fathers, in this study, had expectations of parenthood, but when their infant received the DDH diagnosis and began treatment in a Pavlik harness, they felt that they had to adjust these expectations. Fathers recalled that when their baby was first fitted into the harness, family life and family routines were chaotic. This was underpinned by the fathers' sense of ***psychological distress about the diagnosis and abhorrent nature of the harness***. Whereas many fathers felt a sudden re-alignment in expectations. A few fathers felt reassured that the treatment did not affect their infants' development.

The finding that fathers felt psychological distress due to the diagnosis and specifically, the Pavlik harness treatment for their baby is in accordance with other parental DDH research by Corbett (1988); Jennings et al (2017); McHale et al (1989). However, a weakness of all of these survey studies is that they refer to the participants as 'parents'; they do not specify the number of mothers and fathers in the studies. The ambiguity about the parent participants in these studies means that there is an element of caution about these findings since they aggregate the results under the generic term of 'parents'.

A literature review by Pelchat et al (2007) examined research about parenting a child with a health problem. This was a broad review of six studies of quantitative and qualitative designs, and it focused on a range of disabilities amongst children. Pelchat et al (2007) highlighted that fathers felt more distress than mothers about specifics of their child's health problem. Moreover, Pelchat et al (2007) cites research which supports the need for fathers

to be present at the point of a child's diagnosis for a health condition to reduce stress and in a positive sense, help them to adjust to the new family situation. A disappointing aspect to Pelchat et al (2007) review is that despite its aim to capture the experiences of mother and fathers caring for a child with a health condition, the review tends to focus on the mothers' experiences and the collective parental experience, with scant references to research findings about the fathers' experiences.

It is important to acknowledge that wider research indicates that in general circumstances with a healthy infant, new fatherhood is an event that demands an adjustment in the lives of men. Fathers experience a major shift in their lives when they become fathers, even when it is not their first time of becoming a father. A meta-synthesis of six studies revealed that fathers felt a sense of psychological adjustment to fatherhood (Chin et al 2011). Moreover, this adjustment to new circumstances can take place very suddenly for fathers (Premberg et al 2008). Sometimes, fathers struggled to adjust to new family life (Barclay and Lupton 1999). Research by Hakulinen et al (1999) investigated family dynamics in Finland and found a correlation between parents experiencing low levels of strain when they received support from public health nurses. This study involved using two validated questionnaire instruments with 85 mothers and 79 fathers. However, this study was limited by the focus being on parents of children aged between 3-4 years old. On the other hand, this study could suggest that improved support from health practitioners could improve the experience.

In the context that new fatherhood is a major time for adjustment in the lives of men, the current study findings have suggested that fathers caring for an infant with DDH in a Pavlik harness do experience psychological distress and a 'biographical revision to their new father role'. Moreover, fathers affiliated their paternal distress with the nature of the Pavlik harness and the nature of the DDH treatment. Therefore, this current study adds original knowledge and understanding to the literature as it offers a rich qualitative insight to the lived experiences of fathers caring for an infant with DDH in a Pavlik harness.

The DDH diagnosis was a pivotal point when fathers began to regard their infant as ***being 'different' from being a 'normal' baby***. However, it was not clear exactly why fathers perceived their infants' as different. Did these fathers consider their infant to be different because of: the DDH diagnosis; the harness treatment; a change in home routine; the family dynamic; they had a disability? Fathers wanted to form a quality **psychological**

**attachment relationship** to their infant. However, they perceived it to be a challenge to adhere to the health practitioners' instructions for their infants, while simultaneously form a good quality attachment with their infant. Nevertheless, fathers reconciled their perceived predicament by prioritising the positive outcome of the treatment over all other paternal concerns.

This finding has similarities with the findings of other DDH parental quantitative research by Corbett (1988); McHale et al (1989); Jennings et al (2017) which indicated that parents experience psychological distress. However, this research is focused on parental experience as opposed to, specifically, fathers. The wider literature which focuses on infants and physical disabilities concurs with the finding of this study. Research suggests that parents shift their perceptions of their disabled baby from being normal to "different" (Daniel et al 2005; Kearney and Griffiths 2001; Larson 1998; Nelson 2002; Nelson 2012). Taking a constructivist grounded theory approach to understanding the parental experiences of caring for a child with cleft lip and/or palate, Nelson et al (2012) conducted a study with 24 mothers and 11 fathers. The findings revealed that parents experienced psychological tensions regarding their own perceptions of parenting a 'normal' versus 'abnormal' child. As a result of the findings of this study, Nelson et al (2012) recommended that health practitioners carry out a parental assessment of their psychological wellbeing and offer access to appropriate services. There were several weaknesses to Nelson et al's (2012) study. Firstly, the study sample was predominantly the mothers of the children. Secondly, when fathers participated in the interviews, they were mostly dyadic interviews. Therefore, it would have been difficult for fathers in this interview setting with the mother of their child to be fully candid about their experience. Thirdly, the parents discussed their experience of caring for their child who were of a broad age range, from 20 weeks old to 20 years old. The findings of the Nelson et al (2012) study could have been more relevant if the age range of the children had been narrower, for example, pre-schoolers.

Research about the quality of fathers' attachment relationship with their infant is a mixed landscape in comparison to the empirical evidence regarding the maternal-infant attachment relationship. The empirical research about the quality of the father-infant attachment relationship is nuanced in relation to individual, family, community and society factors (Bretherton 2010; Cox et al 1992; Freeman et al 2010). Earlier in this chapter, attachment theory and the emerging concept of paternal attachment was discussed (Ainsworth and Wittig 1969; Bowlby 1969; Redshaw and Martin 2013). Although

quantitative research indicates that infants are less likely to seek attachment to their father, other quantitative research indicates that fathers who spend more time with their infants have more positive interactions with them, which in turn enhanced the quality of their attachment relationship (Cox et al 1992; Freeman et al 2010). Qualitative research highlights the importance of attachment between father and infant. A phenomenological study by Fegran et al (2008) with six parental dyads explored the development of the parent-infant attachment relationship in a neonatal intensive care unit. Fegran et al (2008) concluded that skin-to-skin contact between father and infant had a positive effect on the fathers' sense of self-esteem and coping. A criticism of this study is that the sample did not include younger fathers with the sample consisting of fathers aged between 27 and 59 years old. Understanding the in-depth experiences of fathers aged under 27 years old could have offered new perspectives to the phenomena.

Another finding of this study that ***fathers sought and connected with other people outside of their family and healthcare circles*** to discuss their infant's DDH diagnosis. It seemed that fathers took psychological comfort from these conversations and it gave them a sense that the experience of having a health problem with a young baby was 'normal' in the wider community. Hence, these fathers were experiencing a 'normal' fatherhood. In this study, fathers greatly valued the opinions and experiences of other people who had encountered DDH with their own children, family or themselves. Wider research suggests that parents feel a sense of psychological wellbeing when they connect with other people who have/had a similar experience (Bray et al 2017; Shilling et al 2013). On the other hand, there appears to be a paucity of literature which refers specifically to fathers.

A systematic review of qualitative and quantitative literature about peer support for parents with children with chronic disabilities was conducted by Shilling et al (2013). The qualitative findings of the review suggested that parental peer support: created a social identity and sense of belonging; generated empowerment and self-efficacy; ability to learn from other parental experiences and developed reciprocity in support (Shilling et al 2013). Conversely, when parents were pressurised into taking part in peer support by health professionals, this was not beneficial to the parent. On the other hand, although some of the quantitative studies indicated that peer support gave a positive psychological impact on parents, this result was not consistent across the review (Shilling et al 2013). A limitation of this review is that it was a collective parental experience of peer support, rather than separating mothers and fathers, though this was likely to be a methodological barrier due to the data analysis

within the individual studies. Another weakness of this study was that some of the studies included in this systematic review were almost 30 years old. Therefore, the findings of this review could have been more relevant, if the inclusion criteria stated a more recent date range, such as within the last ten years.

The key finding of this current study in relation to fathers seeking out support from beyond their family and healthcare circle, to connect with other people who had a similar experience, adds to the body of DDH parental literature and wider literature about fathers' experiences of caring for a child with a health condition. This finding could also prompt further research into the potential benefits of peer support specifically, for fathers in paediatric healthcare settings.

The development of the concept of this intermediate theme, 'biographical revision to the new father role' has evolved from Bury's (1982) popular concept of 'biographical disruption'. Bury's (1982) qualitative study with 30 adults with rheumatoid arthritis revealed that on receiving the diagnosis, participants felt a sense of disruption to their knowledge and understanding of themselves in the world. To continue with their own notion of normality, participants '*mobilised*' their cognitive and material resources around them and re-aligned their future expectations for their lives (Bury 1982:180). As acknowledged earlier in this chapter, fatherhood is a major life event which brings expectations. However, in this current study, fathers revealed that they revised their notion of fatherhood when they were informed of their infant's diagnosis of a physical disability, and then seeing them being treated in a device which was physically repellent and a physical barrier to them. Furthermore, in this study, fathers grappled with their psychological perceptions of their infant as being "*different*" and their desire to develop a quality attachment relationship with their baby. In addition, fathers mobilised their own resources by psychologically adapting to the new family situation around them and reaching out to other people with a similar experience, who were outside of their immediate family and healthcare circle. Therefore, the newly coined conceptual term, 'biographical revision to the new father role' in this thesis can be applied to fathers who have to revise their expectations of fatherhood to an infant undergoing treatment for a physical disability. This is an original contribution to the literature.

#### **8.4.4 Intermediate theme: Empowerment through the acquisition of information**

A key finding of this study in relation to the fathers, was that they felt disempowered and ***frustrated about the poor information provision by health practitioners***. They referred to both poor verbal and written information. It seemed that the fathers' sense of disempowerment and frustration was underpinned by their ***desire to understand the DDH diagnosis for their baby and use the information to manage the disruption to family life***. Fathers felt a sense of annoyance that the information that they received was by proxy from the mother of their infant.

Amongst the literature, there is a lack of knowledge and understanding about fathers caring for their infant with DDH and their support needs. This current study revealed that fathers wanted improved information support and gave examples of good aspects of information support as well as poor examples. Despite this dearth of literature in the field of DDH, within the field of paediatric hospitalised care, there is some research about fathers and their information support needs. Similarities between the findings of this current study regarding fathers' sense of empowerment with information provision was also found in qualitative research by Lindberg et al (2007) and Arockiasamy et al (2008). A recent literature review examining the experiences of fathers in neonatal intensive care units identified that fathers encountered unique challenges (Arockiasamy et al 2008; Pohlman et al 2005; Walmsley and Jones 2016). As well as needing information support from health practitioners, the review highlighted that fathers had to navigate gender power relations in the hospital environment (Deeney et al 2012; Hollywood and Hollywood 2011; Walmsley and Jones 2016). Fathers often faced the brunt of gender-based inequality exhibited by both the mother of their infant and the health practitioners (Deeney et al 2012; Hollywood and Hollywood 2011; Walmsley and Jones 2016). Although Walmsley and Jones (2016) adds depth to understanding fathers' experiences of caring for a hospitalised infant, the review has several weaknesses. Firstly, Walmsley and Jones (2016) do not specifically outline the search strategy in the literature review, such as the names of the databases and the date parameters of the review. Secondly, Walmsley and Jones (2016) do not reflect on the strengths and limitations of the review. An interesting quantitative study by O'Brien and Warren (2014) examined 58 fathers experiences of neonatal intensive care unit. The study concluded that health practitioners should develop bespoke caregiver plans for fathers by identifying the support in terms of information, caregiving and psychological needs. These

support needs could be carried out using a carers' needs assessment tool (O'Brien and Warren 2014; Knighting et al 2015).

This current study adds to the findings of Lindberg et al (2007) and Arockiasamy et al (2008). Moreover, as far as the researcher is aware, the finding that fathers were frustrated with mothers being the conduit of information is an original finding. Further research to understand this issue could have important healthcare practice implications. This key finding about fathers' experiences of the information provision regarding their DDH baby, is also an original contribution to the DDH parental research.

## **8.5 Comparing the lived experiences of mothers and fathers caring for their infant with DDH**

### **8.5.1 Parental resilience: Mapping the comparative parental key findings of their lived experience on to a conceptual model of parental resilience**

Earlier in this chapter, the key findings of this study about the unique, idiographic lived experience of mothers (Chapter Five) and fathers (Chapter Six) as they cared for their infant with DDH were discussed in relation to existing research. In the following section, the key findings of Chapter Seven, which compared the lived experiences of mothers and fathers, will move the discussion further with a focus on the emerging literature about parental resilience. The findings from this current study which explored the experiences of both mothers and fathers as they cared for their infant undergoing DDH treatment, can be used as examples of parental resilience and mapped on Gavidia-Payne et al's (2015) hypothesised conceptual model of parental resilience (see Figure 9). As a result, this current study can make an original contribution to the literature about parental resilience.

Rutter (1987) was amongst the first wave of researchers to develop the concept of psychological resilience through his studies of the positive, protective factors of children with adverse childhood experiences (ACEs) (Garmezy 1983; Garmezy, Masten and Tellegen 1984). The value of understanding resilience theory is linked to the factors which can predict long-term health and wellbeing (Masten, Monn and Supkoff 2011; Walsh 2011). From this substantial body of research about the resilience of the individual child, into the concept of family resilience (Black and Lobo 2008; Patterson 2002; Rosenberg 2013; Walsh 2003; Walsh 2011). Moreover, recently, there is an emerging conceptual sub-field of research about parental resilience (Brodsky and De Vet 2000; Luthar et al 2000; Gavidia-Payne et al 2015). Gavidia-Payne et al's (2015:111) define parental resilience as:

*'The capacity of parents to deliver competent, quality parenting to children despite adverse circumstances.'*

Gavidia-Payne et al's (2015) conceptual parental resilience model promotes the protective factors, while acknowledging the risk factors associated with parental resilience. The model was developed from studies which conceptualised this type of resilience (Gavidia-Payne et al's 2015). There are six elements to the model: child and family characteristics; parental psychological well-being; parental self-efficacy; family functioning; social connectedness; resilient parenting in terms of 'good parenting'. At this point, it is important to highlight that there is some overlap in these elements; the model is dynamic, evolving and lacks nuances (Gavidia-Payne et al's 2015). Another limitation of this model is that there is no universal measurement of parental resilience (Black and Lobo 2008; Gavidia-Payne et al's 2015).

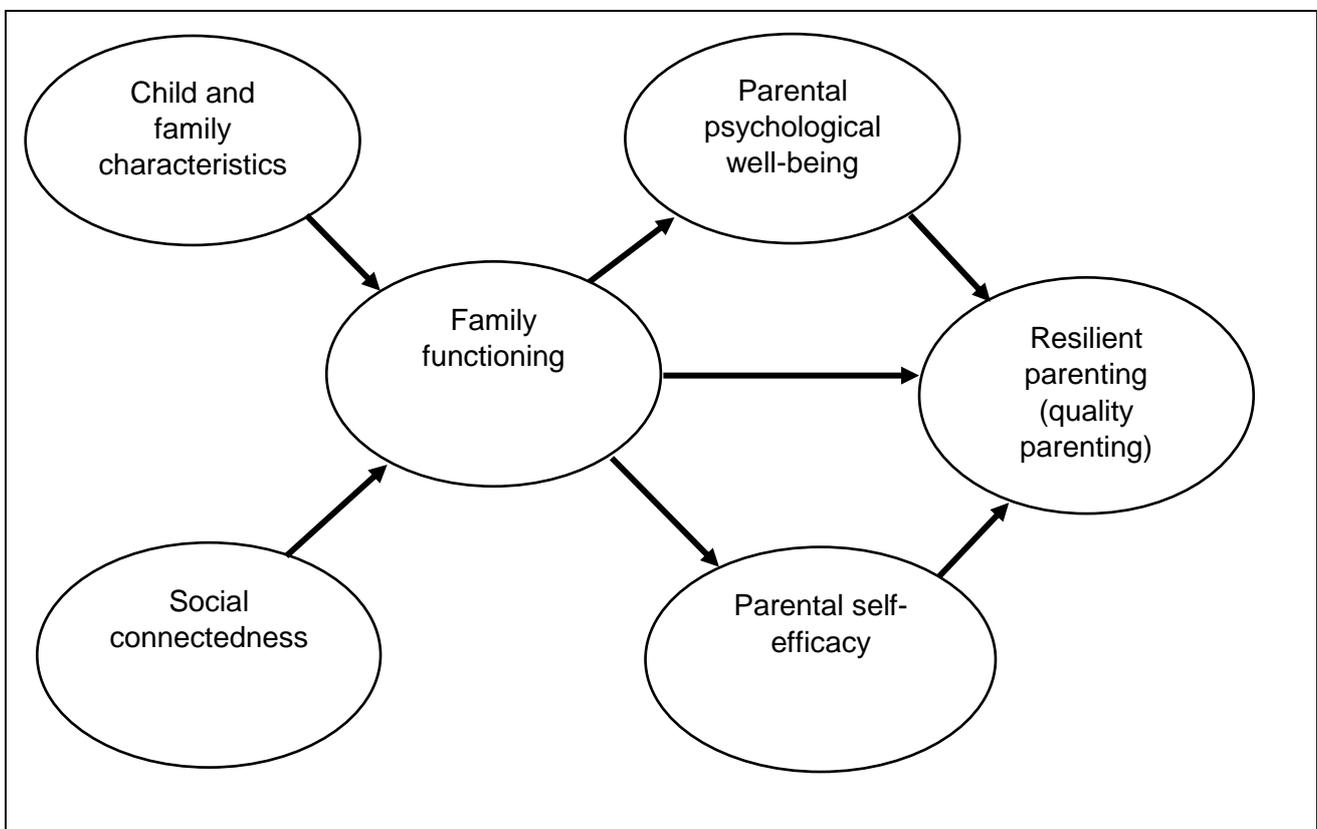


Figure 9: A conceptual parental resilience model (Gavidia-Payne et al 2015)

### Psychological wellbeing

The concept of negative parental psychological well-being linked to poor quality parenting is well documented in research (Masten et al 1990; Smith 2004; Carro et al 1993).

Furthermore, research indicates that poor quality parenting competencies are associated with lower parental resilience (Conger and Conger 2002; Roberts et al 2004). However, the

concept of parental psychological resilience offered by Gavidia-Payne et al's (2015) is based on research about child abuse and domestic violence. This current study contributes to this construct as key findings from parental accounts revealed that there were points during their infant's DDH care pathway that cause them psychological distress. For example, the physical look and the application of the harness to their infant; the early stage of the harness treatment and the challenges that parents faced as they managed their baby in a harness; the sense of grief and adjustment as the newborn clothing was removed from the home; parental perceptions of new perception of normal parenthood. These findings concur with the findings of other studies by Chao and Chiang (2003); Gardner et al (2005); Jennings et al (2017), which have examined the psychological impact of parenting a child with DDH (see Chapter Two). In addition, it appears that this current study offers examples of the positive effects of the parental psychological wellbeing, such as the importance that they placed on their attachment relationship with their infant; the use of time charts as a coping strategy and acquiring information about DDH. Yet, the application of these findings from this current study to the parental psychological wellbeing construct are limited by the self-reported nature of these perceptions in interviews by the participants and therefore, they are subjective.

### Self-efficacy

Research suggests that parents' sense of self-efficacy is associated with quality parenting. It is also thought to act as a protective factor against stress, anxiety and depression (Bandura 1997; Giallo et al 2013; Meirsschaut et al 2010; Teti and Gelfand 1991). In the current study, parents cited examples of occasions when they felt a sense of self-efficacy. For example, when parents were well supported and informed by health practitioners; through the acquisition of DDH information; by maintaining daily infant care routines while the baby underwent treatment in the harness. The findings of this current study support the findings of recent studies by Giambra et al (2018) and Aarthun et al (2017) that parents can develop self-efficacy when their child is diagnosis for a health condition and undergoing clinical treatment. Notably, Aarthun et al's (2017) qualitative study with 12 parents of hospitalised children study emphasised the central role that health practitioners played in facilitating the self-efficacy of parents in the healthcare decision making of their child. They concluded that when health practitioners acted with sensitivity with parents and responded to their needs, such as information provision, this enhanced parental perceptions of their self-efficacy with their child's healthcare. A weakness of Aarthun et al's (2017) study is that

only two fathers participated in the study compared with ten mothers. This study could have benefitted from recruiting mother and father participants in equal numbers. Another limitation of this study is the single setting for the study in one hospital in Norway. Utilising a multi-site setting for this study, such as other hospitals and primary care community clinics could have improved the conclusions of this study. On the other hand, the findings of this current study and other research could suggest that health practitioners have a role to be at the forefront of a parental focused intervention in the context of paediatric DDH.

### Family functioning

The model of parental resilience proposed by Gavidia-Payne et al (2015) suggests that the main family life activities are pivotal to the concept of parental resilience and these family life activities act as a protective factor. The key findings in this current study concur with this construct. For many fathers in this study, they emphasised the importance of the continuation of daily family life. As mentioned earlier in this chapter, mothers also reflected in the interviews that regardless of DDH harness treatment, the functioning of family continued as they had originally anticipated with a new baby in the home environment. Moreover, they were able to form a psychological attachment with their baby, which was an important feature to their expectations of motherhood.

The findings of a mixed methods study by Harkness et al (2011) conducted with parents about meanings that they placed on various family activities also supports the findings of the current study and Gavidia-Payne et al's (2015) family functioning construct within their model. Harkness et al's (2011) study encompassed a total of 60 parents from middle class communities across five countries in Europe and the United States of America. Using parental diaries which logged family activities, followed up with semi-structured interviews, the study found that parents regarded certain family activities as key to the functioning of the family unit. Family activities such as mealtimes; family time; play; school; child development activities were highly valued by parents as a means of organisation and understanding their child's lives. In the context of the continuation of family functioning and enabling parental resilience, this could also be interpreted as a means of parents gaining control of a difficult family situation, such as the new baby undergoing treatment for a potential disability.

### Social connectedness

Previous research suggests that parental resilience, underpinned by quality parenting and family functioning can be strengthened by enhancing perceptions of 'social connectedness' with family, friends and wider social support (Armstrong et al 2005; Hess et al 2002; Landau 2013; Gavidia-Payne et al's 2015). Furthermore, Masten et al (2011) theorised that social connectedness in adulthood, with the development of close relationships, was a mature form of attachment which was a protective factor for resilience. In the current study, Gavidia-Payne et al's (2015) concept of social connectedness was a key finding for both mothers and fathers. Whereas mothers tended to look to their maternal family for support, fathers played the role of supporter to the mother of his infant. Furthermore, an important finding of this current study suggests that fathers also wanted to reach out beyond their immediate family circle to connect with work colleagues and others to discuss their baby's condition and gain reassurance. This current study also offers an additional dimension to the concept of social connectedness, specifically, the role of internet social network platforms. Internet based social networks afforded parents the opportunity to: acquire knowledge about the reality of caring for an infant in a Pavlik harness; feel empowered and hope; less isolated; feel 'normal'; develop an identity and sense of kinship. There is a potential opportunity for a cost-effective intervention for parents to signposted to the Steps charity's online discussion forum.

### Other elements to the conceptual model of parental resilience

Based on research, the model acknowledges the importance of child and family characteristics, including socio-economic factors and family structure, to the concept of parental resilience (Black and Lobo 2008; Walsh 2011). However, Gavidia-Payne et al (2015) only makes a brief reference to this key element. With regards to this current study, socio-economic data was not collected from participants. This was due to the gathering of this data being beyond the aim and objectives of this current study. Therefore, this current study can not offer any examples to support or contradict this element of the model. Another criticism of the construction of this model is the element, 'Resilient parenting'. This element is not specifically addressed within the model. This element appears to be threaded through all of the elements of the overall model. Therefore, it could be argued that this element of the model should not feature in the current model, or it could be suggested that the model could be reconfigured to strategically represent, the concept of 'Resilient parenting'.

In sum, the comparative study of the key findings of the lived experience of mothers and fathers on to a conceptual model of parental resilience contributes to the emerging literature about the protective factors of parental resilience. It also adds to the literature in the context of parental resilience in relation to an infant undergoing treatment for a physical disability.

## **8.6 Strengths of the study**

This study has several notable strengths. These relate to: the successful recruitment of participants, especially fathers; the effective role of the pilot study; the value of the public and partnership involvement; the credibility and trustworthiness of the research design and findings; the practical implications of this study.

Over the years, researchers have noted difficulties in recruiting fathers to studies (Mitchell et al 2007; MacFadyen et al 2011). Often fathers are recruited to research by proxy through the mothers of children (MacFadyen et al 2011). An important strength of my study was my ability to successfully recruit the number of father participants required for this study. Moreover, these fathers were recruited over a short amount of time. The vast majority of fathers recruited to this study were facilitated by the mothers who acted as 'maternal gatekeepers' (Fagan and Barnett 2003). Specifically, mothers who had volunteered to participate in this study were sent a follow up email by the researcher inquiring if their infant's father would also consider taking part in this research. I successfully recruited my target sample number of nine father participants within a month.

Another important strength of this study was that parent participants were self-referred to this study. The self-referral was independent and outside the realms of the health services, such as the NHS (Newington and Metcalfe 2014). In this study, there was no association between the NHS and the researcher. During the parent interviews, the lack of affiliation of this study to the NHS was helpful because parents could share their unique perspective of caring for their infant with DDH, without worrying that they were directly compromising their relationship and quality of their infant's clinical care within the health services.

A notable strength was about the personal reflexivity of the researcher to overwhelmingly prioritise and accommodate the needs of the participants in the data collection stage. Throughout this study, I have always been conscious of the 'power imbalances' in research of the dominant role of the researcher and the participants (Marshall and Rossman 2011). I have also been mindful that parents participating in this study were giving up precious family time with their children. Although realistically, I could not completely readjust this

power imbalance between the participants and myself, I strove to be as accommodating as possible to fit around their busy family and employment commitments. I encouraged participants to state their preferred meeting date, time and venue. I would suggest a community centre or library very close to where they lived or worked. Interestingly, three couples of parents strongly insisted on conducting their interviews in university settings. I sensed that this was a credibility check by these participants gave them reassurance that the research was genuinely being conducted by Edinburgh Napier University. Moreover, in advance of the research interview, I emailed participants the interview questions. This action was to: put the participants at ease before the interview; to enhance the transparency of the study to the participants; to give reassurance about the nature of the interviews.

Another strength of this research was the pilot study. The pilot study was conducted with two parent participants, a mother and a father. It judged the suitability of the interview questions and practise using an IPA interview questioning technique (Creswell 2013). In addition, the pilot study assessed the quality and richness of the data as well as the ability of the researcher to analyse and interpreted the data to the depth required by IPA (Mason 2002; Smith, Flowers and Larkin 2009). The analysis was checked, and it concurred with the findings of an experienced IPA methodologist within the University. The pilot study was informative, and it showed the robustness of the research design to achieve the aims and objectives of the study. Furthermore, it enhanced the credibility of the study (Elliot, Fischer and Rennie 1999).

'Patient and public involvement' (also referred to as 'service users'/ 'lay involvement') in health research is an increasingly important element of health research due to their personal insights, knowledge and experiences of a health condition (National Institute of Health Research 2014). A notable strength of the research design of this study is that it benefited from public involvement with a parent of infant who had received DDH treatment. This mother reviewed and commented on the research design, the interview schedule and the interview settings. She also offered pivotal insight into the recruitment of parent participants using social media. Furthermore, there was a close partnership with professionals from family focused organisations, Steps DDH charity and Knowsley Children's Centres about research design of this study. In a meeting, the researcher discussed the option of giving participants an incentive to compensate them for their time and to recognise their need to make childcare arrangements, so they could take part in the

research interviews. Interestingly, the feedback from the two organisations was that they felt strongly against a financial incentive and I followed their advice. The professional insight of these organisations was a very helpful and pivotal in this study. As a developing researcher, I greatly benefitted from public involvement in this research and I will seek public involvement again in future research projects.

As highlighted in Chapter Four, this study has shown credibility, rigour and trustworthiness (Elliot, Fischer and Rennie 1999). Throughout each step of the research process, I have provided the details and the rationale of each step undertaken. Moreover, I have supported and provided an annotated sample of a transcript to indicate my IPA analysis technique (Elliot, Fischer and Rennie 1999; Smith, Flower and Larkin 2009).

Another strength of this study is that the findings can have immediate practical implications for the Steps DDH parent charity. The charity can direct the focus of their work on supporting parents through online information about caring for an infant in a harness. The charity can also focus on enhancing its online parental networking platforms.

## **8.7 Limitations and other considerations of the study**

Limitations and considerations have been discussed at several stages through this thesis. Most of the limitations relate to the sample of participants. Firstly, the parental participants in this study were not all in parental dyadic relationships. Amongst the participants, there were two unconnected parents. In the early development stages of this study, it was anticipated that fathers would be difficult to recruit to this study, therefore, no consideration was given to the potential recruitment of dyads (Mitchell et al 2007). In hindsight, this study could have exclusively recruited dyads and the findings could have been triangulated using IPA methodology to explore the phenomenon of parenting an infant with DDH (Clare 2002; Braun et al 2009). On the other hand, it is counter-argued that the lack of dyadic triangulation of parents did not impact on the findings of this study.

The participants were recruited through the social media platforms of a parent DDH charity; therefore, it could be argued that these parents were already engaging with the support offered by the charity. It is possible that this sample of parent participants were at a psychological stage with their infant's treatment in which they felt confident to talk about their lived experience. The experiences of other parents who may have been struggling to

cope with their infant's diagnosis and treatment and who were not engaging with the charity may not have been represented in this research (Costigan and Cox 2001).

Another limitation of this study is that the participant descriptive data which was gathered about the participants was narrow. Descriptive and socio-economic data about the participants was not gathered, such as age, education, employment and marital status. Careful consideration was given for the rationale for not gathering this type of data from the participants. Whereas, on one hand, it could be suggested that the lack of this data could make it difficult to contextualise the findings of this study. On the other hand, the strong counter-argument supersedes this viewpoint. Firstly, the literature review did not identify any association between DDH and socio-economic factors. Secondly, for both legal and ethical reasons, there was no justification for the collation, analysis and retention of this type of data in this study (Legislation.gov.uk 2018). Therefore, although this type of additional data is lacking from this study; there was no justification for gathering and applying it to this study.

The context of this study was a limitation. The participants were not ethnically diverse. The participants were white British parents who spoke English as a first language. Moreover, it can also be argued that the geographical setting of the study in England and Scotland only, means that the findings can only be understood in this geographical context.

Since the participants in this study were emailed the interview questions sheet in advance of the interview, it could be suggested that the participants were primed to talk about certain issues in the interview. However, it can be counter-argued that the interview questions were focused on the aim and objectives of this study. In addition, the interviews followed a semi-structured format which gave participants the opportunity to present their unique lived experience and divert the interview conversation to talk about the DDH issues which were important to them (Gray 2014).

Aside from the limitations of this study associated with the sample, this study was also limited by its cross-sectional design. Due to the tight timescales to conduct this study, there was only scope to interview the participants on one occasion. By using a longitudinal design, this study could have interpreted the development of the participants' experiences as it unfolded in the present day, as opposed to participants reflecting on their experiences in retrospect (Mason 2002). Conversely, it can be counter-argued that the current views and experiences of participants are still maintained by the participants at the time of data

collection. The participants' reflections and memories are still important, even if they are not the same as those reflections that existed at an earlier point in time.

Initial consideration was given in this study to specifically focus on parental DDH experience of the use of ultrasonography on their infant. This aim would have reflected the narrow focus of much of the quantitative literature in the review (see Chapter Two). In the parental interviews, the use of ultrasonography was mentioned by the interviewer, but all parents in this current study closed this line of questioning down quickly with a short response. They all briefly explained that it was not a specific issue for them. In hindsight, the qualitative aim and objectives of this study would clearly have encouraged a broader exploration of this phenomenon by the parent participants (Mason 2002).

## **8.8 Personal reflexivity**

In this section, I will reflect on my own perspectives and experiences as a developing researcher. I will consider my thoughts and expectations of when I first began devising my PhD research proposal to the present day, on my reflections and understandings as my research project came to a close.

Reflexivity is defined by Creswell (2013, p216) as when a qualitative researcher is *'conscious of the biases, values, and experiences that he or she brings to qualitative research.'* Creswell (2013) suggests that reflexivity has two elements. The first element is when the researcher is explicit about their own experiences to the phenomenon being explored in the study. The second element of reflexivity is considered by Creswell (2013, p216) as *'the heart of being reflexive in a study'*. This element concerns the transparency of the researcher in revealing how their own experiences of the phenomenon may have informed the findings, interpretations and conclusions of the study. Therefore, I will address both of Creswell's reflexivity elements.

As mentioned in Chapter One, a personal experience that I brought to this qualitative study is that I am the mother of two small children who had DDH in infancy. To date, they have both successfully recovered from this treatment. Although my children underwent DDH treatment at different times, I remember it being a challenging time from a practical perspective. I researched DDH and parents' experiences of this phenomenon and my early research influenced my PhD research proposal. At the recruitment of participants stage of this study, I received emails from parents expressing their interest in participating in the interviews. I would respond to these emails with more detailed information and documents

about the study. Moreover, I was keen to be as transparent as possible towards participants, so I would also explain in this email that I am also a parent of children who had been treated for DDH. At a later date, when I met with parents at the interviews, there was always a brief informal discussion about my children who had DDH. Often these discussions were prompted by the parent participants. In my researcher role, I always emphasised to parents in the interviews that I was completely open to their views and experiences; I was not looking for any particular response; I was interested in their specific experience of the phenomenon. However, I acknowledge that the nature of IPA methodology and the hermeneutic circle, it is possible that my own parental experiences of caring for children with DDH may have inadvertently influenced my interpretation of the meanings of the lived experience by the parent participants in this study. On the other hand, qualitative research is subjective and IPA demands the active role of the researcher to interpret the perspective of the participant (Pietkiewicz and Smith 2014) Furthermore, although my interest in this field of research was initially prompted by my own experiences of this phenomenon, by the time I embarked on the interviews, analysis, results and conclusions stage of this study, I was overwhelmingly led by my qualitative researcher skillset as opposed to my own experiences of this event.

Other experiences that I brought to this study are my work experiences as an analyst and as an interviewer in law enforcement and the NHS. As an analyst, I considered myself as a 'mixed methods researcher'. However, it was only until I embarked on this PhD research project that I gained an in-depth appreciation, value and skill of qualitative research methodologies. My initial research proposal indicated a mixed methods study. The qualitative aspect of this proposal was an ethnographic study with a photovoice element (Wang and Burris 1994; 1997). I wrote an autoethnography about my own experiences as a parent caring for children with DDH (Ellis 2004; Maréchal 2010). I also maintained an electronic reflexive journal of my study to show my thoughts throughout the project.

As my study ends, I have noticed a shift in my philosophical assumptions of ontology and epistemology, in the direction of phenomenology, to understand the individual lived experiences of the participants who experienced caring for their infant with DDH. Moreover, I have developed a deep appreciation and understanding of the theoretical underpinnings of prominent qualitative methodologies and their importance in relation to their findings and their implications. In addition, at the beginning of this study, I considered myself an experienced interviewer. I used the 'Who, What, Why and How' interviewing technique to

prompt participants' responses to my interview questions. However, as I reviewed and analysed my interview transcripts, there were at least four occasions which I could have elicited more detail from the participants. Therefore, as I reflect, I appreciate that qualitative research interviewing is subtle and sensitive, compared with a descriptive, information gathering law enforcement style interview.

## **8.9 Chapter summary**

This chapter presented the discussion of the key findings of this current study. It drew on the wider body of literature from other relevant aspects of healthcare. Moreover, the key findings from this study were discussed in relation to the concept of family-centred care (Michalopoulou et al 2018) and Gavidia-Payne's conceptual model of the protective factors of parental resilience. In addition, from the key findings of the fathers' interviews, a newly coined concept was developed which was the 'biographical revision to the new father role'. Signposted throughout this chapter were areas for further research and it highlighted aspects of this current study which contributed to the body of literature in this field. This chapter also addressed the strengths and limitations of the study as well as the personal reflexivity of the researcher.

The next chapter, the Conclusion Chapter, will present the main arguments of this thesis. It will also present the originality and the contribution of this thesis to knowledge and understanding of this phenomenon. Furthermore, the Conclusion Chapter, will offer realistic recommendations for policy, practice and further research which are based on the Discussion Chapter.

## Chapter Nine      Conclusion Chapter

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### 9.1 Chapter overview

This is the final chapter of this thesis. It will present the main arguments of this thesis and state the originality and contribution to knowledge of this study. Based on the key findings of this study realistic recommendations will be made for policy, healthcare practice and further research. The chapter will close with a brief conclusion about the thesis.

### 9.2 The main arguments of this thesis

The main arguments of this thesis about the experiences of mothers and fathers caring for their infant with DDH are summarised below:

- The paternalistic model of healthcare appears to still exist in DDH outpatient clinics in the UK. It could be suggested that embedding the principles and practice of Family Centred Care in this setting could begin to counter-balance this bio-medical power imbalance and any gender power imbalance. However, before applying Family Centred Care in an outpatient setting, there needs to be clarity about: what mothers and fathers want, need and expect from DDH outpatient health service.
- Parents do feel psychological distress when their infant receives a DDH diagnosis and begins harness treatment. Many parents grappled with coming to terms with their own psychological perceptions of their baby as being different from being normal. It could be suggested that this parental perception could affect the quality of attachment relationship of the parent towards their infant, as well as the parents' ability to cope with the care of infant in the home.
- Health practitioners play a pivotal role in the parental experiences of this phenomenon. As well as clinical skills, specialist DDH health practitioners, need enhanced interpersonal and communication skills, to convey empathy, provide psychological support and empower self-efficacy to parents caring for an infant with DDH. It is also important that health practitioners are particularly sensitive to the new mother and infant status and support their needs including breastfeeding an infant in a Pavlik harness. Health practitioners also need to have an intuitive awareness of

the subtle nuances of maternal covert and overt behaviours that could indicate a need for further parental support. In addition, mothers and fathers have different carer support needs which should be identified and addressed by health practitioners.

- Mothers and fathers highlighted their information needs at the point of their diagnosis for DDH and during the treatment stage. There is scope to improve the verbal and written DDH information delivered by health practitioners in DDH outpatient clinics. When parents receive poor quality information, this can heighten parental psychological distress. Often there was a lack of practical infant care information about harness treatment. On the other hand, some mothers felt empowered to search for information on the internet. Furthering their knowledge about DDH gave mothers a sense of self-efficacy. Whereas fathers wanted to understand the reality of the caring for an infant with DDH, from other people (peers) who had their own DDH experiences. There are opportunities for health practitioners to signpost parents to reliable high-quality internet-based information. However, information provision should be holistic and inclusive of all parents and not exclude those without internet access. Signposting to internet information sources should not be a substitute for high quality verbal and written information from health practitioners. Furthermore, a holistic approach to information provision by health practitioners could enhance the engagement between parents and health practitioners. This would be in keeping with Family Centred Care principles and practice.
- Fathers were frustrated with the delivery of information about DDH by proxy through the mother of his infant. This may have suggested that there are gender power dynamics in hospital settings which results in the fathers being subjected to inequality.
- Parents are repelled by physical appearance of the Pavlik harness on their baby. In the early stage of the harness treatment, parents also struggled with the initial day-to-day care of the infant in the harness. Parents felt psychological and practical challenges with their baby while undergoing harness treatment. This was perceived as a barrier the enhanced quality of their own attachment relationship to their infant.

- Parents felt psychological distress at the adjustment, from their notion of having a healthy 'normal' baby to having a 'different' infant. For fathers, this was conceptualised using a newly coined term, 'biographical revision to the new father role'.
- Mothers and fathers felt a dissonance between their socially constructed notion of parenthood and sensed a shift towards their perceived experience of a 'different' parenthood.
- The caring experiences of fathers of this phenomenon reflected the psychological health behaviours of the Health Belief Model.
- It is clear from the fathers' experiences of caring for their infant with DDH that fathers needed support, but it was lacking. It seems that fathers have different support needs to those of mothers caring for the DDH baby.
- By mapping the comparative findings of the mothers and fathers' experiences (see Chapter Seven) on to Gavidia-Payne et al's (2015) hypothesised conceptual model of parental resilience, these findings offer context to the model.

### **9.3 The originality and contribution to knowledge of this study**

The concepts of originality and contribution to knowledge are amongst the main objectives in the evaluation and award of a Ph.D. qualification (Clarke and Lunt 2014). This current study took a qualitative approach and therefore, the findings are highly contextual, though they can provide nuanced insight into the experience of mothers and fathers caring for their infant with DDH. Here I present my argument to show the originality and contribution to knowledge of my study:

- It has progressed the international field of DDH with original knowledge and understanding about the experiences of mothers and fathers caring for their infant with DDH;
- In the broader context, this study contributes to the wider body of international literature about mother and fathers' experiences of caring for a young child with a health condition, in particularly a potential chronic physical disability;

- It shows that mothers and fathers converge and diverge in aspects of this experience. This finding has potential policy and practical healthcare implications;
- The comparative findings of the experience of mothers and fathers (see Chapter Seven) were mapped on to Gavidia-Payne et al's (2015) conceptual model of parental resilience and provided context to this hypothetical model. The application of this mapping to the model adds to the literature base in the emerging theoretical field of parental resilience;
- From the findings of the fathers' experience of caring for an infant with DDH, a newly coined conceptual term, 'biographical revision to the new father role'. This term can be applied to fathers who have revised their expectations of a fatherhood to a 'normal' healthy infant, to a fatherhood with an infant undergoing treatment for a physical disability.
- It contributes original elements to the qualitative paradigm. As far as the researcher is aware, this is the first qualitative study to recruit parent participants from a non-healthcare setting. Moreover, it is potentially the first study to recruit parent participants from a charity's social media platform. It is also novel research as this is the first study to utilise IPA to explore parental experiences of caring for an infant with DDH.

#### **9.4 Recommendations for policy and practice**

1. Enhanced training for specialist DDH health professionals about the application of interpersonal and communication skills to support parents with a young infant.
2. Implement family centred care in DDH outpatient clinics which is actively and equally inclusive of fathers; development of policy and practical procedures which delivers information and follow up support to fathers of the infants with DDH.
3. Establish peer-to-peer DDH parental support groups within hospital settings.

4. Improve the quality of the written DDH information provision for parents of infants with DDH, in terms of leaflets and NHS information website. This information should include practical information about the day-to-day care for an infant in a harness.
5. Development of best practice toolkit which focuses on the breastfeeding techniques for feeding infants in a Pavlik harness.
6. Additional health practitioner support to parents at the point of the infant's DDH diagnosis and aftercare, when the infant is fitted into a Pavlik harness.

## **9.5 Recommendations for research**

From the findings of this current study, there are several recommendations for further research inquiry:

1. A quantitative study to test Govidia-Payne et al's (2015) family resilience model in DDH outpatient settings.
2. A mixed methods study which uses an existing evidence-based carers triage tool to identify the bespoke needs of mothers and fathers caring for an infant undergoing DDH treatment in a Pavlik harness. For example, the 'Carers Alert Thermometer'. This is a triage tool which identifies the specific information and support needs of family carers (Knighting et al 2015).
3. A mixed methods study which develops an evidence-based mobile phone app to support the information and wellbeing needs of parenting an infant with DDH (Lupton 2016; Wallwiener et al 2016).
4. A longitudinal qualitative study which explores paternal perceptions of their attachment relationship with their infant with DDH (Ainsworth and Wittig 1969; Bowlby 1969; Redshaw and Martin 2013).
5. An ethnographic study involving DDH health professionals (such as nurses, sonographers, doctors, senior managers) shadowing parents of infants with DDH through the outpatient clinical care pathway. The health professionals could follow

the families from the DDH outpatient reception desk infant to the sonography area to the clinic, with a follow up appointment in the family home (Michalopoulou et al 2018; Shield et al 2015; Point of Care Foundation 2018).

## **9.6 A brief conclusion to the thesis**

DDH is a physical disability which can affect morbidity in mid-adulthood, such as a walking disability and chronic back pain. However, if DDH is diagnosed and treated at a very young age, before eighteen months old, there is a very favourable prognosis. The review of the literature identified a gap in knowledge and understanding about the experiences of parents with a young infant who had been diagnosed and treated for the condition in a Pavlik harness. Using IPA, semi-structured interviews with nine mothers and nine fathers revealed new key findings about their lived experience. This study argues that parents psychologically struggled with the diagnosis and initial care of their infant in a Pavlik harness; the paternalistic model of healthcare appears to still exist in DDH outpatient clinics; mothers and fathers have differing carer support needs; fathers needed support and experienced inequality in these DDH clinics. A new conceptual term, 'biographical revision to the new father role' was coined to reflect the experiences of fathers in this study. Also, this study argues that by embedding the principles and practice of family centred care (FCC) could counterbalance any bio-medical power imbalance and any gender power imbalance. Health practitioners were pivotal to the parental experience. Their enhanced interpersonal skills could provide psychological support and empower self-efficacy among parents caring for an infant with DDH. Furthermore, the comparative findings of the parental experience contribute to a theoretical model of parental resilience.

It is important to reiterate that these findings of parental experiences of caring for an infant with DDH are indicative, but they are not conclusive. They represent a specific demographic group of parents in Scotland and England. However, these findings do make a new contribution to the knowledge base about parenting an infant with DDH.

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## Appendices

### Appendix 1: Raw database search results using search strategy (conducted on 5<sup>th</sup> March 2018)

#### CINAHL database search results

#	Query	Limiters/Expanders	Results
S1	(MM "Hip Dislocation, Congenital") OR (MM "Hip Dislocation") OR DDH OR Developmental Dysplasia of the Hip	Search modes - Boolean/Phrase	2,394
S2	(MM "Parents+")	Search modes - Boolean/Phrase	41,076
S3	(MM "Attitude to Health") OR (MM "Health Knowledge") OR "health knowledge, attitudes, practice"	Search modes - Boolean/Phrase	30,120
S4	S1 AND S2	Search modes - Boolean/Phrase	13
S5	S1 AND S3	Search modes - Boolean/Phrase	5
S6	S4 OR S5	Search modes - Boolean/Phrase	14

#### Cochrane Library database search results

#	Query	Limiters/Expanders	Results
S1	'Developmental Dysplasia of the Hip'	Search modes - Boolean/Phrase	1

### Medline database search results

#	Query	Limiters/Expanders	Results
S1	(MM "Hip Dislocation") OR (MM "Hip Dislocation, Congenital") OR DDH OR Developmental Dysplasia of the Hip	Search modes - Boolean/Phrase	13,675
S2	(MM "Parents+")	Search modes - Boolean/Phrase	56,219
S3	(MM "Health Knowledge, Attitudes, Practice")	Search modes - Boolean/Phrase	50,705
S4	S1 AND S2	Search modes - Boolean/Phrase	17
S5	S1 AND S3	Search modes - Boolean/Phrase	5
S6	S4 OR S5	Search modes - Boolean/Phrase	21

### PsycINFO database search results

#	Query	Limiters/Expanders	Results
S1	(MM "Hip Dislocation") OR (MM "Hip Dislocation, Congenital") OR DDH OR Developmental Dysplasia of the Hip	Search modes - Boolean/Phrase	113
S2	(MM "Parents+")	Search modes - Boolean/Phrase	19,235
S3	(MM "Health Knowledge, Attitudes, Practice")	Search modes - Boolean/Phrase	12,615
S4	S1 AND S2	Search modes - Boolean/Phrase	1
S5	S1 AND S3	Search modes - Boolean/Phrase	0
S6	S4 OR S5	Search modes - Boolean/Phrase	1

### Pub Med database search results

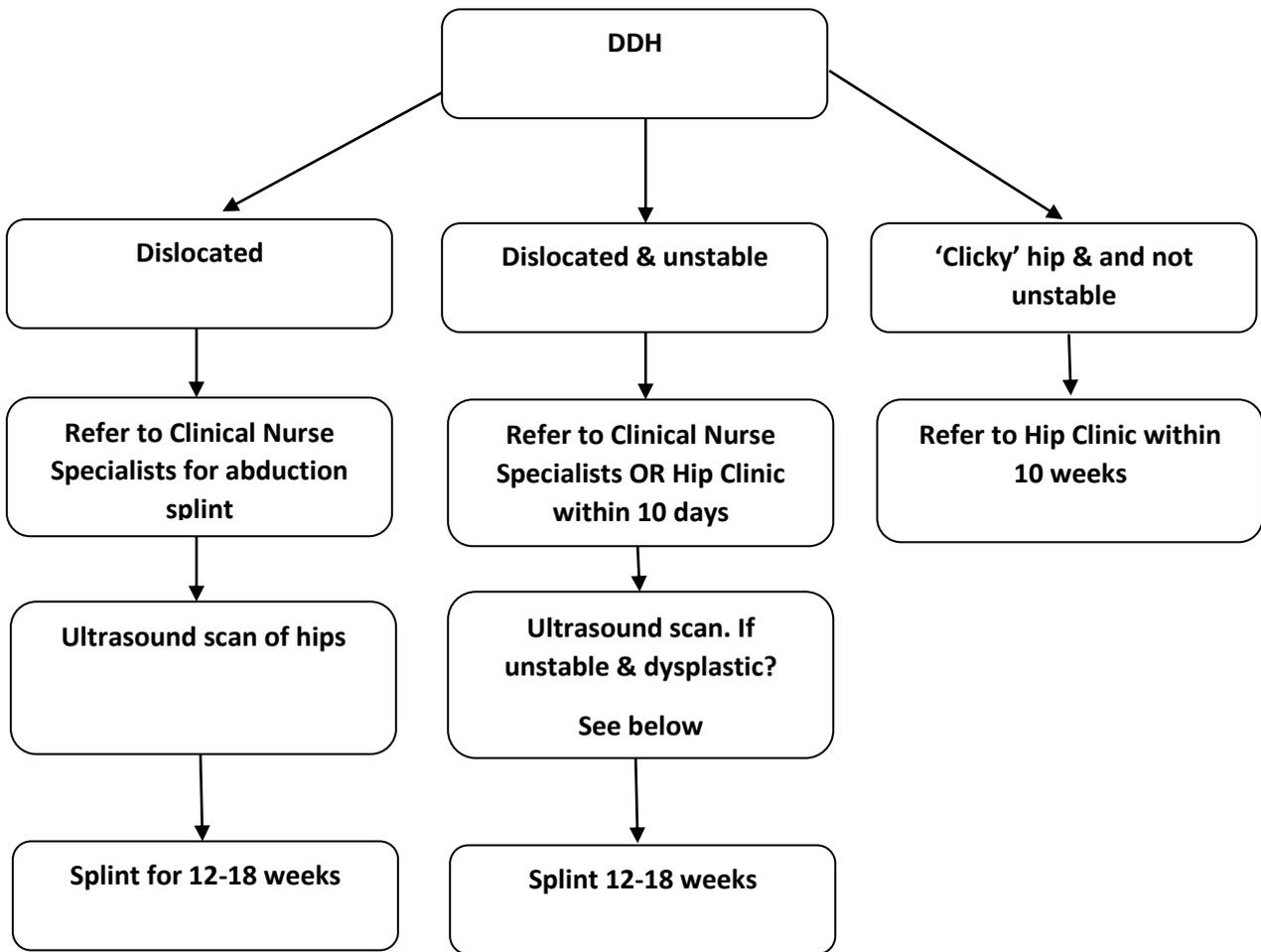
#	Query	Limiters/Expanders	Results
S1	(MM "Hip Dislocation") OR (MM "Hip Dislocation, Congenital") OR DDH OR Developmental Dysplasia of the Hip	Search modes - Boolean/Phrase	9301
S2	(MM "Parents+")	Search modes - Boolean/Phrase	95168
S3	(MM "Health Knowledge, Attitudes, Practice")	Search modes - Boolean/Phrase	94011
S4	S1 AND S2	Search modes - Boolean/Phrase	34
S5	S1 AND S3	Search modes - Boolean/Phrase	82
S6	S4 OR S5	Search modes - Boolean/Phrase	4

**Appendix 2: A detailed summary table of database search results**

	CINAHL (n=)	Cochrane Library	Medline (n=)	PsycINFO (n=)	Pub Med (n=)
S1 + S2	13	5 (studies within 1 paper)	17	1	34
S1 + S3	5	Not applicable	5	0	82
S4 OR S5	14	Not applicable	21	1	4
<b>Total:</b>	<b>32</b>	<b>5</b>	<b>43</b>	<b>2</b>	<b>120</b>

Overall total number of journal articles found in search of electronic databases= **202**

**Appendix 3: DDH care pathway for infants** (Lee 2017)



**Appendix 4: Structure of literature review with studies: Following the care pathway for DDH**

Neonate screening for DDH using CPHE and / or ultrasonography	Parental involvement in infant screening for DDH using ultrasonography  (3 months old infants)	Diagnosis & treatment of NHI / mild DDH amongst neonates  (Ultrasonography for diagnosis and monitoring)	Early treatment & management of moderate to severe DDH  (Splint)	Treatment for DDH at a late stage  (Spica cast and surgery)
Rosendahl et al (1994)	Witting et al (2012a)	Gardiner & Dunn (1990)	Corbett (1988)	Newman & Fawcett (1995)
Holden et al (2002)	Witting et al (2012b)	Elbourne et al (2002)	McHale, Major & Corbett (1989)	Cox & Kernohan (1998)
Mace & Paton (2015)	Witting et al (2013)	Rosendahl et al (2010)	Gardner et al (2005)	Chao & Chiang (2003)
McAllister et al (2018)	Jennings et al (2017)		Hassan (2009)	Demir et al 2015
			Bergo & Rosendahl (2013)	
			Fabricant et al (2013)	
			Groarke et al (2017)	

**Appendix 5: A chronological summary table of empirical studies** (Based on Greenhalgh and Brown 2015)

Author(s) & date	Location of study	Aim of study	Research strategy & design	Study timeframe	Participants & sample size	Data collection method or instrument	Theoretical context	Key findings	Strengths & limitations	Implications of study
Corbett (1988)	United States of America	To understand the extent & types of problems encountered by families with infants being cared for in a Pavlik harness.	Quantitative approach. Survey.  Longitudinal.	6 months	Parents.  n= 22.	Qnn with parents.	Not used	<p>1. Parents experienced problems with applying the harness, bathing, clothing and transporting the infant.</p> <p>2. Parents stated that they lacked information. They misunderstood what they had been told by health professionals &amp; had difficulty recalling the information given to them by health professionals. Parents needed regular access to information &amp; support from health professionals. 3. Also, parents felt guilt &amp; self-pity regarding the diagnosis of DDH for their infant.</p>	<p><i>Strengths:</i></p> <p>1. The descriptive survey was useful in identifying the nature of parental problems as their infant was being treated in a harness</p> <p>2. Interesting &amp; appropriate questions on the Qnn.</p> <p><i>Limitations:</i></p> <p>1. Lacked detail about the recruitment of the participants, such as the procedure utilised to randomly select participants to take part in the study.</p> <p>2. It does not clearly define the participants in the survey. Interchanges the use of the terms 'families' and 'parents'.</p> <p>3. The sampling &amp; recruitment of participants is unclear as it states that they were selected at: 'random from different care providers from a population of normal</p>	Health professionals need to improve the delivery of the information they give to parents about their infant's diagnosis & treatment. Parents need to be taught about how to apply & remove a Pavlik harness and health professionals need to be available to parents to provide guidance to parents. This is essential for the treatment to be effective.

									infants having been diagnosed with DDH'.  4. More detail is needed about the method of the study.	
McHale, Major and Corbett (1989)	United States of America	Explores the views and attitudes of parents who have a child undergoing treatment in a Pavlik harness.	Quantitative approach.  Survey  Cross-sectional.	Not stated	Parents. n=32.	Qnn & a patient chart review.	Not used	1. Parents experienced emotional demands, such as difficulties adjusting to caring for their infant in a harness.  2. The majority of parents did not comply with the instructions of the doctor, though only the treatment failure of 1 infant could be linked to the non-compliance of the parent.	<i>Strengths:</i>  1. The hospital setting. It enabled the researchers to directly recruit participants and collect data quickly.  <i>Limitations:</i>  1. Lacked clarity about the parent participants- 28 participants were the mothers of the infants, but they were unclear about the relationship of the infants to the remaining 4 participants.  2. Throughout the study, interchange the term 'parents' and 'mothers'.	1. Caring for an infant in a Pavlik harness has emotional and physical demands on parents.  2. Most parents do not follow the doctors' instructions about keeping the infant in the harness constantly.
Gardiner & Dunn (1990)	England, United Kingdom	A controlled trial of immediate splinting versus ultra-sonographic surveillance in congenitally dislocatable hips	Quantitative approach.  RCT.  Longitudinal.	April 1988-Sept 1989	Infants with clinically dislocatable hips (not dislocated). n=79 infants. Initially, they all received a physical hip examination and an ultrasound scan. They were subsequently allocated to a group:  In the Control Group/ Group A,	Clinical medical records of the infants at birth, 6 months old and 12 months old.	Not used	There was no significant difference between those infants at birth, at 6 months and at 12 months who received ultrasonography compared with those infants who received a physical clinical examination only.	<i>Strengths:</i>  1. The use of the longitudinal timeframe to collect clinical data at intervals during study.  <i>Limitations:</i>  1. There was no evidence or analysis of the practical or cost implications were presented in this study to	Contrary to their findings, they did not recommend ultrasonography for universal screening for practical and costs reasons.

					<p>(n=41) - infants immediate had their hips splinted</p> <p>In Group B (n=38) – infants received sonographic monitoring for 2 weeks. At 2 weeks, another ultrasound scan of infants. If the hips were still clinically unstable or showed no improvement on the ultrasound scan, then they were splinted. Otherwise, infants continued to be regularly monitored via ultrasound scan.</p>				<p>support this conclusion.</p> <p>2. This study mentions that if infants are over-treated for DDH, parents experience anxiety. However, the researchers do not evidence this statement.</p> <p>3. The researchers do not state which type of splint was used, for example, the Pavlik harness, Frejka pillow or another type of splint.</p> <p>4. The researchers did not explain the reasons about the follow up loss of 44% of the total sample of infant participants at the 12 months stage.</p>	
Rosendahl, Markestad & Lie (1994)	Norway	To determine whether general or ultrasound screening had an impact in treatment and prevalence rate for late DDH.	Quantitative approach. RCT. Longitudinal.	Not stated	<p>Infants. n=11,925</p> <p>General ultrasonography group (n=3613); selective screening due to DDH risk factors group (n=4388); no ultrasonography (n=3924).</p>	Clinic follow up when infants reached 24 months old.	Not used	<p>The results of the study indicated that the infants in the general ultrasonography group had a higher splint treatment rate at 1 month old than the selective or no ultrasonography groups (3.4% vs 2.0% and 1.8%, p= 0.0001)</p>	<p><i>Strengths:</i></p> <p>1. Blinding of the staff to the existent of study in order to control for bias, even though they were not directly involved in the study.</p> <p><i>Limitations:</i></p> <p>1. The researchers do not clearly identify any limitations with their research.</p> <p>2. Approximately 155 records were missing from the study, which was</p>	The researchers did not recommend universal ultrasound screening.

									acknowledged by the researchers, but no explanation was given.	
Newman & Fawcett (1995)	United States of America	To understand the impact on the care giver caring for a child in a body cast.	Quantitative approach.  Survey.  Cross-sectional.	Not stated	Mothers.  n= 35.	Data from 11 mothers collected from an Open Ended Qnn, which was adapted from the Roy Adaptation Model (Roy 1984). Data from another 24 mothers was obtained from the comments section of instrument called the Inventory of Functional Status-Caregiver of a Child in a Body Cast (IFSCCBC). This was also derived from the Roy Adaptation Model (Roy & Andrews 1991)	Not used	This study highlighted that the mothers as primary carers, had to make major adjustments to their lives in terms of their family and personal life, their occupational activities and social activities. such as physically moving, dressing, transporting the child and trying to maintain a usual routine.	<p><i>Strengths:</i></p> <ol style="list-style-type: none"> <li>1. The use of a questionnaire in a clinic setting which gave direct access to participants and enabled the data to be collated within a short period of time.</li> </ol> <p><i>Limitations:</i></p> <ol style="list-style-type: none"> <li>1. It was not exclusively a study about DDH, but about body casts, of which the vast majority of participants were being treated for DDH.</li> <li>2. The sample was very small for survey research.</li> <li>3. Literature review was weak.</li> <li>4. Combined Qnn data from one group of mothers, with the comment section from a different instrument with different group of mothers. Not clear how the comments were analysed.</li> <li>5. Low Qnn response rate.</li> </ol>	Nurses need to consider the needs of the parents as well as the needs of the child in the body cast.
Cox & Kernohan (1998)	Northern Ireland & England, United	To identify the problems of parents when a child is undergoing treatment in a	Quantitative approach.  Survey.  Cross-	Not stated	Parents. n= 37	Using a functional-life scale, the Qnn was custom-fitted. It featured 89 questions	Not used	It identified the main problems as mobility, emotional & social problems for families who	<p><i>Strengths:</i></p> <ol style="list-style-type: none"> <li>1. Qnn was piloted.</li> </ol>	Parents problems could be alleviated if they were provided with special equipment to allow mobility in a car &

	Kingdom	spica cast for DDH.	sectional.			featuring both structured and open questions.  37 Qnns were completed. 35 x self-administered postal Qnn &  3 x interviewer-administered.		have a child being treated in a spica cast for DDH.	<i>Limitations:</i>  1. Lack of an explanation as to where the questionnaires were sent, for example, parents' homes or a health centre/s.  2. It is unclear who is responding to the questionnaires, for example, mothers, fathers or both parents.  3. A low Qnn response rate of 34%.  4. Too many questions on the Qnn (89 questions)	pushchair & seating in the home.
Elbourne et al (2002)	United Kingdom & Ireland	To analyse the clinical effectiveness of ultrasonography amongst neonates compared with clinical physical hip examination of neonates only.	Quantitative approach.  RCT.  Longitudinal.	Dec 1994-Jan 1998	629 infants.  Split into 2 groups: ultrasound hip monitoring group (n=314) or to a clinical physical examination only group (n=315).	Clinic records and radiographs.	Not used	Fewer children in the ultrasonography group had to be placed in a splint over the 2 years compared with the clinical physical hip examination only group.	<i>Strengths:</i>  1. A multi-centre study which reflected a variety of settings and health practice.  <i>Limitations:</i>  1. The researchers did not explain the lack of availability of radiographs in 15% of infants at 2 years old.	The use of ultrasonography reduced the splinting rates in neonates.
Holden et al (2002)	Norway	To evaluate whether universal or selective ultrasound screening of newborn hips should be recommended.	Quantitative approach.  RCT.  Prospective, longitudinal.	Between 1988-1992	15,529 infants.  They were randomly allocated to either a CPHE and ultrasonography group (n=7840) or CPHE only group (subjective)	Follow up with infants when they reached between 6 to 11 years old	Not used	In the ultrasonography group, just 1 of the neonates was diagnosed with late DDH (prevalence rate of 0.13 per 1000 births). In the	<i>Strengths:</i>  1. RCT is regarded as the most effective design.  2. Sample size was based on power analysis.	Although the results suggest a case to support universal ultrasound for neonates, the researchers do not and argue that health professionals who are trained in CPHE is adequate for screening.

					(n=7689). However, within in the CPHE group, those infants with risk factors for DDH did undergo an ultrasound scan (n=872, 11.3% of the sample in this group).			CPHE (subjective) group, five neonates were later diagnosed with DDH (prevalence rate of 0.65 of 1000 births).	<i>Limitations:</i> This study was conducted in one hospital only.	
Chao & Chiang (2003)	Taiwan.	To investigate the impact & coping behaviours of a Chinese mother with a child being treated for DDH.	Qualitative approach.  Case study. Longitudinal.	6 months & 5 days.	Mother. n=1.	Participant observation (pre & post operation) over 5 days. Followed up by monthly telephone interviews over 6 months.	Not stated	It highlights the challenges of a mother caring for a child with a late diagnosis for DDH such as acquiring DDH knowledge & caring skills, meeting child's needs, seeking out family support, managing her positive & negative emotions. It also provides original insight of the impact of culture & society on the mother.	<i>Strengths:</i> 1. Offers detailed original insight & thick description into the challenges of a mother caring for a child with DDH.  <i>Limitations:</i> 1. The fathers' experiences are reported by the mother & researchers, not by the father himself. 2. The clinical information in the Literature Review is not referenced. 3. The data analysis was not described in detail. No theoretical context was offered, such as grounded theory, even though the researchers stated that this case study can offer theoretical insight. Moreover, there is scope to do provide theory within the study. 4. It does not state how the participant was	There is a role for father of the child to share the care of the child while in the spica cast & to support the mother. There is scope to explore this gap.

									recruited to take part in case study.  5. Very limited detail about ethics. Just states that participant consent was obtained. No detail about ethical approval from the hospital or university.	
Gardner et al (2005)	United Kingdom & Ireland	To report on the psychosocial consequences for mothers using ultrasonography & Pavlik harness to manage their infant's DDH condition.	Quantitative approach.  Experimental.  RCT  Longitudinal.	Not stated	Mothers.  n= 629 (561 qnn completed at 8 weeks. Another 494 qnn completed at 1 year)	33 hospitals in the UK & Ireland.  Infants were randomised to either the ultrasonography examination group with clinical assessment or the non-ultrasonography group i.e. received clinical assessment only.  Used standardised qns to measure anxiety, postnatal depression & parental stress. Specifically the following instruments: Spielberger state trait anxiety inventory; Edinburgh postnatal depression scale; Parenting Stress	Not used	1. When an infant was 8 weeks old, there was a significant association between early treatment of an infant in a harness maternal distress and clinical anxiety.  2. At 8 weeks old, there was a significant association with early harness treatment and mothers' sense of worry about their infant's hips. These feelings continued to be significantly high when the infant reached 1 year old, even though the infants had completed their treatment in the harness months earlier.	<i>Strengths:</i>  1. High response rate – average of 84%.  2. Utilised a RCT research design which are the gold standard for research.  3. Used standardised qns, with exception of the Hip Worries Inventory which was tailored.  4. Consulted a parents' support group, STEPS, to conduct pilot interviews to ascertain the issues which concerns parents in this situation. This pilot guided the outcome measures.  5. The sample size was based on a power calculation.  <i>Limitations:</i>  1. A mixed methods or qualitative research strategy may have added depth to the findings.  2. A lot of qns given to participants at the same	Maternal distress should be considered in policies where early splinting and ultrasonography is used.  The authors suggest a smaller study, such as an observation, could examine the mother-child relationship more directly.  Since ultrasonography is being used in some countries, the findings can inform these policies across these countries.

						Index;  Also, to measure maternal worries about hip problems, the researchers used the Infant Hip Worries Inventory. This was tailored to study. Not the standardised version.			time may have caused participants research fatigue. In total, 4 qnns used with participants when infant was 8 weeks old & again when the infant was 1 year old.  3. Very limited finding regarding mother-infant relationship. Just stated no-association between mother  -infant relationship & splinting.  4. No follow up of the non-responders.	
Hassan (2009)	Not clearly stated. Appears to be Jordan.	To determine the incidence of parental compliance & factors encountered during an infant's use of a Pavlik harness. To improve parental compliance & commitment to using the harness.	Mixed methods approach. Case study.  Prospective, longitudinal study.	Jan 2003 - Jun 2006	Mothers. n=160	Diary, clinic attendance, interview, physical examination & survey.	Not used	The parental compliance rate with Pavlik harness was high - 94.37%.  Active participation by specifically, mothers, in the care of their child with the harness can ensure an satisfactory outcome for the infant.	<i>Strengths:</i>  1. Mixed methods research design.  <i>Limitations:</i>  1.The researcher was the only person involved in the giving the initial instructions & closing interview with parents.  2. Interchanges the use of the term 'mothers' and 'parents' throughout the study, even though the participants are all mothers' to the infants.  3.Very limited analysis of qualitative data & no method of analysis is stated.	1. The engagement of mothers with the use of the harness is essential.  2. Providing a leaflet for parents with information leaflet.  3. Hospitals should procure Pavlik harnesses from reputable manufacturers.

Rosendahl et al (2010)	Norway	Compared immediate treatment to sonographic surveillance for NHI	Quantitative approach. RCT. Longitudinal.	Feb 1998 – Apr 2003	128 neonates.  Group 1: immediate splinting and ultrasonographic follow up of NHI amongst a group of neonates (n=64) Group 2: Neonates only received ultrasonographic hip monitoring (n=64).	Infant hip angle measurements on a radiography at 1 year old.	Not used	When the infants reached 1 year old, there was no significant difference between the two groups. Also, by 1 year old, all of the infants in both groups had normal hips and none of the infants needed surgery.	<p><i>Strengths:</i></p> <ol style="list-style-type: none"> <li>1.No loss to follow up of participants during the course of this longitudinal study</li> <li>2. RCT research design.</li> </ol> <p><i>Limitations:</i></p> <ol style="list-style-type: none"> <li>1.They did not present a cost analysis of splinting versus sonography.</li> <li>2. Researchers speculated that the immediate splinting of a neonate had a negative effect on the parent and infant relationship, but do not have evidence to support point.</li> </ol>	<ol style="list-style-type: none"> <li>1.The researchers stated that if CPHE is performed correctly by health professionals, there is no requirement for universal hip sonography of neonates.</li> <li>2.Researchers suggest qualitative research explore this issue.</li> </ol>
Witting et al (2012a)	Netherlands	To analyse the influence of gain- & loss-framed messages on parents' participation in ultrasound screening for DDH.	Quantitative approach. Survey. Cross-sectional.	Aug 2007 – Dec 2008	Parents of 3 month old infants. n=4150.	Parents were given a brochure about ultrasound screening of their infants for DDH. 2043 brochures were gain-framed (emphasising the benefits/advantages) brochures & 2107 brochures were loss-framed (emphasising the negatives/disadvantages) brochures.  Parental participation was measured by their attendance for the	Prospect Theory	<ol style="list-style-type: none"> <li>1. When parents were given the gain-framed message about ultrasound screening for DDH, they were significantly more likely to participant.</li> <li>2. It challenges Prospect Theory which indicates that when participants are given a choice, they are more likely to take a risk</li> </ol>	<p><i>Strengths:</i></p> <ol style="list-style-type: none"> <li>1.The researchers conducted a manipulation qnn check to ensure that the intended message, either- gain-framed or loss-framed was well-received. This was carried out with 1096 parents.</li> <li>2. Uses theoretical context with key findings.</li> </ol> <p><i>Limitations:</i></p> <ol style="list-style-type: none"> <li>1. There were different approaches to recruit participants in the urban</li> </ol>	Using gain-framed information brochures may lead to higher parental participation rates for ultrasound screening for DDH.

						ultrasonographic screening.  Also, a survey-based manipulation check was conducted with 1096 parents to check if the intended message in the brochures was well received by parents.		when they are faced with a loss-framed choice as opposed to a gain-framed choice.	area compared with the rural area. In the urban area, participants had to opt-in to take part in the research. In the rural area, the participants had to choose to opt-out of the research.  2. The information brochures were in Dutch language only. Therefore, this may have hindered the participation of parents who were not fluent in Dutch, particularly in the urban area where the researchers acknowledged that there was a large non-Dutch speaking population.	
Witting et al (2012b)	Netherlands	To assess parental satisfaction with a new type of hip screening, namely ultrasound & to gain insight into the factors which influence satisfaction.	Quantitative approach. Survey. Cross-sectional.	Nov 2007 – Apr 2009	Parents of 3 month old infants. n= 703.  Mothers completed 84.3% of qnn.  Fathers completed 7.7%  Both parents completed 7.4%	Custom-fitted qnn was handed to participants after the ultrasonography had taken place.	Conceptual models of Donabedian (1997) and Butt et al (2009)	1. Satisfaction with the ultrasonographic screening was high amongst the participants. Satisfaction was measured by process factors not structure or outcome factors.  2. Providing information before the screening & good communication during the ultrasonography between sonographers and parents, positively influenced	<i>Strengths:</i> 1. Large sample.  <i>Limitations:</i> 1. No follow up of participants who did not respond to qnn.  2. The study was not piloted.  3. Responses were mainly from mothers. There was no analysis of the qnn data from the fathers who accounted for 7.7% of responses.	High satisfaction rates by parents can be achieved if they are given information prior to the ultrasonography & there is good communication between the sonographer and parents during the screening.

								satisfaction levels.		
Bergo and Rosendahl (2013)	Norway	To determine parent satisfaction with early treatment of their infant (at birth) for DDH or delayed treatment (at 5 weeks old).	Quantitative approach. Survey. Cross-sectional. Comparative.	16 months.	Parents. Total n= 91  Consisting of 76 mothers, 10 fathers & 5 by both parents.  66 parents had neonates treated from birth & 25 parents had infants treated from 5 weeks +)	Custom-fitted qnn with comments section.	Not stated	1.No significant difference was found between parents who had neonates treated from birth & parents whose infants were treated at a later stage.  2. Parents having their newborn treated at birth found the treatment more cumbersome than those parents with an infant who had delayed treatment.	<i>Strengths:</i> 1.. Parents were involved in interviews to guide the design of qnn.  2. Some qnns were answered by fathers & some qnns were answered by both parents.  3.High response rate  <i>Limitations:</i> 1. Gender was not analysed in detail in the results.  2. Unequal sample sizes in two treatment groups.  3. Qnn were completed at different times during the treatment so it would have been difficult for participants to accurately record their satisfaction with the treatment.  4. Study was conducted in just one hospital.	For health professionals, there is no difference in parental satisfaction if their infant is treated for DDH from birth or at a later in infancy.
Witting et al (2013)	Netherlands	To investigate whether psychosocial factors predicted parental participation in ultrasound screening.	Quantitative approach. Experimental. Cross-sectional.	Nov 2007-April 2009.	Participating parents in ultrasonographic screening. n=703  Non-participating parents in ultrasonographic	Custom-fitted qnn based on validated models of health behaviour: theory of planned behaviour; health belief model & protection motivational	Used models of behaviour: theory of planned behaviour; health belief model & protection motivation theory. All	The influence of positive psychosocial determinants does significantly influence a parental participation in ultrasonographic	<i>Strengths:</i> 1.Followed up almost all of the non-participants.  2.Qnn was developed with team of health professionals & was piloted amongst seven	Health policymakers & health professionals should consider the psychosocial determinants influencing ultrasonographic screening to encourage high participation rates.

					screening. n=393.	theory.	used to predict parental decision-making about their infant's health.	screening.	parents. 3.The study also included responses from non-participating parents. 4. A high response rate.  <i>Limitations:</i> 1.Different recruitment strategies used in rural and urban areas.	
Fabricant et al (2013)	United States of America	To examine the quality, accuracy and readability of information available on the internet regarding DDH.	Quantitative approach.  Prospective.  Cross-sectional.	On a single day (19.11.2011)	Not relevant	Searched 3 search engines: Google, Yahoo and Bing and identified 63 websites for assessment by 3 expert reviewers.	Not used	There were significant differences in the quality, accuracy and readability of the information. The websites with the highest quality and accurate information were associated with the search term 'developmental dysplasia of the hip'. The websites that were assessed as having the highest reading attainment level were the least accurate.	<i>Strengths:</i> 1.The clear methods section would enable the full replication of this study.  <i>Limitations:</i> 1.The searches of search engines provide the results as they are performed in North America. Therefore, they have relevance in context there as opposed to other countries of the world.	Health professionals- surgeons, nurses, midwives, health visitors and GPs, should direct their patients / carers to search for information with the term 'Developmental Dysplasia of the Hip' or even refer them to websites that they have personally reviewed for content and clarity of the diagnosis and prognosis.
Demir et al (2015)	Turkey	To assess the problems experienced by parents while providing post-operative home care following their child's surgery for	Quantitative approach.  Survey.  Cross-sectional.	Between March 2010 – March 2013.	Parents . n=33.	A custom-fitted, two-part survey.	Not used	1.Parents, predominately mothers, experienced physical (96.9%), social (75%) and psychological (65.6%) problems	<i>Strengths:</i> 1.The survey in a hospital setting gave the researchers direct access to recruit participants.	For health professionals to improve their support to parents caring for a post-operative child with DDH at home. This support should include providing parents with a comprehensive home

		DDH.						<p>while caring for their child following DDH surgery.</p> <p>2. Parents experienced problems with the home care of their child, including toileting (97.9%), cast care (87.9%) skin care (84.8%) and personal hygiene (84.8) difficulties with their child.</p>	<p><i>Limitations:</i></p> <ol style="list-style-type: none"> <li>1. A very small sample used in the survey.</li> <li>2. Used a custom-fitted survey as opposed to a structured survey. Moreover, it was not piloted prior to the study.</li> <li>3. A copy of the survey proforma was not presented in the journal article. Moreover, no example questions were presented in the article.</li> <li>4. There was no clear inclusion/exclusion criteria for the recruitment of participants.</li> <li>5. The literature review was weak. The majority of the literature in the review was based on nursing guidelines as opposed to evidence based empirical studies.</li> <li>6. Further detail and clarity needed about the graph showing childcare practices at home (see Figure 1). It indicates that 51% of parents were performing 'neurovascular assessments' and 58% of parents were performing 'nutrition'.</li> </ol>	<p>care package with written instructions and visual material. There were no significant differences between the sociodemographic characteristics of parents and the care of the child in the home.</p>
Mace and Paton (2015)	United Kingdom	To assess the effectiveness of clinical physical hip examination	Quantitative approach. Case study	Recruited participants over 4	Neonates /Newborn infants. n= 201	Used patient case data: gender; ethnicity; age at initial assessment;	Not used	The universal use of the clinical physical hip examination of	<p><i>Strengths:</i></p> <ol style="list-style-type: none"> <li>1. Longitudinal timeframe which allowed scope to</li> </ol>	The physical clinical hip examination is an effective tool for the screening of neonates for

		amongst neonates to indicate DDH.	Longitudinal.	years. Jan 1997- Dec 2011.  Followed up the cohort 15 years later.		the presence of instability at birth and/or in clinic; presence of risk factors; abnormal clinical findings; source of referral & sonographic imaging results.		neonates is effective to screen for DDH. Ultrasonography for detection and diagnosis should be utilised when there are risk factors present in the neonate.	follow up the cohort of participants over 15 years.  2. A clear and detailed inclusion/exclusion criteria for recruitment of participants  <i>Limitations:</i>  1. A single setting for the study in one hospital. A multi-site study would have strengthened the findings of the research.  2. No strengths or limitations were noted in the study.	DDH. However, this study requires follow up using an RCT research design.
Groarke et al (2017)	Not clearly stated. The geographical location of the authors suggests the study was conducted in Ireland.	To review GP referrals to hospitals for infants with suspected DDH to ascertain the effectiveness of their clinical examination. This study focuses on the type of clinical indicators which form the basis of these GP referrals to hospitals.	Quantitative approach. Case Study. Retrospective, cross-sectional.	July 2014- July 2015	Infants. n=174.	Clinical hospital records and findings of ultrasonographic hip scans.	Not used	1. When a clinical examination of DDH was performed by a GP, there was no reliable or accurate clinical indicator of DDH.  2. Certain clinical indicators for DDH are not reliable, including asymmetric skin creases and clicky hips.	<i>Strengths:</i>  1. Twin centre study.  2. The two researchers were blinded to the infant's presenting complaint.  <i>Limitations:</i>  1. This study only focuses on the reliability GPs to identify DDH in an infant by clinical examination. It does not include other health practitioners who frequently conduct the DDH clinical examination, such as midwives, health visitors, nurses, SHO and surgeons.  2. The findings are based	The findings of this study imply that the GP clinical examinations for DDH are unreliable.

									<p>on a small sample size.</p> <p>3. The cohort was not followed up at a later date.</p> <p>4. There are no details about ethics or ethical approval from the hospitals.</p>	
Jennings et al (2017)	Ireland	To explore the experiences of parents of infants with DDH attending a DDH hospital clinic.	<p>Mixed methods approach.</p> <p>Survey.</p> <p>Cross-sectional.</p>	Nov 2014-Jan 2015	Parents. n=100	Survey with open ended question section. It was modelled a Clinic Satisfaction Survey (Lee 2005) and the Hip Worries Inventory (Gardner et al 2005)	Not used	<p>1. Parents whose child had received an early DDH diagnosis (infant aged under 3 months old) felt significantly more worry than those parents whose child received a late DDH diagnosis (infant aged over 3 months old).</p> <p>2. An association between the diagnosis and treatment of DDH for an infant with negative psychosocial consequences for the parents.</p>	<p><i>Strengths:</i></p> <p>1. Before the study commenced, the survey was piloted with parents. The researchers responded to the feedback and adjusted the survey.</p> <p>2. The survey was based on other instruments from other studies.</p> <p>3. The survey had an acceptable level of internal reliability as Cronbach's alpha co-efficient (0.7).</p> <p><i>Limitations:</i></p> <p>1. The qualitative aspect of this mixed methods study was poor. It was not embedded in any theoretical perspective or methodology. This aspect of the study focused on service improvement of the clinic and not on the DDH experiences of parents.</p> <p>2. No details about the method of data analysis and the emergence of themes.</p>	For health professionals to provide parental DDH care and support packages.

									<p>3. The title and the aim of the study are completely different. The title of the study refers to exploring parental experiences of DDH. However, in the abstract, the aim of the study is to explore the effectiveness of a DDH clinic.</p> <p>4. There is no clarification about whether the parents are mothers and/or fathers.</p> <p>5. Participants were asked to complete the survey on their first visit to the clinic. The clinic setting is a vulnerable venue for these parents as they await the outcome of their infant's referral.</p> <p>6. The response rate of 100% is a concern. It is based on a 100% return rate. The response rate is not the same as a return rate. Some participants make have chosen not to complete the survey and therefore, they did not return a completed form.</p> <p>7. Several references cited within the paper are missing from the References section, for example, Causon 2010; Tates et al 2002)</p>	
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McAllister et al (2018)	Scotland, United Kingdom	To compare rates of first DDH surgery by 3 years old across 14 areas to two areas before and after the implementation of an enhanced DDH detection service	Quantitative approach.  Quasi-experiment.  Retrospective cohort study.	Apr 1997-Mar 2013	Children aged 3 years and under.  n= 896,594	National hospital discharge records	Not used	The enhanced newborn DDH screening service was associated with halving the rates of DDH surgery.	<p><i>Strengths:</i></p> <ol style="list-style-type: none"> <li>1. Large sample size.</li> <li>2. Data analysis covered a long timeframe of 16 years.</li> </ol> <p><i>Limitations:</i></p> <ol style="list-style-type: none"> <li>1. Participants were not randomised to the intervention and non-intervention groups. Participants allocation to a group was based on the geographical location of their home.</li> </ol>	It supports the wider introduction of an enhanced DDH screening service.
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**Appendix 6: University ethical approval letter**



Edinburgh Napier University  
School of Nursing, Midwifery and Social  
Care  
Research Integrity Committee  
9 Sighthill Court  
Edinburgh  
EH11 4BN

30<sup>th</sup> May 2016

Dear Claire

***Project Title: Exploring the views and experiences of parents of infants who have undergone ultrasonographic screening and diagnosis for Developmental Dysplasia of the Hip (DDH)***

***Project start date: January 2014***

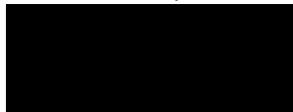
***Project reference: FHLSS/1654 Version no. 1***

Further to your application for Ethical approval to undertake a research study at Edinburgh Napier University, I am pleased to inform you that the committee have approved your application and we wish you all the best with your study.

May I remind you of the need to apply to the Research Integrity Committee prior to making any amendments to this study or of any changes to the duration of the project and provide notification of study completion. All documents related to the research should be maintained throughout the life of the project, and kept up to date at all times.

Please bear in mind that your study could be audited for adherence to research governance and research ethics.

Yours sincerely,



Dr. Barbara Neades  
Chair

## Appendix 7: Participant information sheet

### Research Title:

**Exploring the views and experiences of parents of infants who have undergone ultrasonographic screening and diagnosis for Developmental Dysplasia of the Hip (DDH)**

### Researcher: Claire Poole

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My name is Claire Poole and I am a PhD research student from the School of Nursing, Midwifery and Social Care at Edinburgh Napier University. I am carrying out a research study which explores the views and experiences of parents with children who have undergone an ultrasound screening (ultrasonography) and diagnosed with Developmental Dysplasia of the Hip (DDH).

Developmental Dysplasia of the Hip (DDH) is a common mobility disability in childhood (Woodacre et al 2014). In the United Kingdom (UK), the estimated incidence rate is 1-4 per 1000 live births (Public Health England 2013). This research is being carried out because there is a need to have an in-depth understanding of the parent experience as their infant underwent ultrasound screening and diagnosis. This is to ensure that parents receive appropriate support from health professionals and parent support organisations / charities.

Your comments and experiences will assist the decisions of health professionals, charity support staff and health service policymakers about the experiences of parents caring for their child with Developmental Dysplasia of the Hip. Furthermore, this research can offer a unique insight of DDH from the parents' perspective to health professionals and parent support organisations / charities. It is likely that the findings of this study will be published in a journal and presented to colleagues at a conference. This research is being funded by Edinburgh Napier University.

I am looking for parent volunteers to take part in this study. The participant criteria for this study is: parents who have experienced their child undergoing ultrasound screening and diagnosis for DDH.

If you agree to participate in the study, you will be invited to take part in an informal interview with me and it will last no longer than one hour. It will be held in a public meeting room convenient to you, such as a local library or community centre. Refreshments will also be provided. The conversations that take place in the interview will be audio-tape recorded, so that they can be transcribed by the researcher afterwards.

Since this research relates to your experiences of caring for your child with DDH, there is a small risk that you may get upset and feel uncomfortable. However, I have anticipated that this situation may arise. Therefore, if this situation does happen, we can take a short break. We can also discuss the option of moving on to another question or ending the interview. You will be free to withdraw from the study at any stage and you would not have to give a reason.

The audio recording of the interview and the interview transcripts will be handled as confidential material and it will be anonymised. Your name will be replaced with a participant number or a

pseudonym. It will not be possible for you to be identified in any reporting of the study. All participant details and interview materials will be kept in a locked cabinet in locked room in the University and stored on a computer with password protection. Only the researcher, Claire Poole, has will have access to this storage area. The interview materials will be kept for 5 years and then will be destroyed.

If you would like to contact an independent person at Edinburgh Napier University, who knows about this study, but is not involved in it, please contact Dr Norrie Brown. His contact details are as follows:

Dr Norrie Brown

██████████  
School of Nursing, Midwifery and Social Care  
Edinburgh Napier University  
Sighthill Campus  
9 Sighthill Court  
Edinburgh  
EH11 4BN

Tel: ██████████

Email: ████████████████████

If you would like to be a participant in the study, please now refer to the consent form.

**Appendix 8: Informed consent form for participants**

**Research Title**

**Exploring the views and experiences of parents of infants who have undergone ultrasonographic screening and diagnosis for Developmental Dysplasia of the Hip (DDH)**

Edinburgh Napier University requires that all persons who participate in research studies give their written consent. Please read the following statements and please tick  the following boxes if you agree with these statements:

1. I freely and voluntarily consent to be a participant in the research study regarding the experiences and perceptions of parents as they care for their child who has Developmental Dysplasia of the Hip (DDH). I understand that the researcher who is conducting this study is called Claire Poole and she is a postgraduate PhD student at Edinburgh Napier University.
  
2. I am aware that the aim of this research study is to explore the views and experiences of parents of infants who have undergone ultrasound (ultrasonographic) screening and diagnosis for Developmental Dysplasia of the Hip (DDH). Specifically, I understand that I have been asked to take part in an interview, which should take no longer than 1 hour to complete.
  
3. I understand that my responses in this interview will be anonymised and remain confidential. Furthermore, I understand that the results of this research project will not contain information which will identify me or my child.
  
4. I understand that the interview will be audio-taped. Furthermore, I give permission for anonymised verbatim quotes from the interview to be used in presentations and publications about this research study.
  
5. I am fully aware that I can withdraw from the study at any time and I do not have to give a reason. There will be no negative consequences. However, I understand that after the interview information has been anonymised or after the results have been published, it will not be possible for my comments to be removed as they would be untraceable at this point.
  
6. In addition, during the interview, if I decide not to answer any particular question or questions, I am free to decline.
  
7. I have been given the opportunity to ask questions regarding the interview and my questions have been answered to my satisfaction. I also know that I can contact the researcher at a later date, if I have any further questions.

8. I have read and understand the above and consent to participate in this study. My signature is not a waiver of any legal rights. Furthermore, I understand that I will be able to keep a copy of the informed consent form for my records.

Participant's Signature

Date

I have explained and defined in detail the research study in which the participant has consented to taking part. Furthermore, I will retain one copy of the informed consent form for my records.

Researcher's Signature

Date

If you have any questions about the research or would like further details, please feel free to contact the researcher. The contact details are as follows:

**Name of Researcher:**

Claire Poole

**Address:**

PhD Department  
School of Nursing, Midwifery & Social Care  
Edinburgh Napier University  
Sighthill Campus  
9 Sighthill Court  
Edinburgh  
EH11 4BN

**Telephone:** [REDACTED]

**Email:** [REDACTED]

**Appendix 9: Participant interview topic guide**

1. Can you tell me about the events that took place that led up to their referral for an ultrasound to screen for DDH?  
(Possible prompts: What happened? How did you feel? How did you cope?)
2. How did you feel about your baby undergoing an ultrasound for DDH?  
(Possible prompts: What happened? How did you cope?)
3. Can you tell me about the time when you received your baby's actual diagnosis for DDH?  
(Possible prompts: What happened? How did you feel? How did you cope?)
4. Can you tell me about the time/s when you had to take your baby for their monitoring follow up ultrasound scans?  
(Possible prompts: What happened? How did you feel? How did you cope?)
5. Can you tell me how you obtained information about your baby's DDH condition? What did you think about this information?  
(Possible prompts: How did this information make you feel?)

## **Appendix 10: Debriefing information for participants**

### **Research Title:**

#### **Exploring the views and experiences of parents of infants who have undergone ultrasonographic screening and diagnosis for Developmental Dysplasia of the Hip (DDH)**

The aim of this research study is to explore the views and experiences of parents who have children who have undergone ultrasound (ultrasonographic) screening and diagnosis for Developmental Dysplasia of the Hip (DDH). The findings of this study and the contributions you have made towards this study are important because your comments and experiences can potentially offer health professionals and parent support organisations / charities to ensure the parents are given appropriate support and their child is successfully treated for the condition in the home. Moreover, this research study has the potential to offer health professionals and parent support staff an insight of the condition from the point of view of parents.

If you have any questions regarding this study, please do not hesitate to contact the researcher, Claire Poole. Her contact details are as follows:

Claire Poole  
PhD Department  
School of Nursing, Midwifery and Social Care  
Edinburgh Napier University  
Sighthill Campus  
9 Sighthill Court  
Edinburgh  
EH11 4BN

Mobile: [REDACTED]

Email: [REDACTED]

Furthermore, if you wish to contact an independent person at Edinburgh Napier University who knows about this study, but is not involved in it, you are welcome to contact Dr Norrie Brown. His contact details are as follows:

Dr Norrie Brown  
[REDACTED]  
School of Nursing, Midwifery and Social Care  
Edinburgh Napier University  
Sighthill Campus  
9 Sighthill Court  
Edinburgh  
EH11 4BN

Tel: [REDACTED]

Email: [REDACTED]

If you need advice, support or equipment from a parent support service specifically for Developmental Dysplasia of the Hip, the Steps DDH charity have a useful

website of information: <http://www.steps-charity.org.uk> . They can also be contacted by telephone: 01925 750 271 and by email: [info@steps-charity.org.uk](mailto:info@steps-charity.org.uk)

**THANK YOU AGAIN FOR YOUR HELP**

## Appendix 11: Annotated transcript from a mother's interview using IPA

Emergent themes	Original transcript	Exploratory comments
<p>Mothers as observers to their infant's healthcare</p> <p>Shock and confusion about the diagnosis; health practitioners are the 'guardians of knowledge'</p> <p>Health practitioners are the 'guardians of knowledge'</p> <p>Shock and confusion about the diagnosis; health practitioners are the 'guardians of knowledge'</p> <p>Shock and confusion about the diagnosis; Acquiring knowledge about DDH</p> <p>Shock and confusion about the diagnosis; Acquiring knowledge</p>	<p><b>Interviewer (I):</b> <b>What happened at the ultrasound hip appointment?</b></p> <p>Participant (P): Well, the sonographer was there, there was a student who was there; I think there was another member of staff as well and they were all kind of conferring and saying, 'Oh, you know, that's who we need to refer to', but obviously, I wasn't aware of: Who this person was? Why they were referring me? What the problem was? And then when I kind of said, you know, 'What is the issue?' And they said about, you know, 'He's definitely got developmental hip dysplasia'.</p> <p><b>I: So were you 'in the loop' with that conversation?</b></p> <p>P: Not really. I kind of felt a little bit on the outskirts of it.</p> <p><b>I: How did that make you feel?</b></p> <p>P: I was just very, very worried. I just remember thinking, 'What is the worst-case scenario?' You know, 'What's going to happen here?'</p> <p>What is so bad that I have to see a consultant today and what are they going to kind of do? I hadn't done any research into it beforehand; I hadn't thought about what it would be.</p> <p>So then when I was told I think I probably burst into tears because as I think I said, I just remember thinking to me hip dysplasia is what happens to old dogs and old dogs are crippled and can't walk. I remember kind of asking about, you</p>	<p>- A lot of health practitioners in the room. There is a sense of the mother being overwhelmed by the number of staff there.</p> <p>- Mother made to feel like an 'outsider'. They use exclusive language and terminology that the mother did not understand. A referral was being made, but she didn't know what was "the issue." It seemed that everyone knew what was going on, except the mother. There is a lack of clear communication and inclusivity with mother.</p> <p>- Mother is confused and feels isolated, "on the outskirts of it."</p> <p>- Mum is feeling very anxious. Repetition of "very" to emphasise the intensity of her feelings. She is confused, and she needs more information. She does not know the seriousness of the situation. She thinks of "the worst-case scenario."</p> <p>- Interesting use of language "bad". The lack of information makes her think that the diagnosis must be serious. Mother feels that it is her responsibility to seek information about the diagnosis, but she hasn't done <i>her</i> research. Should it be <i>her</i> responsibility to find out information?</p> <p>- Mother felt emotional turmoil about the diagnosis. Due to her lack of knowledge, she thinks the diagnosis meant that her son was not going to be able to walk. The health practitioners were familiar with the diagnosis, but maybe they did not inform the mother quickly and clearly enough?</p>

<p>about DDH; health practitioners are the 'guardians of knowledge';</p>	<p>know, 'Is he going to be in a wheelchair? Is he going to walk?' And looking back it seems almost kind of silly to have thought that, but I had no other knowledge about it, so for me it was a case of, you know, 'Is my son not going to walk now because of this diagnosis?'</p>	<p>Maybe they were distracted by the need to train the student HP in the room? Who did the health practitioners priorities lie with? Mother, infant or student? In hindsight, the mother feels "silly to have thought that". We feel empathy with this mother due to her lack of information and understanding of DDH.</p>
<p>Expectations and adjusting expectations; health practitioners are the 'guardians of knowledge'; Unpleasant experience with health practitioner/s Reflections on the experience now; Recognition by health practitioners of the new baby and mother status</p>	<p>And they were lovely; everybody there was brilliant, but they kind of were all a bit trivial about it. It was, 'Oh, don't be silly, he's going to be fine.' But as a mother, all I could see was, 'It's not going to be fine because if he was fine, then they wouldn't be referring me.' So an appointment that I thought was going to take about ten minutes ended up taking about six hours.</p>	<p>- The health practitioners are warm. However, the diagnosis was unexpected for the mother. She is frustrated with the health practitioners who tried to placate her, "They kind of were all a bit trivial about it". Mother recognises her own vulnerability, "But as a mother...". She reflects on her memories as she tried to understand the situation as she goes to see the Consultant on the same day as the ultrasound scan. This is an excessive amount of time for mother and infant to wait in the hospital. It added to the stress of the diagnosis and her sense of not knowing what to expect. Again, we felt empathy for this mother for the situation that has unfolded for her and her infant.</p>
<p>Recognition by health practitioners of the new baby and mother status; breastfeeding issues</p>	<p>I literally went from ultrasound to waiting to see the consultant; seeing the consultant to having a Pavlik harness fitted; having to have him in the Pavlik harness for an hour whilst they worked out if it was fine; then making plans to see him again. That was a very, very, very distressing kind of time. He was nine weeks old; I was feeding on demand. He wasn't breast feeding very well anyway.</p>	<p>-The mother is in heightened psychological state in the hospital. Much repetition of the word "very" to convey her feelings of distress and anxiety. She was coping with being a new mother and she was having a protracted and stressful time in the hospital. There seems to be a lack of recognition by health practitioners of the new mother and infant needs.</p>
<p>Unpleasant experience with health practitioner/s; Recognition by health practitioners of the new baby and mother status</p>	<p>It was just little things. They left me in a room on my own with him for a long time just wearing a Pavlik harness because they were seeing so many cases.</p>	<p>- Mum was left alone and physically isolated now. This all adds to the stress of the situation. Feels endless and lack of control by mum over the situation. The department was busy, but it also adds to the confusion for the mum over the situation.</p>
<p>Caring for an infant in a Pavlik harness</p>	<p>So I was kind of left in there. They'd put it [the harness] on for me to measure it up and I didn't know</p>	<p>- Mother feels isolated. No explanation by the health practitioner about the purpose of the harness. The baby is distressed and</p>

<p>Caring for an infant in a Pavlik harness; Recognition by health practitioners of the new baby and mother status</p>	<p>what this device was on my baby other than the fact that he was screaming the place down.</p> <p>I wouldn't have known how to have taken it off and...yeah, I remember, he literally had had it on for about half an hour and he just pooped everywhere...and it went everywhere, yeah, exactly. And it was just that thing of...I just remember thinking, 'What on earth do I do? I've got nobody in here; I don't know how to get this off him; he's absolutely covered in poo.</p>	<p>adds to distress of the mum. The health practitioners were doing what they could in a clinical manner, but seemed ignorant to the mother and young infant needs. There is a perception that the harness was intrusive, and the health practitioners were intrusive - 'I didn't know what this device was on my baby'</p> <p>- Mother feels helpless and desperate, but she is isolated in a room in a hospital for a long time. She is desperate to care for her baby, but she lacks the knowledge to remove the harness. Mother is powerless. She lacks control over the situation.</p>
<p>Caring for an infant in a Pavlik harness; Recognition by health practitioners of the new baby and mother status; Expectations and adjusting expectations</p>	<p>They've told me [health practitioners] I'm only allowed one harness and one harness only, and don't wash it, and don't do this ...and it was, 'What am I going to do? I'm the worst mother ever.' So I just remember that being incredibly tough; a really, really hard day.</p>	<p>- Mother felt that the instructions were authoritarian. She feels absolutely helpless and perceives that the decision making over her baby has been taken away from her, "They've told me...". This makes her feel like 'the worse mother ever'. What does society deem to be a 'good mother'? She has taken her baby for the ultrasound screening and is allowing her baby to be treated. The mother does not know what to do with her baby, she wants to care for him, but he is in a harness and he has soiled himself. The mother lacks the knowledge clean him in the harness. She has to sit there and wait until a health practitioner returns and finds them and help her. She feels powerlessness.</p>

