LOOKING AFTER A CHILD IN A HIP SPICA CAST FOLLOWING TREATMENT FOR DEVELOPMENTAL DYSPLASIA OF THE HIP FROM THE PERSPECTIVE OF THE PARENT: A CONSTRUCTIVIST GROUNDED THEORY

Thesis submited for the degree of Master of Philosophy
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Background

Developmental dysplasia of the hip (DDH) is a prevalent musculoskeletal condition in children. Its management involves a combination of non-surgical and surgical methods, with the treatment approach determined by the timing of the diagnosis. Delayed diagnoses often require more invasive surgical procedures and the application of a spica cast. The spica cast's primary goal is to maintain femoral head abduction within the hip joint's acetabulum. The child remains in the cast for 6-12 weeks and is cared for at home by the family (International Hip Dysplasia Institute 2014). Spica cast experience for DDH in childhood is a multifaceted occurrence and the responses to the immobilisation period cannot be simply attributed to the nature of the disease symptoms or treatment alone. It is essential to identify various concerns, including those pertaining to the potential emotional impact of DDH treatment on the child and the fear of its impact on their growth and development. Moreover, these responses are influenced and shaped by context.

Purpose

To generate a theoretical understanding of the experience of looking after a child in a spica cast from the parents' perspective.

Methods

Constructivist grounded theory (Charmaz 2006) was chosen as the research methodology. Data were obtained from a DDH charity's Facebook parent group platform. The data collection process involved gathering posts and conducting semi-structured interviews. The collected data underwent rigorous analysis using coding stages to explore the challenges and responses related to "being in a spica cast."

Findings

Caring for a child in a spica cast is influenced by specific contexts, shaping parents' unique experiences.

The findings from the data analysis revealed three main issues:

1. The phenomenon of being in a spica cast which highlighted the challenges faced by parents in managing their child's condition while in the cast.

2. Changes that occurred in the child, emphasising the impact of the spica cast on the child's well-being and daily life.
3. The daily family routine which delved into the complexities and disruptions experienced by the family while caring for the child in the spica cast.

The challenges of parenting while managing the spica cast are particularly arduous, encompassing both practical and emotional aspects. Respondents expressed facing difficulties due to insufficient understanding and inconsistent guidance, leading them to rely heavily on health professionals for information and support. However, they also expressed frustration at the variability in the management of DDH.

Parents have a diverse set of needs, including informational and supportive needs, as well as practical, emotional and social needs. Ultimately, looking after a child in a spica cast is a dynamic experience and the results are interrelated and complex.

Conclusions

In conclusion, this study provides valuable insight into the lived experience of parents caring for a child with DDH and a spica cast. The responsibility of caregiving significantly affects both the child and the entire family. By exploring various contributing factors, this research has developed a conceptual framework to better comprehend the complexities of this experience.

Support from different sources emerged as a crucial element in managing the challenges, with healthcare provider support playing a vital role. The study underscores that caring for a child at this stage involves daily responsibilities encompassing social, behavioural and physical care. Unfortunately, these circumstances can lead to emotional difficulties and hinder the child's overall well-being during the cast immobilisation period.

It is essential for health professionals to support parents and consistently educate them to better

understand the complex nature of DDH management. By doing so, they can significantly help to improve the overall well-being of both the child and the family in this challenging situation

List of tables

List of figures

List of appendices

List of abbreviations

DDH developmental dysplasia of the hip

FB Facebook Participant

HCPs Health Care Professions

GP general practitioner

IHDI International Hip Dysplasia Institute (IHDI)

NIPE The NHS newborn and infant physical examination NHS National Health Service

WHO World Health Organisation

CGT Constructivist Grounded Theory

Table of Contents

CHAPTER TWO: LITERATURE REVIEW

CHAPTER THREE: PHILOSOPHICAL & THEORETICAL CONSIDERATIONS

CHAPTER FOUR: STUDY DESIGN

CHAPTER FIVE: FINDINGS

CHAPTER SIX: MY CHILD BEING IN SPICA CAST

CHAPTER SEVEN: SITUATIONAL MEANINGS

CHAPTER EIGHT: CONTEXT

CHAPTER NINE: THE DEVELOPMENT OF THE THEORY

CHAPTER TEN: DISCUSSION

CHAPTER ELEVEN: CONCLUSION

CHAPTER ONE: INTRODUCTION TO THE STUDY

Chapter overview

This study explores the experiences of caring for children who have undergone surgical treatment for development dysplasia of the hip (DDH) . While substantial research is available on the clinical aspects of DDH, a noticeable gap exists in understanding the unique experiences of parents dealing with this condition. It is expected that the results of this study will contribute to a deeper understanding of parental experiences when caring for a child wearing a spica cast. This study aims to develop a theory based on the experiences of parents caring for children with DDH following surgery. The research sheds light on this period, encompassing the challenges and changes parents face when caring for their children in a spica cast.

The study introduces DDH, offers a definition of the condition and outlines its epidemiology. A brief overview of the care pathway in the United Kingdom (UK) is presented.

1.1 Background to developmental dysplasia of the hip (DDH)

I. Terminology

The term "hip developmental dysplasia" (or DDH) has replaced the term "hip congenital dislocation" because it more accurately shows the broad spectrum of abnormalities affecting the immature hip (Dezateux and Rosendahl 2007). The disease has not changed although many clinical manifestations are incorporated within the new terminology. A change from "congenital" to "developmental" is crucial since hip abnormalities can arise both during pregnancy and after birth as the infant hip matures and develops (Hart et al. 2006; Jackson et al. 2014).The choice of the term "dysplasia" rather than "dislocated" concedes any abnormality in the shape, size and orientation of the femoral head, acetabulum or both (Dezateux and Rosendahl 2007; Bergo and Rosendahl 2013; Shaw et al. 2016). DDH describes hip disorders, ranging from a slight capsular laxity that resolves over time to frank dislocations requiring surgery (Cooper et al. 2014; Williams 2018). A change in terminology from congenital hip dysplasia to DDH more accurately describes hip abnormalities characterised by shallow acetabula, subluxations and dislocations (Clarke and Dowling 2003a; Wong et al. 2007). Five paediatric orthopaedic societies including the Paediatric Orthopaedics Society of North America (POSNA), European Paediatric Orthopaedics Society (EPOS) and the Brazilian Society of Paediatric Orthopaedics (SBOP) have endorsed this new name (Guille et al. 2000).

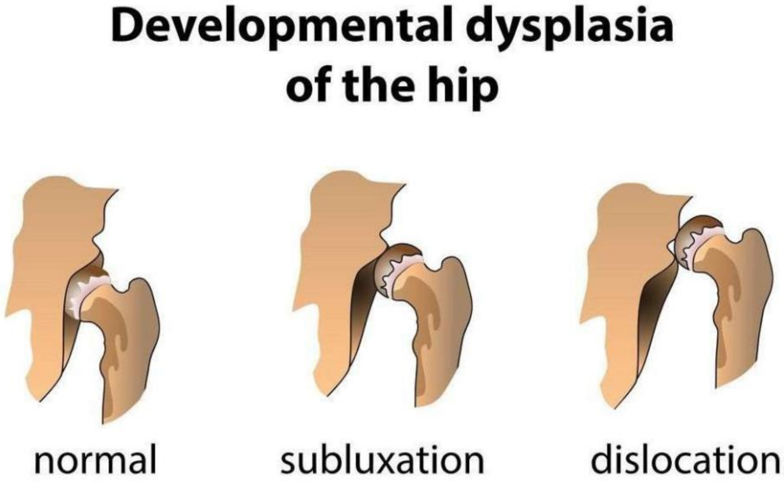


Figure 1: Different types of dislocation (vectorstock.com)

II. Definition

DDH as a condition, has an ancient lineage. Hippocrates recognised it as a congenital dislocation of the hip. Skeletons from medieval times displayed dysplastic hips and false acetabula (Mitchell and Redfern 2008). As a serious musculoskeletal problem, DDH causes disability in childhood and is the most common congenital deformity in newborns (Witt 2003; Dezateux and Rosendahl 2007; Bergo and Rosendahl 2013; Kotlarsky et al. 2015; Woodacre et al. 2016; Swarup et al. 2018). DDH encompasses a spectrum of pathologies that affect the hip in infants. This spectrum ranges from subtle radiographic signs through mild instability, to more severe cases of frank dislocations with abnormal acetabulum (Dezateux and Rosendahl 2007; Kotlarsky et al. 2015; Shaw et al. 2016; Chen et al. 2018). Connolly and Weinstein (2007) highlight how DDH can be defined both anatomically and radiologically. The anatomical definition refers to the abnormal development of the femoral head and acetabulum, whereas the radiological definition centres around specific indicators, including the break in Shenton's line (increased acetabular index).

A malformation includes any abnormality of size, morphology or anatomical relation of the femoral head or acetabular cavity (Weinstein et al. 2004; Storer and Skaggs 2006; Guarniero 2010).The condition exhibits a wide variety of pathologic compartmentalisation. Clinical instability of the hip is a classic feature of this disorder, ranging from mild acetabular dysplasia to an irreducibly dislocated hip (Herring and Tachdjian 2002; Buxton et al. 2004; Dezateux and Rosendahl 2007; Gulati et al. 2013). In an unstable hip, which can lead to subluxation or luxation, the femoral head is reduced in the acetabulum anatomical position (Musielak et al. 2015; Paton and Choudry 2016). Dislocation of the hip joint refers to the complete displacement of the articulating bones, resulting in a total separation of the joint surfaces. Whereas, a subluxatable or ‘loose’ hip joint details incomplete separation of the articular surfaces, where the femoral head and acetabulum cavity remain partially connected. The term acetabular dysplasia refers to an abnormality in the development of the acetabulum, including alterations in size, shape and organisation (Guille et al. 2000; Vitale and Skaggs 2001).

Several studies provide evidence suggesting the existence of two subtypes of hip dysplasia (Aronsson et al. 1994; Guille et al. 2000; Guarniero 2010). These subtypes are described below:

1. **Typical dislocation:** This subtype involves the dislocation of the hip joint in an otherwise healthy infant. It can occur either before or after birth.
2. **Teratologic dislocation** (TDH): TDH is characterised by early *in utero* dislocation of the hip joint and commonly associated with genetic or neuromuscular disorders. At birth, TDH is easily detected due to the fixed dislocation and pronounced morphological abnormalities present in the hip joint. In TDH cases, the hips are almost dislocated, and conditions of subluxation or instability do not exist.

III. Incidence and prevalence

The challenge in assessing the incidence of DDH lies in definitive discrepancies. DDH encompasses a range of abnormalities, from mild dysplasia to complete dislocation. Approximately 1:1000 newborn infants may present with hip dislocation, whereas approximately 10:1000 may exhibit hip instability. Patel and Care (2001) suggest an incidence of DDH in infants between 1.5 and 20 per 1000 births. Benson and Wainright (2004) claim that up to 20 per 1000 infants born in Europe exhibit demonstrable hip instability (Sewell et al. 2009). In the UK, the incidence of DDH is generally estimated to be 1:1000, despite the implementation of a national screening policy in 1986 (Dorman and Perry 2020). Consequently, DDH remains one of the most common and preventable causes of childhood disability in paediatric orthopaedics (Rhodes and Aarvold 2022).

a) Age at diagnosis

Early research indicates that the use of ultrasonography reveals an incidence of approximately 5.5 per 1000 in full-term newborns within the first two days of life, which decreases to 0.5 per 1000 at two weeks of age. In England, the incidence is reported as 1.28 per 1000 live births, with detection occurring between one and eight years of age. Notably, the highest incidence of late diagnosis occurs when an abnormal gait is observed after the child has started walking, typically between one to two years of age (Broadhurst et al. 2019).

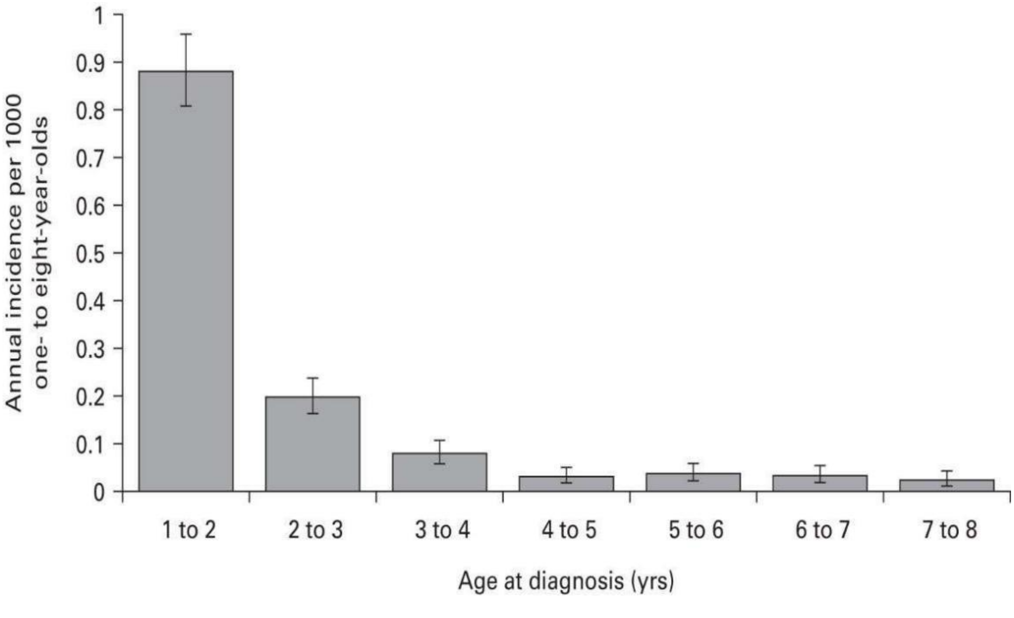


Figure 2: The annual age distribution at diagnosis(Broadhurst et al. 2019).

b) Geographical patterns

1. North East	0.32 (0.21 to 0.46)
2. North West	0.21 (0.17 to 0.25)
3. Yorkshire & The Humber	0.23 (0.16 to 0.32)
4. East Midlands	0.22 (0.14 to 0.32)
5. West Midlands	0.20 (0.16 to 0.24)
6. East of England	0.18 (0.14 to 0.23)
7. South West	0.18 (0.14 to 0.22)
8. South Central	0.30 (0.25 to 0.35)
9. London	0.20 (0.16 to 0.24)
10. South East Coast	0.16 (0.13 to 0.21)

Figure3 :The incidence of late diagnosed developmental dysplasia of the hip (DDH) across England (Broadhurst et al. 2019)

c) Criteria for diagnoses

DDH occurrence is linked to examination methods and clinician skill (Dogruel et al. 2008; Mulpuri et al. 2015). Clinical and sonographic screening raises DDH rates and overdiagnosis concerns (Bialik et al. 1999; Shipman et al. 2006). Ultrasonography shows an incidence of 5% newborn hip abnormalities, even though many of these abnormalities are not detectable during physical examination (Peled et al. 2008). Higher incidence rates are often observed when ultrasonography is utilised in conjunction with clinical examination (Rosendahl et al. 1994).

IV. Risk factors of DDH

The aetiology of DDH is intricate and not completely understood; it is believed to be multifactorial, with physiologic, genetic and mechanical factors implicated (Swarup et al. 2018; Williams 2018) . Notably, most individuals with DDH do not possess any identifiable risk factors. Conversely, only a small percentage, 1%-10% of those with risk factors, develop DDH (De Hundt et al. 2012; Roposch et al. 2020) (see table1).

Risk factors	The reason
Gender	Girls are eight times more prevalent than boys to have DDH.The estrogen produced by a female fetus relaxes the ligaments, increases the chances for the femoral head to go out of position. In addition, females are more likely to be born breech, which is an independent risk factor for DDH
Intrauterine limited Mobility	Due to the tight abdominal musculature and rigid uterus of the primigravida mother, first-born infants are also at an increased risk for DDH. Oligohydromnios is also associated with DDH because fetus mobility is restricted in oligohydromnios
Breech presentation.	Breech position is a strong risk factor for DDH. It was hypothesized that breech position causes excessive knee extension in the fetus, which causes hip instability in the newborn
Family history of DDH	The risk of DDH is 6% when one sibling is affected, 12% when one parent is affected, and 36% when both a parent and a sibling are affected
Race	The incidence of developmental dysplasia of the hip (DDH) can vary based on geographical location, influenced by cultural, genetic, and environmental factors Populations like Lapp and Native American have higher rates, while African and Chinese population show lower rates. In Europe, Southern regions have a higher incidence than Northern regions. Dysplasia affects 1.0% of white neonates and dislocated hips 0.1%. Rural birth and not being the firstborn are also associated with lower treatment outcomes. The persistent supine position for babies, indicated to minimize SIDS, appears to increase DDH risk.
Other risk factors.	DDH is additionally associated with other conditions, including metatarsus adductus, congenital muscular torticollis, congenital dislocation of the knee, and plagiocephaly
(Herring and Tachdjian 2002; Benson and Wainwright 2004; Hart et al. 2006; Shipman et al. 2006; Dezateux and Rosendahl 2007; Noordin et al. 2010; Ortiz-Neira et al. 2012; Seringe et al. 2014; Alsaleem et al. 2015; Ulziibat et al. 2021)	

Table 1: Risk factors

V. Screening and diagnostics

DDH is clinically silent during the first year of life (Shaw et al. 2016). There is currently no agreement regarding the 'gold standard' for diagnosis of DDH, either clinically or sonographically(Perry and Paton 2019). In 1986, the National Health Service (NHS) in England developed national standards for the Newborn and Infant Physical Examination (NIPE) screening programme. In accordance with these UK guidelines(revised April 2021), the assessment of hip joints is conducted neonatally, then followed by a clinical evaluation undertaken by a general practitioner 6–8 weeks later. For hips considered to be 'at risk,' sonographic imaging is recommended at 4–6 weeks. Despite being commonly referred to as screening, the current NIPE hip screening programme does not fulfil most of the World Health Organization's criteria for an effective screening programme. The timing and frequency of screening for DDH in early infancy and childhood are not internationally agreed (Sewell et al. 2009; Shorter et al. 2013). International guidelines offer a range of recommendations regarding the screening methods for DDH which encompass options ranging from physical examination to the universal application of ultrasonography for assessing the hip joint (Williams 2018).

Public Health England introduced the following clinical screening tests for developmental hip dysplasia (see Figure 4):

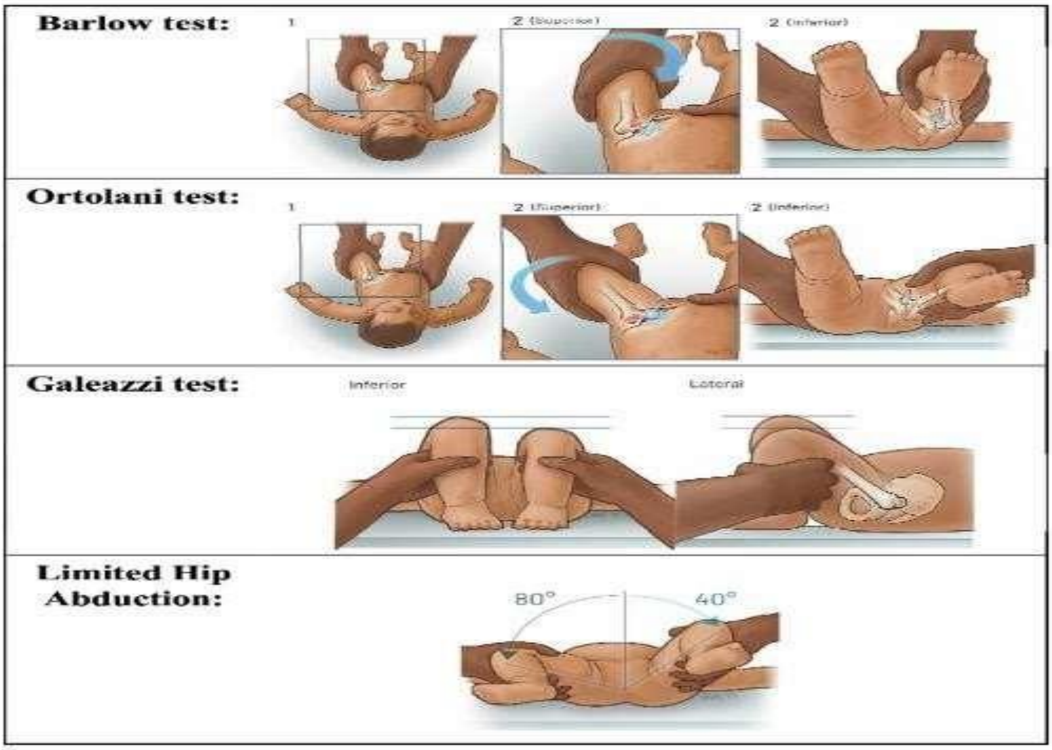


Figure4: clinical tests to screen for DDH(Aroojis et al. 2022).

a) Physical examination

In the UK, newborns have been routinely screened for hip instability since the 1960s using the Ortolani and Barlow tests. Numerous international guidelines and recommendations for DDH screening emphasise the significance of this initial screening assessment(Canadian Task Force on Preventitive Health Care, 2001; Committee on Quality Improvement, 2000; International Hip Dysplasia Institute, 2015; Public Health England, 2021).

b) Ultrasonography and plain radiographs

Ultrasonographic techniques can evaluate the anatomy of the hip and the stability of the femoral head within the acetabular socket, even before ossification occurs(Mulpuri et al. 2015). In comparison to other screening methods, ultrasound demonstrates high sensitivity and specificity, making it an effective tool for diagnosing DDH(Yang et al. 2019). This imaging modality enables visualisation of the bones, cartilage and soft tissues of newborn hips, while also capturing the motion of the femoral head within the acetabulum (AlQemzi et al. 2022). Consequently, ultrasonography is widely utilised for the assessment, diagnosis and monitoring of DDH(Elbourne et al. 2002; Paton 2005). It can be employed universally for all infants or selectively for those identified as being at risk of developing DDH. However, ultrasonography conducted within the first four weeks after birth often reveals minor hip instability or immaturity, which typically resolves spontaneously within a few weeks(Brurås et al. 2011; Roposch et al. 2011).

VI. Treatment and intervention

Treatment decisions for DDH rely on a combination of clinical hip examination and imaging (Shaw et al. 2016). The management approach for DDH involves both non-surgical and surgical options, aiming to promptly reposition the hip joint to its correct anatomical position and ensure proper development of the acetabulum and proximal femur (Vitale and Skaggs 2001; Aksoy et al. 2002; Demirhan et al. 2002; Hedequist et al. 2003). The selection of treatment options for DDH involves the consideration of various factors, including the child's age, the severity of the condition, and professional opinion (Mulpuri et al. 2015). Treatment algorithms are designed to incorporate these considerations in order to determine the most appropriate course of action. Although it is essential to treat each patient as an individual case, treatment algorithms provide a valuable starting point for the development of a logical treatment programme(see appendix 1). The proper development of the hip relies on the femoral head being deeply and centrally positioned within the acetabulum. If subluxation or dislocation persists, it can lead to the development of structural changes in the hip joint. The majority of hips manifesting clinical instability at birth spontaneously resolve within the initial eight weeks of life (Kotlarsky et al. 2015) . This can be attributed to the natural laxity of the hip capsule during the immediate neonatal period and newborns are typically born with a slight flexion contracture (25–30°). This contracture is expected to spontaneously decrease to less than 20° at 6 weeks and 7° at 12 weeks (Williams 2018; Bellevue et al. 2019). Within a few days, the femoral head relocates and stabilises, leading to normal hip development in most cases (Barrera et al. 2019; Vaquero-Picado et al. 2019).

As the child grows, both clinical and ultrasound examinations become more specific in their assessment. This heightened specificity is particularly evident when evaluating limited abduction, which becomes a reliable indicator for DDH between the ages of three and six months (Shipman et al. 2006). The first-line treatment utilises abduction bracing of the hips (using a Pavlik harness) which aims to passively align the hip joint (Gulati et al. 2013; Swarup et al. 2018). In cases involving larger babies, more severe or complex conditions, or a late diagnosis, a stronger and more rigid-style abduction orthosis, such as the Rhino brace, may be utilised (Swarup et al. 2018; Bellevue et al. 2019).

Following a six-month period of conservative treatment, patients who have not exhibited improvement undergo an assessment to determine their suitability for surgical interventions, commonly known as late DDH treatment (Kotlarsky et al. 2015). This treatment approach aims to reshape and preserve the anatomical and physiological integrity of the hip joint through closed or open reduction (Issin et al. 2016; Wicart et al. 2018). A period of 18 months is regarded as a critical timeframe for DDH because bone and soft tissue pathologies are unclear before the 18-month period. The primary objective of the surgical approach is to restore both the anatomical and physiological integrity of the hip joint (Demirhan et al. 2002; Biçimoglu et al. 2003). This involves achieving a stable and concentric reduction of the hip joint while also minimising the potential for complications, particularly avascular necrosis of the femoral head (AVN) (Murphy and Kim 2016). In situations where closed techniques are unable to achieve the desired stable and concentric reduction, open reduction becomes a necessary course of action. In the literature, there is no evidence to clearly show which surgery timing results in a good clinical outcome. Holman et al. (2012) report an increase in age at the time of surgery is an indicator of bad clinical and radiological results, like AVN and re-dislocation. A surgeon who treats hip disease is faced with two major problems. The first is to detect hip dysplasia early so that it can be treated because children have few or no findings in infancy, particularly if the hip is only dysplastic and the symptoms of hip dysplasia are not present until the teenage years when the patient suffers pain. An experienced surgeon does not neglect a patient who has abnormal radiographic indices without symptoms that could be predicted to have a poor long-term prognosis (Shorter et al. 2013; Wenger et al. 2013).

The second problem is deciding what degree of dysplasia requires surgical intervention. Following a closed reduction, acetabular development occurs most rapidly in the first six months, then slowly over the next year. A closed treatment should be abandoned if the acetabular angle does not decrease by four degrees within six months of reduction (Sankar et al. 2019). Moreover, each surgeon has their own time preference for when surgery should be undertaken, and this differs depending on their stage of learning, experience, and their own technique. This can present a challenge for some families when seeking to access expert orthopaedic care, such as obtaining an immediate referral from primary care to secondary care. Thus, childhood hip dysplasia remains a difficult orthopaedic problem, and decisions regarding how and when to intervene surgically remain somewhat complex (Williams 2018).

Nevertheless, the lack of international consensus and guidelines regarding the optimal age for surgery and the need for additional bone time (femoral and/or pelvic) has led to ongoing controversy in this area. Ultimately, the decision regarding which procedure to undertake is determined based on the experience and expertise of the surgeons and departments involved.

a) Complications

Undetected and untreated DDH during the early stages can progressively cause degeneration in the hip joint, leading to significant impairment of its normal function(Angliss 2005; Jacobsen et al. 2005). Dislocated hips are characterized by a shortened posture and a persistent waddling gait which remains throughout an individual's life. Untreated unilateral dislocation can lead to pelvic obliquity which disrupts the distribution of the hip force on the opposite hip joint. This imbalance in force distribution can result in degeneration on the contralateral side. Furthermore, these alterations in hip mechanics can give rise to compensatory dysfunctions of the trunk and knees, further complicating the overall musculoskeletal function (Loder and Skopelja 2011). Furthermore, this progression can ultimately lead to the development of painful and debilitating osteoarthritis (Mahan et al. 2009; Sink et al. 2014).

In severe cases, the degeneration of the hip joint may necessitate total hip arthroplasty during the second, third or fourth decade of life(Engesæter 2013; Schaeffer and Mulpuri 2018; Vaquero-Picado et al. 2019). The National Joint Registry of England and Wales has observed that a significant proportion of hip replacements performed for DDH occur before the age of sixty(Furnes et al. 2001) . This indicates the long-term impact of untreated or poorly managed DDH, to emphasise the importance of early detection and appropriate intervention to prevent or minimise the progression of the condition and subsequent joint degeneration.

DDH can be effectively managed in most cases without causing permanent ongoing issues for the child, as hips treated at an earlier stage tend to have more favourable outcomes compared to those treated later on, although it is important to acknowledge that intervention and subsequent treatment for DDH typically necessitate long-term commitment(Sewell et al. 2009; Wang et al. 2013). This extended duration of treatment and the need for ongoing developmental follow-up have significant implications and place a considerable socioeconomic burden on parents and carers(Thaler et al. 2011; David et al. 2018).

1.2 Hip spica cast

Several critical aspects related to the use of spica casts in paediatric conditions are considered here. Initially, the application of spica casts in addressing paediatric orthopaedic issues such as femur fractures are examined. Potential complications and challenges associated with managing spica casts are scrutinized, shedding light on any practical difficulties that arise. Finally, the potential impact of spica casts on families is investigated, which provides insights from their perspective.

After a surgical repair or trauma, a child's hip and leg joints are immobilised with spica casts. By holding the hip, thigh, and tendon muscles in place, the cast maintains the correct position for healing. Spica casting was used as early as 1898 by Harvey Cushing at The Johns Hopkins Hospital, Baltimore, USA. The use of a body (spica) cast is a common treatment for DDH infants and young children (Leu et al. 2012). Van Douveren et al. (2003) found that various interventions, such as open or closed reduction, and femoral or pelvic osteotomy were effectively managed using a spica cast. This type of cast was widely reported as the preferred option and considered the 'gold standard' treatment for DDH(Mehlman et al. 2000; van Douveren et al. 2003; Yang et al. 2019).

According to Clarke and Dowling (2003), the primary objective of applying a spica cast is to retain the femoral head in abduction within the hip joint's acetabulum. This containment fosters the proper development of the femoral head within the pelvis, promoting normal growth. The cast used in the treatment appears bulky and awkward, usually extending from under the child's axilla to one or both legs. To accommodate bodily functions, an opening is created in the genital area to allow the passage of urine and stools (Clarke and Dowling 2003; Reed et al. 2011). Typically, in the majority of cases, the child is admitted on the day of surgery for treatment and the application of a cast. After a short hospital stay of 1–2 days, they are discharged and returned home.. Once at home, the child continues to wear the cast for a period of six to twelve weeks while the family takes care of the child's needs (IHDI 2014).

a) Cast complications and problems associated with cast management

While the child returns home early, it is not a return to a normal lifestyle. Rather, it is a challenging task to care for a child in a spica cast, which requires a wide variety of adjustments to daily life (Infante Jr et al. 2000; Greisberg et al. 2002; Flynn and Schwend 2004; Shemshaki et al. 2011). Casting-related complications create challenges for both children and their families, adversely affecting family dynamics. (Hughes et al. 1995; Infante Jr et al. 2000; Flynn and Schwend 2004; Mubarak et al. 2006; DiFazio et al. 2011; Flynn et al. 2011; Szostakowski et al. 2017; Ekwall et al. 2018). Difazio et al. (2011) found that 28% of the 297 patients treated with spica casts experienced skin complications. Skin issues from casting can cause pain, infections and greater healthcare use, as well as placing providers at risk of medicolegal action (Szostakowski et al., 2017). Even with a 'perfect' cast, there are numerous medical issues that can complicate the tolerance of wearing it or lead to complications

(Szostakowski et al. 2017).

At least one problem arose in 97.5% of 120 cast patients studied by Dadkhah-Tehrani et al. (2022). Ekwall et al. (2018) found that 25% of cast patients displayed problems. Spica casting causes skin problems for up to 30% of users in developmentally normal children treating femur fractures (DiFazio et al. 2011). Qualitative research on lower limb cast wearers found that pain, swelling and discomfort can be physically exhausting (Williams 2010) (see Table 2 regarding cast complications).

The main causes of hip spica casting complications are immobilization, loose pelvic moulding (loose moulds lead to more motion in the cast and additional skin irritation), cast soiling, increased skin contact with casting materials, and difficulty caring for a body-casted child(Difazio et al2011). Difazio et al. (2011) found that 28% of the 297 patients treated with spica casts experienced skin complications. In some instances, the cast may apply excessive pressure or cause constriction, leading to neurologic injury or compartment syndrome(Tisherman,et al 2018; Ekwall et al., 2018). Additionally, while wearing the cast, the limb may experience increased hair growth and decreased muscle bulk(Stevens et al 2004 Eric et al , 2020).

Prolonged exposure of a child's skin to urine and stool can cause discomfort, rash, and skin breakdown, which can result in open skin lesions and susceptibility to infections. In patients with hip spica casts, it is crucial to be aware of the potential complications related to the proximity of urine and stools (Difazio et al., 2011; Chan et al., 2015). A literature review has found a lack of evidence regarding best practices for spica cast toileting and nappy use(Infante Jr et al. 2000;smith Reed et al. 2011; Demir et al 2015 Tisherman. 2018 Wakely et al., 2021).

Ensuring the cleanliness and dryness of the cast often proves challenging when caring for an infant or child in a spica cast. Managing nappy changes and maintaining good skin positioning are essential steps to prevent common problems like skin irritation and breakdown (Hart et al., 2006). If the cast becomes completely wet or diffusely wet, it should be changed at the next available clinic appointment to prevent skin maceration(Halanski and Noonan, 2008). In the case of localized wetness, initial attempts can be made to dry the area using a hair dryer on the cool or low heat setting(Marks et al., 1983; Seattle Children's Hospital, 2019).

The following factors can make a limb in a cast more prone to complications: heat generated during the drying of the cast, inadequate care and maintenance of the cast, prolonged immobility of the limb in the cast, tightness of the cast, and increased pressure inside the cast (Boyd et al., 2009; Szostakowski et al., 2017). The majority of complications related to casts can be attributed to poor care and follow-up, inadequate patient/carer education on cast care, and lack of self-care while wearing a cast. Several studies have stressed the importance of educating patients and/or their carers on cast complications, self-care, and cast maintenance, in addition to proper casting procedures, to prevent cast-related issues(DiPaola et al., 2014; Nguyen et al., 2016; Adib-Hajbaghery and Mokhtari, 2018; Mokhtari et al., 2020). It is imperative to provide comprehensive education to both patients and caregivers regarding the indicators of cast-related complications, as well as the preventive measures and the significance of promptly reporting any issues. (Esoga and Seidl, 2012; Gadirzadeh et al., 2017).

In traditional casts, a stockinette liner and cotton or synthetic padding are used, which can be hard to clean and can absorb, transmit and retain moisture, leading to challenges in maintaining dryness over the weeks and months that they are worn (Haley et al. 2006). Even with the most diligent efforts of patients and families, maintaining a dry cast is not always feasible (Wolff and James 1995). Failure to keep the cast dry can result in a foul odour, skin problems and infection, necessitating frequent skin checks and possible cast changes (Shirley et al. 2020). Educating parents about proper positioning, nappy changes and skin monitoring is crucial (Halanski and Noonan 2008). Additionally, the qualifications of the casting staff have a significant impact on complications related to casts, as indicated by previous studies. Patients are more likely to experience complications when casts are applied by unskilled staff (Halanski and Noonan 2008; Adib-Hajbaghery and Mokhtari 2018).

Occasion	Complications
During the application of the cast	An incorrect positioning of a limb, such as extreme hip abduction position in immobilization, has been shown to elevate the risk of avascular necrosis (AVN). During cast removal or splitting the cast, the cast saw blade's heat can cause cast saw burns, cuts, burns, or abrasions.
During cast immobilisation may lead to unwanted physiologic changes	Decrease in levels of physical activity, developmental motor delays, and decreased strength. Loss of bone mineral and osteopenia Atrophied muscles Decrease range of motion and static and dynamic balance. Joint stiffness, cartilage degradation, and ligament weakening. Compartment syndrome.
Soiled casts If the cast becomes completely wet or diffusely wet, it should be changed at the next available clinic appointment to prevent skin maceration. In the case of localized wetness, initial attempts can be made to dry the area using a hair dryer on the cool or low heat setting.	The potential complications related to the proximity of urine and stool. Irritant contact dermatitis due to the chemical irritants in urine and feces. Affect the cast's integrity itself. Wet cast may lead to foul odors, skin irritation, skin breakdown, and infection.
Skin-related issues Casts are typically required to be worn for several weeks to months, making it challenging to keep them completely dry. Even with the most diligent efforts from patients and families, maintaining a dry cast is not always feasible	These issues vary from minor skin irritation and redness to excoriations and blisters. Some casts apply too much pressure or cause constriction, leading to neurologic injury or compartment syndrome.
Transportation and transferring The consistent flexion and abduction positioning of Spica casts are essential for preserving the hip's concentric reduction achieved during surgery. However, this positioning can make it challenging for the child to find a comfortable sitting or resting position. Families identified mobility as the major difficulty with Spica cast treatment .	Children in Spica casts often spend most of their time lying supine, relying on pillows for support to accommodate the flexed hip and knees posture. Prolonged recumbency can lead to respiratory issues, skin problems, and discomfort. Challenge of carry and move the child at home. Safe vehicle travel is a major issue for families. Transporting children with a Spica cast requires specialized car seats, as their regular car seats are too small to accommodate them properly.
Cast change. Families should be prepared for the possibility of repeated cast placements due to various reasons, including cast-related issues.	In traditional casts, a stockinette liner and cotton or synthetic padding are used, which can be hard to clean and can absorb, transmit, and retain moisture. Wet casts, tight casts, loose casts, damaged casts, and painful casts are the most common reasons for changing.
Schooling Despite there are no official medical guidelines, it's common for schools to prohibit children from returning while they are wearing a cast.	Obstacles for these children include unsafe transportation to and from school, restricted movement within school, assistance needed with toileting, and liability concerns. Schools might find it challenging to accommodate children with specialized mobility needs or may lack the necessary facilities to provide appropriate support
(Streissguth & Streissguth, 1978; Leblanc et al., 1990; Wolff & James, 1995; Hughes et al., 1995; Haley et al., 2006; Hart et al., 2006; Mubarak et al., 2006; Halanski & Noonan, 2008; Shuler & Grisafi, 2008; Herman et al., 2011; Ceroni et al., 2012; Leu et al., 2012; DiPaola et al., 2014 ;Gockley et al., 2015; Ireland et al., 2016; Difazio et al., 2017; Szostakowski et al., 2017 Ekwall et al., 2018; Maggio et al., 2019; Adams et al., 2019; Sabeh et al., 2020; Ravi et al., 2022; Shah et al., 2022; Shirley et al., 2020)	

Table 2: Cast complications and problems associated with cast management.

As mentioned above, failure to follow care instructions can cause many cast-related issues at home (DiPaola et al. 2014;Balch Samora et al. 2018). Current research lacks studies on cast care quality and cast-related problems. Parents need instruction on home cast hygiene and novel discharge programmes for spica cast care (Smith 2004; Reed et al. 2011). Despite the limited literature on the subject, there remains a need for a theoretical explanation to account for the variability in the effects of hip casts on children. In a recent study, qualitative feedback from families also emphasised the need to improve teaching and family preparation for spica cast treatment (Kocher et al. 2022).

1.3 Potential consequences for DDH surgery and cast period.

The perioperative period is frequently a stressful time for families who often experience worry and fear related to pain and potential complications and their ability to cope with the demands of caring for a child under these conditions(Salisbury et al., 2007; Rullander et al., 2016). Following surgery, the weeks and months are marked by uncertainty regarding the child's condition and care. Additionally, postoperative pain in children can significantly impact their quality of life and have serious implications for the entire family(Rabbitts et al., 2015).

Children's responses to trauma can be influenced by a variety of factors. Despite parents' efforts, certain aspects of illness and treatment, such as hospitalization for surgery can have negative effects on children, often resulting in intense emotional and disruptive behaviour (Wong et al., 2007; Hockenberry and Rodgers, 2013; Praveen et al., 2023). Additionally, carers may find it difficult to justify the restrictions on movement due to a spica cast, which children may struggle to comprehend. This can lead to behavioural changes that parents can find challenging to manage. The central hypothesis is that children's understanding of illness is connected to their cognitive development(Harbeck and Peterson, 1992; Ross and Ross, 1988).

Young children understand illness in the context of how it disrupts their daily activities and choices. For instance, a child might feel upset about being unable to participate in activities they enjoy, such as playing with their siblings or friends(Sparks et al. 2005; Clarke and McKay 2006; Hart et al. 2006). The literature underscores the significance of educating and involving children in comprehending their condition and treatment process(McIntosh and Stephens, 2012 ;McIntosh et al 2013). Children often look to their parents for information about their illness, but this can be challenging if parents themselves do not have a thorough understanding. Hence, healthcare providers and parents should explain the purpose of the cast using simple, age-appropriate language that the child can grasp. Therefore, there is a critical need for a collaborative approach involving both healthcare providers and parents to ensure that children receive education and support tailored to their age and cognitive development throughout their treatment journey. This proactive strategy can help alleviate anxiety, enhance coping mechanisms, and contribute to an overall improved experience for the child.

Tribulation associated with the spica cast mentioned by parents include difficulties with routine washing, preventing cast soilage from excretion, managing the child's increased weight in the cast, transportation and increased burden on the caregiver(Hugheset al. 1995; Infante et al. 2000;Mubarak. et al. 2006). However, there is a lack of literature discussing childcare from the perspectives of parents or caregivers. As noted, caring for a child in a spica cast can be a difficult task. In a study by Hughes et al. (1995) on the socioeconomic impact of hip-spica casting, transportation problems were cited by sixteen families, cast intolerance by five families, and maintaining cast cleanliness by two families as the greatest challenges. Additionally, a psychologist, Streisguth, observed several difficulties her son faced during hip spica treatment, including decreased physical contact with others, eating difficulties, a restricted visual field, challenges changing positions, feelings of helplessness, and difficulty playing with friends(Streissguth ,1978 Cite in Shah, et al 2022).

Although the consistent flexion and abduction position of these casts is integral to maintaining the concentric reduction of the hip achieved at the time of surgery, it also poses challenges in positioning the child comfortably or allowing them to sit up at all (Shah et al., 2021). Children in spica casts typically remain supine for most of the time with supportive pillows to accommodate the posture of flexed hip and knees. However, prolonged recumbency can lead to respiratory issues, skin problems, and discomfort. Additionally, carrying the child at home with a spica cast can be difficult for parents(Shah et al., 2021). Parents often have no control over the size or shape of the cast, which may make them reluctant to move the child.

Mobility is especially challenging for families with children in hip spica casts because the mobility of children at home is achieved through a family member who can raise them(Hughes, et al1995, Ferreira et al., 2012). Parents of older children experienced more difficulties with the hip spica cast than parents of younger children, largely due to the older children being heavier and thus harder to carry(Hughes, et al1995, Ferreira et al., 2012). The cast may limit the child's ability to move around, affecting their interactions with peers and participation in social activities. As noted by Streisguth and Streisguth, a hip spica cast deprives the child of usual forms of body contact and human closeness, as it keeps the child horizontal on the floor(Streissguth ,1978 Cite in Shah, et al 2022).

Limitations on a child's mobility and their ability to participate in certain activities can have social implications. For example, a child in a spica cast may be unable to attend school, participate in sports or other physical activities, or engage in certain types of play. Despite a lack of official medical guidelines, it is common for schools to prohibit children from returning while they are wearing a cast. This can present several challenges when attempting to reintegrate the child back into school, particularly for those in a spica cast. Some of the obstacles include difficult or unsafe transportation to and from school, limited mobility while in the school setting, assistance required with toileting, and concerns around the school's liability for the child's safety(Hughes et al.,1995; Leu et al., 2012). In general, schools may struggle to accommodate children with specialized mobility needs or may lack the necessary facilities to provide appropriate support. Consequently, parents may face additional costs, such as taking time off work due to the absence of daily care for the child during the spica splint period. This scenario places financial and social strains on the parents, potentially forcing one of them, (usually the mother), to forgo his/her job or social engagements, as they are typically required to be available around the clock to care for the child (Reed et al 2011).

Limitations outlined above may also lead to travel restrictions, contributing to social and geographical isolation for families. Studies indicate that individuals with disabilities encounter challenges in traveling due to various restrictions and can be restricted in their choice of transport mode(Bromley et al., 2007; Velho et al., 2016). Additionally, children in spica casts face difficulties in safe vehicle travel, as typical car seats are often too small for them, necessitating specialized car seats. Safe vehicle travel remains a significant issue for families. Herman et al. (2011) found that 69% of patients in their study were not properly secured during motor vehicle travel following spica casting.

Furthermore, the financial strain of caring for a child in a spica cast, which includes medical expenses, lifestyle adjustments, and potential loss of income, can create obstacles for parents in obtaining customized car seats. Families with limited financial resources may find it challenging to afford these specialized products, resulting in transportation difficulties and safety issues(Herman et al., 2011; Gockley et al., 2015; Adams et al., 2019; Collins et al., 2020). These concerns collectively contribute to potential barriers that parents may encounter in obtaining and properly using specialized car seats for children in spica casts, posing safety risks during transportation and limiting the family's mobility(Kocher et al 2022).

Social and cultural barriers in the community can further exacerbate the problem of being isolated (Broady et al 2015 ; Tekola et al 2020; Purtle et al . 2021). Social isolation can also be influenced by a primary carer’s (often the mother) psychological state and her level of acceptance of her child’s condition(Broady et al 2015 ; Tekola et al 2020; Purtle et al . 2021). Attitudes (with issues such as stigma and people staring) towards spica cast-wearing children have led to withdrawal from participation in social activities and events, making the child and their caregivers suffer, which may exclude them from society. Parents have to deal with the way people look at their child whether or not they accept their condition. This study found that some mothers suffered when going outside because people asked questions about their child’s appearance whilst wearing a large cast. According to Masnari et al. (2012), children with visible disfigurement are more likely to experience stigmatisation than other children. Parents have expressed that the attitudes of other people toward them and their children act as a hindrance, making it more challenging for them to engage in their community.It is important to note that social isolation and stigmatisation can have serious consequences for the family(Bayat 2014; Clever and Herna 2017; Boyd 2017).

1.4 The study

I. Framing the research question

According to Corbin and Strauss (1990), the research question's purpose is to guide the researcher in exploring the data and uncovering the issues and problems that matter to the individuals, organisations, groups and communities being investigated.

II. Research question

What are the perspectives of parents looking after their child who has DDH and is in a spica cast?

III. Aims and objectives

a) Research aim

To generate a theoretical understanding of the experience of looking after a child in a spica cast from the mother' perspective.

b) Objectives

1. To understand the impact of the spica cast on the child and parents.
2. To understand how parents responded and adapted to the spica cast.
3. To understand how parents make sense of their experiences of looking after a child in a spica cast.
4. To identify what parents need to manage daily childcare better.
5. To theorise on the meaning of the spica cast from the perspective of the parents.
6. To explore the implication of the theory for families and the healthcare system in the UK.

In this study, I will refer to "mothers'' when talking about the experiences of mothers and their viewpoints which I noticed in the Facebook posts and/or identified in the interview transcripts. I will sometimes refer to "parents and "family" when the caregiving experiences extend to other family members, including the mothers, as well as when I refer to the findings reported in the existing literature on the topic.

1.5 Rationale for the research study

The decision to plan this study was driven by several factors. Firstly, my extensive experience as a paediatric physiotherapist provides valuable insight into the developmental milestones that occur at specific stages and the overall context of child development. I encountered posts in DDH parent groups on Facebook support pages and developed awareness that the information shared in these posts was often questionable and potentially harmful. It was concerning to see inaccurate clinical information being shared because parents often rely on these online platforms for guidance. It became apparent that a significant number of parents lack awareness regarding the significance of promoting child development during periods of immobilization and that they were not fully informed about the strategies and techniques that can enhance child development. Moreover, instances were observed where parents posted videos or pictures of their child in incorrect or harmful positions, which further highlighted the need for better guidance and education.

Secondly, a driving force behind my decision to pursue a PhD was to focus exclusively on diseases related to infancy. While undertaking a master's degree, I concentrated on genetic diseases. During this period, I discovered the influential work of Dr Tina Gambling, a highly respected figure in the field of DDH. Her contributions served as a catalyst to delve deeper into this subject and expand my understanding. Choosing to conduct research in the UK was a deliberate decision based on the country's developed healthcare system which provides numerous advantages for my country of origin. The advanced nationwide NIPE programme, particularly caught my attention as it provides an invaluable framework for studying DDH and allows insight to be gained from the UK's experience and practice in this field. This will significantly enhance the diagnosis, treatment and overall management of DDH within my own country’s context. Knowledge gained from such British expertise provides a foundation to develop more effective strategies and interventions in my country with a focus on benefit for parents to improve their care of children with DDH.

"Cast Life," a book written by Natalie Trace, inspired my decision to conduct research into spica casts. As a mother of a child with DDH, Trace provides a poignant portrayal of the challenges faced by families in such situations. "Cast Life" extends beyond the practical aspects of life caring for a child in a cast, delving into the unique emotional journey parents may undertake, offering guidance for navigating the uncertainties and anxieties associated with this condition. Witnessing the depth of parental struggle depicted in the book, combined with my background as a paediatric physical therapist, solidified my determination to research this phenomenon.

Parents are placed at the heart of the ongoing care of a child with complex needs. Medical professionals may not always witness the full extent of the challenges and burdens that families face at home. Therefore, it is appropriate that parental views and experiences should also be central to research within the field (Strauss and Corbin 1998a; Bryman 2001; Charmaz 2014). By incorporating parental perspectives, valuable insight into the impact of DDH on the family dynamic can arise. Thus, allowing the development of more effective strategies to support both the child and their parents throughout the treatment process.

The limited scope of exploratory methods used, with a primary reliance on surveys to elicit parents' experiences with DDH, has led to a knowledge gap. To enhance maternal support from health professionals and parent organizations a deeper comprehension of parental experiences is required. By addressing this limitation, professionals can improve assistance to parents, while parent support organizations can offer more effective support. It is essential to acknowledge that treating a child patient not only affects their life but also directly impacts the whole family's quality of life. Therefore, surmounting this knowledge gap may yield far-reaching positive effects on both the child and their family.

Existing literature has not identified established theory to comprehend the meaning of being in a spica cast from parental perspectives, therefore, it is appropriate to focus on theory construction with a view to attaining parental contributions to this field. Numerous studies exist regarding the pathology, risk factors, prognosis, complications and management of DDH. However, there remains a significant gap in understanding the quality of life and burden experienced by parents affected by this condition. Parents' perspectives were notably absent in the existing literature, highlighting a crucial omission in current research. The research design of this study was primarily influenced by this gap in current literature, emphasizing the need to understand how parents navigate this challenging period of care. Therefore, it is imperative to employ research methods that enable parents to share their experiences, particularly to include acceptance of the condition, adaptation strategies, and responses to this critical period. Gathering comprehensive data from parental perspectives is crucial to acquire insight and develop theories grounded in the lived experiences of those who have undergone this process (Strauss and Corbin, 1998b; Charmaz, 2014a; Bryman, 2016). Consequently, the planning process explored the reality faced by parents based on their personal accounts of caring for a child in a spica cast.

1.6 Organisation of the thesis

This thesis comprises eleven chapters, each serving a specific purpose. The first chapter serves as the introduction, offering a comprehensive background on the disease under study. Additionally, it offers a rationale for the subsequent studies conducted within the thesis. Furthermore, the introduction outlines the research aims and objectives that will guide the entire thesis. Chapter Two of this thesis conducts a comprehensive literature review using a scoping review approach. The primary objective of this chapter is to identify and explore themes that are relevant to the study at hand. In a grounded theory methodology, the use of literature plays a crucial role in shaping and informing the research process. In the context of this thesis, Chapter Two concludes by highlighting the significance of using literature within the framework of grounded theory.

Chapter Three serves as an introduction to the research methodology, providing a detailed explanation and justification of the chosen research approach and methodological design. The chapter explores the underlying worldview and research philosophy of interpretivism that guides the study, while also addressing the ontological and epistemological considerations inherent in this research. Chapter Four comprehensively covers various aspects of the research process, including data collection methods, sampling techniques and data analysis approaches. The rationale behind these methodological choices is thoroughly discussed, emphasising their alignment with the research objectives and their contributions to the overall credibility of the findings.

Chapter Five presents the results and analysis of the posts and interviews. This chapter introduces the finding chapters, which are separated into three categories, described in Chapters Six, Seven and Eight which present the results of the analysis of study samples that combined the Facebook post and interviews together to explore the impact of hip spica casting after treatment of DDH on the development of the child from the perspective of the parent.

Chapter Six concerns the phenomenon of being in a spica cast, based on data analysis, to understand the diverse paths of children’s reactions to casting events. This exploration encompasses a multifaceted examination of the physical, behavioural, social and psychological dimensions of this period, aiming to shed light on the reasons behind the observed variations in children’s responses. The primary objective of this study is to delve into the dimensions of child development, as perceived through the lens of parents when their child is in a spica cast. This exploration is intricately intertwined with factors like acceptance of the child's condition and the array of strategies employed for adaptation, as well as how they responded to this critical period. Given the diverse range of adaptive response patterns exhibited by children, each child's reaction to their circumstances is inherently unique. Consequently, it becomes essential to strive to comprehend the child's experience (from a parent's perspective).

In Chapter Seven, the process involving action/reaction/emotion that is taken in response to a phenomenon, and the strategies directed towards it, dealing with it and overcoming it, are described.

Chapter Eight shows the context, which is all the circumstances that contribute to the structure of the phenomenon under study. Additionally, the phenomenon always manifests within a particular context or under specific circumstances, which plays a crucial role in shaping the unique experiences of the parents involved.

Chapter Nine describes the theoretical model generated from improving the codes and categories to reach the core variable, its properties, and its theoretical connections with other relevant categories. This chapter outlines the process of theory generation, providing a detailed exploration of mothers' experiences caring for a child in a spica cast. It describes how the model emerged from the data, identifying key patterns, relationships, and underlying mechanisms that shape the maternal journey. By synthesizing these findings into a cohesive framework, it provides a structured understanding of the caregiving experience.

Chapter Ten discusses the theory and also relates the theory to other literature reviews. In addition, it provides a comprehensive discussion of the results obtained from the research. It offers a detailed analysis and interpretation of the findings, allowing for a thorough understanding of the outcomes.

Chapter Eleven serves as the concluding chapter, summarising the main findings and discussing the implications of the present research, as well as emphasising the potential impact and significance of the findings in relation to the theory. The chapter also discusses the limitations encountered during the research process, acknowledging any constraints or challenges that may have influenced the results. Furthermore, it highlights possible avenues for future research, suggesting areas that could be further investigated or expanded upon based on the current study's outcomes.

1.7 Chapter summary

This chapter sought to establish the background to DDH concerning infants and young children. The definition, epidemiology and risk factors were discussed. An overview of the screening process and care pathway specific to the UK was referred to. Early diagnosis of DDH is crucial to prevent long-term health complications. Background information offers insight into the spica hip mould, along with an exploration of the practical challenges and significant complexities associated with it, which can potentially impact the entire family unit. These challenges encompass disturbances in routine, as well as, psychological and social impacts.

The next chapter details the search strategy designed to identify relevant literature. Subsequently, the literature review offers a scoping search of the literature which reveals a knowledge gap regarding the experience of parents caring for a child with DDH.

CHAPTER TWO: LITERATURE REVIEW

Chapter overview

Throughout this literature review, relevant points are supported by references to the wider literature, particularly those pertaining to the spica cast. An overview of the key findings of the literature review is provided at the end of the chapter, as are the knowledge gaps that guided the formulation of the research question and served as justification for further investigation.

2.1 The literature review and grounded theory

This section addresses a crucial aspect which highlights the rationale for conducting the review in two stages. Moreover, I expound on the distinct constructivist grounded theory approach employed to conduct the literature review.

The misconception that grounded theory researchers should begin data collection without consulting the literature is widely held (McCallin 2003; Andrew 2006). This misconception can be particularly detrimental, because understanding the role of literature is crucial for developing sound grounded theories. The origins of this misconception stem from a misinterpretation of one of the fundamental principles of grounded theory which suggests that researchers should set aside pre-existing theories (Urquhart and Fernández 2013). Nevertheless, this principle does not advocate that grounded theory method researchers ignore the existing literature and approach their research with a blank slate or *tabula rasa*. A superficial reading of the literature is at the root of the notion that the researcher is a blank slate (Urquhart and Fernandez 2006). However, within the constructivist grounded theory perspective, there exists a distinct approach towards academic literature in grounded theory studies. According to constructivist grounded theory, researchers bring their prior knowledge, shaped by their training and personal experiences, into the study (Charmaz 2006; Morse 2007; Thornberg 2012). In contrast, the traditional *tabula rasa* approach discourages researchers from acknowledging their preconceptions and limits their sensitivity to diverse perspectives on the data(Corbin and Strauss 1990; Dey 1999; Bryant and Charmaz 2007).Consequently, the literature review is of significant importance, not only for data collection but also for analysis and presentation in this study. This approach can be characterised as an 'informed grounded theory,' emphasising the continuous involvement with pertinent literature to inform and enhance the research process(Thornberg 2012).

Despite the need for a literature review prior to selecting a methodology, there was a noticeable scarcity of existing literature that investigated child development in the context of hip casting. This absence was unexpected but aligned with Glaser's (1998) recommendation to refrain from reviewing literature in the specific subject area and related fields being investigated. Given the limited available research concerning delayed or halted child development during this period, the study begins with a broad exploration of the topic, followed by the collection of relevant information. These steps are consistent with the grounded theory research questions where researchers typically start with a broad inquiry into a specific topic area. This broad question allows flexibility and freedom for the researcher to find an initial focus and gather relevant information about the topic (Strauss and Corbin 1990; Glaser 1992; Charmaz 2006). This approach aims to provide a "thick description" of human interactions in a particular context and identify problems or challenges from the perspective of those experiencing the phenomenon being studied. Thus, the research questions addressing the use of grounded theory analysis are typically guided by empirical questions that ask about real-life problems in the world of everyday life (Auriacombe and Mouton 2007).

Moreover, the authors argue that the potential bias and subjectivity commonly associated with grounded theory methods can be mitigated by adopting a mindful approach called reflexivity (McGhee et al. 2007; Charmaz 2014) .

In practice, completely avoiding a literature review may be impractical, especially for PhD students. A preliminary research proposal is typically required for admission to a PhD programme and to obtain ethical approval prior to data collection. Both of these processes necessitate at least a brief initial literature review. Engaging in an initial literature review offers several benefits. First and foremost, conducting a literature search serves to orient the researcher, providing valuable insights that inform the development of research questions prior to the commencement of data collection (Charmaz 2014). Secondly, conducting a literature review reveals gaps in knowledge related to the topic at hand and verifies the significance of the current study in contributing new knowledge to the area of interest. Hence, a literature review is often considered non-negotiable for PhD students. In this study, the literature review process in grounded theory encompasses an initial scanning phase to establish a foundation, followed by an integrative phase that integratesthe emerging theory with relevant existing literature to enrich the study's findings (see section 9.3). By adhering to these steps, researchers can ensure a thorough and rigorous literature review process in accordance with the grounded theory framework.

Phase	*The goals*
Literature Scan	- Conduct a comprehensive literature search to establish a foundation for the researcher's work and guide their focus, without introducing bias towards the chosen topic. - Identify the research problem based on existing research. - Gain insights into the methodology. The literature search serves as a vital step in identifying gaps, exploring relevant concepts, and shaping the direction of the study, ensuring that it is built upon the existing knowledge in the field.
Integrative Phase	- Position the emerging theory within the knowledge framework by comparing it with existing theories. - Highlight connections between findings and literature(Urquhart and Fernández 2013) -As the study progressed and theoretical concepts began to emerge, I became engaged in literature review, which involves revisiting the existing literature to aid in the development of these emerging concepts. The main goal of this stage is to explore both converging and diverging literature that can be analysed in relation to observed patterns and emerging theoretical conceptualizations. Valuable insights are gained from the literature, enhancing the stud and lending credibility and relevance to the study.

Table 3; literature review and Grounded Theory

2.2 Scoping Review Approach

The literature review explores the perspectives and experiences of parents caring for children with spica casts. Conducting a scoping review charts existing literature, pinpoints research gaps, and provides insight into the subject matter(Arksey and o'malley 2005). Undertaking a review as part of this PhD study offers an added advantage by informing the research design and methodology.

A scoping review plus a thematic analysis of relevant papers was conducted. Thematic analysis enables scoping reviews to transcend mere mapping of the literature, offering a more comprehensive and interpretive synthesis. This approach was chosen to ensure a comprehensive exploration of the existing literature and to identify key themes and patterns and relationships within the literature (Daudt et al . 2013 ; Raysmith et al 2019).

The literature suggests various approaches to conducting literature reviews, as discussed by Aveyard et al. (2016), Coughlin and Cronin(2021) and Booth et al. (2021). The choice of review type should be guided by the research question and desired outcomes of the review. Thus, after formulating the review question, careful consideration was given to selecting an appropriate review approach. These reviews aimed to identify knowledge gaps, scope a body of literature, clarify concepts, or investigate research conduct. After careful consideration, a scoping review methodology was deemed most appropriate. This approach is recommended when the aim is to review and analyze the scope, range, and nature of a research field and to pinpoint gaps in the existing literature(Arksey and O'Malley, 2005; Levac, et al 2010). Scoping reviews aim to offer a thorough overview of existing knowledge and to identify what is currently known and unknown about the topic of interest, as highlighted by Anderson et al. (2008). An essential aspect is to scope the field of research, demonstrating how research has changed over time.

Furthermore, a scoping review can offer insight into the type of evidence relevant to practice and how the research has been conducted. It serves to investigate how research is conducted on a specific topic, providing valuable insights into the methodologies utilized within the field (see section 2.2.6.1.) (Mak and Thomas, 2022).. Ensuring that the research design stands apart from other available methodologies is crucial in this endeavour. The benefit of this feature will be discussed in the section on "Rationale for the selected approach" in the next chapter, with a particular emphasis on the second factor that influenced the choice of a constructivist grounded theory methodology for this study.

Additionally, scoping reviews can be employed to identify and examine characteristics or factors associated with a particular concept. Section 2.2.6.2 of this review will describe the characteristics associated with the concept and potential impact of DDH surgery and cast on family life.

The scoping review helped to identify shortcomings in existing research and methodological gaps among current studies. It guided methodological decisions regarding my research topic, the areas to explore, and the approach to take. In this study, the scope review frameworks proposed by Arskey and O'Malley (2005) were utilized to effectively identify and review the relevant literature. The main framework followed a five-stage process:

I. Research question

The first stage of a scoping review, as advocated by Arksey and O’Malley (2005) involves identifying a research question. This effectively serves as a compass, directing attention towards the essential elements or aspects of the question. The utilisation of the population, concept context (PCC) model assists in identifying key concepts within the research question, enabling the formulation of suitable search terms for exploring electronic databases. PCC helped define terminology and incorporate different ways of defining the population (parents), as well as the concepts of 'experience' and 'parenting', and the context should reflect the variety of different terms used for late DDH treatment. Identifying these aspects is crucial to ensure a focused and pertinent search aligned with the research question. Recognizing these elements is essential to guarantee a targeted and relevant exploration that aligns with the research inquiry. The review question comprises the following components:

- The population is the parents.
- The concept is the ‘Problems Experienced by Parents.’
- The context is ‘Developmental Dysplasia of the Hip surgery and spica cast.’

The literature review explores the following question:

What are parents' experiences and perceptions of parenting a child with a spica cast after late treatment of developmental dysplasia of the hip?

To delineate the scope, specific questions were formulated as follows:

1. What are the experiences of parents regarding late DDH treatment, and how does it impact caregivers' well-being?
2. What treatment burdens do parents face?

The term 'DDH treatment' encompasses both early and late treatment methods and also clarifies the specific types of treatment included in the study.

After formulating the review question, it is essential to carry out an initial scoping search to ascertain whether any studies have already been conducted on the same topic. Typically, researchers cannot proceed with a study if the review question has already been answered in previous research unless they identify a gap in the literature that requires attention (or if they wish to replicate a study to see if subsequent findings yield the same or different results). This step is crucial to ensure the originality of the research and avoid duplicating previous work.

II. The search

This review explored the perspectives and personal experiences of parents caring for children with spica casts after treatment for DDH. To ensure the relevance of the papers included in the review, specific inclusion criteria were established. While the study is contextualised to the British experience, the literature review included all research studies published on DDH and spica casts worldwide.

Databases	Cardiff University Healthcare database resources: Ovid platform (MEDLINE, Embase, PsycINFO), EBSCO platform (CINAHL) Scopus Online research theses (EThOS) Grey literature (the bibliographies of studies obtained through data search)

Table4: Databases

Additionally, the EThOS platform provided access to online research theses, specifically from PhD studies conducted in the UK. One dissertation closely related to my study aimed to investigate the experiences of parents caring for infants with developmental dysplasia of the hip (DDH). To avoid duplication any repeated papers were removed.

Furthermore, an unpublished relevant study was discovered in the grey literature by scrutinising the bibliographies of studies obtained through database searches, specifically focusing on systematic reviews and literature reviews that were highly pertinent to this research. This strategy serves as an additional check, potentially uncovering important published research that may have been missed in initial database searches. It also provides the opportunity to adjust and refine the search strategy to enhance the quality of results.

Due to the scarcity of research directly related to the topic under study, I faced a challenge during the review process. Broad search terms were used to cover all aspects of the topic, resulting in the avoidance of extensive filters and truncation. However, this approach enabled me to refine my inclusion and exclusion criteria and apply them to the reviewed papers. Commencing in 2018 (the first year of my PhD), an extensive literature review was undertaken that continued until 2022, with ongoing efforts to search for any relevant updates on the topic. Whilst this approach placed a considerable demand on my workload, it was necessary to minimise the risk of excluding any relevant papers from the review.

III. The search process

To enhance the search process, truncation and Boolean operators were employed (See table below). However, I also utilized the advanced database search feature to narrow down the search within specific criteria outlined in Tables 7 and 8.

Truncation	
(*) to the root or stem of a word	This approach enables the retrieval of different word endings, thereby broadening the search scope. It is available in all the databases.
($)	I avoided using the dollar sign as a truncation symbol in databases because it is not supported in all platforms.
double quotation marks " "	Used to ensure that keywords are searched in this way, especially when searching for DDH.

Table 5: The search process.

IV. Methods

Based on the research question and key concept definitions, an electronic database search strategy was developed. Yannascoli et al. (2013) note the importance of involving information specialists to determine appropriate keywords, thereby minimising the bias that could arise from overly restrictive terms. Recognising the value of their qualifications, I enlisted the assistance of librarians for this purpose. Several in-person meetings were held with a subject librarian at the Health Library where we collaborated to identify relevant resources for this topic.

To locate pertinent literature for this review, a computer-based search was conducted on relevant databases commonly used by healthcare professionals. These databases were selected for their wide coverage and popularity among researchers and healthcare professionals. As an additional advantage, these resources could be accessed both within the university library and through open access options provided by Cardiff University. The option to request additional resources from the library was also available.

The decision to utilise the MEDLINE database was motivated by its extensive coverage of medical and biomedical research across various domains. Moreover, the inclusion of PsycINFO was justified because it specifically concentrates on abstracts of literature within the field of psychology. This addition was deemed relevant due to the incorporation of life experience in the search criteria. Furthermore, in order to enhance the completeness of the research for different types of searches, the scope was expanded to include additional platforms such as Ovid (MEDLINE, Embase, PsycINFO), EBSCO (CINAHL), Scopus, and online research theses (EThOS). While the previous platform primarily focuses on medical research and is highly renowned for its quantitative experimental studies, the inclusion of these additional platforms enhances the depth of exploration and facilitates the examination of various research methodologies.

V. Search terms

Once the most appropriate databases had been identified, essential keywords and phrases relevant to the research question-based PCC model were generated. However, due to the limited research directly addressing the topic of interest, a challenge was encountered during the review process. As a result, my search terms were broadened to encompass all aspects of the subject, prompting modification of my search strategies and keywords to include all relevant information regarding the topic. Three online dictionary resources, namely Dictionary.com, Thesaurus.com, and Oxford Learner's Dictionaries, were deployed to explore synonyms. Additionally, MeSH (Medical Subject Headings) identified alternative search terms. For instance, when searching for "burden," nineteen research results arose. Alternative terms related to ‘caregiver burden’ were explored and eighteen entry terms found. Among these, three were selected: Care Burden, Caregiver Burdens, and Caregiver Burnout. Search terms and keywords detailed above were carefully selected to encompass a wide range of terminologies, ensuring a comprehensive approach to capturing relevant literature. The same specific terms were adopted across all databases to maintain consistency. The finalized search strategy encompassed the following keywords:

Key terms

All parent terms	Parent* OR Caregiver* OR Carer* OR Caretaker*OR Mother*OR Parent*OR Parent-Child OR Mother-Child
All experience related terms	Experience*OR “Parent Experience*” OR Perspective*OR View *OR opinion *OR family burden*OR lived experiences OR Care burden OR Care Giving Burden OR Caregiving Stress OR Care Burden OR Postoperative Home Care*OR Postoperative Home Care OR Problem Experienced by Parents* OR Caregiver burden*OR Care Burden.
All spica cast of DDH related terms	Spica cast after treatment of Developmental Dysplasia of the Hip OR Spica cast after treatment of Developmental Hip Dysplasia OR Spica cast after DDH OR Spica cast after treatment Dislocation of Hip OR Spica cast after Dislocation of Hip OR Hip Spica cast OR Surgical hip spica Cast .
Search strings	Parent* OR Caregiver* OR Carer* OR Caretaker*OR Mother*OR Parent*OR Parent-Child OR Mother-Child AND Experience*OR “Parent Experience*” OR Perspective*OR View *OR opinion *OR family burden*OR lived experiences OR Care burden OR Care Giving Burden OR Caregiving Stress OR Postoperative Home Care*OR Postoperative Home Care OR Problem Experienced by Parents*. AND Spica cast after treatment of Developmental Dysplasia of the Hip OR Spica cast after treatment of Developmental Hip Dysplasia OR Spica cast after DDH OR Spica cast after treatment Dislocation of Hip OR Spica cast after Dislocation of Hip OR Hip Spica cast OR Surgical hip spica Cast .

Table 6: Search keywords

VI. Identifying relevant studies

This stage defines the inclusion and exclusion criteria, selecting appropriate keywords or search terms, conducting the search, and then systematically identifying and selecting all relevant primary research studies to address the review question (Bwanga 2020).

a) Inclusion criteria

These criteria encompassed studies specifically focusing on late DDH treatment and young children. The rationale behind the inclusion criterion was rooted in the variations in DDH treatment and the associated implications for both children and adults. For instance, adults typically undergo hip preserving surgery or joint replacement surgery, which differs significantly from the surgical procedures performed on children. Conversely, early treatment interventions, which do not involve surgery, were excluded because they did not align with the focus of the review. While the study is set in the context of the British experience, the literature review included all research studies published on DDH and spica casts worldwide. It is important to acknowledge that older studies may refer to the condition as congenital dislocation of the hip because the term DDH was introduced in 1989. This distinction is relevant when reviewing literature that predates the introduction of the term DDH.

To ensure that only relevant literature was located and included the following criteria were applied:

Parents of children under the age of 7 years (pre-school age) as participants
Studies reporting parents or caregiver experiences of Postoperative Home Care
Published in English
Published 2000-2022
Full-text accessibility
Studies reporting parents or caregiver experiences of spica cast in late DDH treatment

Table 7: Inclusion criteria

b) Exclusion criteria

Studies not published in English and those lacking full-text accessibility were excluded. Papers were omitted if they did not pertain to late treatment or surgical intervention, as detailed in the "Treatment and intervention" section. Furthermore, papers focusing on the experiences of parents with children beyond school age were not included. This decision was based on the usual timing of surgery initiation around the walking age.

The exclusion rationale followed that, if studies involving older children were included, they would likely involve multiple surgeries and procedures requiring invasive surgical procedures(Ramani et al. 2014). Also excluded were studies that focused mainly on non-surgical procedures. While literature exists focusing on parents' experiences with these procedures (Lucchesi et al 2021) However, these interventions have been identified as being different in nature compared to surgical procedures and casts, particularly in terms of parental experiences and caregiver burden. During the search process, a meticulous evaluation of papers ascertained whether they delved into the subject of parent experiences and the treatment of DDH, with a specific emphasis on surgical intervention and the utilisation of spica casts. When data on spica cast procedures were difficult to separate from other interventions, papers with late DDH treatments were excluded.

Papers published in other languages
Duplication
Studies for which full text cannot be accessed
DDH treatment for adults
A paper that included only the accounts of health care professionals
Research papers where I could not separate data on surgical intervention from data on late DDH treatment
Papers that were about parent’s experiences of non-operative of late DDH treatment such as abduction splinting/bracing (Pavlik harness)
Articles about the use of a spica cast to treat fractures of the femur in children
Articles pertaining to spica cast for other conditions (such as thumb or shoulder spica, and adult hip) were excluded

Table 8: Exclusion criteria

VII. Study selection

The study selection process was devised by taking into account the particular research question and the researcher’s increasing understanding of the subject matter through extensive reading of various studies. Figure 1 displays the PRISMA flow diagram which outlines the search strategy process and is adapted from PRISMA 2020 providing a concise summary of the data. The flow diagram is an essential tool for summarizing the databases and other resources that have been searched, as well as elucidating the reasons for excluding certain papers during assessment.

A total of 402 papers were initially identified through the search terms present in the abstract or title across all databases. These papers underwent screening of titles and abstracts against predefined inclusion and exclusion criteria. Following the removal of duplicates, the pool narrowed to 180 papers. However, after closer examination, an additional 118 papers were excluded due to lack of relevance to the review. Subsequently, the full text of the remaining 62 papers was obtained, as they seemed to align best with the research question. Upon thorough review, the majority of these papers (32) were deemed ineligible for inclusion.

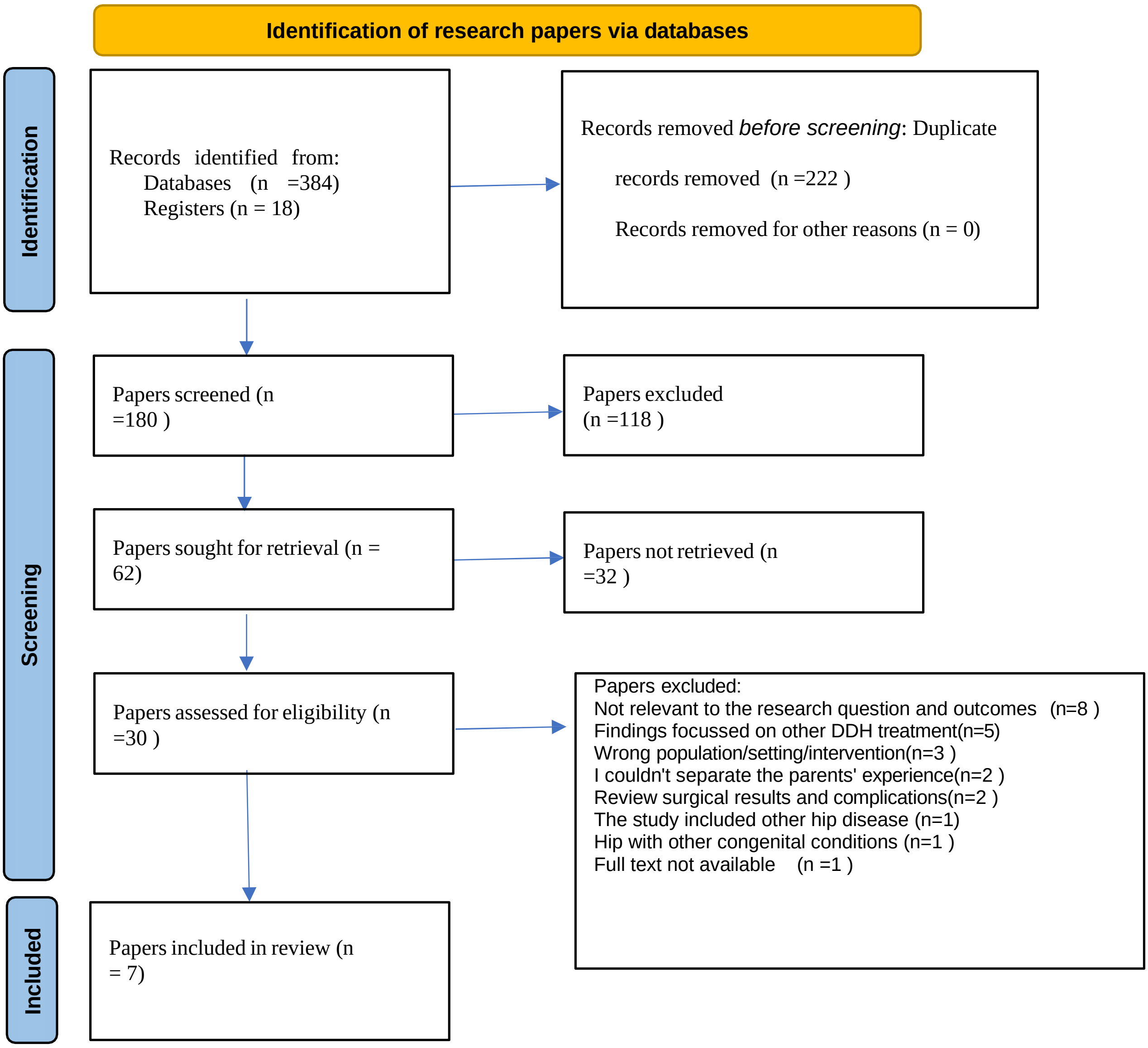


Figure 5: PRISMA Flow Diagram (PRISMA 2020)

IV. The 4 stages of a PRISMA flow diagram

The initial stage of discovery involved searching through the three selected databases platform, resulting in the identification of 384 papers. Filters were applied to two databases, given that Ovid served as the primary database. Specifically, in Scopus, the search was refined to concentrate on hip dysplasia, resulting in a decrease from the initial dataset of 149 entries to 76. Furthermore, for CINAHL, an age range encompassing was selected, leading to a reduction in search results from 1846 to 155.

After running the database searches I selected and adding the records I selected from other sources. I combined all the records returned from the searches into Mendeley.Each database has the following number of papers:

Databases	Number of papers
Ovid	153
CINAHL	155
Scopus	76

Table 9: number of papers taken from each database.

The subsequent stage involved the screening process, consisting of two steps: title and abstract screening follow by full-text screening. If a decision is taken to exclude a paper the reason for exclusion is documented. During the abstract screening step, 118 papers were excluded due to the following reasons:

Number of papers excluded	**Reasons for Exclusion**
49	specialized in examination and diagnosis
18	mentioned the disease either within the context of general orthopaedics or paediatric diseases, or in association with other diseases.
22	specialized in other types of interventions
9	articles focused on surgical outcomes intended for healthcare professionals
15	articles specialized in genetic study of the disease
5	unrelated articles.

Table 10: Screening stage of title and abstract

After that process, 62 papers were scanned by looking over a paper, line by line, hunting for keywords, abstracts, methods and findings. 32 were removed and 30 papers were retained.

Number of papers excluded	**Reasons for exclusion**
6	detecting and screening of DDH
3	Wrong population/setting/intervention
5	The article excluded because data limitations (2000-2022)
5	Articles focused on surgical outcomes intended for healthcare professional
3	Not relevant to the research question and outcomes
2	Full text not available
3	Guidance directed towards healthcare professionals or providers.
1	Commentary on another article
2	The focus of both studies was on the use of a coping strategy such as the Hip Spica or abduction pillow.

Table 11: Screening stage of full text

In final stage, I proceeded with the remaining articles after reviewing their titles and abstracts, and thoroughly reading their full texts. This was done to ascertain whether these articles would contribute to addressing my research question. After assessing all full-text articles, only seven were deemed suitable for inclusion in this review.

The limited number of papers raised concerns about the inclusion and exclusion criteria and search terms. Consequently, assistance was sought from the library during two separate sessions: one at the beginning of the doctoral phase and the other during the thesis writing process. Unfortunately, the number of papers remains low, reflecting the overall scarcity of research on this topic. This serves as a argument for conducting a scoping review. The main difference between scoping reviews and other reviews is that, in relation to the review question, a scoping review offers a broader 'scope' than traditional systematic reviews with correspondingly wider inclusion criteria. In addition, scoping reviews do not aim to produce a critically appraised and synthesized result/answer to a particular question, but rather aim to provide an overview or map of the evidence(Munn et al 2018).

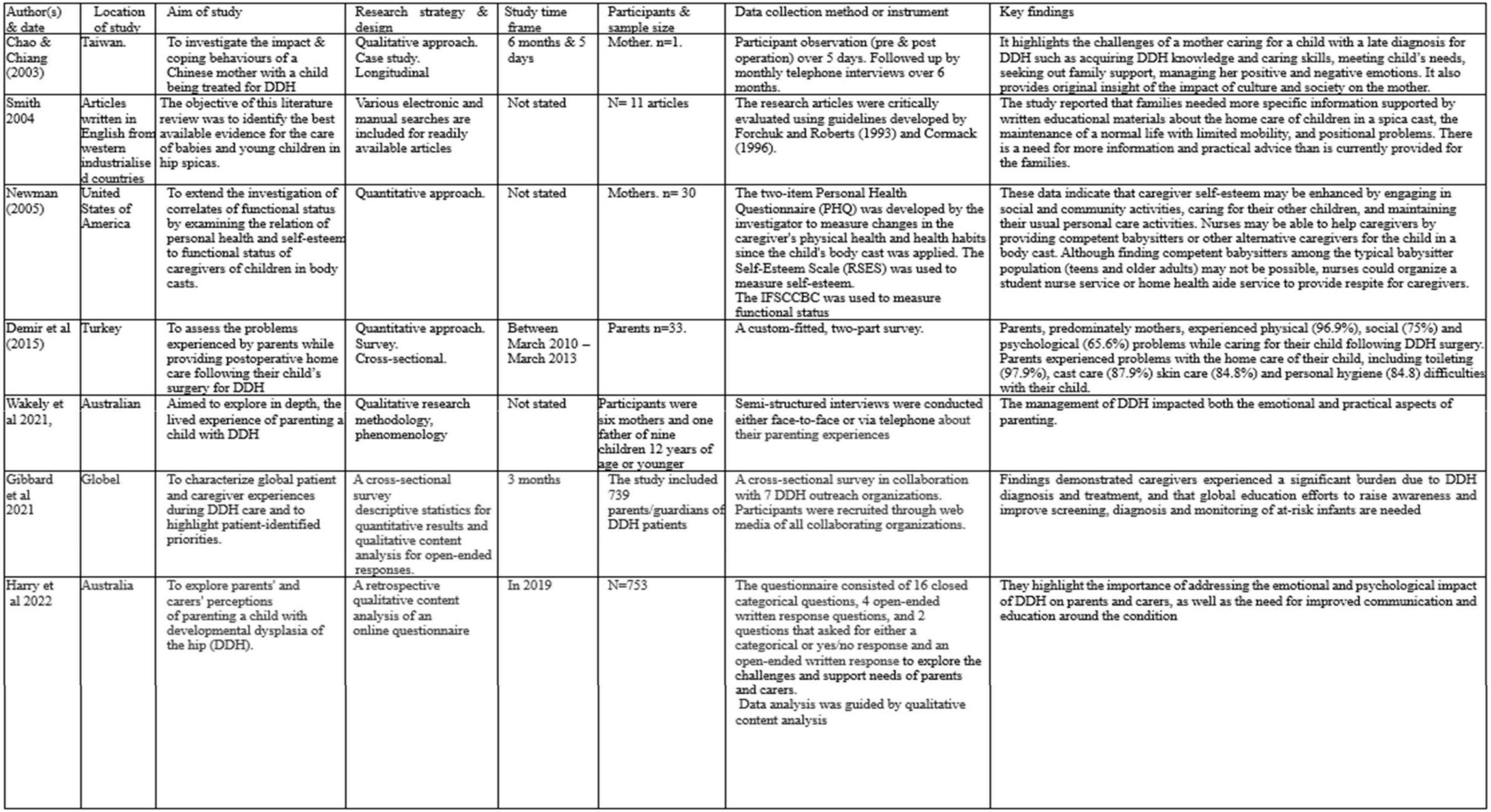
V. Charting the data

Scoping reviews diverge from systematic reviews by prioritizing the mapping and charting of key findings from the literature, rather than placing emphasis on appraisal and methodological rigour(Arskey and O'Malley, 2005; Khalil et al., 2016). Critical appraisal of evidence was not undertaken as it is not a requirement for scoping reviews as per the JBI framework(Peters et al., 2020).

Since scoping reviews do not aim to produce a critically appraised and synthesized answer to a specific question, focus is placed on offering an overview or ‘mapping’ of the available evidence (Arksey and O’Malley, 2005; Coad and Shaw, 2008; Levac et al., 2010). As a result, no formal quality appraisal was conducted as part of this review.

I have reviewed and extracted key data from the studies included in this scoping review. The data was documented in a table according to the guidance from Arksey and O’Malley (2005) to record general and specific information for each of the papers included in the review.A comprehensive review table was constructed encompassing key categories such as the citation details (the author and year of publication), study type, country of study, employed methods, research objective, key findings or important results. Summarising the studies in this manner played a crucial role in fostering familiarity with each individual study and uncovering pertinent themes (see Table 12 below).

The purpose of this scoping review was to examine existing research on the experiences of parents caring for a child with a spica cast after hip surgery. The review sought to identify any gaps in the current knowledge and explore the possibility of addressing these gaps through further enquiry. Further investigation in this area is crucial to gain a better understanding of the potential impact on caregivers and to inform appropriate support and interventions during this challenging period.



Author(s) & date	Location of study	Aim of study	Research strategy & design	Study time frame	Participants & sample size	Data collection method or instrument	Key findings
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.	It highlights the challenges of a mother caring for a child with a late diagnosis for DDH such as acquiring DDH knowledge and caring skills, meeting child's needs, seeking out family support, managing her positive and negative emotions. It also provides original insight of the impact of culture and society on the mother.
Smith 2004	Articles written in English from western industrialised countries	The objective of this literature review was to identify the best available evidence for the care of babies and young children in hip spicas.	Various electronic and manual searches are included for readily available articles	Not stated	N= 11 articles	The research articles were critically evaluated using guidelines developed by Forchuk and Roberts (1993) and Cormack (1996).	The study reported that families needed more specific information supported by written educational materials about the home care of children in a spica cast, the maintenance of a normal life with limited mobility, and positional problems. There is a need for more information and practical advice than is currently provided for the families.
Newman (2005)	United States of America	To extend the investigation of correlates of functional status by examining the relation of personal health and self-esteem to functional status of caregivers of children in body casts.	Quantitative approach.	Not stated	Mothers. n= 30	The two-item Personal Health Questionnaire (PHQ) was developed by the investigator to measure changes in the caregiver's physical health and health habits since the child's body cast was applied. The Self-Esteem Scale (RSES) was used to measure self-esteem. The IFSCCBC was used to measure functional status	These data indicate that caregiver self-esteem may be enhanced by engaging in social and community activities, caring for their other children, and maintaining their usual personal care activities. Nurses may be able to help caregivers by providing competent babysitters or other alternative caregivers for the child in a body cast. Although finding competent babysitters among the typical babysitter population (teens and older adults) may not be possible, nurses could organize a student nurse service or home health aide service to provide respite for caregivers.
Demir et al (2015)	Turkey	To assess the problems experienced by parents while providing postoperative home care following their child's surgery for DDH	Quantitative approach. Survey. Cross-sectional.	Between March 2010 – March 2013	Parents n=33.	A custom-fitted, two-part survey.	Parents, predominately mothers, experienced physical (96.9%), social (75%) and psychological (65.6%) problems while caring for their child following DDH surgery. 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.
Wakely et al 2021,	Australian	Aimed to explore in depth, the lived experience of parenting a child with DDH	Qualitative research methodology, phenomenology	Not stated	Participants were six mothers and one father of nine children 12 years of age or younger	Semi-structured interviews were conducted either face-to-face or via telephone about their parenting experiences	The management of DDH impacted both the emotional and practical aspects of parenting.
Gibbard et al 2021	Globel	To characterize global patient and caregiver experiences during DDH care and to highlight patient-identified priorities.	A cross-sectional survey descriptive statistics for quantitative results and qualitative content analysis for open-ended responses.	3 months	The study included 739 parents/guardians of DDH patients	A cross-sectional survey in collaboration with 7 DDH outreach organizations. Participants were recruited through web media of all collaborating organizations.	Findings demonstrated caregivers experienced a significant burden due to DDH diagnosis and treatment, and that global education efforts to raise awareness and improve screening, diagnosis and monitoring of at-risk infants are needed
Harry et al 2022	Australia	To explore parents' and carers' perceptions of parenting a child with developmental dysplasia of the hip (DDH).	A retrospective qualitative content analysis of an online questionnaire	In 2019	N=753	The questionnaire consisted of 16 closed categorical questions, 4 open-ended written response questions, and 2 questions that asked for either a categorical or yes/no response and an open-ended written response to explore the challenges and support needs of parents and carers. Data analysis was guided by qualitative content analysis	They highlight the importance of addressing the emotional and psychological impact of DDH on parents and carers, as well as the need for improved communication and education around the condition

Table 12: An Overview of included paper

VI. Collating, summarising and reporting findings

a)Study characteristics

Arksey and O’Malley (2005) propose utilizing a descriptive numerical summary to characterize the studies included in a scoping review. The studies in question were published between 2000 and 2022. Out of these seven articles focusing on late treatment of DDH, only three articles exclusively focused on the utilization of a spica cast without mentioning any other methods of late treatment.

The studies employed diverse methods for both data collection and analysis. Among the seven papers included in this scoping review, three reported findings from qualitative studies that delved into the complexities of parenting a child with Developmental Dysplasia of the Hip (DDH). Qualitative research, in contrast to quantitative approaches, aims to explore subjective experiences, opinions, and attitudes. It seeks to produce rich and detailed descriptions of the phenomenon under investigation, allowing for the discovery of new insights and meanings, contributing to a richer understanding of the subject matter. Wakely and colleagues utilized a phenomenological approach, conducting semi-structured interviews with six mothers and one father to delve into their firsthand experiences of parenting a child with DDH. Through this method, a range of challenges emerged, including information scarcity and variability in diagnosis and treatment practices. This underscored the essential role of healthcare professionals in providing support (Wakely et al., 2021). The other study applied different qualitative methodology by using surveys. Harry et al., (2022) conducting a local survey with a substantial cohort of participants to explore parent and carers' perceptions of parenting a child with developmental dysplasia of the hip (DDH). Chao and Chiang’s (2003) study investigates the impact and coping behaviours of a Chinese mother with a child being treated for DDH. It offered original insights into the influence of culture and society on the mother's experience.

Other studies adopted a quantitative approach. Newman (2005) employed validated tools to evaluate the alterations in daily routines encountered by parents tending to a child in a body cast. Regarding another study, led by Demir and colleagues, it assessed the problems experienced by parents providing postoperative home care to their child after DDH surgery, emphasizing practical difficulties and emotional aspects involved in caring for a child post-surgery (Demir et al., 2015). Only one study by Smith (2004) performed a literature review of the care of babies and young children in hip spica to explore the challenges families encounter upon discharge from the hospital, particularly focusing on those with a baby or young child in a hip spica. By synthesizing existing research, the review provided a comprehensive overview of critical themes in the literature concerning the care of babies and young children in hip spicas. It underscores the importance of evidence-based guidelines and training to ensure the provision of high-quality care. Additionally, the review emphasizes the diverse ways nurses can support parents with babies or young children in hip spicas to alleviate difficulties (Smith, 2004). Gibbard et al, (2021) uses a mixed method.

The scoping review discussed in this chapter has certain limitations due to the paucity of contemporary studies that specifically explore the experiences of parents who have a child in a cast. Notably, there is a dearth of research within the United Kingdom focusing on this particular aspect. In contrast, Newman (2005) conducted a study in America examining the correlation between personal health, self-esteem, and the functional status of caregivers of children in body casts. Additionally, studies exist in the Turkish context undertaken by Demir et al. (2015) and in the Australian context by Harry et al. (2022). It is noteworthy that all these studies were conducted outside the British context and utilized quantitative research methodologies, except for the Australian study(Harry et al., 2022).

Two studies, conducted by Gibard et al. (2021) and Harry et al. (2022), encompassed data from a broad spectrum of participants, providing valuable insights into the challenges and specific needs associated with DDH. With 739 and 753 participants, respectively, these surveys offer a profound understanding of DDH care. They comprehensively explore the emotional, physical, and practical dimensions involved in caring for a child with DDH, shedding light on the significant burdens faced by families. In contrast, Chao and Chiang (2003) conducted a case study involving one mother, which gathered longitudinal information at various stages of the child's treatment for DDH. This case report aimed to explore the impact and coping behaviours of a Chinese mother caring for a child undergoing DDH treatment. It outlined the challenges faced by the mother, including acquiring DDH knowledge and caregiving skills, meeting the child's needs, seeking family support, and managing both positive and negative emotions(Chao and Chiang, 2003).

In addition to the six-month case study of a Chinese mother, another longitudinal study conducted by Demir et al. (2015) collected data longitudinally through participant observation and follow-up telephone interviews. This data collection spanned six months, commencing from the child's hospitalization for surgery. This research delved into the emotional impact of the condition on the mother and investigated the coping mechanisms utilized to address the challenges associated with DDH (Demir et al., 2015). In general, longitudinal studies offer a robust method for understanding change, development, and causality over time, thereby providing valuable insights into the investigated topic.

A scoping review plus a thematic analysis of the papers was conducted to review the extent of current research findings and highlight what is known about the experiences of parents caring for children in a spica cast.

2.3 potential impact of a spica cast for late DDH treatment on family life

As a means of clarifying the scope of this review, a description, structured thematically is provided, based on the two-part review question. The studies reviewed here highlight common characteristics associated with the experiences of parents caring for a child with late DDH treatment, based on various studies. A hip spica is an integral part of the standard post-operative protocol in cases of DDH. Despite reducing the time spent in hospital and allowing early discharge, a hip spica transfers the post-intervention burden to the family. The various challenges posed by physical, emotional, family dynamics, relationships, stigma and financial aspects significantly affect the health and quality of life for both caregivers and patients(Chao and Chiang, 2003; Smith, 2004; Newman 2005; Demir et al., 2015). Consequently, it is unsurprising that caregivers' health and quality of life is adversely affected, due to the combination of these challenges during home care(Newman 2005; Demir et al., 2015).

According to previous studies, spica casts place a considerable burden on the functioning of the family using many valid tools(Smith, 2004; Newman 2005; Demir et al., 2015). The current literature on the biosocial life experiences of children in a hip spica and parents' experiences whilst providing postoperative home care is limited and dated(Smith, 2004; Newman 2005; Demir et al., 2015).

2.3.1 Impact on a caregiver’s well-being

Caregivers who care for children with late DDH treatment are often confronted with a complex interplay between physical, emotional, and psychological challenges that can impact their health and well-being. Furthermore, studies primarily focus on mothers and highlight a range of physical, social, and psychological issues.

The caregiver's burden encompasses the physical demands and challenges associated with caring for a child undergoing late treatment for DDH. This includes assisting with daily activities, limitations in mobility, and managing the demands of caregiving within the family. Having a child with DDH and being the primary caregiver for the period after a child's surgery can cause physical problems in parents over time. (Chao and Chiang, 2003 Newman 2005).

The bulky nature of the cast and the resultant restricted mobility pose significant challenges for parents. For children diagnosed late with DDH, parents face even greater handling difficulties due to the child's larger physical size and the nature of the treatment required to correct the dysplasia (treatment often results in an unwieldy child in a heavy cast with the leg positioned at an angle of abduction). Despite a lack of extensive literature on the subject, the physical strain of lifting and positioning the child poses persistent challenges for mothers, often leading to frequent back strain and backache (Newman 2005).

Currently, there is a lack of literature addressing the care of children from the perspective of parents during the postoperative period and its impact on caregivers' quality of life and psychosocial well-being. Newman (2005) conducted an exploratory qualitative study to assess the effect of caring for a child in a cast on caregiver performance. This study involved 30 mothers who participated in open-ended questionnaire (OEQ) interviews structured on the Roy Adaptation Model and the IFSCCBC. The majority of caregivers in Newman’s study observed a decline in their eating and dressing routines as they struggled to find time for themselves. They also reported experiencing insomnia, pain and difficulty managing housework. Moreover, many caregivers experienced adverse effects on their emotional well-being and self-esteem.

Additionally, increased childcare responsibilities for a child in a body cast correlate with decreased engagement in household, social, community, care of other children, personal care, and work activities (As such, their social and communal activities were limited) (Newman, 2005). Previous research indicates that mothers who are caring for their children tend to consume more coffee and cigarettes due to fatigue (Newman, 2005). Additionally, where the child sleeps in the same room as the parents this resulted in periodic awakenings during the night or early morning (Newman 2005). Mothers also reported changes in their sexual intimacy with their partners (Newman, 2005).

Many families encountered emotional and psychological challenges during the recovery period. This encompasses the emotional challenges and stress experienced by caregivers as they fulfill their caregiving responsibilities, the emotional toll of witnessing the child's struggles and difficulties in coping with the prolonged demands of caregiving(Chao and Chiang 2003; Demir et al. 2015). In Demir et al.'s (2015) study, it was observed that most of the parents experienced psychological issues, consistently felt unhappy and had doubts about their children's recovery. Chao and Chiang (2003) also highlighted that parents accepted the diagnosis of DDH but felt anxious and guilty during the treatment period.

Concern arose among mothers regarding the potential emotional impact of the cast on the child, with fears surrounding its effects on the child's growth and development, as highlighted by Smith (2004). Similarly, Gibbard et al. (2021) underscored the emotional strain experienced by parents, highlighting themes of stress, worry, and uncertainty regarding their child's future. Simultaneously, parents struggle with managing their child’s emotional responses and their own emotions. For instance, the limitations imposed on children's activities while their peers remain active can be distressing. A young child who is normally active may find it frightening and disconcerting to find themselves suddenly incarcerated in a body cast. Similarly, older children who have been independently mobile for an extended period before being in spica cast may find the transition to immobility much more difficult. Consequently, families, particularly mothers, may experience psychological issues such as anxiety, guilt, and depression(Chao and Chiang 2003; Smith, 2004; Newman 2005).

Caring for a child in the home environment significantly affects mothers' social lives(Demir et al. 2015). Newman (2005) detailed the experiences of some mothers who expressed difficulty with leaving the house, as witnessing other healthy children playing freely served as a stark reminder of their own child's limitations in a body cast. Similarly, a Turkish survey conducted by Demir et al. (2015) with 33 parents revealed that the challenges of caring for children with late DDH severely restricted mothers' social activities. Parental perspectives often explain this difficulty. For example, social and community activities are often limited because there is little understanding in many communities regarding chronic illness, there are limited facilities such as play areas, and public transportation is often inadequate and frequently inaccessible for wheelchair users. Furthermore, these mothers noted instances where their child in a body cast was sometimes overlooked or neglected by other children. Consequently, their social and communal activities were curtailed(Chao and Chiang 2003; Demir et al. 2015).

In addition to the risks and complications associated with casting, the difficulties for the child and the family all adversely affect familial dynamics. The mobility challenges linked to caring for a child with DDH affect mothers' ability to fulfil their occupational commitments and engage in social activities, ultimately resulting in their confinement to the home and feeling of social isolation(Demir et al. 2015). During this period, the employment status of mothers often undergoes changes when they are unable to work outside the home or have to leave their jobs to care for their children(Newman 2005). They may receive only limited assistance in caring for the children. Managing such a situation can involve taking sick leave, using holiday entitlement, or taking unpaid leave. Consequently, many caregivers quit their jobs and educational activities. They became reluctant to go out, often experiencing feelings of anger. The financial strain was also evident, with studies highlighting expenses such as nappy costs, loss of income due to unemployment, and the high costs of essential equipment, which can be both expensive and of short-term use(Newman 2005).

2.3.2 Burden of care

The postsurgical period for families with children in a hip spica cast presents a myriad of challenges which include routine washing of the child, pain management, preventing cast soilage from excretion, managing the child's increased weight in the cast, feeding, toileting, hygiene, dressings, sleeping, mobility, positioning, and transportation(Smith, 2004; Newman 2005; Demir et al., 2015). Additionally, they may encounter difficulties maintaining a normal life due to limited mobility and positional issues, necessitating significant adjustments in various aspects of their daily routines(Chao and Chiang, 2003; Smith, 2004; Newman 2005; Demir et al., 2015).The existing literature concerning parents of children who have undergone late treatment for DDH predominantly focuses on mobility challenges when their child is in a heavy ridge spica cast which can result in difficulties with washing, toileting, cast and skin care routines, and lifting their child(Demir et al. 2015). Follow-up care for the child was often delayed due to the absence of an appropriate car seat. The parents' inability to seat the child due to the abduction of the spica cast not only heightens the child's reliance on the parent but also presents hurdles concerning positioning, transportation, and facilitating movement, thereby potentially impacting caregivers' daily routines and quality of life (Chao and Chiang, 2003; Smith, 2004; Newman 2005; Demir et al., 2015). The analysis of the problem revealed that the majority of challenges arising from the situation were attributed to the child's diminished mobility and the unavailability of suitable equipment to provide seated support for the child(Wakely et al., 2021). This mobility and seating constraint not only increases the child's dependency on parents but also constrains parental activities(Chao and Chiang, 2003; Smith, 2004; Newman 2005; Demir et al., 2015; Gibbard et al., 2021; Wakely et al., 2021; Harry et al., 2022). Consequently, parents may encounter challenges in maintaining a normal lifestyle due to limited mobility and positional issues, that require significant adjustments across various aspects of their lives(Smith, 2004; Newman 2005; Demir et al., 2015) . Newman (2005) emphasizes that families with children in an immobilized hip spica face challenges in nearly every aspect of their lives, leading to social and emotional disruptions for the families(Chao and Chiang, 2003 ;Smith, 2004; Newman 2005; Demir et al., 2015; Gibbard et al., 2021; Wakely et al., 2021;Harry et al., 2022).

Parents overwhelmingly desire to take their children home because this is considered to be the best place for them. However, families often face challenges due to insufficient education and support in caring for a child in a spica cast, which can lead to a sense of pressure for an early discharge(Smith, 2004; Newman, 2005; Demir et al., 2015). Only a few studies have formally assessed the burden faced by families, highlighting the importance of understanding the significant impact of immediate hip spica casting and the need to discuss these matters with families during the initial treatment phase. Given that parents themselves are often uninformed about what lies ahead, it becomes crucial to provide them with clear and direct information to aid their child's adjustment. In dealing with the situation, mothers commonly seek information and knowledge about the condition(Chao and Chiang 2003; Demir et al. 2015). Smith's (2004) literature review of the care of babies and young children in spica casts identified some common themes, written and verbal information as well as practical, emotional, and social support requirements. Nurses should remain cognizant of the available support networks aimed at aiding families in managing the challenges associated with discharge. This awareness should be integrated into the development of discharge plans tailored to the specific needs of families.

Current research lacks studies on cast care quality and cast-related problems. Parents need instruction on home cast hygiene and novel discharge programmers for spica cast care(Smith, 2004; Newman 2005; Demir et al., 2015). In Smith's review of the literature, qualitative feedback from families also emphasized the need to improve teaching and family preparation for spica cast treatment to support the maintenance of a normal life with limited mobility, and positional problems (Smith, 2004).

Similarly, in the context of caring for a child, a case study employing a qualitative approach was conducted by Chao and Chiang (2003) with a similar objective to other quantitative studies exploring parental experiences of caring for a child with late DDH (Newman 2005; Demir et al., 2015). The study's findings revealed that the mother's negative psychological impact did not solely stem from the demands of the child's treatment. Instead, it offered valuable insight into the pressures and stress arising from cultural and social expectations.

Notably, some Chinese mothers believed that giving birth to an abnormal infant was a form of retribution for a past life. In certain sectors of Chinese culture, mothers face pressure to give birth to healthy infants, which consequently creates stress for them and affects their mental well-being(Chao and Chiang 2003). This, in turn, affects their ability to cope with the demands of DDH treatment for their child at home. The findings of this study underscore the importance of cultural sensitivity among healthcare professionals. Recognising and addressing the potential impact of social and cultural traditions on maternal mental well-being and coping abilities is crucial when dealing with DDH treatment for a child in their home environment. The findings of this study underscore the importance of cultural sensitivity among healthcare professionals.

The experiences of parents caring for children with DDH after delayed treatment have been the focus of a number of studies. At the same time, these studies offer insight into both practical and emotional burdens(Chao and Chiang, 2003; Demir et al., 2015). Treatment journeys for DDH patients vary globally; however, it is evident that DDH imposes significant burdens on patients and their families, resulting in significant disparities between their needs. Gibbard et al conducted a comprehensive global survey to explore the experiences of patients and caregivers throughout the DDH care continuum. The survey emphasized the substantial burden faced by caregivers throughout the diagnosis and treatment of DDH, emphasizing the lack of information and resources on treatment practicalities and the emotional burden of diagnosis as the greatest challenges reported(Gibbard et al., 2021).

A qualitative study conducted in the Netherlands explored the experiences of parents with children diagnosed with DDH, uncovering challenges such as insufficient information, treatment anxieties, and parenting difficulties. Consequently, healthcare professionals need to recognize these obstacles to offer effective support, which should include practical guidance and emotional assistance (Wakely et al. 2021).

Such information referred to above is obtained from various sources including health professionals, the internet and other parents whose children have undergone similar treatment. Despite receiving some information from health professionals, mothers frequently express their desire for more comprehensive and detailed insight(Chao and Chiang 2003; Demir et al. 2015).

Caregivers often rely on online information resources and support communities for emotional assistance, sharing experiences, and clarifying unanswered questions. These resources play a vital role in helping caregivers navigate the challenges associated with caring for children with DDH(Gibbard et al., 2021, Harry et al 2022) It also reveals insights into different dimensions of a caregiver's burden, including, navigation of health care systems, improved awareness, knowledge translation activities, and enhanced support networks to assist families in managing the complexities associated with caring for children with DDH effectively (Gibbard et al., 2021, Harry et al 2022).

The burden on caregivers extends to managing numerous surgeries and procedures, numerous health care visits, and the extended duration of care for children with DDH. The complexities of caring for a child with this condition highlight the critical need for support and resources for caregivers(Gibbard et al., 2021).

It is evident from the literature review that parents of children receiving late DDH treatment face many and complex challenges. It was interesting to note that many parents felt that long-term health benefits made this short-term burden worthwhile; however, there have been many challenges and struggles for many families during the recovery period.

2.3.3 Scoping review Summary

This scoping review was conducted in accordance with grounded theory principles as outlined in Table 3, as it sought to inform the study's design and identify the fundamental aspects of the research problem.

This scoping review highlights the lack of available research on parental experiences while caring for a child with a spica cast. The existing literature primarily focuses on late treatment among children with DDH, including the experiences of the burden of treatment placed on parents and the resulting impact on parent well-being. However, noticeable gap exists in the literature regarding parental experiences of looking after a child with late DDH treatment. Understanding the experiences of parents becomes crucial to ensure a successful outcome for the child and to provide appropriate care at home. Such insights can bring new understanding and meaningful experiences to light.

Conducting an in-depth qualitative study would significantly contribute to the generation of original knowledge. The psychological and physical impact on mothers caring for a child with an early diagnosis and treatment for DDH has been highlighted in existing quantitative studies (Corbett 1988; Gardner et al. 2005; Hassan 2009; Bergo and Rosendahl 2013; Jennings et al. 2017). Furthermore, literature on the late diagnosis and treatment of a child with DDH has indicated that some mothers face physical, social and psychological challenges while providing care (Chao and Chiang, 2003; Smith, 2004; Newman 2005; Demir et al., 2015; Gibbard et al., 2021; Wakely et al., 2021; Harry et al., 2022). However, despite these studies, there is still a significant absence of evidence surrounding the experiences of parents looking after a child with a spica cast. Therefore, several studies have recognised the need for in-depth qualitative research to address this omission. The results of such research may provide new guidelines and recommendations for health professionals to improve care and service delivery and better equip parents and carers to address the needs of children undergoing spica cast treatment and enhance their competence to cope with the many resulting demands (Smith, 2004; Newman 2005; Gardner et al. 2005; Rosendahl et al. 2010)

2.4 Chapter summary

This chapter has presented comprehensive background information through a literature review, shedding light on the nature of parenting a child with a spica cast. The key findings from this review have played a crucial role in identifying significant knowledge gaps which, in turn, guide the research design of the study.

CHAPTER THREE: PHILOSOPHICAL & THEORETICAL CONSIDERATIONS

Chapter overview

In this chapter, a brief overview of the philosophical and theoretical frameworks underpinning this research is described, along with a justification of the chosen research methodology and the specific methods employed to generate data for analysis.

3.1 The ontological self

This chapter delves into the philosophical and theoretical underpinnings that form the basis of this research. It explains the rationale for selecting grounded theory as the most suitable research methodology. A comprehensive exploration of the grounded theory method is provided, encompassing its origins, different versions, and the variances associated with each. This study employed the Charmazian constructivist grounded theory approach and this chapter provides a rationale for that choice and to demonstrate its suitability for the research. Additionally, the chapter introduces and examines the specific grounded theory methods used for data generation and analysis, in accordance with the research objectives. It also outlines the data collection methods and procedures, along with the data analysis techniques employed. Furthermore, a detailed description is provided regarding the ethical principles that were implemented throughout the study.

3.2 Philosophical alignment

Existing research in this area is scarce and, therefore, the participants' viewpoints will provide a rich source of information. An exploration of potential developmental delays and concerns regarding the impact on the child's growth and physical advancement will be particularly pertinent. With my philosophical stance as a researcher, I align with the social constructivist paradigm when approaching the research process.

I. Research paradigms

Understanding research paradigms assists in the evaluation of the study quality and the identification of knowledge gaps. According to Mertens (1998), Patton (2002) and Creswell (2013), research paradigms encompass philosophical assumptions that shape the researcher's perspective of the phenomenon in question and guide their actions. My own concepts, values and methods are uniquely influenced by my history, background, gender, class and race which, in turn, contribute to my individual understanding of reality and have an impact on my role as a researcher.

In this chapter, I analyse the philosophical foundations of four major constructs: ontology, epistemology, axiology and methodology. During the initial planning phase of this study, it was essential to delineate my personal and professional philosophical beliefs and positions concerning the nature and construction of knowledge. This was a crucial step in identifying a research paradigm that aligned with my philosophical orientation, as recommended by Mills et al. (2006). In addition, it is recommended that the theoretical and philosophical underpinnings of research be determined at an early stage (Denzin and Lincoln 2011) because these will define the entire research process and ensure that the findings can be more accurately interpreted by peers. The philosophical position substantiating the study of childhood experiences from the perspective of the parent will largely depend upon assumptions made by the researcher about the nature of reality, knowledge and values, known as the ‘philosophical trinity.’ I will investigate the influence of axiology, ontology and epistemology on my philosophical position when considering the experience of looking after a child in a spica cast from the parent's perspective.

II. Philosophical position

a) Ontology

Ontology has been defined as the philosophical study of existence or what is ‘real’ and the basic ontological position of any researcher can influence the development of the chosen research question and their approach to the design and execution of the study. Ontology encompasses both subjective and objective dimensions, representing two contrasting ends of a spectrum. It is valuable to perceive ‘reality’ as an experiential phenomenon, while simultaneously recognising that reality can extend beyond our personal experiences. This viewpoint encourages us to understand reality based on our subjective encounters, while also acknowledging the existence of a reality that transcends our individual perceptions. In other words, there is no single ‘truth’ because multiple views regarding a single phenomenon exist concurrently. This highlights the importance of understanding the behaviour and beliefs of individuals in the chosen study population.

In this study, the primary focus is on the objective reality of the condition itself (being in a spica cast). When a child is diagnosed with DDH and undergoes a surgical intervention, followed by the application of a spica cast to maintain the correct hip position, it results in a temporary period of immobilisation for the child. This reality is shared among parents who have gone through the same situation because they can relate to the challenges and circumstances associated with caring for a child in a spica cast after surgery.

Reality does not exist independently and must be considered in conjunction with experience. Accordingly, the ‘truth’ is subjective and cannot be considered absolute; rather, we should accept reality as experiential whilst acknowledging that it can exist outside our own experiences and understanding. Constructivism is a philosophical concept which asserts the idea that our perception and comprehension of reality are constructed through the lens of our experiences.

According to Von-Glassersfeld (1995), "knowledge is not passively received but built up by the cognising subject." The phenomenon of individuals perceiving, interpreting and explaining the same object differently is a fundamental aspect of constructivist theory.

Drawing upon my understanding and practical experience of treating patients with DDH, I acknowledge the undeniable objective reality of this condition. The existence of the disease (DDH) is an indisputable fact. However, what intrigues me, evokes empathy and is acknowledged by this research is the fact that parents can possess different perspectives on the same objective reality. Despite the objective nature of the condition, parents may interpret and experience it differently based on their unique circumstances and individual perspectives. This research embraces the notion that subjective variations can coexist within the framework of a shared objective reality.

My own ontological stance has been shaped by personal experiences when working in various healthcare provision services, including several childcare centres. Whilst I anticipated similarities in the experiences of children afflicted by the same disease, I quickly realised that each child and their family possessed a unique narrative that encompassed every aspect of their journey, from diagnosis and treatment to home care. These distinctions arose from several factors, including cultural diversity, individual nuances and geographical disparities. The healthcare system itself undeniably plays a crucial role, determined by the required level of care and the involvement of healthcare professionals. Consequently, it is crucial to recognise and appreciate the intricate and multifaceted nature of these experiences because they can vary significantly from one family to another, from one child to another, and even from one context to another.

a) Epistemology

Epistemology is defined as the philosophical study of the nature, scope and theory of knowledge. Epistemology seeks to discover and understand what knowledge is and how we attain it; essentially to answer the fundamental question: How do we know what we know?

This study seeks to explore the experiences of parents whose children have had surgery to correct DDH. To develop knowledge in this area, it is essential to understand the experiences of parents because there will be a variety of interpretations of objective reality. Each parent constructs their knowledge based on their subjective reality and experiences. Consequently, every parent possesses unique knowledge and understanding of the subject matter. These experiences provide valuable insights into their unique perspectives. By gathering subjective perceptions of the same reality, we can begin to form a more comprehensive understanding. To attain a comprehensive understanding, I actively engaged in contributing and constructing meaning through the utilisation of my own personal perspectives and experiences within the process. These lenses encompass both my professional viewpoint as a therapist and my personal experiences as a mother. According to Strauss & Corbin (1990), an awareness of the subtleties of the meaning of the data is a personal quality of the researcher.

DDH undeniably exists as an objective reality. However, I acknowledge that there can also be subjective perceptions of this reality. As a researcher, I bring multiple lenses through which I comprehend the experiences of parents. My active participation in this research involves interpreting the topic based on my own subjective reality and how it shapes my understanding of DDH. Additionally, my knowledge and understanding are influenced by reading relevant literature and forming my own philosophical position. By actively engaging in the research process, I aim to provide a valuable and unique perspective that contributes to the overall enrichment of the study.

It is crucial to acknowledge that there is one overarching reality but it can be perceived and understood from multiple perspectives. By embracing diverse viewpoints, a more comprehensive understanding of this shared reality can be achieved. These diverse perspectives also encompass different versions of knowledge, all shaped by the participants' experiences of the subject matter and their personal reality. The aim is to develop knowledge that is grounded in the experiences of the participants, rather than attempting to create a one-size-fits-all understanding. Parents acquire knowledge about DDH through various experiences, such as reading books, participating in online forums and employing different techniques in caring for their children with DDH. By actively engaging with these experiences, parents gain insight, broaden their understanding and acquire practical knowledge that enriches their comprehension of DDH. When multiple individuals participate in a study, they bring diverse perspectives and insights, resulting in a rich tapestry of knowledge.

I am actively engaged in the process of comprehending this existing reality by seeking to understand it through the lens and perspective of parents who have personally encountered DDH with their children. By empathetically adopting their viewpoints and seeing the world through their eyes, I am striving to gain an understanding of the challenges, emotions and insights associated with DDH. This approach enables me to acknowledge and appreciate the lived experiences of these parents as a vital means to grasp the true nature of this reality.

b) Axiology

Axiology is the study of values and beliefs and the role that they play when conducting research. In my role as a physiotherapist, I have participated in treating children with DDH. To deepen my understanding of this condition, I have devoted significant time to conducting a comprehensive literature review. This research endeavour has granted me valuable insights into the complexities of DDH and how it affects parents in different parts of the world. As a researcher and academic, I acknowledge that my personal values and perspectives influence the selection and interpretation of scientific data and cognitive analysis. However, I also value and respect the experiences and narratives of others; hence, there is a requirement to balance the need for authenticity when representing participants' experiences, whilst acknowledging that I cannot exclude myself from the research as a participant in the construction of meaning. I will naturally form an integral part of this research owing to the influence of my values and scientific background regarding childhood development and diseases.

Working as a paediatric physical therapist for many years has given me opportunities to learn about both the sequences of milestones that occur at specific times and the context of development. In my first work experience, I worked in an early intervention programme for infants and toddlers; the age group that to me represents the most critical years in any human's development. I learned to use the Hawaii Early Learning Profile Assessment (HELP) strands and evaluate the child in all aspects of life: gross motor, fine motor, cognitive, speech, social and self-care. Following that, I moved to the Disabled Children Organisation in Riyadh which consisted of two main arms: day-time schooling and housing. In this organisation, I was able to spend more time with children and their families. This resulted in a considerable change in my career, from paediatric physical therapist to one of the family members. In addition, my qualification in sport medicine has given me experience and knowledge of kinesiology and biomechanics in sport and general human movement. My values are naturally reflected in the selection of the study topic. For example, my decision to study child experiences from the parent's perspective may reflect a sense of my degree, background and knowledge of childhood. I will be able to interpret my data as a paediatric physical therapist. I will describe the perspectives of parents according to what I see as fundamental properties for child development and childcare.

In this research, my primary focus is on my role as a paediatric physiotherapist. However, I recognise the importance of considering the diverse aspects of being a mature woman who has gone through the experience of motherhood, including the associated practices and the unique dynamics of the mother-child relationship. Furthermore, it is essential to acknowledge the significance of my personal journey as a mother of a premature infant who was conceived through *in vitro* fertilisation (IVF) treatment and who required care beyond standard maternity care. This will unavoidably influence my research methods and interpretation of the results. Also, my religious and social background place a great deal of emphasis on raising and caring for children; in my culture, children and their parents are considered to be one unit because parents are the primary caregivers. Therefore, I am used to showing an equal amount of concern and sympathy for the parent as for the child.

To synthesise and integrate all of the elements discussed, I have employed constructive grounded theory as my study design. This methodology allows me to systematically analyse and interpret the data collected from parents' experiences, the literature review and my own professional insights. These practical experiences and the knowledge I gained shape, influence and colour my epistemological lens when it comes to understanding the topic. It is natural that my lens is likely to be coloured by my axiology. When another researcher utilises the data that I have collected, their epistemological approach to the topic may differ, leading to alternative interpretations and potentially different underlying theories. Each researcher incorporates their unique perspectives, biases and prior knowledge into the analysis and interpretation of the data. Consequently, their conclusions and theoretical frameworks may deviate from my own. This emphasises the subjectivity inherent in research and underscores the possibility of multiple valid interpretations arising from the same dataset.

To summarise, my philosophy is that incorporating the perspectives of lived experiences is vital because only individuals who have personally experienced something are able to grasp its complexities. Certainly, the reality is intricate and dynamic, influenced by the construction and interpretation of personal perceptions, beliefs and societal contexts.

3.3 Research approach

There are multiple approaches to conducting research, including quantitative and qualitative methods. Qualitative research offers the researcher an opportunity to uncover new patterns or themes that have not been predetermined. It acknowledges the participants as the foremost experts of their own experiences because they possess unique insights into the phenomena being studied. The aim of qualitative research is to comprehend the participants' perspectives in natural settings through in-depth exploration and analysis of the data.

The central role of parents in the ongoing care of children with complex needs highlights the importance of considering their views and experiences. Because there is no established theory for investigating child development during hip casting, a qualitative approach that focuses on theory construction was deemed most appropriate for my study. The qualitative research methods, known for their exploratory and descriptive nature, are particularly suitable for investigating parents' experiences related to child development. Nettleton (1995) emphasised that the experience of chronic illness is a complex phenomenon, influenced by the social, cultural and ideological context of the lives of those involved and not simply determined by physical symptoms or individual motivations. Therefore, a qualitative approach that allows for a comprehensive exploration of the context of the parents' experiences was necessary.

Aligned with this, the current study utilised qualitative methods to identify the effects as expressed by the participants, investigate these effects, categorise them based on potential common themes, and develop theories to explain the variations observed in these effects.

3.4 Overview of interpretive approaches

Research aims to capture reality and build knowledge. The process of capturing and defining reality is governed by the selected research paradigm. The research paradigm guides the researcher in philosophical assumptions about the framing of the researcher's view towards the research problem, and in the selection of the tools, instruments, participants and methods used to answer the research questions. There are two main research paradigms: positivist and interpretivist. The research paradigm defines the researcher's worldview in defining the nature of reality (*i.e.*, ontology), how to realise this reality (*i.e.*, epistemology) and the researcher's values (*i.e.*, axiology). The ontological stance can be defined as the single version of the truth and reality being global, as in positivism, or reality being ‘relative,’ different and conditioned based on the context, as in interpretivism. This research aims to understand the perceptions, emotions and feelings of the child and their family towards their development due to the hip spica cast. The reality here is assumed to be different based on the child's age, family background and other potential contextual factors which could influence the child's perception of their self and their parents’ perception of them.

Because the ontological stance assumed in this research is relativism, the reality needs to be captured based on the context (*i.e.*, the social construction of the reality). Unlike the positivist epistemological stance, the researcher uses theory and rationale to examine pre-determined hypotheses; in interpretive research, the researcher seeks to understand reality in the eyes of the case (*i.e.*, the patient and their parents). Schwandt (2000) confirmed that the world can only be known through peoples' experience of it and not independently from that experience. Individuals, in this research, defined as the patients and their parents, develop a meaning of the world in which they live and experience; hence, seeking the understanding people make from their world is the main goal of the interpretivist's worldview. Thus, this research embraces the social construction of reality as an epistemological stance to contribute to the knowledge of this field.

The researcher actively aims to understand the context and narratives of each case; thus, they will not be objective in understanding and documenting the reality. As the axiological stance of interpretivism, subjectivity is inevitable because the nature of the data is qualitative and the researcher is not using 'objective' methods to derive the truth. This is different from the positivists who are led by the deductive and reductionist approach in defining and examining the theory, guided by the literature and tested by 'objective' methods. There is no clear theory that explains 'why' different children can experience different impacts from the hip (spica) cast. Therefore, this research develops the theory using an inductive approach to define the different impacts, classify them, relate them to the context of each case, and theorise the relationships. Accordingly, this research adopts the interpretive approach which embraces the qualitative methodology, aiming to interpret and investigate reality using a holistic approach.

3.5 Research strategy

To fulfil the research aim in terms of understanding and investigating the experiences of casting (spica), there are three research approaches that can be adopted: phenomenology, ethnography and grounded theory. Each approach is uniquely suited for specific types of investigations and the selection of a research design is driven by the overarching objective of the study. The following sections define and evaluate each of these approaches to justify the researcher's selection of grounded theory for this research.

I. Ethnography

Ethnography is an interpretive qualitative research approach related to the social construction of reality that assists researchers in describing and interpreting a culture, as experienced by its members. Ethnographers study human behaviour in the context of a culture in order to understand their worldview as they recognise it, by the immersive monitoring of participants via observations and interviews. This allows the researcher to collect data pertaining to the meaning of the behaviour, language, activities and interactions among group members. In this respect, the researcher serves as the key instrument for both data collection and interpretation. Whilst ethnography offers salient benefits, there are issues associated with this method. Firstly, ethnography requires the researcher to reside within the target culture for a significant period of time to grasp the full experience which is highly unfeasible in this study due to my own cultural values and the challenges of being an international student which have implications for welfare. Secondly, the recent COVID-19 pandemic may impede the acceptance of a prolonged close relationship with the child due to health and safety concerns. Furthermore, ethnography demands that all cases be highly concentrated within a specific geographic area for follow-up purposes which will affect the number of available subjects. Indeed, spica casting is not common in the UK, with only a few cases noted across a wide geographical area. Due to these impracticalities, the use of ethnography was rejected.

II. Phenomenology

Phenomenology is defined as the study of a particular phenomenon from the viewpoint of those with lived experience, with a primary goal of describing the meaning of the individual's experiences rather than generating theories of the phenomenon being studied. Eliminating the pre-suppositions of the researcher allows for the focus to be on a concept or phenomenon, as opposed to the life of an individual, with the researcher extracting the essence of the experience from each individual for analysis. Usually, data collection is achieved via individual interviews which may be semi-structured or unstructured. Semi-structured interviews are frequently employed as a qualitative method in healthcare research, offering a valuable opportunity to delve into individuals' thoughts, emotions and beliefs regarding specific topics, often of a sensitive nature. However, there are weaknesses associated with this approach. The quality of the data obtained depends upon the articulation skills of the chosen participants and interviewing less articulate subjects may result in information being missed regarding their experiences. Additionally, phenomenology is less analytically equipped and, thus, less capable of generating theories to explain and predicted parents' experiences. Therefore, for this study, grounded theory was the preferred approach.

III. Grounded theory

Grounded theory is a method to understand, generate or discover a theory that relates to a particular situation. The grounded theory method is described by Glaser & Strauss (1967) as providing a theoretical explanation of social phenomena in qualitative research. Grounded theory is a type of qualitative research methodology that allows the theory to emerge from the data collected. It seeks to generate a general explanation (a theory) of behaviour, action or interaction shaped by the views of a large number of participants. The study begins by collecting data early, without any pre-existing theory, hypothesis or expectation of findings but rather allows a theory to emerge directly from the data. The main idea of grounded theory is that the researcher does not review literature that is directly related to the research problem and only needs to gain a broad understanding and outline of the research phenomenon. Theoretical sampling and a constant comparative method are distinct features of grounded theory.

3.6 Ontological/theoretical/methodological 'fit'

Knowledge gaps in the literature and the rationale for this study were previously identified, assisting in the study planning process. The predominant aim was to assess the parents' reality based on their experiences of looking after children with spica casts.

The aim of an interpretivist approach is to gain an understanding of the subjective experiences of the study population, including thoughts, feelings and naturally contextualised behaviours. Schwandt (2000) confirms that knowledge of the world can only be discovered by assessing the experiences of individuals and the main goal of the interpretivist is decoding their understanding. Whilst many studies have described the effect of hospitalisation and the impact of illness, immobilisation and movement restraints on young children (see Chapter Two), the experiences of the parent within the same situation are less well documented and likely to be quite different. It is therefore important to consider the multidimensional complexities of the parental experience. Differences in realities are expected according to the child's age, family background and other contextual factors which may influence the child's self-perception and the parent's perception of the child. The methodology chosen is relevant to the aims and questions of the research, gives a voice to the parents, and acknowledges my role and philosophical position as a researcher. As a paediatric physiotherapist, it was challenging to neutrally interpret the participants' reality and my interpretation of the parents' experiences was dependent upon my professional background. Furthermore, there are likely to be many possible theoretical interpretations from one dataset.

The role of parents and the establishment of their reality whilst looking after a child in a spica cast is central to this research. Because reality can be constructed and assimilated in many different ways, subjectivism has been selected as the ontological perspective for this study. This study of real-world experiences in a healthcare setting attempts to make sense of, or interpret, phenomena in terms of the meanings people bring to them.

The ultimate intention of this study is to explore how parents respond to the critical period during which their child is wearing a spica cast following corrective surgery for DDH. This may include factors such as accepting and adapting to the condition, the varying levels of support provided, access to resources and information, and the degree to which they are included in decision-making regarding their child's treatment.

3.7 Constructivist grounded theory

I. A short history of grounded theory

This section focuses on reviewing and exploring the study design of the grounded theory method in detail. It delves into the origin of the grounded theory method, its different versions and the associated differences between them. By examining the evolution and variations of grounded theory, this section aims to provide a comprehensive understanding of the method's development and the nuances within its different approaches.

a) Evolution of grounded theory

Grounded theory was first developed during the 1960s when two sociological researchers, Barney Glaser and Anselm Strauss, investigated the social processes of death and dying in hospital (Glaser & Strauss 1967). The grounded theory tradition, which originated from the seminal book "The Discovery of Grounded Theory" (Glaser & Strauss 1967), has evolved into four main types, with a fifth emerging. The original authors contributed to the first two types: Barney Glaser's "Classic Grounded Theory" (Glaser 1992) and Anselm Strauss and Juliet Corbin's "Basics of Qualitative Research" (Corbin & Strauss 2008). The third and fourth types are Kathy Charmaz's "Constructivist Grounded Theory" (Charmaz 2006) and Adele Clarke's postmodern "Situational Analysis" (Clarke 2005), both of whom were students of Anselm Strauss. The emerging fifth variant is "Dimensional Analysis" (Bowers & Schatzman 2009) which builds on the work of Leonard Schaztman, a colleague of Strauss and Glaser in the 1960s and 1970s. Although there are shared elements among all grounded theory approaches, each approach is distinguished by certain differences, such as the researcher's philosophical stance, the utilisation of literature and the methodologies employed for coding, analysis and theory development. Upon a comprehensive exploration of the three primary divisions in grounded theory approaches, the decision was made to employ constructivist grounded theory as the research methodology for this particular study.

Charmaz's (2006) constructivist grounded theory is an interpretivist methodology selected to provide a flexible and systemic style for collecting and analysing data in order to develop theories. The constructivist philosophical approach applies when the researcher and the participants co-construct meaning during data collection and analysis. Schwandt (1994) suggested that the goal of constructivists is to "understand the world of lived experience from the point of view of those who live it." Constructivists view data as constructed rather than discovered, and not as objective reports or the only viewpoint on the topic but rather as multiple realities that are determined according to the opinion of the person experiencing the situation. Charmaz believed that Glaser and Strauss (1967) and Strauss and Corbin (1990) argued that, from the realist perspective of the world, we accept the world as just existing and that there are no interpretations; thus, the theory emerges from data separate from the researcher. Charmaz (2006) emphasised constructing theory based on collected views and the reflections of the researcher's thinking. Therefore, the fundamental distinction between both the Glaserian and Straussian approaches and the constructivist grounded theory to grounded theory treats the researcher as a passive observer. In contrast, researchers who use the Charmaz approach make an interpretation of what they find shaped by their own experiences and background. Furthermore, an additional notable distinction lies in the incorporation of scholarly literature reviews and pre-existing academic works.

Approaches within the domain of grounded theory methodologies can diverge with regards to the processes of sampling and coding in qualitative data analysis. These aspects, namely coding and sampling, constitute ongoing and iterative procedures. For my research, I opted for a methodology involving three primary coding and sampling stages: initial coding, focused coding and theoretical coding. As described by Charmaz, the initial coding phase involves a preliminary analysis of the initial dataset, aiming to uncover prevalent ideas and concepts. This process of interpretation is steered by the research question. Subsequently, the focus shifts to theoretical coding, a stage characterised by structured data collection and analysis. Here, the existing literature is harnessed to corroborate, validate and enrich the interpretations and insights derived from the data.

b) Rationale for the selected approach

The process began with the recognition that a social constructionist approach could provide answers to the ‘why’ questions while preserving the complexity of social life, essentially an epistemological perspective. Embedded within this approach are facets of an anti-realist and relativist stance. Here, reality pertains not to the objective reality of the natural world but rather to the subjective interpretations of daily experiences. The constructivist approach also acknowledges that life experiences are not simply discovered but are socially constructed through the dynamic interaction between the researcher and participants during the research process. Theoretical understanding using grounded theory emerges from the connection between the researcher and the data, rather than being objectively derived from the data by an unbiased researcher. As a result, the researcher will actively seek to understand the context and narratives of each case; hence, their understanding and documentation of reality will not be objective. Initiating the study, the imperative was to sustain flexibility and remain open to examining various experiences. Aligned with the principles of grounded theory, as the analysis of the data progresses, the primary issues will surface and the researcher will develop a deeper understanding of the phenomena.

The overarching goal of grounded theory is to develop a theory for the phenomena under study that has no theory or where the existing theories are insufficient. The academic contributions emergent for the first two grounded theory approaches would be limited because they ignore the literature in the analysis process. Contrasting the results with the existing literature will help to crystallise and clarify the contributions made to our knowledge. Furthermore, literature reviews offer an opportunity for researchers to identify gaps in the research and help to set the stage for what the researcher will add. The literature review did not identify an established theory regarding how child development may be delayed or stopped during the cast period and, therefore, it is more appropriate to focus on theory construction. Following DDH surgery, children's activities are significantly restricted because they are required to remain in a hip spica cast for an extended period. Furthermore, certain studies have indicated that children in a cast may encounter motor, cognitive and social challenges. In the initial stages of the research, I conducted a literature review to establish the research aims, identify gaps in the existing body of knowledge and provide a rationale for the study. As a PhD student employing grounded theory, it can be challenging for doctoral students to refrain from conducting a literature review. This is because it is essential to present a strong argument supported by relevant literature to establish the need for research and meet the requirements of the local ethics research committees. Therefore, conducting a literature review is necessary before making any determinations.

Consequently, the decision to utilise a constructivist grounded theory methodology for this study was made based on two main factors. Firstly, the philosophical underpinnings of this method aligned with my personal beliefs about knowledge and its construction, as previously discussed. Moreover, this methodology provided an opportunity to incorporate the researcher's prior knowledge and understanding of the phenomenon under investigation. Secondly, the literature review revealed a lack of research regarding the effect of a hip spica cast on child development, making a qualitative approach suitable for exploring this topic. Given the limited knowledge on this subject, the researcher sought to contribute to the existing body of research by generating a substantive theoretical understanding of the phenomenon from the perspectives and words of the participants. Therefore, the use of a constructivist grounded theory methodology was deemed appropriate for this study because it enables the generation of a theoretical understanding of the phenomenon of ‘being in a spica cast.’

To maintain authenticity when representing the experiences of participants, outcomes were evaluated to determine credibility and validity. An initial review of the literature search provided guidance on effectively executing the research and a sampling strategy was used whereby the preliminary sample served as the raw material to provide a basic understanding of all aspects of the phenomenon. A comprehensive description of the collection and analysis methods further enhanced the validity of the research. I have continually sought to balance my philosophical position and the interpretation of the results by presenting all research activities to my supervisor and receiving feedback pertaining to my progress and the relevance of my research question. Overall, these strategies contribute to maintaining researcher objectivity and minimising the risk of poor validity, enabling a more predictable and generalisable truth to be uncovered. The role of the researcher is imperative in terms of positively influencing research via interactions with participants and data, and the researcher's experience in this process is invaluable.

3.8 Chapter summary

Constructivist grounded theory provides a framework to explore the parents' experiences of caring for a child in a spica cast and also recognises that these experiences are shaped by the individual context and that the researcher's beliefs and assumptions can influence their understanding of these experiences. Therefore, the researcher will approach this study with an open mind, acknowledging the subjective nature of the participants' experiences and embracing the potential for new insights and understanding to emerge from the data. By adopting this approach, I hope to establish a more meaningful and comprehensive understanding of the phenomenon and how it affects the lives of those involved.

CHAPTER FOUR: STUDY DESIGN

Chapter overview

This chapter offers a detailed overview of the research route map which underpins this study. This overview is designed to address the research question and establish the stated aim and objectives. The chapter outlines the methodology, to include the setting, participant sampling, data collection and analysis procedures. To align with the research objectives, the research strategy employed is grounded theory, with Facebook posts serving as the primary data source. The data collection and analysis follow Charmaz's(2006) approach.

4.1 Research stages

The application of grounded theory methodologies can vary in terms of the sampling and coding techniques employed during qualitative data analysis. Coding and sampling are continuous and iterative processes, as highlighted by Birks and Mills(2015). Here, a specific approach that incorporated three primary coding and sampling stages was adopted: initial coding, focused coding and theoretical coding. According to Charmaz(2014), initial coding is defined as preliminary analysis of the first set of data collected to identify common ideas and concepts, with the interpretative process guided by the research question. The second stage is focused on theoretical coding, during which the structured collection and analysis of the data occurs, and the reviewed literature is utilised to validate, verify and amplify interpretation and understanding. This allows theory to evolve with the data and its analysis.

The initial stage of this project involved analysing social media posts written by parents of children undergoing medical treatment with spica casts. This enabled the researcher to establish general codes. Whereas the second stage involved interviewing a selection of the participants to generate more focused theoretical codes. As social media posts are written for purposes not directly allied to the interests of a researcher, this provides insight into personal experiences and unfettered details about living with a child wearing a spica cast. It may be surmised that parents know more than a healthcare practitioner about their own child. Therefore, this form of data collection represents a valuable information source that has the potential to offer fresh insights into the phenomenon under investigation. It can draw attention to crucial detail which can inform data collection and serve to capture the perspectives of relevant stakeholders, thus, providing a comprehensive overview of the topic (Glaser 1998; Hopia et al. 2005).

4.2 Recruitment and sampling

The recruitment process in grounded theory evolves in two distinct stages, referred to as purposive sampling and theoretical sampling (Chenitz and Swanson 1986; Charmaz 2006b; Glaser and Strauss 2017) . Typically, the process initiates with purposive sampling to gather initial data and subsequently advances into theoretical sampling to expand the spectrum of perspectives on the particular issue under investigation. Data was generated through two methods: gathering comments posted by parents on a Facebook group and via semi-structured interviews.

I. Purposive sampling

During the first stage, purposive sampling was employed to select participants or data sources which help answer the research question and provide the initial data to elicit general views and gain an overview of the topic. Thus, the first phase sought a support group on the popular global social networking platform, Facebook. Online support communities are a unique source of information, advice and assistance for families. This page led to the identification of many of the main features of the investigation and provided the basis for the research.

The posts were collected as raw sources to comprehend the reality of parents who have a child undergoing treatment with a spica cast. The aim was to capture a wide and diverse array of information about the intricate and multifaceted aspects of child development in a spica cast. For instance, among the most intriguing initial codes were delayed milestones, physiotherapy services, pain, social life, psychological concerns and parental emotions. Depending on the emerging ideas and concepts from the posts, additional sources may be necessary to expand on the initial information and to fill any gaps that appeared during the data analysis. Additional data was needed to further develop categories and their relationships and inter-relationships (Strauss and Corbin 1998; Charmaz 2001).

II. Theoretical sampling

Drawing from significant ideas and concepts extracted from the posts, the requirement for additional sources to delve deeper into the information became evident. In this stage, there was a need to gather further data, known as theoretical sampling.

To fulfil this need, interviews were designed with parents, as the most relevant method to secure detailed sources of information. Parents, who are intimately familiar with the situation, are well suited to provide additional insight into categories that are important for theory building. This is especially relevant when considering elements such as the activities that underwent modification or ceased during the period of casting.

All instances of the interviews underwent coding using a data analysis process similar to the initial coding carried out in the first stage. Codes that appeared to be contradictory or required deeper exploration were categorised and highlighted for more thorough investigation during subsequent rounds of interviews.

Factors that could be deemed causal conditions for the core category were investigated. Following that, attention focused towards the constraints that influenced both the core category and its causal conditions. Subsequently, the context within which the core category operated was considered. Employing this approach allowed me to ascertain category properties, under what conditions it operated, and how and when it was associated with other categories.

III. Pre-search

One of the most important considerations in this study was to secure a sufficient number of participants. Due to the nature of the research project which focuses on a difficult to access sample (i.e. parents of children who have a spica cast), innovative and untraditional means to gain access to them were required. The traditional method would be to contact general practitioners (GPs) or hospital clinics to act as a gatekeeper and facilitate access. However, this is complicated and requires regulatory and organisational approval from the various parties which involves negotiating data protection law, confidentiality and ethical constraints. The convenience of accessing target families without the need to visit multiple clinics significantly reduces the researcher's time and effort (Garton et al. 1997). The researcher utilised social media groups that the parents of children undergoing treatment were posting on. In addition, social media provided access to the first-hand experiences of parents. Within these groups, parents were more easily able to identify the key features of the difficulties they were facing and thus provided a foundation for the research. Support groups offer an anonymous platform for individuals to exchange information and advice. These groups serve as inclusive spaces where diverse families interact and share ideas throughout the caregiving journey on dedicated support pages.

Facebook was chosen as the social media platform for this study due to its unique features which support the sharing of parents' experiences (Gaysynsky et al. 2015; Ahmed et al. 2017). Facebook provides a space where contributors can freely express their ideas via video, audio, and write an unlimited number of words, unlike some other social media platforms, such as, Twitter (Beer 2008; Kietzmann et al. 2011; Hunsinger and Senft 2013). Additionally, in the UK, Facebook ranks as the top platform for special interest groups, non-governmental organisations and voluntary groups (Prescott et al, 2020). Based on these premises, Facebook was selected as the main platform for the search. The parenting support Facebook group is a potentially useful tool to recruit hard to reach patients (Coulson et al. 2007; Plantin and Daneback 2018). By breaking geographical boundaries, this platform enables access to diverse perspectives, experiences, opinions and sources of information (Mendelson 2003). Moreover, the study aims to explore real-life issues and the Internet's anonymity and outreach helps to facilitate participant recruitment. Anonymity plays a critical role in establishing a safe and secure environment for parents to openly share sensitive experiences and engage in interactions without the fear of embarrassment (O'Connor and Madge 2000; Moreno et al. 2013).

IV. Identifying an appropriate support group

Facebook pages and groups were explored using the keywords: "Developmental Dysplasia of the Hip" and "DDH." Instagram and Twitter were excluded from the study due to the insufficient number of accounts or relevant data compared to Facebook. Additionally, Facebook stands out for its ability to provide a common forum for interest groups.

Facebook groups and pages involving public or private groups were included. Data points collected encompassed the number of members, followers, likes, comments or tweets, country of origin, access status, and year of platform creation. Based on this information, each search result was classified into one of five categories: medical institution, news, nonprofit organization, promotional information, or story sharing.

Three search terms were selected: “congenital hip dislocation,” “developmental dysplasia of the hip,” and “hip dysplasia in children.” The inclusion of both "dysplasia" and "dislocation" as search terms was motivated by research indicating that some people might struggle to differentiate between orthopaedic terminology and musculoskeletal anatomy(McCormack et al., 1997).

Although the search was limited to three terms, it is plausible that individuals and families may utilize alternative terms when seeking online information about DDH. Nonetheless, the study-maintained consistency with the terminology used by Fabricant et al. (2013) in their study exploring the quality, accuracy, and readability of diagnosis information available on the Internet regarding this diagnosis.

The selection process for discovering a suitable forum that targets parents of children with DDH was guided by three criterial similar to those used by Gambling and Long(2012) in their experiences of young women living with DDH. Criteria included accessibility to outsiders, a dedicated focus on DDH and active and popular social media sites.

In order to approach as many participants with DDH as possible, Facebook's search function was used, searching for the terms in the title of Facebook groups in March 2019. Afterwards, pages lacking content were excluded; blogs; promotional materials for healthcare services and products, as well as websites addressing general hip problems or aimed at adults with DDH. Numerous support groups were discovered in this manner, including 38 Hip Dysplasia Support Groups and Awareness Pages after eliminating duplicate results. Taking account of geographic locations, number of members, and numbers of posts, the largest groups on Facebook that were focused on DDH patients, their parents, and carers were identified. From the search result the group which contained the highest number of members was selected.

To examine group activity, it was observed over a two-week period. To evaluate the suitability of the data needed for this study, posts from the support group's archives spanning three months were read (Autumn 2018). Subsequently, all posts in the sample were reviewed and their presentation noted. Posts featured included sharing of DDH life experiences, specific feedback to information requested by other users, emotional support to group members as part of a community and advertisements for clothing and equipment.

V. DDH UK charitable trust and hip dysplasia support group

The DDH UK Facebook group was founded in 2015 which is the UK’s only DDH charitable trust. The organisation established by Natalie Trice now has around 2,483 members from all over the world(Available at: http:// www.ddh-uk.org [Accessed: 27/03/2019]). It provides a caring community to support and information for anyone on a hip dysplasia journey, though DDH UK does not provide medical advice. As part of my research, I obtained permission from the moderator to join the closed group and collect data.

VI. Facebook moderator

Accessing the data during both stages (posts or interviews) was initiated via the moderator. Contacting moderators is a necessary step where disclosed or non-disclosed approaches are used. It is necessary to check that the research does not breach any of their site’s terms and conditions. In addition, they may know the online community better than the researcher (Brady and Guerin 2010). Consequently, they can serve as a valuable initial resource for determining and gaining insight into the group norms. Permission must be sought from the moderator to download posts and to post an advert on the Facebook page on the researcher's behalf to request volunteers for online interviews(see Appendix 3).

On July 7, 2020, the moderator was contacted via email to obtain permission to collect data from a Facebook group page. Consent to access and collect parental posts from the platform was specifically sought. The moderator responded promptly to the email, approving this request. After obtaining consent, the data collection process commenced.

4.3 Study recruitment stage

Two main stages form the recruitment process. The first involves Facebook posts alongside comments and interviews with the parents of the children with spica casts. Focus is centred on parents of children who have had a surgical operation. Children under investigation are those who currently have a spica cast. This is to learn about their ongoing experiences.

I. First stage

The first stage involved collating ready-made information on the Facebook group. Relevant posts expressing ‘experiences’ were selected. The sampling process included analysing the posts until data saturation had been achieved and nothing new appeared in the comments.

‘Wall posts’ including comments, pictures or other media posted by group members on the central group webpage were categorised and analysed. Relevant posts were downloaded and stored on a password-protected computer to protect the data(see appendix 4; Anatomy of Facebook page). The posts were manually copied from Facebook and pasted into a Google Docs file.

A primary challenge was to determine the credibility of the posts to ensure they accurately represented the participants and were not misrepresentations. As the researcher lacked face-to-face contact with the participants, it necessitated careful consideration of the credibility of those chosen to participate in the study. When assessing the authenticity of Facebook postings and their relevance to the intended population, several factors needed to be considered. For instance, critically examining profile details such as photos, number of friends/connections, and activity history, as well as claims, and engagement levels, helped differentiate genuine postings from potentially inauthentic ones. In addition, the authenticity of the posts were verified by referring to the owner of the post and reading his/her posts or comments. Drawing on my own experience and maternal instincts and reflecting on my knowledge as a paediatric physical therapist, this helped to discern whether these parents' experiences and narratives were genuine.

The earlier literature review chapter corroborates the primary issues identified in this study, consistent with the discussions observed on Facebook pages. Additionally, the semi-structured interviews conducted during the second stage provided participants with the freedom to discuss their experience, ultimately revealing similar aspects and patterns of caregiver burden within this phenomenon. These facts contribute to the credibility of the findings outlined in the posts.

II. Second stage

An advert was posted by the site moderator on my behalf, asking for volunteers willing to participate in an online interview (see Appendix 5). Messages posted by the page owner are considered to be the most effective method of recruiting participants. Previous studies have shown that such messages are perceived as more credible by individuals when endorsed by trustworthy sources (Maddock et al. 2011; Miller and Bell 2012). An advertising flyer offered a brief summary of the study and requested suitable participants for interview.

4.4. Ethical issues

Ethical approval was obtained for both online and individual data collection from the Ethics Committee at Cardiff University on 21st January 2020 (see Appendix 2). Ethical considerations for each stage were as follows:

4.4.1 Post collection stage:

Posts were collected retrospectively from the Facebook page archive, which is consistent with only using secondary data and/or public information. Consequently, informed consent was waived for the collected data, adhering to the framework for ethical review of research employing secondary data, which included the following consideration. See the table13 below for further clarification.

a) What Constitutes a Public or Private Space in an Online Community?	To determine whether informed consent is required, the classification of postings on an internet community as "private" or "public" communications must be established. If access is not restricted, this means that anyone can participate in the communication without limitation, it can be defined as public communication. Where access to data requires registration, it is considered publicly available if it meets the criteria outlined in Cardiff University's policy on "Publicly Available" data. When initially assessing whether an online community should be classified as private or public, it is crucial to consider the accessibility of the community. "A member of the general public" is a hypothetical average individual without specialized knowledge or research skills. To confirm this condition, the researcher initially registered on the page using a personal account under a pseudonym indicating that she is a member of the public while searching for a suitable page for my research. The second time, she officially identified herself as a doctoral student at Cardiff University interested in the DDH condition. Each time the membership was accepted, which indicated that the requirement to be public, as outlined in Cardiff University guidelines, had been met. It is reasonable to expect publicly visible posts. Despite the registration prerequisite within a DDH support group, these groups were considered a public domain. Access to the posts begins via contact with the moderator to obtain permission, therefore, it is unnecessary to seek permission from each member of the support page before collecting the material. Here, informed consent can be waived as the AoIR ethical guidelines, consider public forums as public domains(Stommel and Rijk 2021;Salwén2021).
b) Is the quality of data obtained online sufficient for research purposes?	Obtaining quality data is fundamental to producing reliable research. Disclosure poses a risk of compromising the validity and reliability of the data as the "natural" research environment may be altered by disclosure, potentially reducing the value of the knowledge obtained. Parents can be afraid to disclose their experiences or may modify their behaviour and opinion if they are aware of being under scrutiny, possibly to avoid blame or judgement of others if they do not provide optimal care to their children.
c) Are there potential risks of harm to the participants?	Where research holds significant scientific value and poses minimal risks of harm, such practical constraints as referred to above may present compelling arguments. This perspective aligns with the Council for International Organizations of Medical Sciences (CIOMS) guidelines in collaboration with the World Health Organization, particularly in highly public settings where there is potential for direct benefit to participants(Sugiura et al., 2016; Rebers et al., 2016; Manti and Licari, 2018). This viewpoint is consistent with section 4.8.2 of Cardiff University's policy on the ethical conduct of research involving human participants, which addresses the legal position within its guiding principles when using social media data or similar internet-based data.
d) How difficult is it to obtain informed consent?	Obtaining informed consent from all members of online forums who participated in an archived discussion session may be impractical, if not impossible, because some members may leave while their contributions remain visible(Dal-Ré, 2023). Even when participants or former participants are contactable, some may be hesitant to disclose information about their offline identity(Roberts, 2015). This is consistent with Item 4 of the Guiding Principles outlined in Cardiff University's policy on the ethical conduct of research involving participants, specifically focusing on exceptions to obtaining informed consent as discussed in Article 4.4.9 regarding human material or human data.
e) How can participants' anonymity be protected?	Compliance with the General Data Protection Principles set forth in the General Data Protection Regulation has been ensured, as indicated in the legal position. This has been accomplished through the implementation of various strategies to prevent quotes from being traced (Salmons, 2015). To enhance the protection of participants' identities, quotations have been anonymized, and only the month in which the data was collected is indicated (figure 9). Brief segments of the original posts were quoted to decrease their traceability through search engines, ensuring they were not searchable. These quotes were then verified using search engines to ensure they were untraceable, consistent with recommendations from several studies (Malik and Coulson, 2013; Sugiura et al., 2016; Granger et al., 2021) (See appendices 4,9).
f) Data storage	All data collected during this research is treated as confidential in accordance with the Data Protection Act and the Cardiff University Research Integrity and Governance Code of Practice.
g) Institutional authority	A decision to waive informed consent is subject to strict regulation and ethical considerations, and subject to approval by Cardiff University’s ethical committee.

Table 13 framework for ethical review of research employing secondary data

4.4.2 Interview stage

Participants received a Participant Information Sheet which included information about the study, the researcher's name and contact details along with further information on whether or not to participate. It clarified that participants had the right to withdraw from the study at any time. If a participant became upset or decided to stop the discussion, the interview would be immediately terminated and the collated data destroyed. All interview participants signed a consent form aligned with Cardiff University policy.

Personal information was not requested. Zoom Cloud was used to record interviews and the data stored on a private password-protected computer. Each interview was transcribed by the researcher in a private workplace. Transcription included all the recorded information excluding any data that may identify participants. Real names were replaced with codes, known only to the researcher. All recordings and transcripts derived from the recordings plus any notes made during and after the interview were locked in a personal office cabinet at Cardiff University.

As with any ethically conducted study, participation in this research was entirely voluntary, the participants could withdraw at any point, and confidentiality was ensured.

4.4.3 Anonymity, safety and confidentiality

The research data was handled confidentially, adhering to the Data Protection Act and the Cardiff University Research Integrity and Governance Code of Practice. The ethical safeguards are reiterated and summarised below:

1. The data was securely stored on a computer with password protection at Cardiff University.
2. All information (oral or written) arising from the study was anonymized. No personal information was retained in any of the posts, transcripts or recordings, and I meticulously ensured the exclusion of potentially identifying details pertaining to locations, procedures, or healthcare providers in both the final thesis and any archived data. Furthermore, no requests for personal information were made in the course of this study.
3. Transcripts, posts and recordings were identified by codes known only to me. Additionally, any potentially identifying information was carefully removed to ensure confidentiality and privacy.

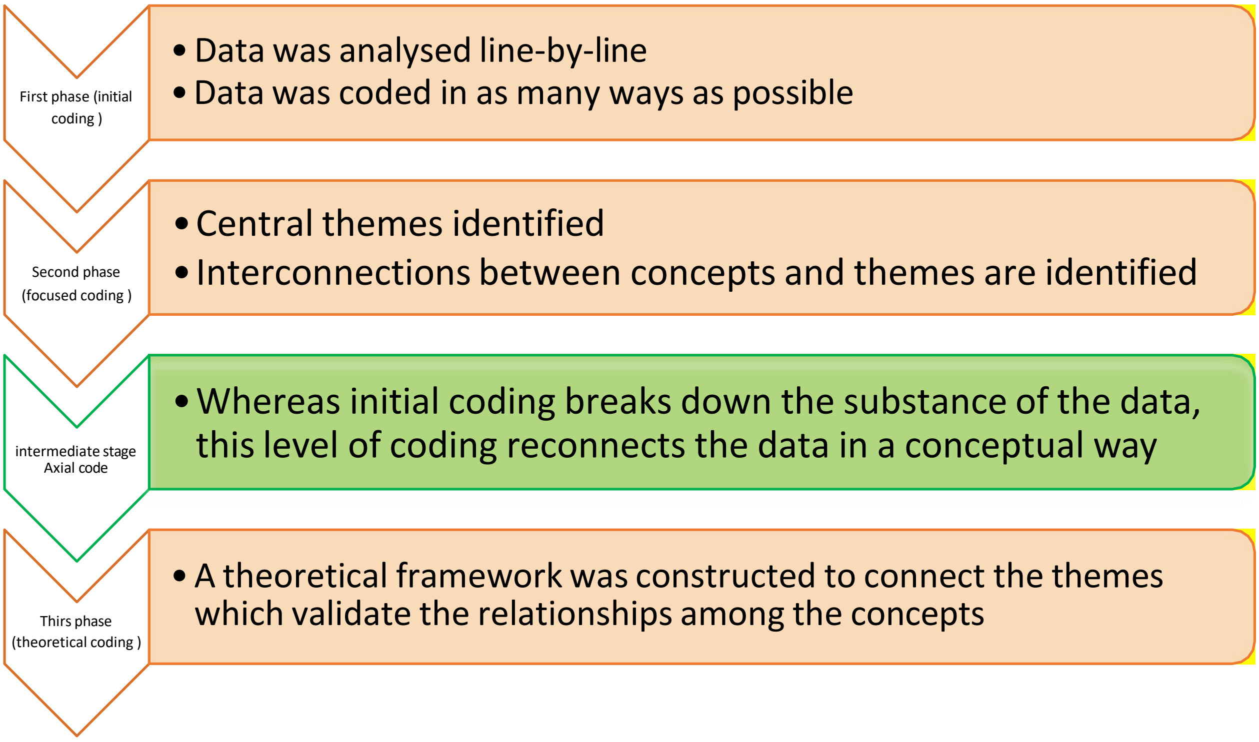
4. All recordings video or audio will be kept on password-protected computer at Cardiff University, and any potential identifying information was removed from the audio-video records.
5. In compliance with Cardiff University's requirements:

a) Paper copies were stored in a secure location (locked filing cabinet) within the School of Healthcare Sciences. In line with university policy, the data was retained for a maximum of five years before being securely destroyed.

b) Electronic data was stored on a password-protected computer at Cardiff University. Data is retained for five years after the project completion, or for at least two years after publication.

4.5 Data analysis

According to Charmaz (2006, p.46), coding is "the pivotal link between collecting data and developing an emergent theory to explain these data." A variety of code types can be effectively applied to the data, spanning descriptive codes that capture the meanings of individual phrases to interpretive codes that represent common experiences and abstract processes (Charmaz 2006; Kelle 2007; Glaser and Strauss 2014). This section reviews the stages of data analysis: initial coding, focused coding, axial coding and theoretical coding (see figure 6).



- Data was analysed line-by-line
- Data was coded in as many ways as possible

- Central themes identified
- Interconnections between concepts and themes are identified

- Whereas initial coding breaks down the substance of the data, this level of coding reconnects the data in a conceptual way

- A theoretical framework was constructed to connect the themes which validate the relationships among the concepts

Figure 6: Summary of data analysis stages

I. First stage: Facebook posts

A study applying grounded theory begins with a general summary of the subject area. The researcher starts with a “general subject or problem conceived only in terms of a general disciplinary perspective” (Dey, 1999, p.3). Here, the group focused on support and information, provided by members sharing their experiences about various aspects of DDH, including children requiring casting following surgery. The content of social media posts may play an important role in the comprehension and contextual analysis of the issues under investigation and can draw attention to the fundamental features of a spica cast experience for both children and their parents. Text-based analysis may be used by researchers because interpersonal communication is a key feature of many aspects of social behaviour (Chichirez and Purcărea 2018) .

Communication through written language on Internet posts allowed extraction and analysis of language and social behaviour, aligned with the findings of the study conducted by Pennebaker et al. (2003). Document analysis in internet-mediated research (IMR) includes unobtrusive data-mining techniques for gathering linguistic data in ways that are difficult to achieve offline; therefore, online posts enable researchers to pursue information retrieval retroactively, which would otherwise be arduous to access (Bordia 1996; Herring 2000). Analysing social media posts can provide insights into the patterns of behaviour, emotions, thoughts and social relationships expressed by individuals facing diverse health conditions.

Studies conducted by van Uden-Kraan et al. (2009), Brady and Guerin(2010) and Gruebner et al. (2022), provide evidence that online support groups serve as valuable resources for individuals seeking reassurance and support from peers. Here, discussion board posts from the archives of online support groups covering a three-month period were accessed. Because the use of logs of past discussions does not allow any scope for researcher intervention, a disclosed, non-participant approach was adopted in the qualitative study of parental experiences of caring for a child requiring a spica cast.

Text posts were downloaded and stored securely (as mentioned earlier). Multi-media posts were viewed online and notes were made for future reference(see appendix 4). Extracting meaning from the data commenced with a close inspection of each post. Four main categories were identified:

a) General questions about the child, their situation or behaviour (for example, some parents asked about making the cast more comfortable to wear).
b) Use of a term that captures an important meaning (for example, one parent described a behaviour's scientific term: trichotillomania).
c) A short phrase that reflected a particular point of view and experience (for example, one mother expressed how her daughter was struggling with DDH and felt it was stealing her childhood).
d) Implicit and explicit statements expressing frustration about the absence of information regarding the child's development or the services available to them (for example, physical therapy services).

These posts were classified as a source of raw data providing a comprehensive overview of the topic. This imparted a broad understanding of the realities of caring for a child with a spica cast, as well as eliciting a diverse range of information regarding the multifaceted nature of child development in DDH.

At this stage, I was eager to gain a basic understanding of the reality of parents' experiences of having a child in a cast. The principles of grounded theory were applied because the theory generates from the data (Glaser and Strauss 1967; Glaser 1992; Glaser and Strauss 2014; Glaser and Strauss 2017). Owing to the objective of this study, it was vital to carefully observe what the parents were saying in their posts regarding their experiences. This facilitated interpretation of the data to encourage the actual connotations of the participants' experiences to emerge without preconceptions. Volunteer participants were recruited from the Facebook page for interviews to ensure that all parents had an equal opportunity to voice their views and experiences. The primary criterion for inclusion in the study was having a child in a spica cast. Potential participants were invited to respond to an advertisement via email or the private message function on the site. Following their response, they received an information sheet and consent form(see Appendix 6 and 7).

II. Data analysis process

The comprehensive data analysis procedure utilised in this research is extensively described in a previously published study by Morrow(2005). Performing immersive manual data analysis was necessary to become familiarised with the subject area, including 'what' the data is and 'how' it interrelates. Furthermore, the integration of thinking and creativity into the analytical process cannot be achieved via a computer. Therefore, a non-automated analysis was most suitable here.

III. Coding methods

The analytic strategies adopted in conjunction with open coding strengthened the data which became more relevant by incorporating line-by-line coding and in vivo coding.

a) Line-by-line coding

As the name of this technique implies, it involves the coding of every line but it does not necessarily mean that every line is coded whether this makes analytical sense or not. Instead, it ensures a thorough analysis of every word and sentence (Charmaz 2006). This is a valuable tool for generating ideas and formulating questions about the data (Strauss and Corbin 1990). During the initial coding stage, researchers inductively deduce as many ideas as possible from the early data, facilitating the exploration of various insights and themes.

b) In vivo coding

Code labels or names should focus on the meaning rather than the word itself. In vivo coding refers to the utilisation of words or short phrases from the participant's own language in the data record as codes (Saldana 2013). Examining stories or ideas through the direct words of the participants can be advantageous because it enables a deeper understanding of the subject matter. This approach is acknowledged for its ability to offer a sense of nuanced meaning that other forms of coding might not allow (Saldaña 2016).

c) Constant comparative

In grounded theory, constant comparative analysis is an analytical procedure used for coding and category development. It is used throughout the coding process to identify similarities and differences by comparing codes, incidents, and categories to themselves and other data sources, resulting in the generation of a theory (Glaser and Strauss 1967; Charmaz 2006; Bryant and Charmaz 2007).

d) Memo-writing

Memo-writing is an important part of grounded theory because it helps to organise and note down thoughts and insights with regards to the data. The memos are used for multiple purposes, including recording the meaning of codes, making comparisons between data and codes, in addition to finding similarities and differences, and raising questions to be answered in future analyses (Charmaz 2006a; Corbin and Strauss 2008; Engward 2013; Glaser and Strauss 2014) (see appendix 15).

4.6 Coding

The preliminary step in grounded theory analysis after attaining the archived posts is coding. The purpose of this stage is to separate the data into a more meaningful configuration, deriving particulars and developing concepts for each word, sentence or segment to help create the basic descriptive codes. This is the first phase towards distilling meaning from the data which it begins with line-by-line coding, to start to understand what the data is describing (Charmaz 2014).

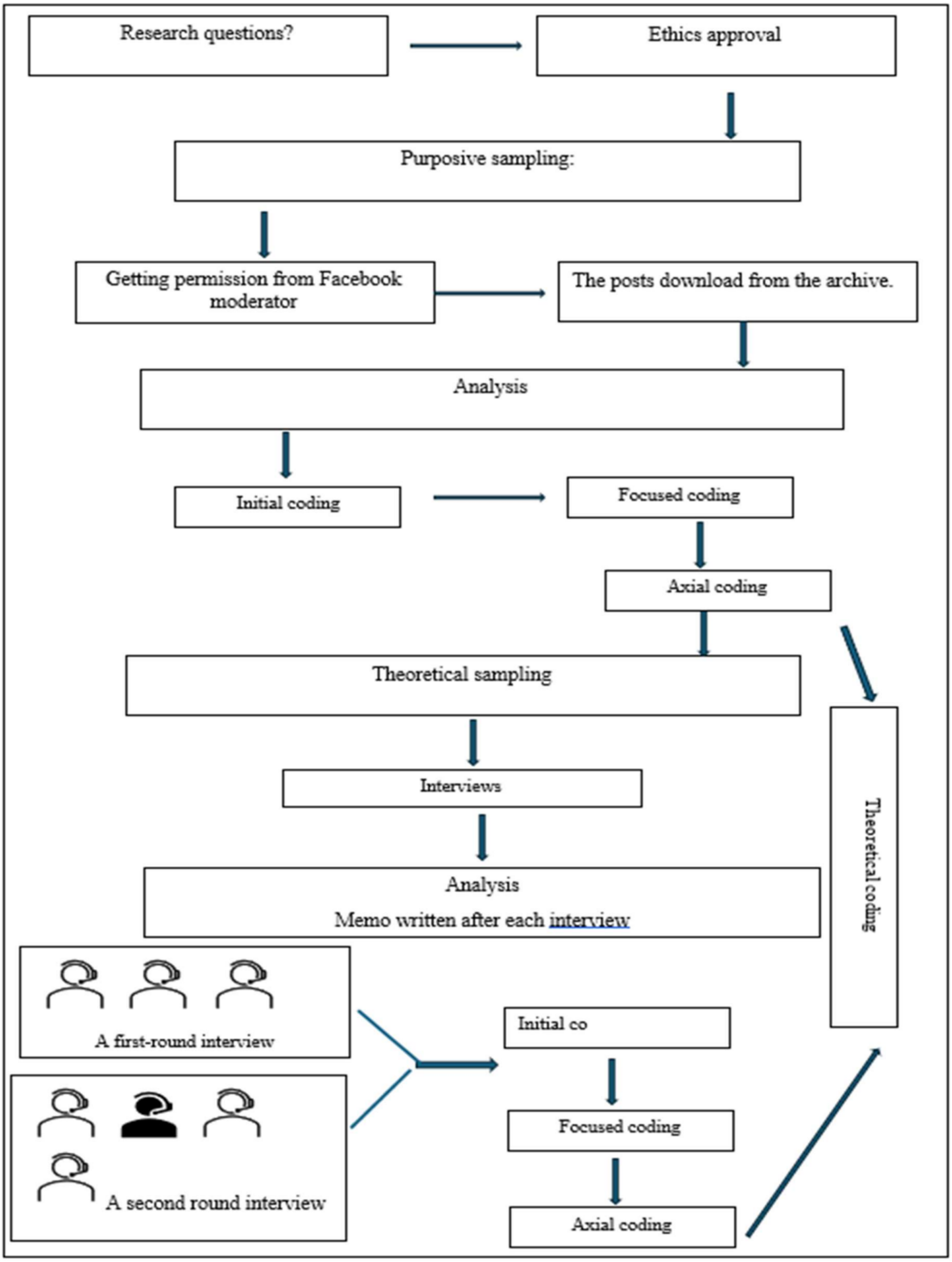


Figure 7: Research Stages

I. Stage one

a) Coding phase I: Initial coding

The primary objective of the initial coding involves thoroughly reading each word, sentence and paragraph and applying open coding techniques to identify actions and incidents. These identified elements are then assigned descriptive phrases that accurately capture the essence of the data. During the process of initial or open coding, similarities and differences are carefully examined and organised into relevant categories, following the principles outlined by Glaser(2001). Open coding allows information from several sources to be extracted from the data and labelled for simplified interpretation (Busetto et al. 2020). This confers possible comprehension of the complexity of the words and to decipher their relevance.

In-depth coding does not mean that every line is tagged with a code if it has no analytical utility. Rather, it ensures a thorough analysis of the available documents to allow the generation of as many ideas as possible from the raw data. Labels should be chosen on the basis that they capture the substance of the data, and, importantly, should focus on the meaning rather than the word itself. In vivo coding, as a qualitative data analysis method, emphasises the significance of using participants' own spoken words (Manning 2017). This approach is also known as verbatim, literal or natural coding Saldaña (2016).

After re-reading the posts, the first cycle of coding in the pilot study explored the six main recurring actions or patterns that appeared to display special meaning within the study: patient information, motor development, social problems, psychological problems, child activities and parents' feelings. It is possible that each post contains one or more of these elements. Different colours were used to highlight and code the data in Microsoft Word with inserted comments for each code(see Appendix 9), describing the content to provide a general explanation for each assigned label (see pilot study appendix 8). This coding is often summarised using a table. The collection and analysis of the data continued in the same way until a saturation point was reached whereby no new information emerged during coding, thereby indicating that an adequate sample size had been achieved. Following this, a constant comparative analysis was applied.

Constant comparative analysis serves as a crucial analytical process within grounded theory for developing categories during coding. It is a continuous method applied throughout the coding process to identify similarities and differences, enabling comparisons between codes, incidents and categories, both internally and using external sources of data. By facilitating theory generation, this approach, as highlighted by Glaser and Strauss (1967), Charmaz (2006), and Bryant and Charmaz (2007), extends the initial coding phase to yield theoretical categories. These conclude when theoretical saturation occurs and the data transforms at the conceptual level, at which point the emergent grounded theory is fully formed.

The insertion of analytic phrases described what was occurring in the data. Although preconceived ideas about the impact of restrictions on children's development arose, as I coded, an open mind was kept regarding the material to not apply pre-existing ideas to coding. Moreover, in vivo coding was applied to keep the codes as close to the data as possible, using the participants' own language to ensure that the analysis was performed from their point of view and not from mine.

Grounded theory as an approach allows the researcher to reflect on the data; who is not passive; and participates in the analysis process, which reflects their experience. In addition, I worked with the participants to construct meaning through the ability to interpret and understand the full meaning of the participants' words. Due to my background as a paediatric physiotherapist, the code 'delayed milestone' was used as an initial code rather than the parents' words (Charmaz 2006; Saldana 2013). 'Delayed milestone' is a medical term used to describe a child's delayed motor development. It became a code for any phrase that parents used to describe their child's movement. This code is my own interpretation, while this comprehensive and clear term encompasses everything that parents say or describe about their child's movement with a cast. I did this to make the code more visible to find out more about this aspect of development in the later stage of analyses.

Fundamental obstacles to normal development were identified during the immobilisation period when I tried to explain all of the hidden assumptions; for instance, when they talked about physical therapy as a service that is provided in some hospitals and not in others. From my professional experience, I know that it is an important protocol at this stage to learn the child's movement and position. It may be an important aspect to generate the theory for this study. These codes have been named based on my knowledge and experience. According to Strauss and Corbin(1990), an awareness of the subtleties of the meaning of data is a personal quality of the researcher. Only those terms that fit the description of the data were used.

In total,132 wall post comments were captured and 247 codes generated. The study sample included 147 initial codes. Each initial code was compared to another using constant comparative methods which is an analytical process used in grounded theory for coding and category development. It was employed in this first phase of data analysis to identify similarities and differences and compare codes (Glaser and Strauss 1967; Charmaz 2006; Bryant and Charmaz 2007).

The constant comparative analysis helped refine, collect and establish connections between ideas. When the initial codes were reviewed, some of the codes were named similarly, some of them were close, and others different. This analytic strategy allowed the main insights that emerged from the data during the comparisons to be retained. After coding the posts, the codes linked to the study's aims were addressed, those that detracted from the original aims of the study were ignored.

Considering relationships between the initial codes helps to discover similarities and patterns in the data. The codes were aligned according to common features where relationships display multiple aspects of child development. Codes were assigned to tables by their features, such as, pain management, delays in motor development, physiotherapy role, social aspect, parent's perspective and psychological aspects, for easy sorting and storage (see appendix 9). Each code was defined by its descriptive characteristics and the conditions under which the aspect emerged. For example, there was a similarity between the delayed motor development aspect and the parent's perspective, although classification depended on whether the code describes the child's movement or relates to a parent's question or opinion on the movement. Strong focus codes were then established. Focused coding synthesises and explains larger segments of data to determine patterns, underlying relationships or issues related to underlying themes. Here, focused coding was implemented in two ways. Firstly, following a review repeated initial codes were identified, and grouped under other codes or combined to form comprehensive codes, to develop distinct individual categories (Cummings and Borycki 2011). Secondly, researchers made decisions regarding which initial codes were related or particularly meaningful to the participants. Some codes were irrelevant or inadequate in providing information useful for addressing the thesis questions and were discarded by the end of the focused coding phase. The clusters of codes that emerged during this focused coding process were referred to as categories, as described by Corbin and Strauss(2008).

b) Coding phase II: Focused coding

Following axial coding, the subsequent phase is focused coding which applies the most important and/or frequently occurring initial codes to efficiently analyse extensive datasets. This requires "decisions about which initial codes make the most analytic sense to categorise your data" (Charmaz, 2014, p.138). The utilisation of focused coding combines and explicates substantial portions of data under primary objectives of identifying patterns, relationships or issues relevant to the core themes (Charmaz 2006) Thus, the second stage is influenced by assessing which initial codes are considered particularly meaningful for participants. Some codes are classified as irrelevant or fail to provide useful information to answer the research questions and are discarded at the conclusion of the focused coding phase (Charmaz 2006).

Initial codes perceived as more interesting to this study included delayed milestones, physiotherapy services, pain, social life, psychological issues and parental feelings. These aspects formed the basis of the focused coding. Traits such as unusual, aggressive or altered behaviours were listed as focus codes. Questions raised by these codes were answered via interviews. Focused coding was conducted in two stages. Firstly, comparative analysis reviewed and identified the repeated initial codes to create sub-groups and combine groups into comprehensive codes. Inserted analytical phrases described what was occurring in the data. This ensured that the strongest and most analytical codes appeared (Cummings and Borycki 2011).

While holding preconceived ideas about the impact of children's postoperative home care on the caregivers, an open mind was retained whilst reading. In vivo coding ensured that the labels represented the data as closely as possible, using the participants' own words to ensure that I was conducting the analysis from their point of view rather than mine (Charmaz 2006; Saldana 2013). Decisions regarding which initial codes were meaningful for participants were taken by grouping codes with similar features and characteristics. Those deemed less relevant were jettisoned.

Identifying and considering relationships between the initial codes finds patterns in the data. The relationship between these codes represented the multi-faceted nature of child development. Code groups were sorted into tables by shared features such as pain management, developmental delays, the role of physiotherapy, social aspects, parents' perspectives and psychological aspects for ease of storage and retrieval(see appendix 9). Each code was defined using a descriptive characteristic and the associated conditions. For example, whilst similarities existed between delayed motor development and the parent's perspective, this was further classified depending on whether the child's scope of movement was explicitly stated or whether this related to a parental question or opinion about the movement. Following this, some strong focus codes were established. Thirty-nine groups of codes emerged during this period of focused coding(see Figure10).

The final group of codes derived from the focused coding process are termed categories (Strauss and Corbin 1990) (see appendix 9). To organise thought and insight, memos chronicled the data. This aids recording the meaning of codes, making comparisons between data and codes, identifying similarities and differences, and posing questions to be answered during the ongoing analysis process (Strauss and Corbin 1998; Charmaz 2006; Engward 2013; Glaser 2014). The main categories which emerge from focused coding are identified as 'core' phenomenon (Kendall 1999; Charmaz 2006). Elements as causal conditions of the core category were considered with focus placed on the limitations for both the core category and the causal conditions. The context within which the core category operated included the type of action and interaction to take place to achieve the core category, where and when these occurred, and what strategies were required.

c) Axial coding

Axial coding has previously been defined as "a set of procedures whereby data are reassembled in new ways after open coding, by making connections between categories" (Strauss and Corbin, 1990, p. 96). The primary objective of axial coding is to efficiently sort, synthesise and arrange vast amounts of data, leading to a more precise and comprehensive understanding of a specific phenomenon (Creswell 2013), to clarify and extend the analytical power of the emerging ideas (Charmaz 2014). While analysing the data, tools developed specifically for grounded theory analysis were applied to capture the dynamics of this experience for the parents.

d) Coding phase III: Theoretical coding

Theoretical coding represents the final stage of data organisation, to examine the previously generated data and determine the inter-relationships of the hypotheses for integration into a theory (Glaser 1992; Glaser 1998; Charmaz 2006; Saldana 2013). This involves the construction of a theoretical framework connecting the final categories and depicts the relationships between concepts by reviewing the literature and identifying theories to explain the data and answer central research questions (Strauss and Corbin 1990; Charmaz 2014).

Grounded theory as an approach encourages the researcher to reflect on the data, analytically engage and use personal experience rather than assuming a passive role in the study. Here, meaning was constructed through the interpretation and understanding of the participants' words when possible. Within some circumstances medical terminology described a wide range of clinical features. For example, the code ‘delayed milestone’ was applied as an initial code rather than the parents' exact words; as a medical term which describes delayed motor development in paediatric physiotherapy. It coded any phrase that parents used to describe their child's movement. Whilst this code derived from my own interpretation, it was necessary to use an encompassing and clear term recording aspects of development. This helped to describe everything that parents said about movement in children wearing spica casts. This also helped aspects of visualisation during development in the later analytical stages. In another example, I identified the fundamental obstacles to normal development during the immobilisation period and attempted to explain the hidden assumptions, such as when parents spoke about physical therapy being available as a service in some hospitals but not others.

My knowledge and experience also contributed to the naming of codes. As a paediatric physiotherapist, with awareness that learning about the child's movement and position is an important protocol at this stage and may be crucial for generating theory in this study. According to Strauss and Corbin(1990), awareness of the subtleties of data expression constitutes a personal quality of the researcher. The complexity of the research process increased during this phase owing to the more intensive engagement with analytical tools and the emanation of additional questions as the analysis progressed (Strauss and Corbin 1998; Walker and Myrick 2006; Rieger 2019). The intermediate phase stage of analysis, involved axial coding, associated with evolved grounded theory and involves interconnecting the pre-defined categories (Chun Tie et al. 2019) .

II. Second stage

a. Internet mediated research

With rapid technological advance, the routine use of networking platforms has integrated the internet into the lives of people worldwide. IMR methods have significantly expanded in recent years due to the scale and diversity of information available from target populations around the world (Grandcolas et al. 2003; Hessler et al. 2003). To maximise connectivity with as many parents whose DDH children wear spica casts as possible, IMR methods proved a highly effective means of connecting with others and obtaining relevant information. This approach can facilitate access to complicated or sensitive data that is difficult to obtain via traditional sources, including, the radio, press or television. This is partly driven by less stringent rules surrounding anonymity which may encourage honesty and remove inhibition to disclose personal experiences (Bordia 1996; Jones 1998; Hewson 2017; Davies et al. 2020). In virtual communities, participants frequently exhibit a notable lack of inhibition when expressing themselves, leading to the rapid development of burgeoning dialogue (Murray and Sixsmith 1998). Harder to reach individuals who display restricted mobility or social isolation are also able to participate. The advantages in terms of timesaving, reduced costs and access to a much larger population further increased the attractiveness of using IMR in this study.

b. Online interviews

In the research context an interview is a directed conversation where the researcher explores a particular topic or experience in-depth, relying on a respondent who may have relevant experience in this area (Charmaz 2006). A planned interview was conducted as a theoretical sampling procedure to provide insight into the emerging categories with participants by asking more focused questions than in the first stage. Numerous justifications exist for the suitability and significance of online interviews as a methodological tool (*e.g.*, interviewing individuals who are often difficult to reach, such as those with restricted mobility or who are socially isolated). Obvious benefits are cost-effectiveness and time efficiency because individuals with computer and internet access can participate without the need for additional equipment.

Furthermore, online interviews have emerged as appropriate and valuable methodological tools for research studies, offering numerous benefits. Their prevalence increased significantly during the COVID-19 pandemic due to the need to adhere to social distancing, stay-at-home rules, lockdowns and travel restrictions (Sah et al. 2020). Contemporarily, remote interviews offer a significant advantage in terms of convenience and practicality, allowing parents to be with their sick or special-needs children and take care of their own needs. This technology enables parents to stay within the comfort of their homes, ensuring their child's safety. Interviews conducted over video conferencing platforms allow conversations to be recorded directly onto the PC for future reference where prior consent is obtained. The synchronous nature of online interviews means that the interviewer and interviewee are online at the same time, thereby allowing the researcher to ask questions that elicit active engagement and responses from the interviewee in real time. Charmaz(2006), explains how this stage brings fractured data to cohere with the initial codes to build more conceptual ideas.

The interviews in this study were semi-structured to facilitate a better understanding of the participants' perspectives and experiences, whilst standardising the interview format and improving data reliability (Isaksen et al. 2013). This approach can be considered the most effective method for identifying the primary concerns or perspectives of the participants (DeJonckheere and Vaughn 2019). The research questions are established at the outset but evolve and adapt with the study's progression (Mertens 2009). This is appropriate for an investigation with a poorly understood topic and extracts the most important aspects of the phenomenon.

Here, the research topic is relatively broad, covering multiple aspects of caregivers experience. Focus was not placed on any particular domains of experience. The aim was to focus the conversation on the activities that a child changed or discontinued during the casting, and examine how parents coped with immobilisation. Subsequent interviews followed the framework and guidelines recommended in an interview guide, which details a list of topics or questions to be covered in the interview, to ensure that the basic lines of inquiry remain consistent throughout each interview while still allowing respondents to speak freely(see appendix10), (Robson 2006; Turner 2010).

c. Theoretical sampling

Theoretical sampling begins when the researcher has been immersed in experiential data, in addition to understanding which theoretical knowledge requires further explanation. When the codes were raised to analytic categories some categories were found to be incomplete or lacked sufficient evidence (Glaser and Strauss 1967; Chenitz and Swanson 1986; Charmaz 2006). To fill these gaps, another sample is collected to make emergent categories more precise, explanatory and predictive (Glaser and Strauss 1967; Strauss and Corbin 1998; Charmaz 2001). Through theoretical sampling, it is possible to determine the properties of a category, under what conditions it is operative, and how and when it is associated with other categories. Participants will be invited to participate in the study according to their knowledge about the topic under research and the type of information that is required to complete or complement the researcher's developing understanding at this stage (Morse 2007).

d. Sample size

One of the features of a grounded theory method is that the sample size is unknown prior to the study. When embarking on a grounded theory study, it is impossible to determine in advance the precise number of interviews that will be necessary. Data will be collected until it reaches a saturation point at which no new information emerges during coding and data analysis, thereby indicating that adequate data has been collected (Strauss and Corbin 1990; Glaser 1992; Strauss and Corbin 1998; Charmaz 2006). The data is deemed to be sufficient when a new round of data collection does not produce new statements or provide additional insight and where topics begin to repeat. At that point, a decision must be made to end the data collection process (Corbin and Strauss 1990; Clarke and Braun 2013). Furthermore, in a grounded theory methodology, the size of the sample is determined by data saturation. The aim is not to collect all the data pertaining to a phenomenon but rather to gather sufficient information to develop meaningful themes and theories (Charmaz and Smith 2003; Creswell 2013).

e. Procedure

The research process involved several steps to ensure effective data collection and analysis , which were first tested through a pilot interview (see Appendix 11)..Once potential participants agreed to participate, an information sheet outlining the study's content and purpose was provided. Prior to each interview, a signed consent form was collected from the participants. Reminders were sent a day before the interview to confirm the interview time and address any technical requirements for online interviews. The interviews were conducted online using Zoom, thereby enabling the participants to choose a comfortable setting. Traditional interview etiquette was followed, including a brief introduction to the researcher’s work and the project. Participants were informed about the recording of the conversation and asked for their consent. The importance of the study and the selection of the interviewee were emphasised, acknowledging their valuable knowledge and experience.

The interviews began with specific questions related to the child’s age, their age at diagnosis, surgeries and cast status.

The interviewed mothers were asked about various aspects concerning their child, encompassing the child's age, whether there were risk factors, age at diagnosis, duration to confirm the diagnosis, types of surgical procedures, and age at surgery. This approach aimed to capture a wide range of experiences, to ensure variability in terms of experiences such as time of first diagnosis (early diagnosis or surprise diagnosis). Unlike the collection of posts from a Facebook page, online access may yield a more varied sample, demographic information is typically unavailable(Battles 2010; O’Brien and Clark 2011). The demographic information concerning the mothers and their children is outlined in the summary which is described in table 14 and appendix(12). Chapter ten explores how factors such as the demographics of both mothers and children may impact this experience.

Socio-demographic data	
Who is the caregiver	Mother
Employment status	4 Employed : -One extended maternity leave -One takes paid time off. 2 Unemployed
Participants’ age	24 to 35 years old
Marital status	6 Married
Level of Education	6 College /Higher Education
Family history of DDH	2
Gender of the Child	female

Table14: Socio-demographic data

The interviewees were briefed on the interview procedure, highlighting the topics that would be covered concerning the child's development in the cast. Interview guides were used to ensure that important questions were addressed, particularly focusing on the activities the child had to modify or discontinue whilst wearing the spica cast and exploring the parents' coping mechanisms regarding their child's immobilisation. At the end of each interview, the participants had the opportunity to share any additional relevant information.

Audio recordings of the interviews were transcribed to facilitate data analysis. Analysis occurred after each interview or in batches, allowing for adjustments to interview questions to delve deeper into emerging ideas and concepts. Previous interviews informed and shaped subsequent interviews, playing a crucial role in the evolving research process (Charmaz 2006).

f. Interview guide

In a qualitative interview, the researcher typically constructs a guide to which they can refer. It is referred to as a guide because its sole purpose is to direct the interlocutor. A guide for interviews is a list of topics or questions that the interviewer intends to cover during an interview. The guide aims to ensure that every person interviewed is asked the same questions. This provides a more focused and purposeful conversation but still allows a degree of freedom of expression to obtain information from the interviewee. The interview guide helps to direct the questions that the researcher wants to ask. Ultimately, the questions asked in the interview are also dictated by the responses of the interviewee (Morris 2015) (see appendix 14).

As data collection and analysis progress, the interview questions develop, based on the emerging categories (Charmaz 2014). Furthermore, the questions are not pre-written but are formulated and developed based on three main aspects discovered during axial code analysis.

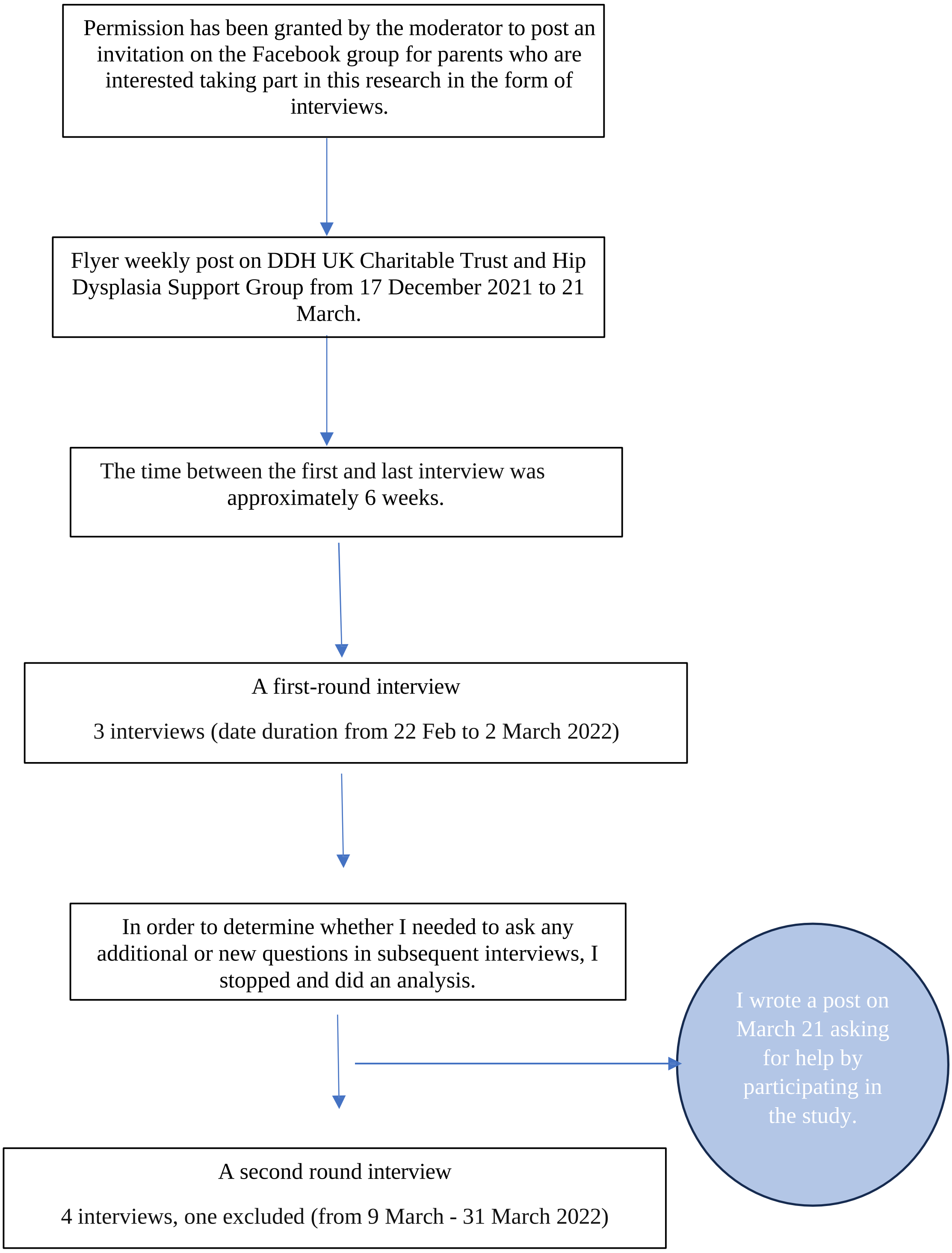


Figure8 : Process of recruiting participants for the second stage

g. Data analysis

The coding paradigm developed by Strauss and Corbin (1990) was employed to investigate the meaning of and the responses to the problems that parents faced when caring for their spica-wearing child during the specified period. This method uses conditions to answer the 'why,' 'where,' 'when' and 'how' questions. In this study, parents described what happened to them during the time their child was in a cast, how they felt and how they tried to make sense of their experiences, including physical, emotional and psychological aspects. The participants were asked about their main concerns, the coping and management strategies they used, the consequences of deploying those strategies, the knowledge they acquired during this period and the causal conditions influencing the occurrence or development of the phenomenon. The paradigm model shows the connections between the categories (see figure 12). The model generated three main components: conditions, interaction and consequences.

A similar process of data analysis was carried out in phase one. All of the interview transcripts were coded and categorised by comparing data to data, data to codes, and codes to categories in order to capture and interpret the participants' perspectives. Focused coding employs a filter to transform the necessary data into more abstract concepts, allowing the theory to emerge(see Appendices 13 and14). Data analysis was conducted, as previously described. Codes that appeared contradictory or required additional investigation were grouped and highlighted for further exploration during the next round of interviews. Interview transcripts were coded and categorised by comparing data to data, data to codes, and codes to categories, as referred to earlier. This helped to capture the participants' perspectives and simplified the interpretation of the extracted data more accurately.

In qualitative research, interviews are especially useful to garner the backstory of the participants' experiences and to pursue in-depth information about the specific study question. Interviews can be used to build upon the findings from phase one of a research study to further investigate the parents' experiences (McNamara 1999) .

CHAPTER FIVE: FINDINGS

Chapter overview

This chapter introduces the findings chapters which follow in Chapters Six, Seven and Eight. This section presents the results of the analysis of the study samples that combined the Facebook posts and interviews together to explore the impact of hip spica casting. The results of the analysis and theoretical conceptualisation are presented in three chapters.

Chapter Six focuses on the phenomenon of being in a spica cast, utilizing data analysis to comprehend the various trajectories of parents' reactions to casting events and to explore the physical, behavioural, social, and psychological burden during this phase, alongside the underlying causes. It examines the disparities in parents' experiences throughout this process compared to pre-surgery or their previous experiences with other siblings.

The main goal of this study is to explore parents' experiences of having a child in a spica cast from their perspective, focusing on factors such as acceptance of the condition, adaptation strategies, and responses to this critical period. Parents employ a range of adaptive response patterns, and each child reacts to events in their unique way. Therefore, it is essential to comprehend the experience from a parent's perspective. In Chapter Seven, the process involving action/reaction/emotion that is taken in response to a phenomenon and the strategies directed towards it, dealing with it, and overcoming it are described.

Chapter Eight explores the contextual factors that shape the phenomenon under study, encompassing all the circumstances that contribute to the structure of the phenomenon under study. The phenomenon always manifests within specific contexts or under particular circumstances, which play a significant role in shaping the unique experiences of parents. In this study, the context revolves around the healthcare system and access to knowledge.

5.1 Stage one: Initial finding

This chapter interprets each aspect using verbatim quotes from the participants. Then there is an explanation of how these relate to DDH child experiences which of the following two steps are associated with the wrote down initial memo:

1. In step one, I read and reread the generated data line-by-line, noting anything of interest about their experience as they look after the child with DDH.

2. In step two, I generated initial codes and noted anything relevant to the research objectives. I highlighted interesting features and made initial notes of their possible meanings.

After the initial coding of each post was completed, I also took the time to think about each comment in its entirety and write down the interpretation of each one. This was the beginning of the thinking process about emerging codes, in terms of whether and what they “fit" the data were relevant to the topic and how relationships between codes may potentially meaning (Charmaz 2006). Furthermore, I found this reflection process helpful in reflecting on some of my preconceptions and existing knowledge about the topic after analysing each participant's contribution in the initial analysis of each. It is common for initial codes to cover a wide range of topics (Charmaz 2006). Due to the potential for a concise statement or snippet to encompass multiple themes, it has the capacity to exemplify various categories. The interpretation of evidence is contingent upon one's preexisting perspectives. Hence, you can choose to use terms that only fit your data. The strength of grounded theory derives from the active involvement in the process .The process of writing memos encourages individuals to engage with the information in novel ways that may diverge from the views of their research participants. My analytical eyes and background led me to look at their comments in deeper ways to understand the problem. These memos create patterns and relationships between the codes. Memos are intended to raise the ideas expressed in the data to a conceptual level and encourage their sorting and reformulation (Engward 2013). Moreover, the focus was on the language used by the participants to search for patterns of their experience. These themes reflected not only the original words and ideas of the participants, but also my conceptual interpretations.

By studying the data, I made the basic problem elements a lot more apparent and made hidden assumptions visible, to give new and deep insights into understanding what is happening in childcare with children in the cast. I also wrote memos about the initial codes and the focused codes being developed, as described by Charmaz (2006).

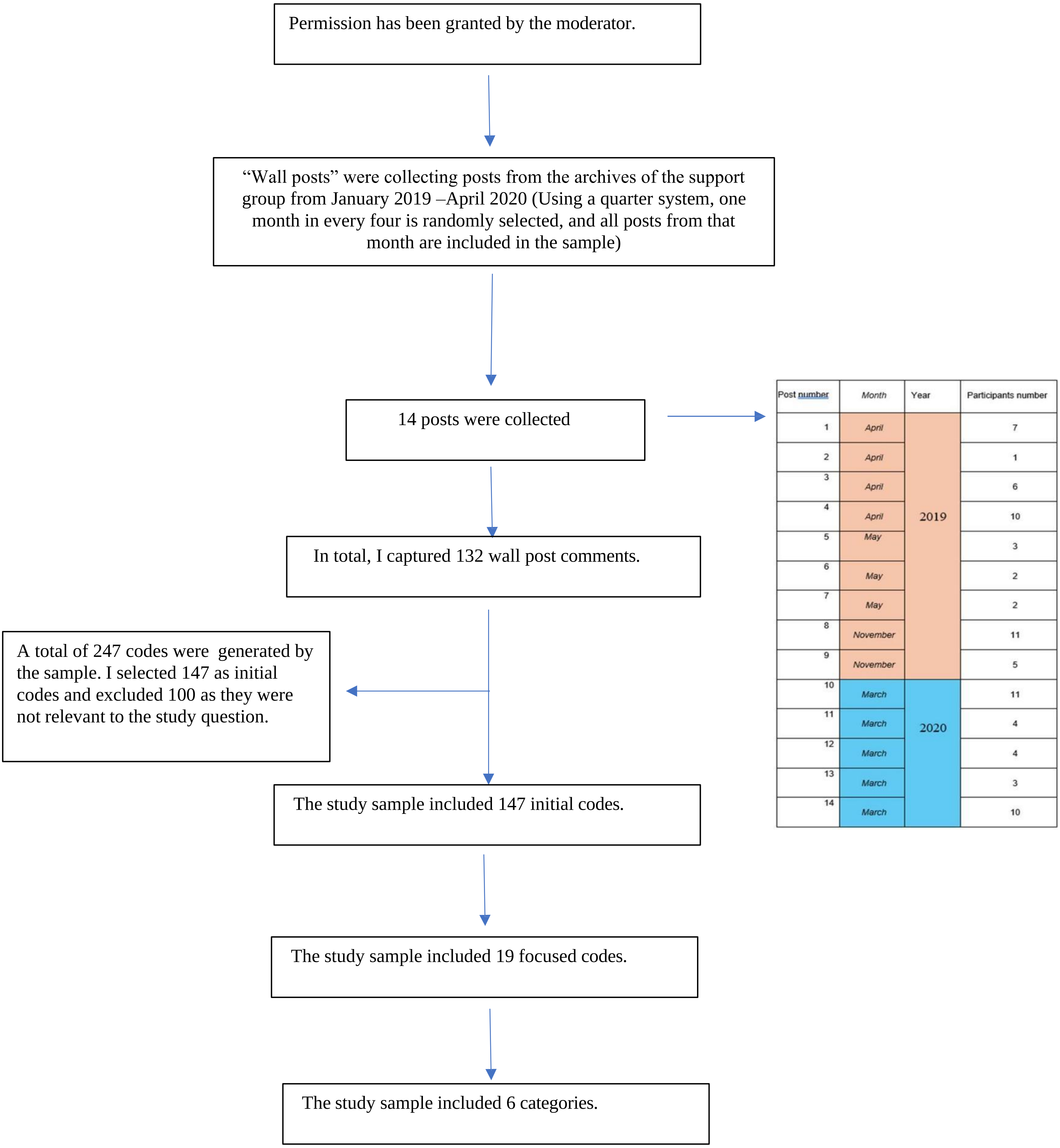
Based on the notes, the data were crystallised which contributed to the development of six important aspects that described the parents' experience in every aspect of their lives with the cast. Any given post could contain one or more of these aspects. Appendix (9) shows these six aspects.

After I had established some strong analytics through initial line-by-line coding, I started focused coding to develop the themes and bring all the codes together to capture and reflect my understanding about the parents' experiences. Focused coding is the process of sifting through large quantities of data by employing the most significant and frequent earlier codes. The following table illustrates the first step of the coding process (see table 15)

Focused coding necessitates choices regarding which initial codes make the most analytic sense to classify your data precisely and exhaustively. In these memos, I compared data, cases, and codes to identify similarities and differences, as well as posed queries to be answered during the interviews.

Raw data	Initial coding	Memo	Focused coding
PARENT 1: This is a random question but has anyone's children done weird things to an extreme after being cast?	- The mother asked other parents about her daughter an odd behavior at the cast. - It may be a sign of negative impact of the cast and hair-pulling is way of dealing with anger, depression, stress, or anxiety.	The following are examples of aggressive behaviour: nipped, hair pulled, hit with a remote, bottle, parent, hit in the face, bit and screamed. Nighttime is also worse.	Behaviours changes
PARENT 2: Sounds like baby trichotillomania.	Shearing information		
PARENT 3: I only noticed because she didn't want her teddy at bedtime anymore she was too busy pulling her hair haven't seen anyone about it yet I kept hoping it would stop as I doubt they can do much about it other than distracting her and that's not gonna work when she's sleeping	Some of bad habits or odd behaviour to express the feeling about restraint		

Table 15; Code example from first stage



Permission has been granted by the moderator.

“Wall posts” were collecting posts from the archives of the support group from January 2019 –April 2020 (Using a quarter system, one month in every four is randomly selected, and all posts from that month are included in the sample)

14 posts were collected

Post number	Month	Year	Participants number
1	April	2019	7
2	April		1
3	April		6
4	April		10
5	May		3
6	May		2
7	May		2
8	November		11
9	November		5
10	March	2020	11
11	March		4
12	March		4
13	March		3
14	March		10

In total, I captured 132 wall post comments.

A total of 247 codes were generated by the sample. I selected 147 as initial codes and excluded 100 as they were not relevant to the study question.

The study sample included 147 initial codes.

The study sample included 19 focused codes.

The study sample included 6 categories.

Figure 9; Recruitment and Initial Result of the first stage

I.Study sample

In total, 132 wall post comments were used to generate 247 codes. This included 147 initial codes (see Appendices 9). Each initial code was compared to another using constant comparative methods, which is a coding process used for category development in grounded theory and for refining concepts throughout the entire exercise (Chun Tie et al. 2019). This technique was employed during the first phase of data analysis in order to identify similarities and differences and compare codes, helping me to collect, establish and clarify connections between ideas. This also allowed me to retain the main insights that emerged from the data during the comparisons. Whilst reviewing the initial codes, it became apparent that some of the code labels were similar and others were very different. After completing the coding, I concentrated only on those codes that were clearly linked to the original aims of the study. In total, 19 focused codes were generated (see figuer10).

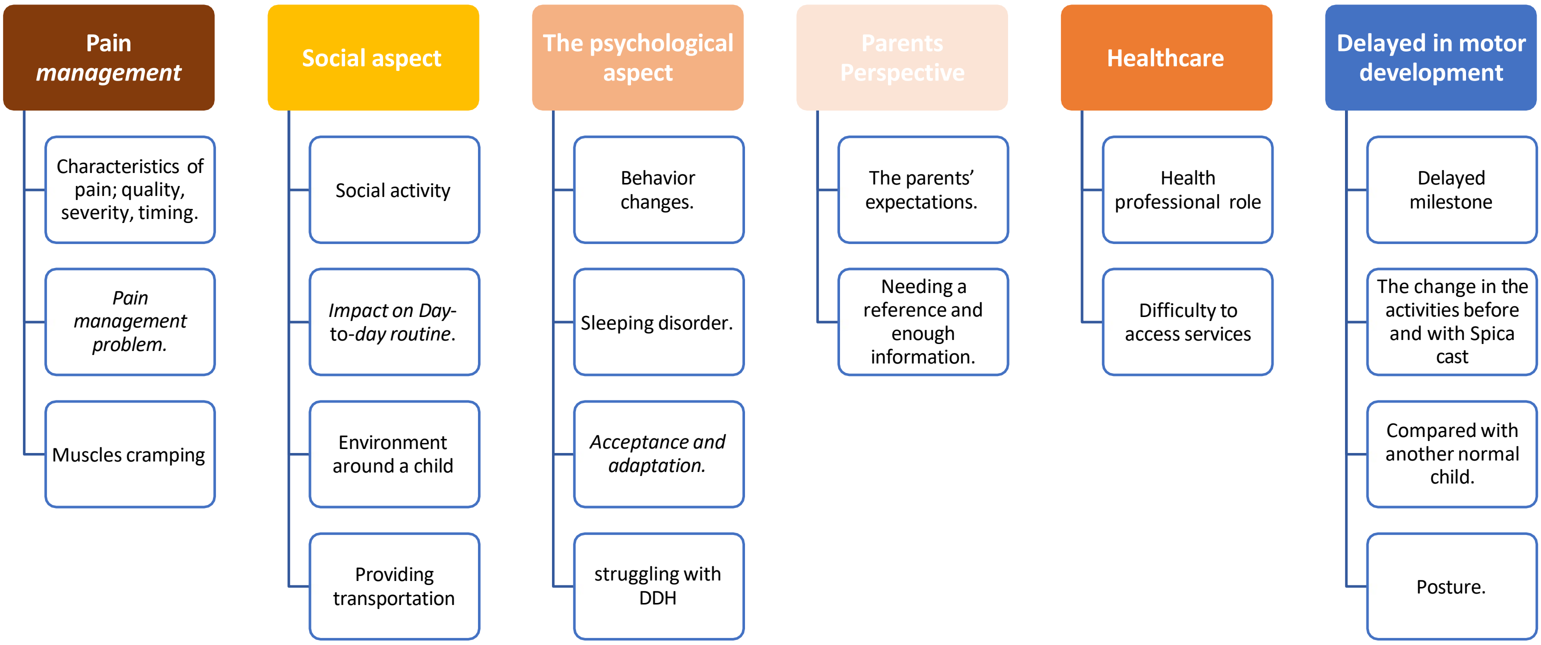


Figure 10 ; Visual presentational to Focused Coding for post

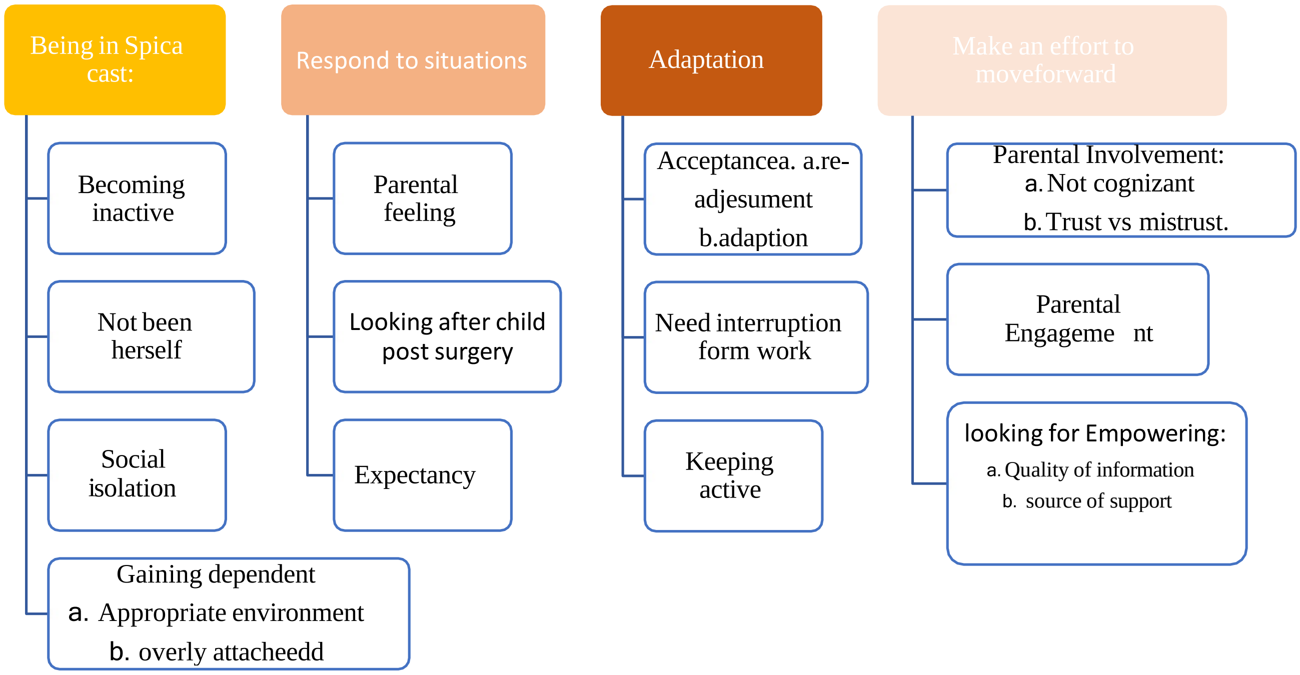
II. Initial result

Focused coding is the process of sifting through vast quantities of data by employing the most significant and/or frequent earlier codes(grouping codes that share similar features and characteristics to form categories). Therefore, the process of focused coding necessitates making informed decisions on the selection of initial codes that make the most sense analytically to classify your data (Charmaz, 2014).Thus, the second stage concerned which of the initial codes may be related to or particularly meaningful to the participants. Therefore, some codes were classified as irrelevant or as failing to provide information useful to answering the thesis questions; these codes were discarded at the end of the focused coding phase (Charmaz 2006).

The groups of codes that emerged during this focused coding consisted of 19 focused codes which I believe are the most important and repeated codes in the first analysis phase (Charmaz 2006) (see figure10). Focus coding emerges from this coding which identifies the coding categories to focus on (called the “core” phenomenon) and then theoretical sampling was employed for the collection of additional data. To understand more about the properties and components of the focused codes, new participant guidance was developed based on categories. In order to validate these hypotheses, the following data were collected using categories in designing interview questions (Morse 2010). The participants were asked what their main concerns were; the strategies they used to manage those concerns; the consequences of those strategies; the kind of knowledge they had during this period; and what were the causal conditions influencing the occurrence or development of the phenomenon?

5.2 The finding of the second stage

In this study, parents talked about their experiences with their children from the perspective of holistic development and the effects of the period spent in the cast upon each aspect of development. Their experiences included both physical and psychosocial aspects of their children. The following sections describe how casting after surgery affected the family (see Appendix 13) (see Figure 11).



Figer 11 : Visual presentational to Focused Coding for interview.

5.3 The development of the theory and an overview of the findings

Grounded theory methodology perceives theorizing as an ongoing analytical process (Charmaz, 2014). The initial phase of theory development commenced during the process of initial or open coding of the Facebook posts analysis. The subsequent step, as outlined in the previous chapter in section 6.3 and demonstrated in Appendix 9, These initial codes were clustered based on similarities, with emphasis on clusters that appeared significant and most frequent, resulting in the identification of 19 focused codes. These codes guided the second phase of data collection, which involved interviews. During the analysis of data in the second phase, 13 focus codes under four concepts were developed, as shown in diagram 11 : Being in Spica cast ,Respond to situations ,Adaptation , Make an effort to move-forward . These focused codes were established by considering the properties of the codes as detailed by the interviewees. They represent characteristics and dimensions that contribute to a deeper understanding and description of the concept (Corbin and Strauss, 2008).

The research process was more complex in this phase, and I engaged more intensively with the analytical tools and questions (Strauss and Corbin 1998a; Walker and Myrick 2006; Rieger 2019). As I looked closely at the specific properties of each focused code, I identified areas of overlap and repetition among them, as well as potential conceptual categories that could be explored independently. Some focused codes seemed to be more peripheral and aligned better when combined with others focused codes (Charmaz, 2006). For instance, the focused codes related to healthcare, such as "health professional role" and "difficulty accessing services," were integrated into a memo titled "There were obstacles preventing the family from feeling like they had agency and controlling the station". In this phase, I wrote memos and diagrammed to find the best fit between focused codes and their properties (Charmaz 2006).

Subsequently, to further refine the theory, the third stage of analysis involved axial coding (Corbin and Strauss 1990; Charmaz 2006) .In the next section, the logic behind axial coding is described. In addition, how to link data at the cause, context and consequence levels will be demonstrated.

I. Axial coding

Strauss and Corbin (1990) defined axial coding as "a set of procedures whereby data are put back together in new ways after open coding, by making connections between categories"(p. 96). The purpose of axial coding is to sort, synthesise and organise large amounts of data and reassemble them in order to provide more precise and comprehensive explanations of the phenomenon (Creswell 2013).

While analysing the data, I borrowed analytical tools (paradigm model) developed by other grounded theorists because I was looking forward to capturing the dynamic of this experience for the parents. Charmaz (2014) is also not opposed to using an axial code because it clarifies and extends the analytical power of emerging ideas (Charmaz 2014).

II. Paradigm model

In this study, the research methodology employed was constructivist grounded theory, following Charmaz's (2006) approach. The adoption of Charmaz’s stance on the use of a literature review was integral to the study. To identify relationships between categories and subcategories, Corbin and Strauss’ paradigm model was utilised (Corbin and Strauss 1990) (see Fig. 12).

Corbin and Strauss (2008) use conditions to answer ‘why,’ ‘where,’ ‘when’ and ‘how’ questions. The conditions are all related to the circumstances that contribute to the structure of the phenomenon being studied. The "who" and "how" inquiries are addressed by the process, which constitutes the ongoing action, interaction, or emotion in response to the phenomenon. The strategies are aimed at managing or surmounting the phenomenon, to handle or overcome it, to perform it, or to react to it. Additionally, the phenomenon consistently manifests within a specific context or under particular circumstances.. As contextual conditions change, adjustments are made in action/interaction/emotions. Consequences answer questions regarding “what happens” because of these actions/interactions (Strauss and Corbin 1990; Charmaz 2014).

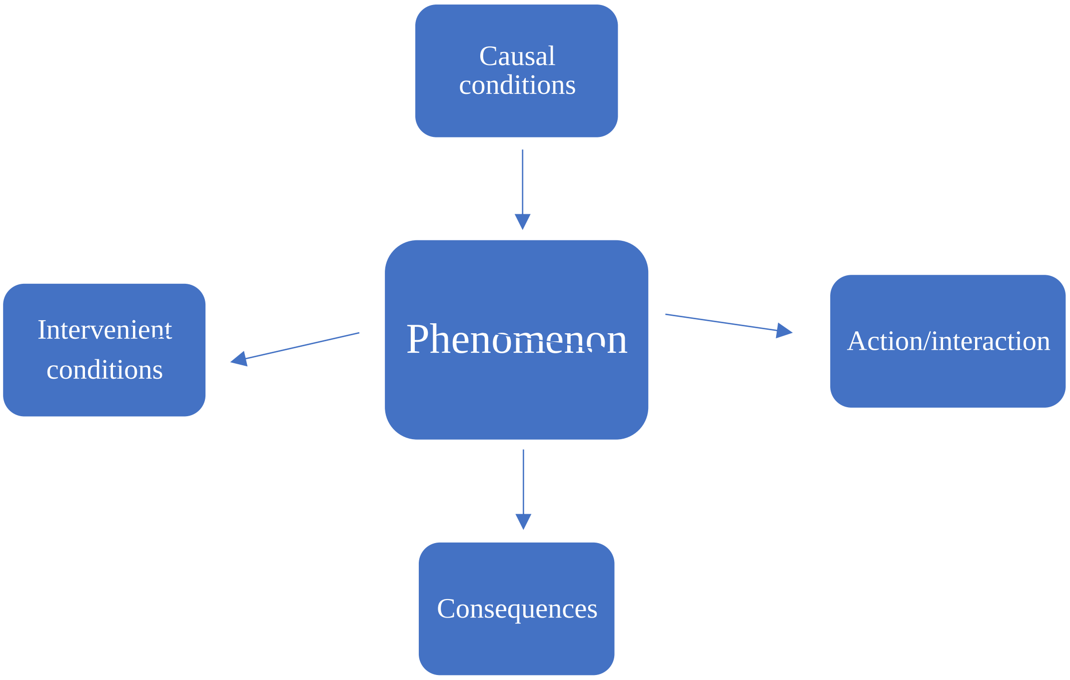


Figure12 : Paradigm model adapted from Strauss and Corbin (1990)

To demonstrate the connections between the categories, I utilised the paradigm model which consists of three components: conditions (phenomenon), inter/actions (processes) and consequences (context) (see fig 12). The central focus for analysis in this study is the phenomenon. This aspect involves understanding parents’ perspectives of their experiences while their child was in a spica cast, encompassing their emotions, thoughts and attempts to comprehend the situation. The focus includes the physical, emotional and psychological dimensions of their journey.

The second component is processes which refers to the actions and interactions undertaken by parents in response to the phenomenon. These actions may involve addressing, coping with, overcoming, implementing or responding to the challenges posed by their child's situation. Finally, the context is an essential aspect because the phenomenon being studied is always embedded within a specific context or occurs under particular circumstances. Understanding this context is crucial for a comprehensive analysis.

Thus, during this third stage of theory development, In the category-building phase, I took the focused codes, printed them out and physically separated the coded data segments with scissors. After a more in-depth examination of the codes, their interpretations, and discussion with my supervisors, which involved voting on them, certain pieces of data were reorganised into different categories. This process unfolded on a notice board (a cork board) where I interactively engaged with the data (see Figure 13). I initially sought to separate the snippets that represented codes into distinct categories for both posts and interviews. Following this initial step, I transitioned into a more detailed clustering process, organising the data into three overarching themes: phenomenon, process and context. This marked a shift in the analysis, moving from the intricate complexity of focused codes to the development of abstract conceptual categories that would ultimately interconnect to shape the theory's core category.

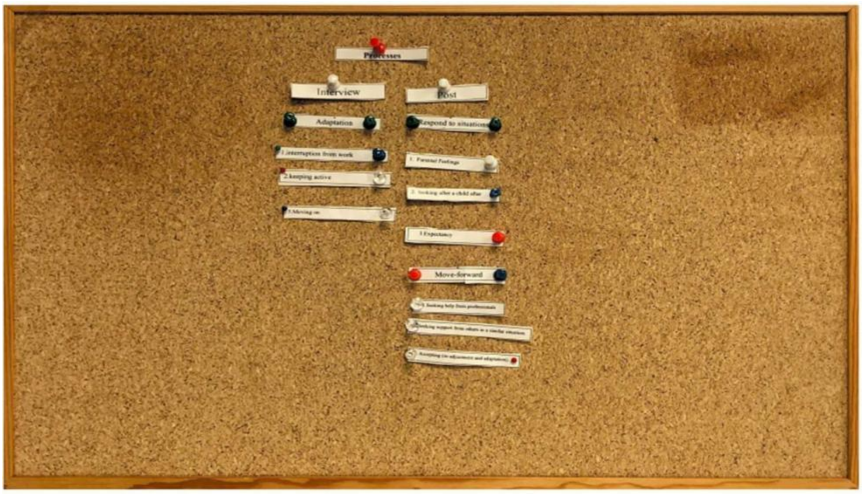


Figure 13: Category-building phase

Throughout this journey, I made use of memos, capitalising on their value for reflection and insight. The tactile experience of physically rearranging data fragments, as previously described, played a vital role in this analytical process.

During this phase aimed to refine emergent theoretical ideas for further enhancing "theoretical adequacy" in the developing theory (Charmaz, 2014). Using the Paradigm model, as mentioned above, focused codes were elevated to conceptual categories. This was accomplished through approaches of data presentation.

III. Data presentation

The study findings were grounded in the data; thus, as part of the presentation of the results, each of these categories and subcategories provide evidence using quotes from interviews or parents' Facebook posts. In order to meet ethical research standards, parent pseudonyms were used in the interviews and publication dates were used for Facebook posts to ensure anonymity.

The discussion that follows relates to the studied phenomenon of 'my child being in a spica cast', as experienced by the mothers participating in the research

CHAPTER SIX: MY CHILD BEING IN SPICA CAST

Introduction

In this chapter, the category 'being in a Spica cast from parent perspective' is described in detail. The experience was described by parents caring for a child in a Spica cast and the category emerged during the coding and categorisation of the Facebook posts and interviews. The phenomenon can be viewed as a two- step process: (1) Forming a new family identity after being in a cast, and (2) the interactions of this phenomenon with the surrounding systems.

The 'being in a Spica cast' category describes the perspectives of mothers with children placed in a Spica cast on the effects these experiences on mothers physical, social and psychological well-being. In addition, the category includes mothers' perspectives on the changes in their children's lives since the cast was applied. It is a central category in this study, and it encompasses several other sub-categories that are closely related to how the children experience being in a spica cast. The category is dynamic and complex, primarily due to the interplay of many factors. For example, some of the subcategories concerning child development include 'Becoming inactive,' 'Not being themselves' and 'Being isolated,' as shown in Figure 14. These subcategories are described below.

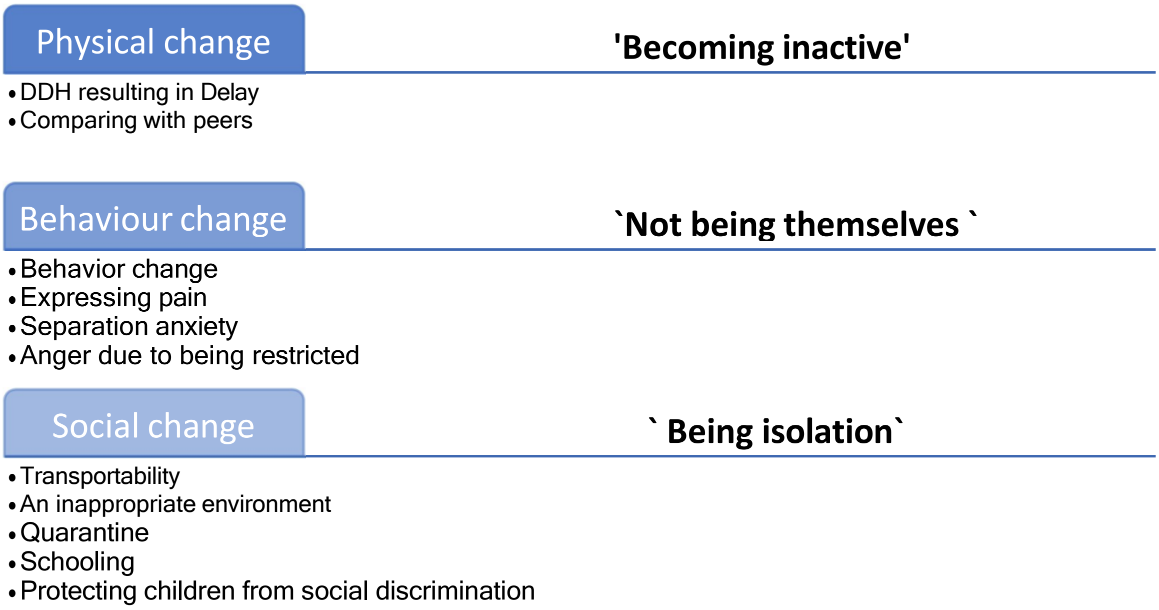


Figure14: Phenomenon; Being in cast from mother perspective

6.1 Becoming inactive

The participants viewed mobility as their child being able to access social and community activities, attend school, take part in sporting activities and keep up with their non-disabled peers. Therefore ‘becoming inactive’ was seen as a lack of mobility when their child was unable to do one of these activities. The category contains five subcategories: DDH resulting in a delay, comparing movement before and after the cast, comparisons with peers, movement inside a cast is influenced by the shape, and compensating.

6.1.1 DDH resulting in delay

Some mothers described how their children exhibited postponed motor-skill progression prior to undergoing surgery. This experience was illustrated in an interview with Beatrice’s mother who described how her child was unable to move, and the daily difficulties and struggles this caused. This is described in the data extract below.

She couldn't move at all; she couldn't even shuffle across the floor because she couldn't move her left leg.
(Beatrice’s mother)

This question was posted on a Facebook page inquiring about the typical age at which a child with DDH is expected to start walking.

What age did your DDH child start walking? My 18-month-old can’t even stand let alone walk and it breaks my heart every day.
(March FB Participant (1)post number 13)

The surveyed mothers underscored that following surgery, the children’s activities are constrained due to the extended period they spend in the cast. The subsequent excerpts show how the mothers contrast their child’s mobility before and after the cast has been applied.

I would say is... that for most it has to delay it slightly. I think my daughter will spend approximately 24 weeks in SPICA after her op at 1year and that’s got to delay development slightly.
(March FB Participant (3)post number 14)

These accounts highlight the impact of DDH on children's motor development, with delays in standing and walking causing significant concern for parents. The inability to move independently not only affects the child's physical development but also places an emotional burden on caregivers.

6.1.2 Comparisons with peers

When wearing a spica cast, each child has experiences and reactions which are unique to them and their circumstances. In some cases, mothers delineated the difficulties by comparing their cast-wearing child to their peers. The data extract below highlights the sense of frustration felt by the mother when comparing her child to their peers and their ability to engage in activities with other children.

> *She's definitely behind where my eldest was at this age but doing so well on the other hand.*
> *(* March *FB Participant (1)post number 10)*

> *She doesn't have the same level of ability as peers so, for example in nursery and in school, they like to children to sit with their legs crossed. And Elizabeth can't do that she doesn't have the outward rotation in their hips to be able to do that. When she had PA in school, she said to me "a mom every time we do running I'm always the last (Elizabeth's mother)*

The above quote shows how her cast-wearing daughter was cognisant of the differences in her physical abilities and those of her classmates.

This feeling may be exacerbated when comparing their child's achievements with their peers. This effect is explained in the data extract below:

> *Our son uses a wheelchair in school and out and about. It took a while to get used to as well as the acceptance that he isn't 100% the same as his peers. Simple things like P.E., playtime.it gets easier*
> *(November FB Participant (2)post number 9)*

These accounts illustrate how parents recognize and grapple with the differences in their child's physical abilities compared to their peers. The comparisons made between their child and others highlight the emotional strain and concern for their child's.

6.2 Not being themselves

‘Not being themselves’ is a subcategory that includes cast-wearing children’s changes in behaviour, mood, agitation, anxiety and the inability to control their temperament. It is difficult for adults to understand a child’s behaviour following surgery because children’s reactions are very different from our own. This category arose when mothers described the psychological challenges and problems facing their family when their child was in a spica cast and the psychological effects on their child. When children cannot convey how they feel, it creates a sense of frustration which can result in anger and ultimately affect their overall behaviour. Spica-cast wearing children may exhibit aggressive behaviour but this may be how they can express their feelings. Children have a limited vocabulary and aggression may be the only outlet they know when they feel stressed and frustrated. Another reason for a worsening in a child’s behaviour can simply stem from their immobilisation which is difficult for a child to understand. It may be difficult for them to understand the reasons for the surgery and why they need to wear the cast to improve their physical ability in the future. Wearing a spica cast often affects children’s mood, energy levels and their sleep, as evidenced by the following quotes.

6.2.1 Behaviour changes

Numerous parents conveyed observations of emotional and psychological shifts during their child’s recovery period. One mother, in particular, reached out to fellow parents to inquire if their child had exhibited unusually extreme behaviours after being placed in a spica cast. Her interpretation leaned toward viewing such behaviours as potential indicators of the cast’s negative impacts. For instance, she assumed hair-pulling to be a coping mechanism for anger or stress. The mother speculated that this habit might have developed due to the stress of the situation, expressing the belief that it would eventually cease.

> *This is a random question but has anyone’s children done weird things to an extreme after being on cast ?Around the time of the first op she started rubbing her dummy through our hair and this has gradually turned to her hair and pulling her hair out to the point her hair is almost non-existent on one side.*
> *(* March *FB Participant (1) post number 10)*

For some mothers, the behaviour changes were indeed temporary, manifesting only at specific points during the post-operative treatment period. For instance, immediately after surgery, many reported a notable change in their child's behavioural patterns. Their experiences during the recovery period were highly emotional, as illustrated by the following quotation.

> *After the operation, when she was in cast, she wasn't normal. She had a bubbly personality sometimes. She sorts of not herself a little bit.*
>
> *(Charlotte's mother)*

This mother commented on how following her child's surgery, they changed from being a very calm child into an aggressive, screaming child who hit.

> *For the first week, she has a tearful, angry and sad. But after about a week she got back to herself. She's more withdrawn, but she wasn't aggressive for tantrum or anything she just withdrawn. For the first week she was incredibly sad and cried and said "take it off take it off" and just angry and upset*
>
> *(Angela's mother)*

> *She definitely got frustrated at her situation and dished out several scratches and bites. Ultimately, she didn't understand and was unable to express how she felt, so a bit of lashing out was understandable. She soon adapted to the cast and now with the cast off is back to her usual self.*
>
> *(November FB Participant (11)post number 8)*

Based on the preceding instances, mothers tend to speculate that negative habits or unusual behaviours are transient in nature and will cease as the child becomes accustomed to their new circumstances.

6.2.2 Expressing pain

A particular Facebook post postulated how such behaviours could be a means of conveying pain. Drawing from this mother's own encounter, she described how prior to surgery, her daughter had been notably composed and seldom cried; yet following surgery, her child's behaviour shifted significantly. Furthermore, some parents described how they had spoken with other parents who had similar experiences to help them manage the issue of their child's changing behaviour.

> *I’ve been nipped, hair pulled, hit with a remote, bottle, you, hit in the face, bit and screamed at. From a baby that never ever cried and was so placid. Anybody experienced similar and anywhere to turn for help and advice? HELP*
> *(November FB Participant (1) post number 8)*

6.2.3 Separation anxiety

Parents shoulder the foremost responsibility of looking after the child, especially as their requirements intensify following the surgery and application of the cast. According to the mothers surveyed, a spica-cast wearing child needs someone throughout the day to help carry out their needs and meet the challenges of their new situation. This role was viewed as essential for their child’s well-being. In the following extract, a mother describes her belief that wearing a spica cast changes the child’s personality. They exhibit increased attachment because they want their parents to always be close to them due to their immobility and dependence on their parents.

> *She is very clingy, she wants to be by my side, the whole time. It might be part personality that I feel it part of it was just me having to carry her everywhere and do everything.*
>
> *(Angela's mother)*

Certain situations of separation from parents can trigger feelings of anxiety in some children, such as when parents and children are separated within a hospital setting or during transitions to formal childcare. This phenomenon is described in the following data excerpt:

> *When she woke up from recovery, she was very angry for about a day because when she woke up in recovery, I wasn't there.*
> *(Daisy’s mother)*

6.2.4 Anger due to being restricted

Some described how their child demonstrated aggression in response to their being restrained by the cast. The majority of parents thought aggressive behaviour was a way for their child to express their feelings about their state of immobility. In some mothers’ opinions, there are other factors and situations that provoke anger, for example when their child wants to participate in activities or play like other children. The data extracts below describe some of the behaviour demonstrated by spica-cast wearing children in response to their state of immobility.

> *If they were in the same room then she could join in a bit, but they would often be going off exploring, going out in the garden, and they would go off and do things and she couldn't. it was frustrating for her*
> *(Angela's mother)*

This mother spoke analytically about the child's behaviour when wearing a cast and provided a simple explanation to the other parents about aggressive behaviour.

> *You know and understand why this is happening but your little one doesn't - all they know is that one day they were free and able to do what they wanted and now suddenly they can't. Your little one is taking their frustrations out on you because they feel safe - you are their place of safety*
> *(November FB Participant (3) post number 8)*

Daisy's mother emphasized that the timing of the surgery has the most significant influence on how the the child understands why they must wear the cast and how their movements will be restricted.

> *I think because she wasn't crawling, she doesn't know that she's being held back. Because she's not things yet. And I think the reason for that is she'd been in a brace for four months, so used to being restricted from a brace to the cast. It kind of eased her into being that restricted.*
> *(Daisy's mother)*

6.3 Being isolated

Undoubtedly, the context of a child's social life and the subsequent changes that wearing a cast causes play a role in their overall experience. The presence of a spica cast affects a child's social activities and their social interactions with friends and family, and social isolation or exclusion can be an issue for some children. This section describes the impact of wearing a spica cast on a child's social life.

6.3.1 Transportability

One key issue for families is the transportability of a child in a cast. The shape and nature of the cast restricts a child's mobility and, therefore, makes travelling difficult. Constrained transport mobility is problematic because it can cause social and geographical exclusion and adversely affect people's well-being. In response, parents frequently share their experiences of traveling with a cast-wearing child to provide encouragement, support and help for other parents to reduce the impact of a spica cast on their travel arrangements. For example:

> *Random question but does anyone know about flying while in a Spica. My family live in Scotland and Spain (I live in Essex) and while I have time off with her post surgery they have asked if we would like to come to either place to see them and have a bit of a break.*
> *I don't want to drive so flying would be our best option but not sure if it would affect swelling etc.*
> *(April FB Participant (1) post number 4)*

The above quote relates to a family looking for transportation options for their cast-wearing child. Notably, the parents asked the Facebook community before they asked their doctor. While they weigh the option of embarking on lengthy drives against opting for a flight of under an hour to their desired destination, their apprehensions centre around any potential side-effects. Even though a car can be adjusted for a child in a cast, they may have difficulty sitting comfortably in a car for a long period of time. Some parents further discussed the issue of a child's comfort when travelling in a car.

> *My daughter could only do half hour max in the car in her Spica and that was pushing it. They really can't sit comfortably.*
> *(April FB Participant (3) post number 4)*

> *"Maybe check position of the cast as you may find your child may not fit in the seat.*
> *(April FB Participant(4)post number 4)*

It should be noted that travelling with a child in a spica cast can lead to health issues. This is especially true for mothers.

6.3.2 An inappropriate environment

This section summarises the category of 'appropriate environment.' This is a notable part of the mothers' experiences and it is a crucial element of the social isolation that some mothers described. It refers to a lack of a supportive environment for children with a spica cast. Several factors contribute to the difficulties of social interaction when wearing a cast, including the inability to move around easily. This characteristic is also related to the sub-category 'Disempowerment.' According to the surveyed mothers, getting out of the house requires a lot of planning, including choosing places and activities that are suitable for their child. Such activities must match their child's limited abilities and/or include suitable equipment.

it’s not a case of just jumping out of the car with the baby but very heavy to hold, she is getting the push chair and so it’s definitely not she wasn't leaving the house. I have to really carefully considered, like the facilities and make sure, would there be somewhere, even parking the car. And I need to make sure that there's wide enough space that I can get her out. Now, it is a lot of things that you consider
(Daisy’s mother)

The need to handle caregiving responsibilities in public settings further constrains the duration of certain outings and activities for certain parents. This circumstance is illustrated in the following example:

When you're going to plan where can we go, what when we're going to stop for a break where's going to get changing, and it was just really stressful.you have to make sure that you had so much changing nappy it because you couldn't be damp at all, you have to find baby changing. Changing is where they could facilitate it the cast
(Angela's mother)

6.3.3 Quarantine

The COVID-19 pandemic has posed a significant challenge to many parents but notably those parents with a child in a cast. While quarantine and lockdown measures were essential to curb the virus’s spread, they also brought about sensations of solitude and social isolation. The following quote illustrates how the lockdown adversely affected

some cast-wearing children’s well-being, becoming a source of frustration for this particular mother.

Advice needed please!
my 18-month-old son is in week 4 of the Spica tomorrow. I am sick of just letting him watch tv but cannot for the life of me think of what else to do and I cannot go outside due to this virus and being put in self isolation. Please help me
(March FB Participant(1) post number 10)

As a result of the lockdown and the inability to interact with others, a strong need for attachment developed, as noted by Angela’s mother.

I think lockdown part contributed a bit that she couldn't mix with other people very much, but she was just dependent on me so much. It is absolutely horrendous that we don't have to go anywhere.
(Angela's mother)

6.3.4 Schooling

Charlotte’s mother recalled the difficult period when her daughter was mostly confined to the house.The sense of isolation weighed on the whole family, making it a challenging time for everyone.

> *she was stuck in the house, most of the time she was not at school,There were times, where we all felt a little bit isolated*
> *(Charlotte’s mother)*

Angela’s mother also faced challenges with preschool policies, making it difficult to navigate early childhood education while managing her child's cast period, much like Charlotte’s family

> *Preschools are saying, if he's in the cast you get a better to wait for that six weeks.*
>
> *(Angela's mother)*

6.3.5 Protecting children from social discrimination

Parents of children with medical conditions or visible differences often face challenges in protecting their children from social discrimination while managing their own emotions. The fear of judgment, misunderstandings, and social isolation can add an emotional burden to an already difficult situation.

One parent shared their heartbreak over limiting their child’s activities for safety reasons.

> *“Vent away. Big hugs to you all and the guys are right our little warriors are so resilient. I totally know how you feel about stealing childhood I have to stop my little girl joining in sometimes with her friends and it breaks my heart.”*
>
> *(November Participant(4) post number 9)*

This sentiment reflects the internal struggle parents face balancing the need to protect their child while wanting them to experience a normal and fulfilling childhood.

The following extracts highlight the emotional and social challenges parents face when caring for a child with a visible medical condition like DDH.

> *I try to cover her up in some ways I don't have to cast completely on show So I suppose there is not shame. I don't think it's kind of trying to avoid those conversations. When people think you've hurt your child or you've broken their legs. I think that does make you feel quite a shame. Because you think do people think I could do that? And covering her little bit.*

i'll have somebody stopped me yesterday, what have you done to her, and I said I haven't done it

(Elizabeth's mother)

I would say throughout the whole six months I had quite a bit of social anxiety.going out and about so, for example, when we went to kinds of parents and toddler Groups and I felt quite isolated, people were much less inclined to do that with myself and Daisy because they didn't know what was wrong with imaging and perhaps didn't know what to say to me, and they just didn't interact with us in the way that they were interacting with all the parents.

(Daisy's mother)

Both accounts illustrate how visible medical conditions can impact not only the child but also the parents' emotional well-being and social experiences.

Conclusion

In summary, this chapter has explored the multifaceted impact of having a child in a Spica cast, focusing on mothers' physical, social, and psychological well-being. It has also highlighted the ways in which their children's lives have changed due to the cast. These experiences shape how parents navigate daily life, interactions with others, and their own emotional responses.

Building on this, Chapter 7 will delve into the process of finding meaning in these experiences. It will examine how parents make sense of their journey by reflecting on key aspects such as responsibility, adaptation, and the broader consequences of caring for a child in a Spica cast.

CHAPTER SEVEN: SITUATIONAL MEANINGS

Introduction

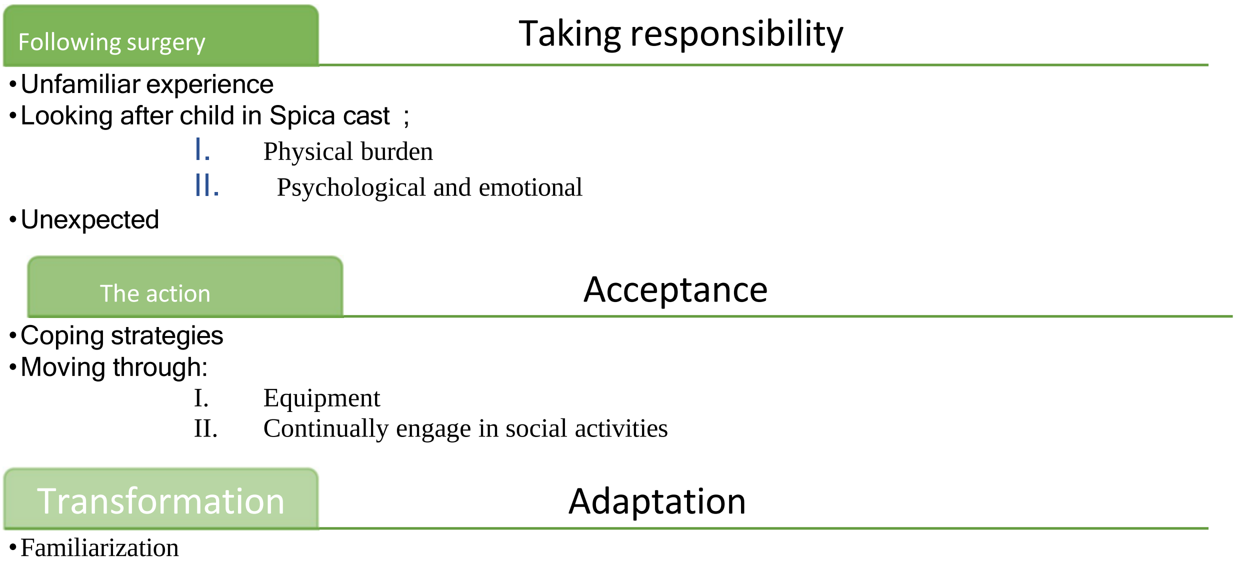
Finding the meaning of an event is a process which in reality includes action and interaction. The meaning-finding process was investigated by asking questions about the phenomenon such as ‘when,’ ‘where,’ ‘why,’ ‘who,’ ‘how’ and ‘with what consequences?’ (Strauss and Corbin 1990). In essence, the term ‘process’ refers to taking responsibility for a child who has undergone hip surgery and is in spica cast.

This chapter begins by clarifying the responsibilities and efforts placed on a mother as the primary caregiver for a child in a spica cast. This section summarises mothers’ experiences and the coping strategies they have adopted in the face of the difficulties, challenges and needs of their children. It describes the roles they have needed to play when caring for their cast-wearing child. A mother is always responsible for her children but the spica-cast experience, according to the mothers’ narratives, is not comparable to the experience of typical care for a healthy child. Also, mothers make intense efforts and do their best to care for their child and ensure that they remain active and socially engaged. This includes the active roles of mothers, their physical efforts and their perseverance to do their best to care for their children with limited resources.

Process is a series of actions that take place over a period of time, where one action must precede another. Acceptance and adaptation are two main features within the ‘process’ that cut across both things (see Figure 12). Although acceptance precedes adaptation, time is always a factor, as described by Strauss and Corbin (1990).

Although this study draws on information gathered from the parents’ perspective, it is important to try to understand the child’s experiences when wearing a cast. This is because the intensity and duration of the response to the cast depends on a variety of factors. These experiences are conceptualised as multidimensional, beginning with an acceptance response which then develops into an adaptive response.

Acceptance is a stage intertwined with the interpretation of a phenomenon, in this case, wearing a spica cast. To help understand why a child is in a cast, a parent should explain the medical condition causing the situation and what the consequences of not treating the malady would be. This can add meaning to the event and help parents understand their new responsibilities. There is generally a balance between needs and abilities in the family system. However, this balance may be disturbed when caring for a child in a spica cast because it is an unfamiliar experience requiring new methods of care to address the new challenges. As a result, acceptance begins and then moves through, which might be their way of adapting to the new situation to achieve a balance between needs and ability.



Following surgery — Taking responsibility

- Unfamiliar experience
- Looking after child in Spica cast ;
    I. Physical burden
    II. Psychological and emotional
- Unexpected

The action — Acceptance

- Coping strategies
- Moving through:
    I. Equipment
    II. Continually engage in social activities

Transformation — Adaptation

- Familiarization

Figure15: Situational Meanings, being in Spica cast

7.5 Taking responsibility

The presence of illness and physical challenges associated with DDH early in a child’s life may make it difficult for parents to relinquish their supervision and responsibility for the full care of their child. Parents are often only supportive because they are the primary caregivers and they are expected to take on a caring role to support their child throughout the treatment journey. This role includes caring for the child with their physical limitations, their aftercare, and other family responsibilities. This degree of responsibility frequently necessitates modifying work schedules and social engagements in order to accommodate the care requirements of their child.

7.5.1 Unfamiliar experience

Following surgery, the family is confronted with a set of relentless demands: the daily burden of care, uncertainty about the cast, and other child-care responsibilities. Therefore, parents must adapt to and manage the new challenges as they learn to manage caring for a child in a spica cast, mainly through trial and error. For example, Freya’s mother was struggling to take care of her cast-wearing daughter with regards to simple daily needs like nappy changes.

> *it took a little bit of getting used to just working out which size to put inside the cast and which side to put out how to roll her over and like try and stop leaks and stuff. It's a bit of trial and error*
> *(Freya's mother)*

DDH has the potential to interfere with customary family regulation processes, including routines and rituals, due to the necessary endeavours undertaken to address the difficulties involved with caring for a kid in a spica cast (e.g., activity restrictions). Mother described caring for her daughter as being extremely different compared to her experience of motherhood with her first child.

> *I haven't a military way so there's a lot of stuff goes through in my direction that is unexpected and you can't survive unless you just get on with it*
> *(Beatrice's mother)*

> *I found only took us a few weeks to get use to caring for the child in a cast and same things remains difficult throughout the six months. we have to just kind of take it day by day in terms of how we care for her.*
> *(Elizabeth’s mother)*

Likewise, Freya’s mother delineated the distinct nature of tending to her daughter in a cast compared to her experience of motherhood with her first child.

> *By this age, my son was coming in emptying cupboards and crawling around and trying to walk. The you know, with Freya, it's going to be delayed. It's very different.*
>
> *(Freya's mother)*

7.5.2 Looking after a child in a spica cast

Compared to the experience of caring for a healthy child, there are additional challenges to consider when caring for a child in a spica cast. Therefore, the mothers of cast-wearing children have a different maternity experience.

According to the mothers, their experiences were comparable to caring for a new-born, which some described as being 'terrifying.'

I think it's changed everything we do, really, even small . It's like having a newborn again, you can't leave them.
(Daisy's mother)

Below is a description of Angela's mother's experience; she pondered how she would care for her child when she was physically unable to perform even the most basic daily duties such as feeding, bathing or holding her.

At the beginning it was just panic like.I think you do not know how is she going to sit up, to eat ,how do we get around and then we just started coping and manage, but in the beginning it's just so overwhelming how would we do anything else you have a bath, how do we change her,how she going to eat I can't physically hold all the time, what she going to do, and to know that was gone for six months was horrendous.
(Angela's mother)

Caring for a child in a spica cast can be a challenging experience for parents because it is an around-the-clock commitment because the child is completely dependent on their parents.

it's really hard, you are their rock. My daughter is an absolute terror for me now because I was there 24/7, if you can get some time apart it will do you both the world of good.
(March FB Participant (2)post number 13)

Several mothers shared their experience of shouldering increased responsibility while caring for children with spica casts, owing to their heightened dependency and care requirements. This increased burden can affect their obligations towards their other children. The examples below illustrate how mothers struggled to balance these additional responsibilities when caring for their other children in addition to a child in a cast who has special needs.

In terms of just I guess parental guilt feeling you can't spend the time with her brother that you wanted to I had to always be looking out for her .
(Angela’s mother)

So I gave birth to a brother when she was 14 months. And I really thought having her walking would be easier because I'll be able to go easier like when she inevitably climbs the stairs, I can not get her to come back down but I had to put the baby down and go and see her. And we were trying really hard to encourage her to walk but she wasn't having any of it.
(Freya's mother)

I. Physical burden

The difficulty moving a child in a spica cast was an issue that parents shared on the support page on Facebook. The cast is bulky, awkward and usually extends from the mid-chest to below the knee. Parents usually have no idea how to deal with their child or how to move them. Daily care also concerns mothers regarding the correct positioning of the child to ensure their safety and comfort. The importance of positioning to avoid sores and prevent the cast from digging in was also described in the Facebook posts. In the following example, a mother was afraid to put her child in a sitting position because she thought it would harm her owing to the possibility that the pin would come out and the surgery would fail.

We’ve been so scared of doing anything with her apart from holding her and taking her everywhere (think our backs are going to give in soon).

(March FB Participant (1) post number 12)

Meeting their children’s mobility needs was also part of looking after a child in a spica cast. The mothers described how the shape and weight of the cast affected their physical health and that they did their best to meet their children’s care needs, including holding and positioning them correctly and moving around.

it was bulky and it was heavy, but this is life I've just got to get on with it, I just take care her and I just did what I still do with any other child
(Beatrice's mother)

There is a possibility that the situation could worsen by affecting the physical health of the caregiver, as in the example in which the mother required physiotherapy sessions due to back pain.

It was horrendous I had to see a physiotherapist because of back problems because from lifting and carrying has so much, I had to have physio.
(Angela's mother)

II. Psychological and emotional

Some parents believed that they suffered as much as their child did in the recovery period, although in a different way. Parent (1) and parent (2) exemplify this in the following extract:

So after 4 major reconstruction surgeries and from the age of 11 months to 2.5 years in numerous casts .I hate DDH our journey is far from over and my little girl still hasn't took her first step. I don't post very often as our little girl has severe hip dysplasia but I am just so upset and angry that DDH is stealing my daughters childhood
(November FB Participant (1) post number 8)

Preventing the child from joining and playing with her peers made her feel that her daughter's childhood had been stolen or incomplete. All of these feelings made her depressed and sad.

I know it's really hard for you, but you need to find the strength and patience from somewhere to get you both through this .I know, especially when most of have a lot of guilt over what we've put our babies through (even though deep down we made the decisions for the best), but little one is raging against the situation, not you
(November FB Participant (2) post number 8)

The mothers admitted that their anxiety was partly due to uncertainty and the strange situation, their unfamiliarity with the care their children needed after surgery, and their being in a cast for a long time.

What age did your DDH child start walking? My 18 month old can't even stand let alone walk and it breaks my heart every day.
(March FB Participant (1) post number 12)

The following example illustrates how one mother felt about her child's health condition and surgery decision:

I felt so guilty, because I made her go through this and it ultimately made the decision we were going to go along with this surgery, I felt like it was my fault that she was so sad and upset and getting frustrated and, obviously, in the *back of my head I knew it was for the best but there were times when I was just like, 'oh why have I done this?'*

and initially in the hospital was when I felt the worst about it when she'd had the surgery.
(Charlotte's mother)

"She never walked in the cast, it wouldn't have been possible because it was all the way to toes on both feet really and her feet were about a metre apart!!! She didn't even fit through doors bless her!! She was crawling again about a week after, cruising furniture maybe 2-3 weeks after then I would say back to "normal" walking this week, so 8 weeks later. It sucks, she was walking, running everything before the op, just with a good wobble, I know it'll be worth it in the long run but I do feel so bad for her! Luckily she probably won't remember it!!".

(March FB Participant (2) post number13)

7.5.3 Unexpected

Because the mothers did not know what the cast was, they were unaware of the care challenges that would arise from its application. The importance of this subcategory derives from the crucial information that the family receives about the nature of the problem, its characteristics, needs and possible future expectations. There were questions and inquiries raised in this stage, where the family needed someone to answer their queries and provide further information. This is reflected in the conscious and constructive interaction between the family and health practitioners. It is a new and unexpected stage for them that needs a lot of support in order for them to feel empowered.

it was quite scary being sent home with a small child enter cast and not knowing how to handle her what it was safe and what wasn't.
(Beatrice's mother)

Taking care of a child in a hip spica cast can be a difficult experience for parents.

once you were in the cast, you have no choice but to get on with it. But beforehand, no matter what you research and what people tell you. You just don't know what it's going to be like
(Angela's mother)

Pain is a recognised complication following surgery in children and it can make the care of a child incredibly difficult. I tried to shed light on the parents' experience of pain and pain-management by exploring the main aspects of this problem related to the child and their family. The mothers reported that the main problem was coping with their child’s pain after the surgery. They were worried about pain management and sought advice on issues such as muscle cramps. Accordingly, their Facebook comments were directed towards the wider community of parents in their attempts to identify, understand and manage the issue of pain. Below are some comments where parents discussed the topic of pain in terms of their feelings, further questions, suggested medicines, and what they did to alleviate their child’s pain.

> *We’ve just thankfully stopped with the morphine now as she was only having it once a day and then we thought because the calpol was taking it off we’d just use that .That must have been absolute torture! I nearly passed out due to shock when she was in recovery after hers*
> *(March FB Participant (1) post number 13)*

> *For the first week she was incredibly sad and cried and said, “take it off take it off” and just angry and upset and then after about a week she seemed back to herself in terms of playing or finding ways to get around and things.*
> *Angela's mother*

These quotes demonstrate that managing children’s pain at home can be a stressful experience for many families. These posts provided clear insights into managing postoperative pain at home. Notably, after surgery, children have difficulty accepting the change in their abilities and thus express their rejection of this new situation in several ways. Some posts show that parents encounter changes in their children’s behaviour and expect it to be a temporary disruption, solely due to their child’s inability to move in the cast.

> *Wild exactly and when you say no they just do it more. I feel I’m fighting a losing battle. (* March *FB Participant (1)post number 11)*

> *When she was in the cast for six months, the first couple of weeks, the behavior was very, very different. She was very quiet; she was very clingy, and she wouldn't even let me put it down to sleep. I have to stay up all night to hold it.*
> *(Elizabeth’s mother)*

7.6 Acceptance

Parents acknowledged the life-changing nature of having a child with DDH but they also emphasised that they were trying to provide a normal life for their child by accepting the new event, finding their own definition of 'normal' and integrating the spica cast into their daily lives. The idea of striving for normality is explained by incorporating the cast into 'normal' life, treating the child as a sibling or peer, and recognising their limitations and practical challenges. The following quotes illustrate some mothers' acceptance of this new event.

> *I guess every child is different and I also think that it slightly depends when they are in cast as to what stage of development will be effected. Anyway. I'm sure when they all reach school age it will make no difference whatsoever*
> *(March FB Participant (3) post number 14)*

> *We've been trying really to just make it as normal as possible. we've told her that she's got superhero trousers to make her poorly leg better She kind of accepted it's a cast*
>
> *(Freya's mother)*

7.6.1 Coping strategies

In this case, the parents actively managed the stress and demands associated with caring for a child post-surgery. This included changes to their home management techniques and the implementation of strategies specific to their individual contexts. Coping strategies reported by the majority of mothers included focussing on what needed doing, getting enough information to feel confident about providing care, and talking to people with similar experiences. The Facebook posts and interviews show how parents created their own version of normality in the face of a difficult situation and developed their own narratives to integrate their children, being aware of the restrictions placed upon them.

Some mothers assumed the main responsibility for looking after their children because fathers usually could not take time off work so that they were able to support the family financially. It was generally the mothers who had to take time off to care for their child in a spica cast. Parental leave was one of the aspects of managing the child's care because the timing of the surgery defined many decisions regarding childcare. Many parents extended their leave from work in order to accommodate their child's treatment. As an example of this finding, Daisy's mother expressed the view that care was the mother's responsibility because there was rarely the possibility of putting her daughter in childcare and she did not want to leave her daughter with someone else because she was dependent on her for every aspect of her care.

> *I've extended my maternity leave and I'm going to go back to work, just part time .So I'm around more for her and I know other parents do, but I don't feel that I can put her in childcare*
> *(Daisy's mother)*

Similarly, Charlotte's mother was working full-time and her partner was self-employed, so she extended her leave. However, this had to be unpaid due to the timing of the operation and it is not possible to know or choose the timing of the operation.

> *My husband's self-employed, so if he wasn't, he… if he didn't go to work, you know we lose his wage and I'm a full time nursery nurse and I had because this, we were told to expect to 12 month wait for the surgery, and this was in last March of last year, so we were working on that 12 month period I've used all my annual leave at work. And then two weeks before operation, I got a phone call saying we have this date, come available, can you do this day ? I'm having all this time off unpaid. that's a massive financial impact.*
> *(Charlotte's mother)*

All parents spoke of making sacrifices, including their employment status, family time, and social activities, but fully embraced them as part of their responsibility to provide the best for their children.

> *It's kind of she's with me all the time and I don't get much done but it's just the way it is. It's only temporary, you know we'll get through it, but it's definitely you have a different , you have to parent differently in the Spica cast, because they have so many more needs .*
> *(Daisy's mother)*

During the interview stage of this study, the mothers were asked questions specifically about the strategies and changes that they made following the surgery. The questions were designed to learn more about the topics related to the strategies used at this stage to help them accept the increased care responsibilities and how they adapted to the needs of their children. The adaptive methods employed differed among the surveyed mothers. In Charlotte's family, they either modified the house to be more suitable for a girl in a cast, or changed the type of activities they used for entertainment.

> *Her bedroom had to move from upstairs to downstairs because of wheelchair access and also she was too heavy for us to carry up or down the stairs And so occupational therapy said she would have to sleep downstairs. So her dad moved her bedroom downstairs for a period*
> *(Charlotte's mother)*

Also,

> *That we sort of had lots of sit down activities for to do so we've got lots of arts and crafts things so when friends came around would say you know if they've got children would say to them, or can you bring a book or will they be happy to sit and do some arts and crafts, with Charlotte if not they're going to have to sit in the other room and watch TV*
>
> *(Charlotte's mother)*

Emotional support encompasses the act of demonstrating care and concern, whereas informational support entails the provision of relevant information or guidance. This is what the Facebook support page offers: a way for parents to build relationships with others in similar situations who can provide relevant support. Interestingly, parents at this stage wanted information and emotional support to help them care for their children from experienced people like themselves. While parents

in general wanted support, they had a particular interest in establishing connections with those who shared similar problems and encountered difficulties in finding practical solutions. Chapter Eight discusses what sources of information parents rely on during the treatment journey.

All of the parents who responded to this post emphasised that the reason for the change in the child’s behaviour was underlying pain, especially the presence of muscle cramps. Everyone who responded to this post was unaware of muscle cramps until they sought medical advice and knew that their children were upset due to muscle cramps.

7.6.2 Moving through

Following this stage, parents begin to respond to the situation that they are also reacting to. As part of this process, parents are transitioning back to their former lives. As a consequence of the unpredictability of this event, parents try to find a meaning for it and change the meaning of their responsibility as a result.

> *it's been tricky to try and treat her like a normal child, but also recognizing that she's limited. I don't want to say you can't do this because of this. But I also don't want to let her do things that's gonna cause problems and affects that.*
> *(Freya's mother)*

I. Equipment

They try to normalise this event, to become active, to become social, and to use equipment. According to the mothers' experiences, keeping the child active was part of meeting their developmental needs. Some mothers reported that obtaining equipment such as car seats or buggies, either by donation or loan, was necessary for their child's comfort and to keep them active. Previously purchased prams and car seats had to be replaced to accommodate the hip cast.

> *We have a special car seat for her which we managed to hire so that was thankful that we could hire a car seat. She did manage to fit in the buggy which was really helpful. (Angela's mother)*

> *I think equipment was one of the things that made that six months bearable for us and allowed Elizabeth to have as normal and experience as possible. It made her a life more enjoyable. So we have quite a lot of equipment that we could continue to do things that we wouldn't have been able to do without the equipment.*
> *(Elizabeth's mother)*

Through forward planning and adaptation to the activities they engaged in, as well as the equipment used, the parent and child were able to resolve the restrictions on their mobility:

> *I didn't really let it restrict us when she was in the cast we got we loaned a Spica re- adapted car seats which meant that we could take her out and we had to buy a new pram because she didn't fit in in the pram that we had for her, so we had to buy a lot of equipment for us to be able to get out and about*
> *(Elizabeth's mother)*
> *I think it nice to had some special equipment that could have be loaned to us for that period.*
>
> *(Angela's mother)*

> *it was expensive in terms of we did have a lot of equipment to buy. we were fortunate that we could afford to do that, but I think that some parents would struggle to afford the equipment that we got for*
>
> *(Charlotte's mother)*

> *I mainly got all of the information and equipment that I needed for her through the DDH Facebook group*
>
> *(Daisy's mother)*

II. *Continually engage in social activities*

This sub-category highlighted mothers' efforts to ensure that their children remain active. They also continued attending various activities and children's groups as a part of their social life.

> *Socially I didn't feel isolated, I was very lucky I had lots of baby groups and lots of friends and I still saw.*
> *(Beatrice's mother)*

The mother tries to integrate the child into social life.

> *It prevented Beatrice from the one that had DDH from moving around like appears but it never prevented her joining in I still took her long to be in classes and I just hold her and move her around on my own, or she would lie in her tummy on the cast, so there was never any negative impacts.*
> *(Beatrice's mother)*

The mother tried to integrate the child into social life to avoid any feelings of isolation.

> *I still take her to a baby groups. And there was I take it a Bumbo seat for her that she can sit in. So she's still interacts with other children. We've, we've tried not to let it hold us back. So we still take her and do everything that we normally would do with our son.*
> *And as a family we don't want it to hold us back at all. (Daisy's mother)*

One mother described how she kept her daughter's teacher informed regarding her condition and movement limitations.

> *I gave them some information about DDH they've never had a child in the school with DDH before, and so they very much just follow her lead. So the*

> *teacher knows that she can do anything that she's comfortable with, but not a force her into anything that she's struggling to do*
> *(Elizabeth's mother)*

These mothers stated that they used the equipment and explained how this encouraged them to do their best to prevent their children from being socially isolated and helped them stay engaged in social interaction. This was one of the strategies to overcome the phenomenon of social isolation discussed in Chapter Six.

Mothers recommended using assistive devices to give a child a sense of independence and allow them to be social and do what their peers do. This includes participating in school activities and enjoying outdoor activities. The mothers also felt that the child's motor independence helps others accept them and reduces the feeling of being different. This view is reflected below.

One parent described that her daughter loves the wheelchair because it gives her independence and allows her to play with her peers. She reports that other children handled her kindly and did not find the chair an obstacle to enjoying play activities, such as racing.

> *My girl is in a wheelchair full time, she's 6. They can give them some absolutely amazing independence! My little girl absolutely loves her chair. Other kids are so kind, they mother her so much and always look after her, she loves doing wheelies and most of all she loves racing.*
> *(November FB Participant (1) post number 9)*

> *Our son uses a wheelchair in school and out and about. It took awhile to get used to as well as the acceptance that he isn't 100% the same as his peers. Simple things like P.E., playtime.it gets easier.*
> *(November FB Participant(2)* post number 9*)*

7.7 Adaptation

The adaptation of a family to stressful life events is significantly influenced by the process of meaning-making. A significant component of the process of adaptation is defining the circumstance or attributing meaning to the illness event that has invaded their lives. Illness imposes an additional burden on the family because their usual routines are disrupted. However, parents begin to adapt to the fact that the family needs to assimilate the required changes into the family system. The adaptation phase begins when the mother attempts to organise and balance their response to the many management-demands of their child’s illness. How easy the experience is from the mother’s perspective is influenced by multiple factors that contribute to the child’s care, whether medical or daily. In the next section, I discuss how parents’ resources influence the experiment’s context.

7.7.1 Familiarisation

There is a critical difference between interaction and transition in families that care for a child after surgery. An interaction becomes a process when the parents engaged in the interaction undergo an internal change, allowing individual beliefs, emotions and behaviours to be modified during this process. Transition periods are accompanied by the parents’ desire for information regarding their children’s health, anticipatory guidance to prepare for care challenges, and acceptance to adjust to the caregiving role. The role of healthcare professionals, hospital services and knowledge are tangible resources for parents when caring for their children.

A successful journey begins with becoming aware. In order to do this, transparent information about their child’s condition and treatment methods must be passed on to them by their doctors and health providers. This encourages parental empowerment and ensures parental awareness and ease of childcare. Beatrice’s mother described during her interview that they were very lucky to have a good medical team and this is discussed in the next chapter in detail: the impact of the medical team in knowing how to care for the child during this period. Furthermore,

the shape of Beatrice’s cast helped her facilitate her hygiene and changing because the issue of toileting was a notable problem from the point of view of those who take care of children in casts. To clarify, this issue was due to the spica cast being a full frame that covers the baby and keeping it clean and dry was one of the problems that mothers had to deal with.

> *We were very lucky she has a really good team and the cast was absolutely brilliant had a really good, the one that we had a really good space for her to go to the toilet. And her scar has healed really well so she doesn't have any issues with that and she was perfectly happy, she was obviously in pain the first few days after surgery.*
> *(Beatrice's mother)*

Explored within Chapter Six, attachment emerges as a notable expression of the evolving behaviour of children during this phase. Moreover, it is revealed that this attachment yields advantageous adaptations, with mothers asserting that the attachment formed between them and their child during this period fostered a deeper connection, resulting in a stronger bond. This bond or connection evolved due to the caregiving responsibilities and the child's full reliance on them as their primary caregivers. This relationship served as a strategic approach to ensuring the well-being of their child, enabling them to gauge whether the child was enduring or rejecting something causing discomfort or distress.

Charlotte's mother in this example explained how she was able to recognise her daughter's feelings and needs.

> *I just try and remind myself that if she's in any pain, or if she's worried about anything, she will stop and she will tell me, and because you know we've always had sort of like an honest, open door kind of policy, I suppose, if you like, and So she knows if she's hurting she can tell us, and if she's not happy about something she will tell us, and so I suppose it's the trust between and her know in her body.*
> *(Charlotte's mother)*

Also here was the mother's educational background that makes her able to manage this period

> *i've got a level three diploma in child care.I mean working in a nursery it's definitely helped and sort of knowing when I work in a baby room as well and knowing different ways of self-regulation and care regulation that really helped. Yes, I suppose, so yeah like my background is a lot working in a stressful environment.I think her mood development and kind of things and my experiences at work, helped me to sort of manage*
>
> *(Charlotte's mother)*

As a result of context, parents' reactions during adaptation may vary depending on the circumstances and this is addressed in the next chapter. The need for information is seen as fundamental in improving the experience with DDH - even more so during these difficult periods of the growth and development of the child. Understanding what parents need to know and from whom they receive information during the period of care is essential to ensuring quality care and being better able to manage their expectations. I present the sources of parental information in the next section. Parents find that their children have a high self-adaptation ability because they do not do something if it hurts or repeat movements they do not like.

> *I think the thing to remember is that they won't do something if it hurts them so let her try and see what happens, she won't repeat something if she doesn't like it. It's all about building confidence and using lots of techniques*
> *(March FB Participant(2) post number 14)*

> *realizing she could do things a bit more and giving her a bit more independence and she can move a self around that's what made a big difference to her in terms of and to all of us in terms of once I knew she could move yourself a round I had to get everything for her that really helped.*
> *(Angela's mother)*

In the Facebook post shown above, one participant responded to a mother's question about the possibility of changing positions for her daughter after surgery. It was clear that the mothers were trying to adapt and change some of the things in their environment to help their cast-wearing child's mobility and keep them safe and comfortable. Mothers can be extremely creative when making and modifying objects to help them improve their child's care. Mothers reported that they had difficulty finding the right equipment to help them care for their children with casts. They described that the equipment, if it was available, was too expensive to buy. So, they made tools to help them transport and care for their children during this period.

Most mothers reported using buggies or baby walkers to keep their children active and to help with daily care, as shown in the following example.

> *We were just trial and error, so we try sitting her and different things and realized she could sit up so then we found like a baby Walker she could use and then for let's put cast on this and see if she can scoot around in it so some of it was trial and error (Angela's mother)*

Beatrice's mother described how she developed a method of holding her child.

> *It was difficult for me to lift her, but we found our ways and I learned to use a woven rope to carry her waist, rather than trying to carry her in my arms and so that was all. (Beatrice's mother)*

There were adaptation techniques mentioned in some posts that dealt with challenges which consistent with the fact that acceptance leads to adaptation by rebalancing the increased care requirements, as well as the ability of the parents to provide the child with the care they now need, safely and healthily.

> *Its super important they go in different positions to avoid sores apparently!! We used a big floor beanbag particularly before she would move so that everything was well supported, pillows under legs/tummy etc, basically wherever was need to ensure the cast wasnt digging in.*
> *(March FB Participant (2) post number 13)*

> *I'm very patient with her as I know it's not her usual self. I lay and cuddle her and rub her feet (seems to settle her a bit) just in the middle of the night things always seem harder.*
> *(November FB Participant (1) post number 8)*

7.8 Conclusion

It is apparent that the family unit performs the basic roles that a spica-cast wearing child needs in this journey. One of the most important duties of the family is that it provides a supportive, stimulating and reassuring environment in a correct manner and without any obstacles or influences. This is why they must feel empowered and involved in providing adequate care during the spica cast period. I found that the mothers employed a number of strategies to care for their cast-wearing children. These strategies were also effective coping mechanisms for dealing with major concerns and difficulties during this period. This is when the family progresses from the acceptance stage to the adaptation phase. In the acceptance phase, the family starts to effectively manage the situation and adaptation emerges in response to the care demands. At the same time, the parents' knowledge levels depends on how much information they have access to. This helps the family adapt and achieve a new sense of balance in the family system.

CHAPTER EIGHT: CONTEXT

Introduction

This chapter focuses on issues of parental empowerment and agency that increase their control over their situation. Parents' experiences are influenced by various contexts, including knowledge, information resources, support and healthcare. It is their responsibility as caregivers to accept and adapt to the situation, to be able to make control choices, and for parents to try to master that experience. A lack of knowledge regarding their children's situation and the resulting anxiety illustrates a lack of empowerment from the parents' perspectives. Empowerment comes from two sources: personal and external. The elements 'support' and 'healthcare' are external resources, whereas 'gaining agency over the situation' and 'information' are internal resources (see Figure 16). A detailed explanation of each element is provided in the following sections.

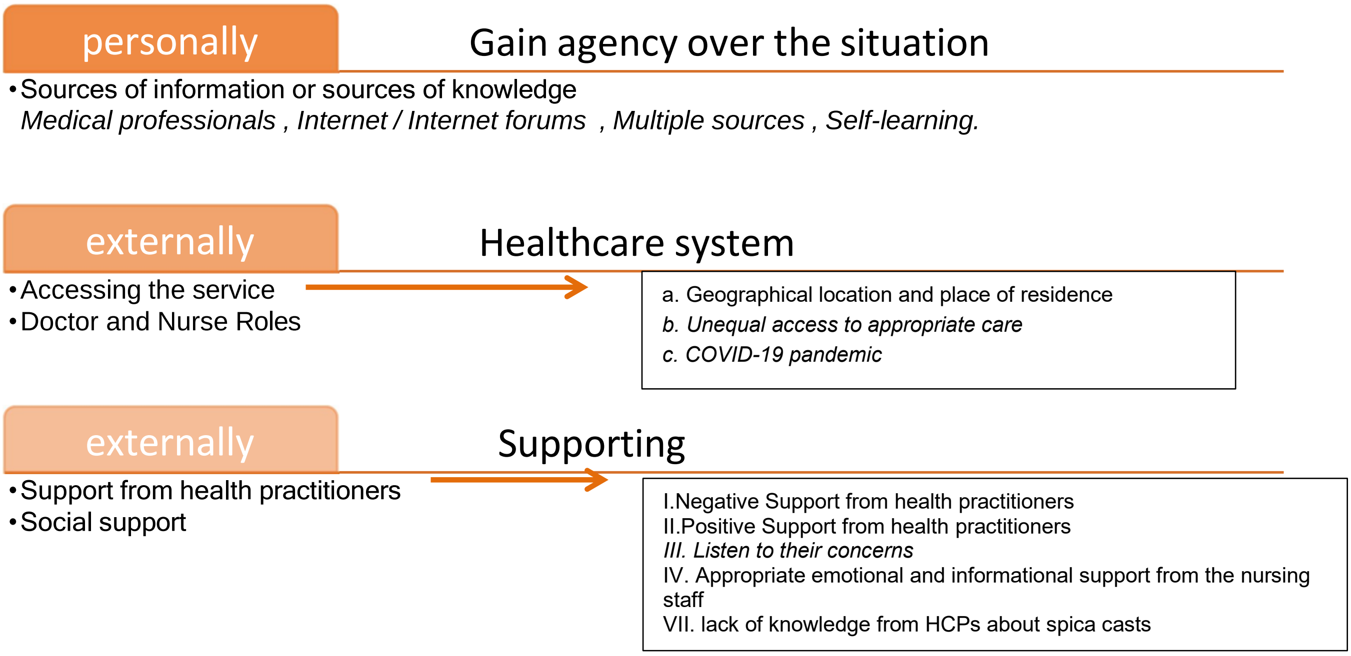


Figure16: Contexts

8.1 Internal (personal) sources

8.1.1 Gaining agency over the situation.

It was apparent that the parents moved through experience initially with little knowledge of what their child's condition entailed. Thus, surgery and treatment of the condition posed a threat to their sense of empowerment. Feeling empowered is important for parents because they can take control of their children's lives and better understand the change that is taking place when caring for a child in a cast. It may have been necessary for them to prepare psychologically for any potential outcomes if they were given more information through the journey of the treatment. For this reason, parents would have preferred a higher degree of transparency and sensitivity from their health practitioners. It was important to them to know what they were going through and how to deal with it. This category overlaps with the category that was discussed in the previous chapter regarding the responsibility of the parents and how they initially suffer because this is not an ordinary motherhood experience.

Lack of knowledge is regarded as the main problem because knowledge means providing the family with scientific and practical information that helps them deal with their child's condition. This allows the family to accept and take responsibility for the child who has to undergo surgery and will have a period of immobility. The family has to understand how this means they will by totally dependent on the parents for their daily care. In some families, there was frustration and despair at the poor provision of information by health practitioners. They felt that better provision of information would help to alleviate their fears and that it would help them understand what was happening to their child. Daisy's mother believed that there should be more health education for parents and that new-born health checks should involve the sharing of knowledge with parents using language that is easily understandable by lay people.

> *I think the only thing I mean with DDH it's not well known. Hip dysplasia it's not rare but it's not that common because people aren't educated on what it is*
> Daisy's mother

8.1.2 Sources of information

In this sub-category, parents described how they found the sources of information that they needed to feel empowered and care for their children. Mothers received information about their child's hospitalisation, surgery and aftercare from a variety of sources, including medical and nursing staff and the Internet. This usually entailed using search engines or social media platforms to communicate with other parents who had similar experiences and interests. Parents felt that providing themselves with information helped to alleviate their fears and gave them a deeper understanding of what was happening to their children. The struggle regarding adequate care and how to move the child in the cast was a problem suffered by all parents without exception, as described in the previous chapter.

The sources of information discussed in this section were found to be important ways to promote parental understanding, acceptance and empowerment. Their limited experience or knowledge of the condition and the surgery adversely affected them and strategies were needed to support parents in the processes of meaning making, as mentioned in the previous subcategory.

I. *Medical professionals*

> *They kind of sugar coated everything for us at first until it was actual day and then what they said was going to be 2 hours turned out to be a 5 and half hour operation she's getting on so much with pain wise but she's trying to push it down and wanting to sit up*
> *(March FB Participant (1) post number 13)*

This quote effectively illustrates the contrast between expectations and reality. Initially, the situation was presented in an overly optimistic manner, suggesting that the difficulties and duration of the operation were understated. This significant discrepancy underscores how the actual experience was markedly more challenging than what was conveyed, thereby highlighting the gap between the information provided and the experiences endured.

Additionally, parents often described the anxiety they felt about their children's movement as the primary cause of their distress. As the doctor was the first and most reliable source for any problem related to the child's physical health from the parents' perspective, they asked the doctor about developmental delays or any abnormal movements they noticed. The following example categorise frustration with the information provided by health practitioners.

The parent expresses concern and uncertainty about their child's developmental progress, emphasizing the challenges they have encountered due to multiple failed treatments and the continued effects of developmental dysplasia of the hip (DDH).

> *Hi my sons 18 months old and can't stand or walk, diagnosed at birth failed pavlik harness 3 months old failed closed reduction 10 months old successful open reduction 17 months old were still in the spica at present it comes off in May. Hoping for some more milestones to be reached then. His surgeon also told me DDH doesn't delay walking.*
>
> *(March FB Participant (7) post number 14)*

The category, 'lack of support by doctor' was prominent in the parents' unsatisfactory experiences with health practitioners. It is also closely related to the category, "frustration with information provided by health practitioners" which highlights frustrating experiences during this time. The participants talked about the lack of information and knowledge about the surgery that their children underwent and also about their delayed motor development.

Parents desired further information during treatment to prepare for the potential outcomes and sought transparency and sensitivity from practitioners. The individuals experienced a sense of frustration due to the limited availability of information regarding the diagnosis and treatment of DDH, which may have resulted in a diminished ability to effectively manage the unforeseen circumstances.

> *The problem we had was that they didn't know the extent of work needed until she was under so we had no clue exactly what would happen until they had done it. To the point that they thought they might do one leg at a time! It ended up being 8hrs in theatre doing everything that had been a possibility but thankfully doing both legs at once*
>
> *(March FB Participant (2)* post number 13)

Many of the parents were frustrated because they believed they had insufficient information about DDH. It is also important to note that parents frequently identified concerns about their child's movement as a major source of distress.

> *I don’t know really. I think she’s just still working on her balance. Her ankles seem to fall inwards a bit and her foot on her bad side definitely out-toes when she walks but her consultant says that’s not a problem! Her head control and the rest of her body has always been strong though*
> *(March FB Participant(4) post number 12)*

II. Internet searches and Internet forums

All of the mothers had sought information about DDH from the Internet, often because of the poor provision of information by health practitioners regarding how to care for a child with DDH. Mothers used the Internet as their primary source of information about DDH. Google was specifically mentioned as the first source of information for mothers. Some parents sought information directly from a DDH parent charity website (Steps).

> *As a mum with the first thing you do, and you find out there's something wrong you take to Google and you do all research and everything you don't know*
> *(Charlotte's mother)*

Elizabeth’s mother had been doing a lot of research and found that there was a lot of medical information about the condition of DDH itself but there was only a small amount of informational support for parents about the most practical aspects in search engines.

She admitted that she probably should not Google but for areas where she lacked information from the medical team, she was tempted to look for support in Facebook groups and websites such as DDH UK, ‘My hip baby’ and Steps. She felt the need to do her own research to see if there were better ways to do things and to see if other people’s experiences could help her.

> *I do quite a lot of research, about the condition I find there's less information on there about the more practical things that don't think there's a huge amount of that information there's quite a lot of medical information about the disorder itself. The treatment support I haven't found a huge amount about practical support for parent.*
> *(Elizabeth’s mother)*

She also confirmed that she tries to do things on her own but if it is too hard, she looks online to see if there are better ways to do them and see if other parents’ experiences can help. However, if the issue is medical, she will call the doctor.

> *Usually, my first port of call is my social media group with people in there we've got a lot of experience of going through what we've gone through. So, sort of ask for advice on there and see what comes back off there and then sort of if it is something serious and medical then I’ll get in touch with sort of the doctors.*

(Elizabeth's mother)

As the mothers pointed out, having conversations with people who have similar experiences is crucial. Often, the hospital staff are not sufficiently informed regarding how to handle children in a spica cast, so the parental support forum was the best source of information because of the tips and advice available from other parents.

I remember being in touch with somebody else, whose daughter was due to have the operation, just after mine and I could help them because so it's all about having those conversations with people who have the experience, because the hospital staff aren't trained in how to lift and handle the children a spice cast.
(Beatrice 's mother)

If something we don't know, more than anything, I use that Facebook group. The real people that know what they're talking about are not in medical nonsense, and I don't have to wait half an hour to speak to a nurse on the phone. There's just real mums that have done it.
(Freya 's Mother)

Through their Facebook posts, parents can connect with other parents who have experienced or are facing the same problem. Some parents described their experiences with many problems and how they dealt with them. Other parents focused on seeking information that could help them solve a specific problem they had encountered.

It's the practical experience of day to day care and for the child in a cast and caring for the child, she was come out of the cast and I have found the parental support absolutely vital, I think we would have really struggled without it.
(Daisy's mother)

Currently, more people are researching their own or their family's medical conditions online. It is beneficial for patients to seek information and understanding of their condition, although as Daisy's mother pointed out, the Internet can also be a source of confusion and misunderstanding.

I mean do a lot of research, and you don't we sometimes read the best positive stories, sometimes it can be quite negative what you read.
(Daisy's mother)

I asked sort of on the social media group and what's, the best thing for me to do regarding toileting so that we don't get the cast dirty and in a mess basically.

(Charlotte's mother)

These extracts emphasize the vital role of peer support and online communities for parents managing their child’s medical condition. Many parents rely on social media groups and online research as their primary sources of information, often valuing the experiences of other parents over medical advice. While medical information is accessible, several parents highlight a lack of practical support, particularly when it comes to everyday challenges like caring for a child in a spica cast.

III. *Multiple sources*

Many parents reported that they relied on a range of information resources, depending on the specific challenge they were facing. For example, if it is a medical issue, they ask the health practitioners but if it is something related to the daily care of their child, they would search for it themselves or seek advice from experienced parents in the forums.

> *The orthopaedic surgeon has been really good with me. She calls and she checks and she makes sure that I actually understand all of these medical words. I've been a little bit of research on my own. So the Facebook group has been really helpful. Kind of reading NHS documents online. Just to understand a little bit more.*
>
> *(Freya's mother)*

> *At three o'clock in the morning, when the cast is soaking wet you want someone else to say don't worry about it and it's a case I think other parents were the biggest source of hints and tips and practical ideas, I think the nurses was fantastic and reassurance medically giving advice. Getting hints and tips it's the practical experience of day to day care.*
>
> *(Angela’s mother)*

> *The only resources, I had were from external charities like steps and DDH UK and My hip baby, so there was nothing at all on the hospital*
>
> *(Charlotte's mother)*

The mothers also used the forums to ask for advice and information when they needed further clarification of something which had been explained to them by the medical team. Finding support from someone who has had the same experience reassured the mothers. This finding therefore overlaps with the previous section regarding using a support group as a strategy for coping and adaptation.

IV. Self-learning

To help parents understand what the doctor is telling them in the follow-up appointments, they educate themselves by reading articles on the Internet. An example of how the Internet helped mothers is when articles explain the importance of understanding clinical terminology when talking to healthcare providers. During the interview with Daisy's mother, she described how her child had been diagnosed using appropriate language that was easy to understand. Moreover, she was able to use the correct medical terms such as 'hip angle,' a medical term that I believe is not known to non-health practitioners. This prompted me to ask her how she knew these terms.

> *They give you a lot of information, they talk to you about how the hip is positioned and where they want it to be, and they talk about the angles and the angle they want to put the hip at. So, I did some research and I probably need to do a good deal of research to understand this issue. I read a lot and I do quite a bit of research and probably do need to do quite a bit of research to understand this issue. Kind of layman's terms for me so I understand a little more.*
>
> *(Daisy 's Mother)*

Help and support from those with prior experience of caring for a child with DDH is therefore important. This mother was grateful for her mother's stories of her previous experiences caring for children with DDH.

> *There are no support staff and the hospital nobody who could tell me what to do so, I just learned by myself and I am very lucky that I'd had my mom and that she had an experience with me. I think if I'd been a parent who didn't have any experience I have nobody else who knew what they were doing that would have been difficult*
>
> *(Beatrice's mother)*

Although all mothers felt that the surgical procedures had been thoroughly explained, there was a lack of advice and support during aftercare. Hygiene issues, such as changing nappies, were a particular challenge leading some to use their own limited experience, Steps or the Facebook group. Many of these challenges relate to the practical aspects of childcare in the cast, which the medical team do not discuss with parents.

The purpose of this section is to describe how most mothers prefer information to be supplied by reliable sources because it is an individual experience. The healthcare provider was at the top of parents' preferred sources of information for several reasons, including that the hospital has all of the details of each child. This is good from the parents' point of view and, as mentioned above, there were Facebook posts where mothers said that each child’s case is an individual condition according to the degree of dislocation, its severity and the child’s age. In addition, other parents who are going through the same thing can be helpful. Therefore, according to the mothers surveyed in this study, receiving lots of information and having group support makes the journey easier, so there were many sources of information.

8.2 External sources

8.2.1 Healthcare system

This chapter is concerned with the parents’ experiences with the phenomenon of having a child in a spica cast and how the response to it varies. The variable in qualitative research is context, which is all of the circumstances that contribute to the structure of the phenomenon under study. Moreover, the phenomenon always appears in a certain context or under specific circumstances that contribute to creating different experiences for the parents. In addition, three main components (accessing the service, understanding the practitioners and their roles, and service recipients expectations from the healthcare system) emerged during the data analysis as factors that shape the parents’ perspectives of the healthcare system. The role that the health practitioner plays in terms of the expectations of the mothers and the dynamics of the relationship between the mother and the health practitioner in gaining and understanding information about DDH are explained below.

I. Accessing the service

This section details how parents describe their experience with health providers and highlights the difficulties they face. Such problems included assessment difficulties, delays in services, and the inability to access support services. Meeting medical professionals in person can be difficult, depending on your location, and sometimes you cannot refer to orthopaedic or paediatric doctors.

a. Geographical location and place of residence

Although she had access to all of the appointments . Their ability to access services was only possible because they live near a specialist hospital and this is consistent with the fact that geographical location affects access to appropriate services.

> *The general hospital, they sent us there for a specialist. We're very fortunate they sent us actually, I think because it's on our doorstep. It took about two to three weeks for an appointment to come through, whether she needed treatment, I felt it could have been quicker when she was young.*
>
> *(Daisy’s Mother)*

Mothers noted that their access to services varied based on their geographical location. One family reported intensive physiotherapy sessions due to their therapist being from another hospital.

> *Where we live, physio from another hospital have to see her and don’t come out for a few weeks yet.*
> *(April FB Participant(2)post number 3)*

Furthermore, another mother opted to stay in a nearby hotel to be in closer proximity to the hospital.

> *We live an hour from the hospital to driving up and down several times a day seemed crazy. We stayed a week in hospital hotel*
>
> *(April FB Participant (1) post number 3)*

Parents thought it was a kind of external control by others that might change the context of their experience to find the right medical provider.

> *So I think, to begin with the General Hospital, they should have started treatment with her when she was six weeks old and she should have had treatment and the hospital that we it's our local hospital. It's not got a good reputation.*
> *(Elizabeth’s mother)*

> *I've fast learned that every single surgeon, hospital etc is very different. We’ve had no physio, no brace and no hydro whereas others do. Our consultant has her own views on which type of cast etc to use so it is all very individual. Obviously every case is so specific too that can impact.*
>
> *(March FB Participant (2) post number 13)*

These comments highlight several challenges families face when accessing healthcare services for their children’s treatment. Geographic location plays a significant role, with some families experiencing long wait times for appointments or long travel distances to reach specialists.

b. Unequal access to appropriate care

Moreover, because she did not trust the opinion of the NHS doctor, she went to a private doctor. After examining her daughter, it was determined that surgery was required. The doctor transferred her to an NHS hospital due to the high costs, so they still had a long wait for the operation.

> *We went for a private consultation with another orthopedic consultant and then, he said, you know, obviously private was going to cost us a lot of money which we couldn't do, but he said after my reasoning with him, he was more than happy for to transfer to a different hospital and take over her care under the NHS so then we did that he popped here straight onto a waiting list for Pelvic Osteotomy*
>
> *(Charlotte 's mother)*

Daisy's mother blamed the General Hospital for the delay in diagnosing her daughter's condition, despite repeated examinations, which denied the possibility of an early treatment intervention.

> *To begin with the General Hospital they missed, they should have started treatment with her when she was six weeks old, they should have done it when she was eight weeks old. So those first two scans that we had, and she should have had treatment and the hospital that we it's our local hospital. It's not got a good reputation, there was failings there, they miss that. But since being under the Royal National Orthopaedic, and we have our own baby hip clinic . It's a very specialist and I think because of that we have a really dedicated care, which are the parents and babies that go to main general hospitals, I don't think they would receive the same.*
>
> *(Daisy 's Mother)*

> *I think that is because we're a specialist hospital. And I think General Hospital just wouldn't be same. I think because of that we've had really dedicated care, the parents and babies that go to main general hospitals, I don't think they would receive the same .So I think for us, we're very fortunate because our hospital is a specialist Orthopaedic Hospital.*
>
> *(Elizabeth's mother)*

> *the staff in the hospital and the hospital were useless with giving me any sort of indication there was nobody to support in that respect*
>
> *(Beatrice 's mother)*

This highlights the gap in the healthcare system, where access to specialized services can greatly improve care and outcomes for children, while those at general hospitals may not receive the same level of expertise and support.

c. *COVID-19 pandemic*

The COVID-19 pandemic was an additional factor affecting access to services, although this varied depending on location. Faye's mother provides insight into the impact of the pandemic on the home visits of the health visitor in her area. Because the service was discontinued, she believed that this contributed to the delay in her child's diagnosis. She added that if she had seen the health visitor repeatedly, she would have been able to detect the condition earlier and not wait until her child had started to walk poorly. More frequent visits would have allowed her to better understand the situation. Although she initially alerted the health visitor about Faye's delay in movement, she was told that Faye was only slow in terms of motor development.

She was in the system, I think the care we couldn't have asked for better care for her but to get into the system, especially with lockdown and the huge delays.It would have been having at least a year before he had a surgery I think i've been reading on Facebook forums
(Angela's mother)

I haven't seen, they've had to report in my area because of COVID, so they stopped doing home visit, they don't come here anymore.

(Faye's mother)

For the same issue of delayed medical service, this mother shared her experience in a post (March post number 11), part of which concerned that her daughter had not been evaluated since the age of two years.

*She's 2.5 and I'm waiting for her 2 year check still as they're behind in our area. (*March *FB Participant (1)post number 11)*

as we're going into the third lockdown and hospital stopped all operations. She desperately needed to cast change because their skin was deteriorating and we were told by the hospital that we can't do a cast change my frustrations with all was no one drawing lockdown, but as we can see here, that's inevitable in that situation.

(Angela's mother)

The quote highlights the profound impact of the COVID-19 pandemic on healthcare services, showcasing the delays and disruptions families have faced in accessing timely care. These include prolonged waits for surgeries, suspension of home visits, delays in routine check-ups, and the cancellation of operations due to lockdown measures.

II. Doctor and nurse roles

A wide variety of health practitioners are involved in the DDH care pathway. It is imperative to possess a comprehensive comprehension of the respective responsibilities assumed by each member comprising the healthcare team, particularly in the context of chronic condition management. Having a clear understanding of the responsibilities and distinctions between various professionals is beneficial for parents. It is common for parents to expect healthcare professionals to be attentive to their concerns and rely on their opinions.

> *She had her six week check, because the doctor which didn't show anything untoward but because there was a history with myself, because I have DDH, she was then scanned at hospital and the phones that both of her hips were out so by quite a significant amount*
>
> *(Beatrice's mother)*

Active communication with the hospital made this mother feel at ease.

> *We've got a clinical nurse specialist at the hospital. And she's very easily contactable, so I can email her. She's been there about 20 years. She's really knowledgeable*
> *(Daisy 's Mother)*

The following post is from a participant who was frustrated because her son, aged approximately 18 months, could not stand or walk even though he had received the appropriate surgery to repair his hip. She described how he was still delayed in developing some movements. This led to the mother becoming frustrated and trying to seek advice and support from the DDH support page on Facebook.

My son was diagnosed at 13 months. Had to wait till 17 months for his open reduction and Spica . He has never stood or walked.. I'm frustrated. The health visitor seemed to think he may have hypermobility but people just hang the not walking on the DDH My understanding is DDH doesn't delay walking. Yes if they have a cast then development will pause while in it and regress a bit but it shouldn't stop it.
(March FB Participant (10) post number 14)

Daisy’s mother expected that the health visitor would play a role after the operation, where she would come to check the family’s situation to ensure that they could take care of a child in the cast.

I think it is about the health visitors and they've not been in contact, really, I think that kind of have a child that goes into the cast I would expect health professionals to get in contact with us, but that didn't happen, the hospital were great, they looked after us, but the rest of like the GP was where and the health visitors they're meant to sort of look after you. And I feel that they should have more input, they should probably come and check on a family with a child going through this just to make sure they're Okay, and, maybe helping.
Daisy’s mother

Some parents feel frustrated by delays in diagnosis and a lack of support from health visitors and GPs. Better coordination and more proactive involvement from all healthcare providers could significantly improve the support families receive, especially in complex medical situations.

Psychological and medical support for parents of DDH-children is extremely beneficial. Hence, it is necessary to seek help from specialists in the field and parents should be guided by a qualified medical team. Most importantly, the parents should be able to place their full confidence in the system. The family plays the most crucial role during the care period. One of the most important duties of the family is to support, motivate and reassure the cast-wearing child. Although it is a temporary stage, the child’s future well-being depends on adequate care at this time.

The person we were passed on to every appointment , he seemed to have somebody sitting there saying, if we do this we're at risk of this if we don't do this we're at risk of this and it was almost as though someone it. It almost felt like the field we were in wasn't his thing , what I mean if I didn't have the most confidence in him, like I didn't trust him

(Charlotte's mother)

However, her opinion of the second consultant was:

> *Really informative they were brilliant when we changed hospitals and consultant.so I wasn't particularly happy with my consultant, and our original trust, so I went for a private consultation with a paediatric .He seemed more knowledgeable in the area, he seemed to know more about DDH and it just made us feel more ease*
>
> *(Charlotte's mother)*

This shift from mistrust to trust highlights how much parents' confidence in their child's care can be influenced by perceived competence and clear communication.

8.2.2 Support from health practitioners

While parents are the primary caregivers, they see the role of doctors and nurses as offering emotional support as an essential skill in their profession, in addition to providing information and treatment. In this way, negative emotions such as stress, fear, anxiety, and lack of confidence that may occur during the care process can be alleviated. Empowerment from the mother’s perspective includes active listening which enables the health practitioner to find solutions to problems or specific worries that parents have. For some mothers, this was a prerequisite. Just feeling that someone else understands their feelings and listens to their doubts goes a long way in helping them overcome their fears. Additionally, being able to communicate with the medical team and be easily accessible if needed relieves a lot of parental stress. By being able to rely on them when there is an urgent problem or when they have a question about the situation reassures a mother. She knows that she is not alone and that there are people to support her if needed. This relates to the subcategories discussed earlier such as ‘unfamiliar experience’ and the ‘unexpected’ sub-category.

I. Negative Support from health practitioners

A lack of empathy or emotional response by the clinician to anxious parents is a negative aspect of this experience. In this case, the mother has major concerns about the health and development of her child.

> *Just wondering if anyone in similar position, When we go back to hip specialist next week he won’t be happy she isn’t walking yet as he was*

shocked she wasn't at 18mth review and couldn't understand why she wouldn't be, as in his words "DDH doesn't delay walking

(March FB Participant (1) post number 14)

Despite the high regard in which surgeons were held, other aspects of the aftercare process were not as positively described: many mothers commended the consultants more than the other health professionals.

At first when she had her six weeks scan and they didn't contact me to tell me what was happening, I was wonder how to chase that up. So there was no communication so she could have been in her brace sooner. And sometimes I wonder if that helps but then as soon as we got some consultants stage, everything was really good, and the pre - operative before we saw consultant there wasn't much monitoring of what was happening

(Beatrice's mother)

Angela's mother thinks that she was misdiagnosed because everything was normal when she examined the baby, despite being at risk because Angela was born prematurely (in week 36) and she was breeched.

X Ray was when she was too young and I also feel there should be a bit more follow up when she was a baby in terms of while she was clicking in breach let's do a few more checks and see how it is

(Angela' s mother)

Daisy's mother believed that parents should know their children well and be able to seek the best course of treatment for them.

I knew that she was uncomfortable and it was really when we saw a physio who tried to move her and she really crying; I said she cries as soon as you move the hips and said actually she is in pain it's to do with everything being so tight
(Daisy 's mother)

The mother considered that what the consultant had said did not make sense to her because he was delaying the surgery:

I suppose it felt like he wasn't listening to what I was saying, so I was saying okay our previous consultant said this, I was more than happy to go with that but her hips still not improving and so can we get something done about it, but he seemed to not want to do it
(Charlotte 's mother)

> *She’s been unable to practice any of these skills for 9mths, so surely it sets her back a bit but he was adamant not as research showed it didn’t affect physical development (March FB Participant (1)post number 14)*

The mother in question exhibited a prevailing sentiment of frustration and diminished expectations towards healthcare professionals as a result of her negative encounter with the local hospital.

> *It's really difficult to get hold of anybody in the hospital ,So I always just come to the online support group for any help. We were in hospital I got very upset and very angry at the lack of care.*
> *(Elizabeth’s mother)*

> *They sent a nurse out to Elizabeth in shortly after she came home from hospital but the nurse told us herself she didn't know anything about DDH really and I don't really know what the nurse thought she was coming out to do, because she couldn't really offers any support because she had no experience or training in in children and Spica cast.*
> *(Elizabeth’s mother)*

However, Charlotte’s mother’s view was that the nursing staff did not train her child in toileting at the hospital because of her pain.

> *I asked sort of on the social media group and what's, the best thing for me to do regarding toileting so that we don't get the cast dirty because, when she was in hospital she was in so much pain they didn't want to put pressure on her go into the toilet properly.*
> *(Charlotte’s mother)*

Many of the parents were frustrated because they believed they had insufficient information about DDH.

II. Positive Support from health practitioners

This section emphasizes the positive influence that supportive healthcare professionals can have on both the emotional and practical aspects of a child's treatment.

Charlotte's mother describes how the doctor explained the surgical procedure directly to her child in an accessible and reassuring way:

> *When we saw the doctor he says, I’m going to do this one, because and then explained why he was doing it and then she sat there, and she said to him I’ve got poorly hips are you going to fix them and the man says oh yes you'll have an operation, he said I’ll do a little cut here and showed on a hip where he was caught and he said and then I’m going to fix your bones, and then you'll be all good to go dancing again and everything, and we sort of explained the process of the operation, so she would go to hospital should go for a sleep. The doctor would fix a hip and then she'd wake up she'd been a little bit of pain in a cast.*
> *(Charlotte 's mother)*

Similarly, Angela’s mother highlights the practical and emotional support provided by nurses:

> *I think the nurses was fantastic and reassurance medically giving advice. Getting hints and tips it's the practical experience of day to day care.*
>
> *(Angela’s mother)*

This underscores the crucial role of healthcare professionals in ensuring timely adjustments to the treatment plan, thereby preventing complications related to the cast.

> *She needed to early cast change because it was so bad. The nurse and consultant completely fought as high up as they have to get our casts change because they said we're Otherwise, we have to remove a cast early, which is going to deteriorate, or the work so. They should we advocating for early they were pushing for her to be supportive, and they couldn't do more, they've been absolutely fantastic*
> *(Angela’s mother)*

It becomes clear that healthcare professionals play a vital role not only in delivering medical care but also in fostering trust and providing practical support.

III. Listen to their concerns

This section emphasizes the importance of healthcare professionals actively listening to parents' concerns. These examples highlight how essential it is for healthcare providers to engage with parents and consider their perspectives in order to build trust and improve care outcomes.

> *We'd already been transferred from our original consultant So as you can appreciate we've built up a good boundary with this consultant, you know we trusted this original consultant but then the person we were passed on to every appointment went to he seemed to have somebody sitting there saying, if we do this we're at risk of this if we don't do this we're at risk of this and it was almos as though someone it. I suppose it felt like he wasn't listening to what I was saying*
>
> *(Charlotte 's mother)*

> *they've been really good it once they started to listen, so I see me to orthopaedics we went from appointment to X Ray to surgery within about three or four weeks and had paid, about a year from when we initially raise the concern and to get the X- ray*
>
> *(Faye's mother)*

This demonstrates the importance of active listening and responsiveness from healthcare practitioners in building trust and ensuring timely care. It suggests that when parents feel heard and understood, the overall experience improves, both in terms of efficiency and emotional reassurance.

III. Appropriate emotional and informational support from the nursing staff

This section highlights the essential role of nursing staff in offering emotional and informational support. The examples show how skilled and empathetic nurses assist parents in navigating the challenges of caring for a child with medical needs.

> *We've got a clinical nurse specialist at the hospital. And she's very easily contactable, so I can email her. She's been there about 20 years. She's really knowledgeable this nurse specialist and she did actually come around and see me she they lent us a table in a chair for Isabel to sit in the taught us how to hold her we weren't really taught how to clean house or anything like that, but I think kind of we just do that. And but yes, they did come around and they showed us you know what to do how to care for how to check for sores so I think yeah, they did show us really well how to*
>
> *(Elizabeth's mother)*

Angela's mother also recalls the support provided by a designated nurse, who offered clear instructions on how to protect her child's skin under the cast

> *on under the cast to keep her skin protected*
>
> *(Angela's mother)*

Similarly, Faye's mother shares her experience of consistent and helpful communication with her nurse.

> *the nurse when I speak to her if she doesn't know the answer she knew she can help me work it out or she can ask somebody else to call me back and they're very good trying to help.*

(Faye's mother)

These examples underscore how nursing staff contribute to both the emotional well-being and practical care of parents, fostering confidence and providing essential guidance in managing their child's medical needs.

VII. lack of knowledge from HCPs about spica casts

Nurse was amazing, but he hadn't got a child doing it, so you could tell you what this is what to do
(Angela's mother)

I did ask the nurse and the GP and the doctors and they said, well, we don't really know we haven't got much experience with this so.(hospital in the middle of a city) . there are no support staff and the hospital nobody who could tell me what to do so, I just learned by myself and from my mom.

(Beatrice's mother)

This mother asked the health visitor how to take care of her child in the spica cast but she was told:

She made it very clear, She said oh I don't know, have no knowledge about Spica casts and had never seen one before
(Elizabeth's mother)

Daisy's mother explained that the reason for this was a lack of education and training for the health visitors.

An untrained, you know with the NHS under pressure, it just doesn't happen to her.

Daisy's mother

Freya's mother found that the ward staff could only offer basic advice and were unable to provide more specific instructions regarding how to take care of a child in a cast.

They can give me is kind of really basic advice. They don't understand because they don't have a child in this cast. And they've not done this before I mean in terms of like care, so when she spills something on her cast, the nurses don't really know how to help me clean it up or anything because they're not used to that care.
(Freya 's Mother)

This was also confirmed by Elizabeth's mother because the nurses at the hospital showed her how to take care of her child by training her on a doll to show her what a spica cast would look like. Therefore, she received all of the information that she needed about post-operative care through the DDH UK support group rather than through the NHS. She described her reasons in her interview, as the following excerpt shows.

> *They sent a nurse out to Elizabeth in shortly after she came home from hospital but the nurse told us herself she didn't know anything about DDH really and I don't really know what the nurse thought she was coming out to do, because she couldn't really offers any support because she had no experience or training in in children and Spica cast.*
>
> *(Elizabeth's mother)*

Both Elizabeth's and Freya's mothers found that when they returned home following the operation, they did not even know how to change a nappy. They both emphasised how for spica-cast wearing children, childcare involves a lot of trial and error and it is one of those things that unless you have experience of doing it, you would not know how to do it.

This section found that some mothers described a lack of healthcare for their children in terms of the services provided to them and their accessibility. In addition, the mothers' perceptions of the health practitioners' roles and expectations differed greatly. Despite being comfortable with the clinical decision-making power exercised by the practitioners, the mothers indicated that they wanted to participate in the decision-making process of their child's medical care through positive interaction between the family and the medical team.

8.2.3 Social support

Several forms of social support had been experienced by parents in this study, including family and friends, support groups on Facebook, and seeing a helpful doctor. Many caregivers' negative feelings were ameliorated as a result of these support methods.

Support from a husband plays a crucial role in this experience.

> *I was the one looking after her, I was the one cuddling her changing her nappy picking up taking it to the table and my husband did as well, but it was primarily me*
>
> *(Angela's mother)*

> *so occupational therapy said she would have to sleep downstairs. So dad bless him moved her bedroom downstairs for a period*
>
> *(Charlotte's mother)*

This family managed to overcome the feelings of isolation with support from family and friends.

> *We all felt a little bit isolated I guess we were limited to what we could do with Charlotte while she was in the cast, but we were lucky in that we've got friends and family who live close by, who would come round by appointment and that sort of booking with us to see or can we come in for an hour see Charlotte will have a chat and a catch up and that was kind of it was nice that they were able to come around*
>
> *(Charlotte's mother)*

As part of the coping strategies that the mothers described, the presence of family and friends was an important factor that supported mothers.

> *I was very fortunate that I had a family who came down to help me and I have wonderful friends who took me meals, so that I could, and they would bring them to the hospital and I was very fortunate that it didn't happen in (name of place) so people could come and visit us in hospital and bring me foods.*
> *(Beatrice's mother)*

Parents of children with DDH have created a support system within their community with other families of children experiencing similar conditions.

You want someone else to say don't worry about it and.it's a case I think other parents were.Your biggest source of hints and tips and practical ideas, I think the nurses was fantastic and reassurance medically giving advice.
(Angela's mother)

I got all the information that I needed about post operative care through the DDH UK support group rather than through NHS support
(Elizabeth's mother)

This mother is unsure about the correct or safe positions for her baby and is hesitant to place her child on the floor, fearing the splint might be an obstacle. However, in the following dialogue, another mother explains how to do it properly.

"Oh so they can lay on their fronts? We've been so scared of doing anything with her apart from holding her and taking her everywhere (think our backs are going to give in soon)"

(March FB Participant (1)post number 12)

"absolutley!! Its super important they go in different positions to avoid sores apparently!! We used a big floor beanbag particularly before she would move so that everything was well supported, pillows under legs/tummy etc, basically wherever was need to ensure the cast wasnt digging in. To be honest, we ditched the beanbag in the end because she wouldn't stay on it anyway You get some kids on scuttle bugs etc or skateboards getting around, they'll find the most comfy way for them."

(March FB Participant (2) post number 12)

Parents' networking opportunities were provided on Facebook which allows for the exchange of information, emotional support, and is a place to mutually solve problems.

Due to the fact that participants were recruited through a DDH parent charity's social media platforms, it can be argued that these parents were already involved with the charity's support.

Social media support has been identified as a powerful mediator of parental wellbeing and family adjustment in this study.

> *“Vent away. Big hugs to you all and the guys are right our little warriors are so resilient.”*
> *(November FB Participant 4 post number 9)*

> *I think, the forums on online they're really helpful because there's other parents there who just know what you're going through.*
> *(Daisy’s mother)*

Social media platforms, particularly those associated with DDH support groups, serve as essential resources for information exchange and mutual support, further strengthening parental resilience and coping strategies.

Conclusion

Parents struggle with uncertainty regarding their child’s condition and how they should take care of them. Caring for a spica cast-wearing child is not like a typical mothering experience; thus, parents want to know the factors and variables they can change to master the required care. As a result, they seek to minimise their uncertainties regarding the situation.

In conclusion, this chapter explores the factors contributing to parental empowerment and agency, emphasizing how both internal and external resources enhance parents' control over their situation. Empowerment arises from two main sources: personal resources, such as gaining agency over the situation and accessing information, and external resources, including support systems and healthcare services. The following sections provide an in-depth discussion of each of these elements, highlighting how they contribute to a parent's ability to navigate the challenges of caring for a child with DDH.

The concluding phase of the coding process involves theoretical coding, whereby the fragmented narrative is meticulously interwoven to construct a cohesive and well-structured theory, as discussed by Charmaz (2014). This is explored in Chapter Nine.

CHAPTER NINE: THE DEVELOPMENT OF THE THEORY

Chapter overview

This chapter details the process of generating my theory about the experience of being a mother for a child in a spica cast. To develop a theory about this experience, I used a constructivist grounded theoretical approach that aligns with the qualitative paradigm, aiming to gain a descriptive and analytical understanding of the world as perceived by participants within their context. The grounded theory approach then seeks to understand how and why phenomena occur and how and why people may react in a certain way to a situation using categorised data to explain. This approach is particularly suited to my study, as it involves generating or "grounding" theory from participants who have experienced the process of caring for children in a spica cast. Given that my topic is relatively new and has limited existing literature, I chose an inductive qualitative approach to investigate the experiences of mothers caring for children in a spica cast.

The grounded theoretical approach I adopted in this study involves the collaborative construction of meaning through interaction between mothers and my interpretation which is tightly aligned with my philosophical stance. As discussed in Chapter 3, my study of parents' experiences is informed by my assumptions about the nature of reality, knowledge, and values. I hold the belief that reality is subjective and constructed through one's experiences and interactions with the world (Charmaz 2014). As mothers are usually the primary caregivers of children in a spica cast, they have the most authoritative voices on their firsthand experiences. Consequently, this study seeks to delve into the experience of being in a cast from the vantage point of those directly immersed in it.

In what follows, I discuss the process I followed to develop my theory (Section 9.1). I will then provide a detailed account of the application of the theory.

9.1 Theory generation

The development of my theory has followed a series of stages. First, I collected and analysed the data using a constant comparison method (See Chapter 4). Through axial coding, I organised all focused codes into three main categories. To illustrate the relationships between these categories, I created a model that involves three components, namely: conditions (phenomenon), interactions (processes), and consequences (context). In this study, the phenomenon under investigation is the experience of caring for a child wearing a spica cast from the caregivers' perspective. The process category emanates from the grounded theory method and outlines how these caregivers come to accept the condition of caring for a child wearing a spica cast and adapt to this situation. As parents develop their coping abilities, they gradually become empowered to deal with the situation, which is the final context or stage in the theory I propose. These three categories served as the basis upon which I developed a theoretical model of caregivers' experiences illustrated in Figure 17.

This theory is based on analysing the extracted data and the codes formulated.

As the research progressed and categories began to emerge, theoretical sampling was employed to gather additional data supporting the conceptual and theoretical development during the data analysis (Charmaz, 2014). The interviews enriched the evolving understanding of this phenomenon.

I used the same coding technique for analyse the FB and the interview, as explained in Chapter Four. There was a continuous process of comparing new data with existing data, codes, and categories. In the final phase of coding, theoretical coding was used to examine each of the codes generated in the axial coding stage. Many of the axial codes were elevated to conceptual categories. The axial codes from both posts and interviews produced three basic categories that represented the central phenomenon under study, specifically focusing on the experience of caring for a child in a spica cast from a caregiver's perspective.

Throughout this process, memos were written to document the ideas, insights, and rationale behind decisions about codes and categories and how caregivers' experiences were interpreted. The final step involved constructing a substantive theory that established connections between the final categories and presented the relationships concerning the concepts (see section 9.2).

In Section 9.2 below, I detail how the three individual categories I mentioned above informed the development of my theory. This will be followed by an overview of my theoretical model in Section 9.3.

9.2 Theorising from categories

Before I explain how the three categories helped me to build a theory about parents' experiences of looking after children in a spica cast, I show the diagram (Figure 17) details below, which clearly illustrates the different stages and constructs of development, as well as the progression of movement between them, depicted by the arrows that show the interconnection and progression through each stage. The diagram clearly illustrates processes and interactions experienced by caregivers looking after children wearing spica casts after DDH surgery. As parents face new challenges after coping with previous ones, they may revisit or regress within and between stages. As illustrated in Figure17, there is considerable overlap between the three main categories in terms of making meaning and normalisation because each element of this experience involves processes that contribute to these aspects.

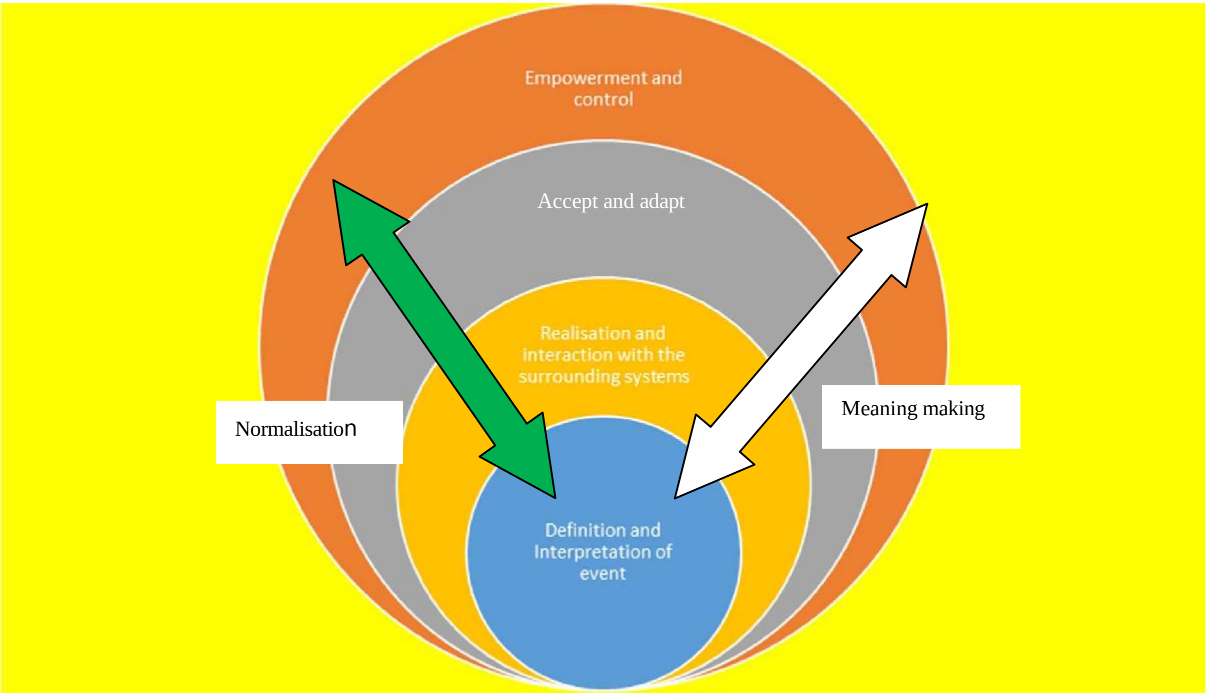


Figure17: Theory of "Being in Spica cast after DDH surgery from mother perspectives"[1]

Using the categories I determined to construct the theory involved a thorough analysis and synthesis of the collected data. I identified recurring themes and patterns, and correlations within the data and organised them into coherent categories. These categories serve as fundamental building blocks, providing a structured framework to understand the phenomenon being studied (Charmaz, 2014). I will now detail each of the three fundamental categories: phenomenon, process, and context (See Figure 17).

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[1] The purpose of this study was to investigate the experiences of parents who look after children with Spica casts. However, many of the Facebook posts I analysed were made by individuals who used pseudonyms, making it difficult to determine their gender. The initial phase of my research involved collecting a wide range of information about the topic through a purposeful sampling strategy, followed by a more focused theoretical sampling approach. Although all interviewees were mothers, it is important to note that having a child in a Spica cast affects the entire family. Therefore, the insights obtained from the interviews primarily reflect the mothers' perspectives on their individual experiences. References were made to parents and the family as a whole where necessary because the experience of caring for a child in a cast does not affect mothers only. As my theoretical framework developed in the subsequent stages of my study, it is accurate to say that it was mainly informed by the experiences of mothers.

9.2.1 Category 1: The phenomenon of caring for a child in a spica cast

This first category is about caregivers’ perspective on looking after children placed in a spica cast, as derived from the findings of Chapter 6. My data analysis, which involved a “constant comparison method” (Charmaz, 2014), revealed that mothers of children with a spica cast first define the event and meaning of this caregiving experience, and the effects of the period of cast on the perceived physical, social, and psychological well-being of their children. ‘Being’ in a spica cast describes caregivers’ perspectives on the temporary change in the children’s life after surgery. This first category is important and elevated to a concept that encompasses several other categories closely related to the aspects of the child's development, behaviour and social interaction during this period. Mothers then interpret this new event with the surrounding systems and try to adapt to the arising responsibilities.

The definition of events (situation definition) and the caregivers’ understanding of their children’s situation in a spica cast is influenced by various factors such as psychological, physical ,and social . When surgical intervention and the application of a spica cast occur, they introduce unique challenges and restrictions that deviate from the typical parental experience of caring for children who do not have a physical disability. Parents then need to navigate many changes as their children experience post-operative pain, immobility, and emotional disturbances, including feelings of social isolation. As families navigate through these new experiences characterised by added demands and shifts in routines, roles, and responsibilities, expectations, they seek to find meaning in these challenges and develop an ability to cope with these emerging challenges.

Parents' interpretations of this event are dynamic and evolve as the family adapts to the new experiences of caring for children with distinct needs, especially those that cause stress. These interpretations may stem from daily concerns and doubts about meeting the children’s care demands, leading to changes in work patterns and social activities to meet their needs.

9.2.2. Category 2: The process of acceptance and development of adaptive coping strategies

As discussed in Chapter 7, this category summarises parents' experiences and the coping strategies they adopted to address the caregiving difficulties and to meet the needs of their children. Mothers are usually responsible for their children, but the experience of caring for a sick child is different from the typical care of a healthy child, as narrated by the mothers I interviewed.

During my analysis, I also discovered that mothers put in intense physical effort to provide the best possible care for their children, even with limited resources. They also play an active role in their children's lives by ensuring that they remain socially engaged and active.

Parents try to understand this new experience through acceptance and adaptation. The initial uncertainty surrounding the event changes the parents' usual responsibilities, making them try to accept new demands and cope with the situation. Indeed, my findings have revealed that the level of uncertainty surrounding the child's condition, changes in parental roles, and adjustments to family functioning were major sources of stress for parents.

Subsequently, parents progress from the acceptance stage to the adaptation phase, endeavouring to address various practical and emotional aspects related to the experience of having a child in a spica cast. They strive to adapt to these new responsibilities by reconfiguring their roles and duties to address their child's needs effectively. They also try to reintroduce elements of their previous routines and habits to restore a sense of normalcy to their lives, to a certain extent. Mothers frequently resort to professional and family support as coping mechanisms. Experiences vary among families interviewed, potentially influenced by factors such as context, available support, and individual characteristics. Caring for a child in a spica cast places significant physical, financial, and emotional burdens on the parents. Compared to parents of typically developing children, those caring for a child in such circumstances often report lower subjective well-being and are at greater risk of experiencing physical and mental health challenges, including depression.

9.2.3 Category 3: Contextual factors shaping the phenomenon

This category is about the contextual factors that encompass all the circumstances contributing to its structure and play a significant role in shaping parents’ unique experiences, as discussed in Chapter 8. It is widely recognised that the family plays an essential and influential role in this journey for a child. One of the primary responsibilities of a family is to create a supportive, stimulating, and comforting environment free from obstacles or negative influences. It is therefore essential for families to feel empowered and actively involved in ensuring a child's well-being during this time.

Families often need to develop coping strategies when caring for a child with a health condition. This involves identifying resources that are available to them. As parents move through different stages of caregiving, they may seek information about their child's health, anticipate challenges, and accept their role as caregivers. From the parents' perspective, healthcare professionals, hospital services, and knowledge are tangible resources that can help support their child's care. Throughout this process, parents also educate themselves about their child's diagnosis, symptoms, and treatment, which can boost their confidence in providing care.

This study categorises support into three main types: social support, healthcare support, and informational support. Social support is especially important for reducing caregiver stress and promoting positive family adjustment.

9.3 Overview of the theory

In this section, I introduce my emerging theory on caring for children in a Spica cast from a mother’s perspective. The role of theories is essential in providing a structured framework that informs every stage of the research process. By providing descriptive language and conceptual frameworks, theories help researchers communicate their observations effectively. In my study, the theory has brought attention to the characteristics, patterns, and aspects of parents' caregiving experiences. It has also provided explanations for the underlying causes of these experiences by suggesting relationships between factors and observed patterns or behaviours.

Through my philosophical stance, I have been able to effectively communicate this parental experience in a way that contributes to the broader body of knowledge in this field. The theory I have developed has helped position my findings within the existing literature on parents' experiences caring for children with an illness and synthesise diverse empirical evidence into coherent explanations. Thus, it has enabled me to enhance the credibility and validity of my study. Considering this, the perspectives of caregivers are presented in relation to what are regarded as the fundamental properties of parental experiences in caring for a child in a Spica cast.

The theoretical framework underpinning this study posits that within the context of caring for a child in a spica cast, four interrelated processes occur simultaneously, without distinct or sequential stage boundaries. Analysis of the data presented in Chapters 6, 7, and 8 suggests that while these processes appear to follow a discernible order. This model can be visualized as a series of concentric circles, where everything happens at once but at different levels of intensity. At the center of this model is (situational definition) the point where everything begins. Parents must first define and understand what being in a spica cast means. They are trying to make sense of the situation while simultaneously working toward acceptance and adaptation.

Moving from the inner to the outer circles represents an evolving struggle; while challenges remain, the intensity and nature of the experience may change. Factors such as hospital resources and specialized care can influence their experience, making it either more manageable or more overwhelming. The outer layers of the model represent these external influences, which can shape and modify parental experiences as they navigate the situation.For instance, experiences may be more positive if the parents access specialized healthcare, but the core challenges remain similar. Adaptation, then, involves parents acting based on the meaning they have attributed to the experience. However, meaning itself is not synonymous with acceptance or adaptation. Rather, it represents the parents' acknowledgment of the situation, followed by the process of adapting to it.

Ultimately, this framework emphasizes that parents do not progress through fixed, sequential stages but rather navigate these challenges in a continuous and evolving process, where experiences are interconnected and overlapping. Their journey of meaning-making, acceptance, and adaptation unfolds dynamically, shaped by ongoing interactions and adjustments to their changing circumstances. The research conceptualizes this as a dynamic process involving phenomenon, process, and context all occurring simultaneously.

When parents are discharged from the hospital with their child in a spica cast, they face a variety of challenges. They quickly realize that their daily routines, childcare practices, and responsibilities have all changed, necessitating a redefinition of these aspects. The experience of having a child in a spica cast requires parents to accept these changes, adapt to them, and ultimately regain a sense of control over their lives. This phase of adaptation is characterized by an ongoing search for meaning, particularly concerning their new responsibilities. It is not merely about redefining "responsibility," but rather about understanding the new roles and responsibilities they must assume. Parents often struggle with the uncertainty of these changes, especially when they are unprepared for the new demands placed upon them. This struggle is further complicated by emotional reactions and the challenge of balancing their new caregiving responsibilities with other aspects of their lives. The research contextualizes this process within the context of a phenomenon-based model, where all elements–the changes, challenges, and emotional responses–unfold simultaneously.

This phase is often accompanied by emotional distress, as parents must continually assess their ability to meet their child's needs while also interpreting their evolving roles. Moreover, families establish expectations regarding how they should navigate the situation and engage with healthcare providers, which significantly influences their overall experience.

This theory aims to conceptualize the meaning of the spica cast from the perspective of parents, exploring its impact on both the child and the family unit. It seeks to understand how parents interpret, respond to, and adapt to the challenges associated with caring for a child in a spica cast. By examining how parents make sense of their experiences, this framework identifies the key factors that influence their ability to manage and control these circumstances effectively.

Furthermore, this theory has broader implications that extend beyond individual families. It emphasizes the specific needs of parents navigating this experience and the strategies they employ to regain a sense of control. Understanding these dynamics not only enhances support systems for families but also informs improvements in healthcare services. Within the context of the UK healthcare system, these insights can lead to more effective interventions, improved communication between healthcare providers and families, and policies that address gaps in care and information accessibility for parents managing a child in a spica cast.

My theory also provided a two-way causal interaction between the factors described in the model. The dynamic nature of this experience is attributed to the synchronous occurrence of these three factors (phenomenon, process, and context), thereby establishing their interdependence. Parents may notice different aspects of their child's condition and understand them in their own way. However, it is an ongoing process to achieve acceptance, adaptation, and empowerment within the systems surrounding the child. As the child grows and recovers from surgery, things continue to evolve, and the child's needs change constantly. Therefore, parents have to redefine, reinterpret, reaccept, readapt, and regain empowerment and control repeatedly throughout the entire recovery and caregiving process.

In the following section, I explain the layers of my theory as illustrated in Figure 17 and support my discussion with references from the existing literature.

9.3.1 Definition and interpretation of the event

This theory explores how parents create meaning from their experience of caring for a child in a spica cast. At its core, this process involves defining the event and recognizing its immediate limitations. Parents assess how the cast influences their child’s physical abilities, social interactions, behavioral adjustments, and emotional well-being, as well as the broader impact on family dynamics.

Family constructs of meaning are not fixed; they evolve as families encounter new challenges, particularly in times of stress. The difficulties posed by the spica cast demand new coping strategies, shaping how families adjust to and interpret the situation. Understanding these shifting interpretations is crucial in comprehending the overall experience.

As parents process the reality of the spica cast, they gradually find ways to accept and adapt. Acceptance means acknowledging the limitations imposed by the cast, while adaptation involves adjusting daily routines and activities to accommodate their child's needs. Over time, parents strive to normalize their circumstances despite the challenges.

Represented by the blue circle in Figure 17 is the process of defining and interpreting the event. This category is about the initial response of parents to their child being in a spica cast.

9.3.2 Realisation and interaction with the surrounding system

The category represented by a yellow circle in Figure 17 emphasizes that the concept of "definition" in this context refers to the objective reality of the situation , recognizing that their child's condition has altered their daily life and routine. Initially, parents must understand and accept that everything has changed. Following this realization, they begin interpreting their new reality, identifying what has changed, what is required of them, and what resources they have to cope. These interactions occur within the context of their home environment, where they realize an imbalance exists between their ability to meet these new demands and the resources available to them.

As they extend their focus beyond the home, they further recognize that the external environment is often ill-suited to accommodate a child in a spica cast. This realization underscores the specific challenges and limitations they face, including restricted mobility and the need for specialized care.

Exploring the external environment, parents come to realize that it is not suited to the needs of a child in a spica cast. This realization highlights the differences, difficulties, and challenges they face. It also underscores the specific limitations imposed by the cast, such as restricted mobility and the need for specialized care.

As they recognize the imbalance between demands and their ability to meet them, parents seek coping strategies. The surrounding environment ,including family, community, and healthcare support, can either ease or intensify their experience.

Ultimately, the core of the process is about meaning-making. It is not merely about parents finding meaning after the event, but rather it is about the ongoing journey to understand the meaning of having a child in a spica cast. This journey is shaped by acceptance, adaptation, and the availability of external support, which together can ease the experience for the parents and facilitate their adjustment to the new reality.

9.3.4 Acceptance and adaptation

Moving to the third category represented in grey in Figure 17, which is about how parents try to make sense of the different facets of the new situation. Parents are faced with recognizing the changes that occur, the responsibilities placed upon them as caregivers, and the challenges encountered while taking care of a child in a spica cast.

In grounded theory, Corbin and Strauss (1990) define process as a series of evolving actions, interactions, and responses that individuals engage in as they navigate a particular phenomenon. A process in this context is dynamic and unfolds over time as people respond to challenges, make sense of their experiences, and adapt their behaviors accordingly.

Meaning itself does not change (being in a spica cast), but parents go through a process of acceptance and adaptation. The first level of meaning involves accepting the restrictions imposed by the spica cast, followed by a phase of actively responding to these constraints by modifying routines, responsibilities, and caregiving strategies to accommodate their child’s new needs. Acceptance and adaptation do not mean redefining meaning itself; rather, they involve embracing a new reality and adjusting to it. Meaning-making, therefore, is not a passive process but an ongoing negotiation between understanding, acceptance, and adaptation.

In my study, I explored a variety of maternal experiences and meanings. Parenting a child in a spica cast is a completely different experience compared to parenting a child without one. It is challenging to fully understand the lessons until you have lived through them, faced them, and sought out ways to cope with them. The responsibility and new demands that have arisen after the child undergoes surgery and the period of the cast are considered a challenge for the family. In such cases, the family must exert some unusual effort to get back to their normal daily routines, such as observing, experiencing, defining, understanding, and taking special action. These sequences of experiences and actions at times of challenge, in their endless variety, are known as coping strategies. Spica cast children are extremely reliant on their parents, and their parents are constantly burdened with tasks and responsibilities. Parents feel vulnerable due to their children's helplessness and constant need for attention. Having a child in a spica cast means dealing with challenging emotions and understanding that the child is different from their previous self and other healthy children of the same age.

Reported coping strategies among the majority of mothers in my study included focusing on what to do, obtaining sufficient information, and seeking advice from experienced individuals. Parents created their version of normality in the face of the situation and developed their narratives to integrate their children, being aware of the restrictions placed upon them. All parents mentioned making sacrifices, including employment status, family time, and social activities, but accepted these as part of their role as parents to do what's best for their child. Over time, the family redefined its overall situation in response to these demands and altered its perception of the circumstances. The spica cast placed an additional burden on the family as their usual routines disintegrated. However, the parents began to adapt to the fact that the family needed to assimilate the required changes into the family system.

The adaptation phase began when the mothers aimed to achieve organization and balance over time in response to the many management demands of the disease. Balancing the caregiving responsibilities with personal, physical, and mental health care needs (medical care, sleep, nutrition, exercise, and personal time) was highlighted as a big challenge. The ongoing responsibilities and activities required of parents can lead to caregiver burden, social isolation, changes in employment, uncertainty, and physical and emotional health problems. These factors can contribute to caregiver burnout. Concurrently, during this transition, the primary focus is on meticulously evaluating any potential alterations in the child's behaviour, personality, and motor activities. This evaluation aims to ascertain whether these changes fall within the scope of normal development and discern between normal and concerning behaviours.

Long-term caregiving roles require adequate support from services. According to my participants, looking after a child with a spica cast is an unpredictable and uncontrollable experience. Parents took the initiative to figure out the cause of their child's delayed motor movements or to notice if something was wrong with their child. Some changed their medical care provider to find a specialist in paediatrics or orthopedics. Parents were more likely to take action when they were given a choice, as that increased their sense of control.

9.3.4 Empowerment and control

This is represented by an outermost amber circle in Figure 17. My theory acknowledges the significant influence of control and empowerment, which are crucial for parents to effectively navigate their caregiving journey, enabling them to manage challenges more effectively. One of the study’s key findings highlights that parental experiences are deeply influenced by the broader healthcare and social context in which they receive care. Through this process, empowerment changes how parents accept and adapt to the situation, altering their interpretation of the event and how they interact with the surrounding system.

Control can be categorized into two forms: internal and external. Internal control refers to the parents' efforts to actively search for knowledge and information that helps them manage their child's care. This often involves looking for resources that are beyond their current understanding, such as medical research or advice from other parents. External control, on the other hand, occurs when parents seek assistance from healthcare professionals or services to support their child’s care.

A key challenge arises when parents are discharged from the hospital without clear guidance on how to care for their child, such as how to keep the cast dry or manage daily tasks, as discussed in Chapter 7 under the "Taking Responsibility" subcategories. Without proper instructions or preparation, parents may feel uncertain about how to proceed, leading to heightened stress and difficulty in managing their child's care.

In some cases, parents attempt to regain a sense of control over their child's care by seeking alternative healthcare providers, especially when they feel that their current support system is inadequate. This may involve consulting specialists or transferring to different hospitals in search of better care. However, their ability to make these changes is often constrained by the availability and quality of healthcare services, which directly impacts how much control they feel they have over the situation.

9.3.5 Meaning Making

The concept of ‘meaning-making’, represented by a white arrow in Figure 17, encompasses the intersection of coping, adaptation, control, and empowerment, all centered around the pivotal role of parents as caregivers. At the core of their experience is the pursuit of a meaningful understanding of what this journey signifies within the context of their parenting. Essentially, meaning-making is their attempt to make sense of the experience itself. They strive to understand what this new parenting experience entails and how it differs from the normal parenting experience.

This process extends beyond merely interpreting the event or acknowledging the physical, social, and behavioral changes linked to the cast. It entails understanding what the spica cast signifies—how it represents challenges and transformation. Through this continuous process, parents engage with the challenges they face, ultimately recognizing them as integral components of both their child's healing process and the evolving dynamics of their family experience.

The reason for representing meaning-making with a bi-directional arrow cutting across the four layers is to illustrate that parents construct and develop meaning from their own experiences across these layers as they move back and forth. As the child's recovery journey progresses, parents move through these layers continuously, and the experience evolves accordingly. As the child's needs shift, so does the meaning attributed to the experience. Meaning-making evolves with the situation, reflecting the dynamic nature of events. Therefore, meaning-making is not a one-directional process; it occurs back and forth across the four layers. As the experience changes and new developments arise during the recovery journey, parents continually adapt and reinterpret their understanding, thus reshaping the meaning of their experience. This depiction signifies a reciprocal relationship, suggesting that the layers and meaning-making influence each other simultaneously or cyclically.

9.3.6 Normalisation

Illustrated by a green arrow in Figure 17, normalisation in this study was described as a constant process of adjustment of the environment to provide experiences that will meet the child’s changing social, intellectual, and emotional needs. Parents reported that they tried to give their children as normal a life as possible. They used strategies to normalize family life by balancing children's needs and adapting family life patterns to reduce the difference between the current life and the previous life, all while integrating the presence of a spica cast into their everyday lives.

Parents should not only encourage normal life experiences for their children but also carefully assess the accessibility of activities and make necessary environmental adjustments to accommodate the child’s restrictions. Thus, normalisation involves effort beyond that of the usual parenting role. In this study, parents reported using strategies to normalize family life by balancing their children's needs and responsibilities while still meeting their own needs. Initially, parents grappled with uncertainty and did not know how to manage and care for a child in a cast with few information resources and medical support. However, over time, practical experience and various turning points modified the process. While the goal of normalisation remained constant, the specific behavioural strategies used to achieve that goal changed. Trial and error was the primary method used to find solutions and achieve normalisation, as the experience of care was unfamiliar.

Normalization after surgery, particularly when managing a spica cast, is a complex and ongoing process in which parents work to create a sense of routine and stability for their child while adapting to new challenges. A full return to their previous state of normalcy is not entirely achievable; rather, families engage in a continuous cycle of acceptance and adaptation. As discussed in Chapter 7 and Figure 15 (p.125), this process involves implementing coping strategies, incorporating medical equipment into daily routines, and fostering social connections to maintain a sense of normality. Despite the physical limitations imposed by the spica cast, parents actively seek ways to keep their child engaged in everyday life, including activities such as visiting friends and attending playgroups.Ultimately, normalization is not about restoring past routines but about redefining and restructuring daily life in a way that accommodates the child’s evolving needs while ensuring stability, inclusion, and emotional well-being.

The key aspect of a bi-directional arrow is that it visually represents a two-way relationship, interaction, and flow between the connected elements to convey the idea of mutual influence, exchange, or cyclical relationships between different components or concepts during the period when the child recovers and their needs change over time. Many parents said that they moved between the layers of defining and interpreting the event, perceiving it and interacting with the surroundings, accepting and adapting, as well as gaining control until a balance between demands and responsibilities is achieved. Mothers, in particular, emphasised their journey towards establishing a new normal for their families over time.

Conclusion

In this chapter, I presented Figure 16 which provides a holistic framework that encompasses the journey from initial interpretation to normalisation, incorporating parental identity, adaptation, and contextual influences. The theory emphasises the interplay of factors, highlighting the intricate nature of caring for a child in a spica cast and the significance of contextual factors and available resources.

The theory presented in this thesis has emerged from studying parents' experiences with a spica cast. It also has implications for similar research areas, such as healthcare system contexts, caregiver burdens, and changes during any new event that disrupts normal life routines. This theory provides a thorough examination of the challenges families encounter after undergoing surgery, particularly when dealing with being in a spica cast. It delves into how families perceive and engage with the changes associated with this situation, considering the available resources. Coping and adaptation are portrayed as dynamic processes shaped by the family's interpretation and response to the new event. An essential aspect highlighted by this theory is the crucial role played by healthcare providers in empowering parents to look after children with spica casts in their everyday lives.

In the next chapter, I will delve into the issues revealed by the theory regarding child care and the experiences of parents caring for children with a spica cast after late treatment for developmental dysplasia of the hip (DDH). The chapter will focus on situating the theory within the broader research context, while Chapter 11 will examine the practical implementation of this theory in clinical settings and offer recommendations for its application.

CHAPTER TEN: DISCUSSION

Chapter overview

This study has explored the situation of looking after a child in a spica cast from the perspective of mothers, using a grounded theory as my methodological approach. In so doing, I addressed a major gap in the literature, as there is a limited number of studies using grounded theory to examine the caregiving experiences of children in a spica cast after DDH surgery. I conducted a qualitative analysis of parents’ posts on a Facebook support page and interviews with mothers to gain insights into the effect(s) of having a child in a spica cast on their lives.

The findings presented in Chapters Five, Six, and Seven delineate the experiences of parents caring for a child in Hip Spica cast post-treatment for DDH as a phenomenon, process, and context. My study has established the meaning of looking after a child in a Hip spica cast post-treatment for developmental dysplasia of the hip from the parent's perspective, starting with the definition of the event, its acceptance, and the various adaptation strategies. Additionally, it has examined the circumstances contributing to the multifaceted meaning of this phenomenon.

This chapter discusses key findings in relation to the existing literature. As there is a dearth of research on parental experiences of caring for a child in a spica cast, my discussion draws on existing theoretical insights on parents' experiences of caring for children with chronic illnesses. The discussion will also present the contribution of the study and the implications to healthcare services in the UK context. It explains the overlap I noticed between the three categories relationships between the three categories: the phenomenon of being in a spica cast from mothers’ perspectives, the process of accepting new experiences and coping strategies, and the contextual factors shaping the phenomenon under study, as parents tried to make sense of what happened to their children and to control the situation. This will help me “weave the fractured story back together” (Glaser, 1992: p72) in line with my theory about being a mother of a child in a spica cast.

This chapter is structured in three sections. Section 10.1 delves into how mothers define the event of being in a spica cast and interpret the associated changes. My second theoretical category is explained in Section 10.2, the process of accepting this new experience. Section 10.3 looks at how parents seek control and empowerment through sources of control and support .

10.1 Being a mother of a child in a spica cast

I hate DDH, our journey is far from over and my little girl still hasn't took her first step. I don't post very often as our little girl has severe hip dysplasia but I am just so upset and angry that DDH is stealing my daughter's childhood

(November FB Participant 1 post number 8)

The mothers in my study associated numerous variables with the experience of looking after a child in a spica cast, which were categorised as the meaning of being in a spica cast from the parent's perspective, how parents interpret this situation . In the theory diagram in Chapter Nine, these categories were centrally positioned within the circle, indicating that experiments begin with this phenomenon (Figure 17).

Being in a spica cast, as highlighted in this study, is an event that causes a shift in family dynamics and forces the family to cope with the new changes. As part of this reorganization process, it is necessary to interpret the stressful event and find meaning. Mothers define this event by comparing it to their child's previous life before surgery and the cast, noting developmental differences (refer to section 6.1,6.2,6.3). They recognize areas where their child struggles compared to siblings or peers, e.g., physical, social, and emotional limitations, as well as developmental delays that made them aware that the experience of caring for a child in a cast was different from caring for a healthy child. In other words, parents understand limitations and change and also when mothers search for meaning, they embark on the process of accepting and adapting, and these can be used to understand the event and its consequences.

Suffering and health can manifest in different intensities and dimensions. This implies that an individual's relationship with illness and health can be viewed as a transition between health as doing, health as being, and health as becoming (Bondas and Eriksson 2001. In this study , 'health as being' denotes the child's state after surgery and being in a spica cast, representing a new identity for the child. ‘Being’ means the child's state of existence and life experiences in the present moment. For parents, it involves defining the child's condition while in the cast. Conversely, ‘Health as becoming’ is influenced by this specific situation. When a child undergoes surgery and is placed in a cast, their identity, knowledge, understanding, abilities, skills, and relationships transform (Hanson 2017; Huang 2019)(see appendix 15).

I. Meaning of the spica cast from the mother’s perspective.

When a child is placed in a spica cast, the caring experience of parents starts as soon as they return home. Although the child is the one placed inside with the spica cast, it is mainly the parents who have to adapt to this situation. In this study, ‘meaning’ emerges as a cognitive phenomenon resulting from event of “being in spica cast” from mother perspective, influencing how family adapt to daily life within this event. Interpreting the health situation of their children was found to be crucial for the mothers who participated in my study because this helped them regain a sense of control. Experiencing heightened emotional vulnerability was a consequence of the loss of control mothers felt when caring for their children after surgery. In response, mothers looked for meaning in their situation to help them cope with this situation. The mothers found purpose in offering appropriate support and care to their children.

In literature, meaning is how an individual relates to their world through specific events. This involves two related aspects: how the illness affects one’s identity and perceived attributes of the event and the social context (Reker and Wong 2013;Oris et al. 2016; Raymaekers et al. 2020). Research indicates that a critical component of this restructuring is the family's interpretation of the stressful event, influencing the development of coping strategies and appraisal of the situation (Henry and Harrist, 2022). Situational meanings relate to how people interpret the demands of a situation and how capable the family is of managing them.

My findings revealed a bi-directional relationship between the construction of meaning, which is a primarily cognitive phenomenon, and emotional responses, whereby the families sought to regain control. These findings resonate with

Årestedt et al. (2015) who indicate that families often respond to illness by forming new beliefs about the illness to improve well-being and alleviate suffering. To preserve normal family life, parents assign considerable meaning to their child's illness, acknowledging the changes it brings to his/her behaviour, movement, and social participation (Stanisławski 2019).

My results indicated that mothers construct and share feelings about three themes: (1) what it means to be a child in a spica cast; (2) finding a meaning for what has happened by accepting and adapting to it; (3) the context of the event. These themes provide a framework for how a family accepts and adapts to what has happened, as well as how they define their identity. Mothers share a common definition of the event and there is a developmental trend whereby mothers compare differences in their child and their development. There were also developmental changes in event concepts in the interpretation of the event.

My findings show that parents created their understanding of why their child was in a spica cast. As explained in Chapter Nine, the process of meaning-making for mothers is dynamic and occurs through multiple layers. Parents said that they compared their child's previous state with their condition in a spica cast. Comparisons were made between the child's situation with that of his/her peers with their peers and how the activities of the family changed. When parents tried to define the new situation, they embarked on the process of acceptance and adaptation. According to Chen et al (2021), these three intertwined processes can help understand the event and its consequences

II. Interpreting the meaning of caring for a child in a spica cast

Interpretations of events are subjective and vary depending on whether they are perceived to be challenging, difficult, different, or unmanageable (McCubbin and Patterson 2014). Interpreting an event enables parents to clarify issues, challenges, and tasks so that they are easier to manage, and the family can continue fostering the child's social, physical, and emotional growth (ibid.). In this study, the event revolves around the child undergoing surgery and being in a spica cast. This event compels parents to define caregiving demands and responsibilities .

> *I found it took us a few weeks to get use to caring for the child in a cast and same things remains difficult throughout the six months. we have to just kind of take it day by day in terms of how we care for her.*
> *(Elizabeth's mother)*

Having a child in a spica cast imposes additional demands on other family members, thereby changing the family dynamic. The interpretation of stressful events leads parents to control their caregiving responsibilities and manage their stress levels. Mothers are well positioned to recognise where their child is struggling and to identify any developmental delays in comparison with peers (see Section 6.1.3). This finding is consistent with changes observed in a child placed in a spica cast, as reported by parents in another study. A mother noted the following observations regarding her son being placed in a spica cast, they experienced "decreased physical contact ... with others, difficulty eating, a lowered visual field, a feeling of helplessness, difficulty playing with friends" (Shah, et al 2022).

Chapter Six presents the findings about being in a Spica cast. This section explores mothers' perspectives on how the spica cast has impacted their child's overall development, including physical, social, and psychological well-being.

Mothers reported a shift in their children's behaviours following the procedure including becoming more demanding, 'clingier', moodier, and more aggressive (see Section 6.2) and the children became more attached to their mothers. In Children displayed behaviours differing from their typical selves, such as engaging in peculiar actions or experiencing personality shifts. Understanding or envisioning a child's behaviour post-surgery proved to be challenging. Reactions varied, encompassing difficulties in sleeping or changes in behaviour. For instance, some children exhibited trichotillomania, while others displayed aggression, perceived by some parents as a means of expressing their feelings about their immobilized situation. If the child's behaviour subsequently changed, the parents said that they believed they were responsible for making a wrong decision which made them feel guilty and stressed out. This stress affected their mental health and self-efficacy. For example, Charlotte's mother said :

> *“I felt so guilty because I made her go through this and it ultimately made the decision we were going to go along with this surgery, I felt like it was my fault that she was so sad and upset and getting frustrated, obviously, in the back of my head I knew it was for the best but there were times when I was just like, ‘oh why have I done this?’”*

There is no consensus on whether DDH causes physical discomfort in children (Seçinti et al. 2022). However, when infants became restless or cried excessively, the families I interviewed said that they often sought medical support. This confirms the findings of Riddell and Racine (2009) who noted that wearing a spica cast causes a child to experience unfamiliar limitations, including postoperative pain, immobility, separation, and social isolation. So, parents must be prepared for this.

Difficulties explaining the treatment to children were reported to cause behavioural changes which parents struggled to manage. In this study, mothers noted that children were unlikely to grasp the logical reasoning behind the treatment, like how the surgery and cast will improve movement in the future. Although children may not fully comprehend the meaning of their experience, they are aware of the changes in their identities resulting from being in a spica cast (see Section 6.2). Piaget's theory of cognitive development in psychology can explain this observation. According to Piaget (1896–1980) , children progress through four distinct stages, each representing varying cognitive abilities and each stage involves a different type of intelligence(cited in Badakar et al 2017). He proposes that children’s understanding of illness evolves in a systematic and predictable series of developmental stages. During the pre-operational stage (2-7years old), children interpret events through their own experiences and concrete thinking (Byrnes 2020). At this stage, some children may attempt to remove a cast when they realise it restricts their movement. They interpret illness in the context of how it disrupts their daily activities and choices. For instance, a child might feel upset about being unable to play with their siblings or peers. Children are unlikely to recognise the long-term benefits of wearing a spica cast in terms of enhancing their physical abilities and instead focus on how it prevents them from playing.

In the social aspect ,Participant (1) said in post number 4 published in April 2019 "Does anyone know about flying while in a spica?", as she was looking for transportation options available for the casting period. This demonstrates the social and geographical isolation that can occur due to the inability to travel by air when in a spica cast. In such a situation, even travelling by car requires the installation of special equipment to accommodate the child (see Section 6.3.1Transportability in Chapter six for more examples). It has been reported that those with disabilities find it more difficult to travel and many find that their choice of mode of travel is limited (Bromley et al. 2007; Velho et al. 2016). The scale of the problem varies from one country to another. For some parents, travelling with a child in a spica is hard and full of requirements. Additionally, published guidelines often lack a systematic approach for correctly positioning a child inside a car seat, which complicates their usability for parents. This is reflected in my data, posted on Facebook in April post number 4 (p ,121).

In addition, a mother's psychological state and acceptance of her child's condition can also influence the degree of social isolation experienced. This study revealed that some mothers found it difficult to deal with people's questions when they took their children outside(refer back to the examples on page 123). Furthermore, the parents reported that people's attitudes made it hard to participate in their community. Masnari et al. (2012) state that children with visible disfigurement are more likely to experience stigmatisation. If a child is discriminated against, both the child and their parents can suffer emotionally and psychologically (Boyd 2017; Daniel et al. 2021). On the other hand, some mothers aimed to maintain their previous level of social participation by engaging in social activities *(*p ,136). The problem can be exacerbated by social and cultural barriers. Some parents may be reluctant to expose their children to potentially harmful situations. However, social interaction is usually overwhelmingly beneficial for children .

Mother in looking after child in spica cast shared varied experiences, encountering new demands and challenges that influenced their stress levels as they adapted to their new responsibilities. Section 7.1, "Taking Responsibility,"delves into this aspect. Compared to caring for a healthy child, the experience of caring for a child in a spica cast presents additional challenges to consider. Consequently, mothers of children in casts have a unique maternity experience.This aligns with findings from another study, which identified that parents during caregiving offered explanations that included issues that can be understood (i.e., constructing reality), contextualised (i.e., dealing with stress and responding to supportive environments), and operational (i.e., creating an effective daily management strategy) (Charenkova 2023).

The present study established that the acceptance and adaptation stages are influenced by how the situation is defined by the mother, the meaning attributed to the event, and how the child was before surgery. Subsequently, the mother typically becomes more accepting, strives to adapt to their situation, and learns how to enhance their quality of life by normalization. This dynamic shift from a Definition and interpretation of the event to Realisation and interaction with the surrounding system, expanding from the blue circle to the yellow(detailed in Chapter 9).The following section will provide an overview and examples of this development.

10.2 Accepting and adapting to the new experience

Caring for a child in a spica cast can be a challenging experience for parents because it is an around-the-clock commitment and the child is completely dependent on their parents. In Chapter Seven, the theme of the unexpected is reflected through the mother's experiences during these events. My findings indicate that parents face multiple challenges in providing care to their children in spica casts. The primary concern is the children's inability to move freely, which can cause discomfort and hinder their daily activities. Additionally, parents experience emotional stress due to the increased responsibility and the need to balance their caregiving duties with other responsibilities.

> *it's really hard, you are their rock. My daughter is an absolute terror for me now because I was there 24/7, if you can get some time apart it will do you both the world of good.*
> *(March FB Participant (2)post number 13)*

This implies that the feeling of guilt is combined with a lack of control over the situation. The demands of a child in a spica cast can also lead to physical and emotional exhaustion, which may further contribute to stress and strain on the family system. Indeed, the mother interviewed offered numerous examples of physical burden along with psychological and emotional challenges (see Chapter 7).

Following hospital discharge, parents face the challenge of taking care of a child in a spica cast. Parents try to return to normal life amidst the presence of obstacles, progressing through two consecutive stages: acceptance and adaptation. During the initial stage, mothers evaluate the event of 'being with a spica cast', assess its requirements and available resources new demands and challenges(refer to p,126). During the next stage, parents select appropriate strategies based on the family's available resources to rebalance the family system and try to make life as normal as possible. This approach aligns with the 'family stress model' (Germeni et al. 2018). This definition interacts with the family’s resources and their capacity to manage stress, expanding the family's perception of the original stressful event to include their perceptions of family resources.

The process of adaption includes a series of steps. It involves building meanings immediately after a stressful event happens (McCubbin and Patterson 2014). Individuals’ response is influenced by cognitive appraisals of life events and this may be the single most important factor (Boss et al. 2016). When mothers in this study offered their perspectives regarding the meaning of looking after their child, their responses ranged from describing it as difficult to terrifying. This experience presented caregiving challenges for mothers. However, these difficulties prompted parents to move towards acceptance, adaptation, and normalization (see Section 7.2.2).

The concept of ‘meaning-making’ encompasses the intersection of coping, adaptation, control, and empowerment, all centred around the pivotal role of parents as caregivers. The experiences of my participants' were shaped by the meaning they associated with caregiving, which then helped them identify appropriate coping mechanisms. The mothers interpreted their new reality by understanding the emerging demands, responsibilities, and shifts in routines, roles, and expectations over time, new challenges , which were not expected before, might arose. For example, caregivers reported that children often soiled their spica casts while eating or using the toilet.

Furthermore, the meanings are often reconstructed to care for a child in a cast. As the parents progressed through the process of acceptance, they understood that it entails constant management, learning about their child's physical needs, surgical procedure, regular monitoring, and considering contextual factors and available support. This process of acceptance culminates in establishing a balance between requirements and responsibility, thereby creating a semblance of normality. The theory generated in this study shows that the process of making meaning is dynamic, going back and forth through all experiences (see Chapter 9).

The adaptation process is affected by the family's response to the stressful event, their resources, and the presence or absence of effective coping strategies. They develop competencies, to handle the new responsibilities and to protect the family from major disruptions or changes. When confronted with situations requiring changes in family functioning, families tend to work to restore order, harmony, and balance (Oja et al., 2021).

As mentioned Chapter 7.1, the mothers admitted that their anxiety was partly caused by the strange situation and lack of knowledge about how to care for their children after surgery. The relationship between caregiving and health is described generally in terms of stress. Aneshensel et al (1995) define stressors in the context of caregiving as "the problematic conditions and difficult circumstances experienced by caregivers (i.e., the demands and obstacles that exceed or push the limit of one's capacity to adapt)".This conceptualisation underscores that stress originates at an intersection between one's external environment and internal state, occurring "when the demands imposed by a patient's condition collide with a caregiver's subjective ability to respond, or when these demands obstruct the pursuit of other objectives"(ibid. p.34). This intersection between the individual and their environment can explain why some caregivers seem less affected by caregiving stress, while others experience serious health issues.

Why do some families cope well while others struggle? To understand parents' adaptation, it is necessary to acknowledge the complex nature of the stress process and attempt to describe the factors that play a role in the caregiving experience. Several scholars consider the coping process as being based on the congruence between internal coping resources and external circumstances or situational demands. The situational and social context can mediate the diversity of meanings or experiences related to caregiving. The situational meaning model of Park and Blumberg (2002) assigns meaning to a particular life situation, its demands, and consequences. In this theory, meaning appraisal and meaning-making are integral components of the coping process (cite in Park and Ai 2006).

The family’s burden is caused by the needs of their child in a spica cast. These affected the health and well-being of the families under study. Halama and Bakošová (2009) examined whether the level of meaning in life acts as a moderator in the relationship between perceived stress and coping. As mentioned earlier, processes related to meaning in life play an important role in coping with difficult life situations and traumas, and managing ordinary everyday problems. meaning in life influences the coping process in various ways.

As parents developed an understanding of what it means to be the carer of a child in a spica cast, they faced challenges related to the child’s changing needs. This requires parents to use their abilities and the available resources to address these needs effectively. In what follows, I detail parents’ interpretations of caring for a child in a spica cast.

I. Unfamiliar experiences

This study revealed that parents' hardship was intensified by the necessity for surgery, healthcare visits, and a long period of caregiving. Consequently, many parents expressed high levels of uncertainty and worry (p,130). This supports the findings of previous studies which highlighted that when a child is ill, there is considerable uncertainty in the household regarding the caregiving role (Årestedt et al. 2015; Fairfax et al. 2019).

The subcategory "Taking Responsibility" and its associated themes align with the findings of Newman's (2005). Newman surveyed parents of children in hip spica casts and discovered that caring for a child in such a cast necessitated significant adjustments to nearly every aspect of their lives. Despite studying parents of older children compared to this study, Newman (2005) noted similar challenges, including impacts on employment, difficulties accessing childcare, and changes in day-to-day parenting practices.

Existing literature on parental stress models underscores the significance of new events for families, suggesting that various diagnoses of developmental disabilities or delays can impact families (Louie et al., 2017; Latif et al., 2023). This study's findings align with previous research in several aspects. Firstly, parents try to find meaning in the situation. Secondly, critical moments arise for parents, such as when their child is discharged from the hospital, necessitating interpretation of events and adjustments to changing needs. Thirdly, parents adapt their styles to cater to the specific needs of their children. Fourthly, they develop strategies to accept and adapt to the new circumstances they find themselves in. Lastly, parents try to control the situation. Importantly, variables related to health, social support, and access to information were found to be positively correlated, indicating the importance of these factors in supporting parents during challenging times (see Section 8.2.2).

When a child with DDH is placed in a spica cast, their parents are provided with instructions for cast care, but there is rarely an accompanying practical guidance ,leaflets or videos to reinforce these procedures. The majority of the parents said that the information provided is inadequate (see Section 8.1.2.). Parents require comprehensive information to address the complex needs of their children, ensuring their lives remain as normal as possible despite the presence of a spica cast. This finding about the lack of information is similar to what many scholars (Gibbard et al. 2021; Harry et al. 2022) reported. The study therefore highlights the necessity for more detailed information, supported by written educational materials, regarding home care for children in spica casts and maintaining a normal lifestyle with limited mobility. Mothers expressed a desire for troubleshooting information on various aspects including hygiene, skin care, diet, toileting, play, sleep positioning, transportation, maintaining body temperature, cast care, and addressing potential problems. This finding mirrors Clarke and Dowling's (2003) recommendation that parents should be given detailed information about hygiene, clothing, toileting, diet, positioning, movement, handling, and transportation (including car seats) to appropriately care for children with spica casts.

My finding about parents' empowerment through information is in line with numerous articles which have highlighted that parents who receive information regarding their children's health, diagnosis, and treatment tend to feel empowered. Conversely, a lack of information, feeling overwhelmed with information and advice, or having unanswered questions was identified as contributing to disempowerment. Furthermore, acquiring the necessary skills and information to provide daily care for the child, e.g., gaining practical experience through hands-on practice was identified as the precursor to empowerment (Gibbard et al 2021; Theunissen et al 2022).

The findings of this study confirm that caring for a child in a spica cast disrupts family life because of the associated uncertainty and efforts required to balance needs and responsibilities. The original contribution of this study lies in its exploration of the events of a child in a spica cast and the underlying dynamics of the process, to comprehend and navigate this new responsibility (see Chapter 9).

Understanding the experience is necessary to develop an adequate caregiver role and to find ways to balance the caregiver role with other roles. However, Cohen (cited in Major,2003) emphasises that "the illness itself is not the most powerful predictor of family coping". This perspective, referred to as 'balanced coping', acknowledges that the functionality of the family system is critical to effectively managing the illness and that the demands of the illness need to be met without sacrificing the individual needs of family members(p64). If it is perceived that the capacity to care is outweighed by the demands being placed on the family, equilibrium will only be restored if major systemic changes are made to the family's structure and interactions. In this study, the parents sought to actively manage the associated demands and stress. During the acceptance phase, the level of family coping and adaptation emerges in response to (a) the care demands on the family, (b) the parents' level of knowledge and access to information, and (c) concerns about the child's health and physical needs. My findings showed that mothers identified differences in the meanings they attached to caring for a child, indicating that participants' experiences were derived in part from unique meanings linked to caregiving (see Section 10.2).

This shows that meaning in life affects parents' coping process by identifying conflicts, frustrations, and assessing cognitive disturbances and various situational stresses. It enables the observation of experiences in key social roles, together with the use of coping strategies and personal resources. A perspective known as 'balanced coping' recognises the essential role of the family system in effectively managing illness while ensuring that the individual needs of family members are not overlooked (Major, 2003). This balanced coping perspective underscores the importance of parents as primary caregivers and partners in the child's health management. However, present standards fail to consider the other substantial role responsibilities of caregivers.

This study found that caring for a child in a spica cast poses significant challenges. Faced with a series of relentless post-surgery demands, parents inquire about the care and recovery processes during what is a very stressful time. Some mothers likened it to having another newborn child, noting that the provision of care involved significantly more time and effort than before.

> *I think it's changed everything we do, really, even small. It's like having a newborn again, you can't leave them.*
> *(Daisy's mother)*

This study assessed the stress parents experienced when caregiving. Post-surgery care tasks were found to be most challenging (e.g., bathing, sleeping, dressing, toileting, pain management, and travel). Parents also struggled to engage the child in social activities and supervise their play. Even experienced mothers with several children reported that the spica cast compounded daily tasks and demands. Emotional challenges were also reported by the mothers, some of whom felt guilty that they were responsible for the limitations experienced by their children. Parents were concerned that a lack of mobility could delay their children's development and movement, thereby making them overly reliant upon their parents for day-to-day tasks. These challenges, not documented in the wider literature, reveal a series of caregiving challenges experienced by parents of children in a spica cast. These findings confirm Abidin's observations that life events happening outside the parent-child system may moderate or worsen parenting stress, as they impact parental emotional resources and coping abilities with the parenting role. Parents may experience increased parenting stress if their demands to raise their children exceed their resources (Abidin, cited in Fang et al., 2022).

II. Family burden

In chapter 7 I explained the challenges which parent face after hospital discharge, managing it daily, meeting their developmental needs, and coping with ongoing stress are all part of the process.They have therefore to adapt to new roles, reorganise their lives, and cope with the child's demands. The findings of my study support those of Wakely et al., (2021). These scholars have indicated that caring fora child with DDH affects all aspects of a parent's life. This is also reflected by Cohen et al. (2020) who state that caregiving requires significant adjustments to almost every aspect of parents' lives, thus making it challenging to maintain a normal life (Clarke and Dowling 2003; Newman 2005; Causon 2010). Therefor , my study agree with finding reported by Chao and Chiang (2003) and Demir et al. (2015) that the experiences of parents of children undergoing treatment for DDH at a later age, scholars haverevealed physical, social and psychological problems associated with them .However, my study highlights different challenges compared to those associated with early treatment using a Pavlik harness. Issues such as breastfeeding were problematic because the harness functioned as a physical barrier, and caregivers also faced difficulties in fitting the harness correctly. (Gardner et al. 2005; Hassan 2009; Bergo and Rosendahl 2013).

The interviews I conducted revealed that the single most notable challenge encountered by mothers was changing nappies without getting the cast wet. Despite their best efforts, it was not always possible for mothers to keep the spica cast completely dry, and any moisture could result in skin irritation and unpleasant smells. There is no consensus in the literature regarding what constitutes best practice when toileting children in a spica cast (Reed et al. 2011). Therefore, parent-specific information should be issued before discharge concerning maintaining the cleanliness of the cast at home (Smith 2004). Some parents learned how to deal with this through a process of trial and error, whereas others sought advice from parents, with similar experiences, on Facebook. This served as an informal form of support. Simple methods like using a hairdryer can be effective, but parents are not routinely offered such advice by healthcare staff.

The mothers I interviewed reported having less free time due to their caregiving responsibilities. These affected their social lives. However, while this imposed an additional strain on family life, four of the interviewed mothers believed that this was a worthwhile sacrifice given the long-term benefits for their children. Some mothers stated that caring for their children had become a round-the-clock process, leading to feelings of isolation. With limited opportunities for rest, leisure activities, or personal time, they reported experiencing burnout and distress. This supports findings of Demir et al. (2015) who found that most of the parents experienced psychological problems and felt unhappy. Additionally, all caregivers in Newman’s (2005) research reported that a lack of time for themselves affected their eating habits and personal care, made them insomniac, and had difficulties managing housework. A small number of his participants reported feeling so overwhelmed that they were forced to resign from their jobs or places of education, and they lost interest in socialising. Other studies found that caregivers increased their consumption of coffee and tobacco while their child was in a cast. They also noted disruptions to their sex lives due to the need to sleep in the same room as their child (e.g., Clarke and Dowling 2003).

> *In terms of just I guess parental guilt feeling you can't spend the time with her brother that you wanted to I had to always be looking out for her .*
> *(Angela’s mother)*

In my study, parents reported spending less time with their other children due to caring for their child in a spica cast. Some mothers also stated that their responsibilities towards other siblings had changed because of their new responsibilities . This aligns with what scholars observed: the well-being of siblings of children with developmental disabilities may be compromised by the stress experienced within the family (Sharpe and Rossiter 2002; Hastings 2016; Martinez et al. 2022).

Families with children affected by DDH face additional financial challenges, including medical expenses, travel costs, and the need to purchase specialised equipment (Williams et al., 2017). This financial burden can lead to families facing difficulties in meeting basic needs and may require making sacrifices, e.g., extended maternity leave or one parent quitting their job to provide full-time care (Vatansever et al., 2022). In such cases, mothers often find themselves compelled to take leave from work, sick leave, and vacation time, or opt for unpaid leave to care for their child in the spica cast (Nelson 2002). This change in employment status was experienced by my study participants, with some mothers unable to work from the office and deciding to quit their jobs to focus on their children's care needs. For instance, Charlotte's mother decided to forgo her job to prioritise caring for her daughter. She added that her husband's income was essential for the family's financial stability. This indicates that the presence of a working husband, who can take on financial responsibilities, can help mothers extend the duration of maternity leave. Timing can also play a significant role in terms of convenience. Initiating the process at a younger age holds benefits, as it aligns with the mother still benefiting from extended maternity leave. This was echoed by Angle's mother who extended her maternity leave to care for her child. She highlighted the socioeconomic benefits of early diagnosis and treatment of DDH.

As children undergo DDH’s treatment, mothers’ jobs and social activities become affected. Newman (2005) found in his study of 30 mothers of children undergoing DDH treatment at an older age in North America, that their social activities ceased, resulting in social isolation that caused them to feel depressed. Similar findings regarding social isolation were reported by Demir et al. (2015) who surveyed 33 parents of children receiving late DDH treatment in Turkey. This is clear evidence that parents caring for a child with DDH usually experience stress. During this period, families often assist mothers and fathers can reassure both mother and child emotionally and practically (Chao and Chiang 2003).

The decision of the mothers I interviewed to take leave from work was influenced by various factors, including the child's attachment to the parents and the challenges associated with finding reliable formal childcare. Many of the mothers expressed concerns about entrusting their child's care to others and the difficulty of finding suitable educational and nursing institutions that accommodate children with disabilities. Studies have established that this particular challenge accentuates parents’ stress levels (Nemati et al., 2020; Heffernan et al., 2021).

Schooling can also be affected by the use of hip spica casts, potentially leading to isolation (see Section 6.3.4). Hughes et al. (1995) state that many children are not allowed to return to school while wearing a cast, thus requiring parents to take time off work to care for their children. If they were to attend school, these children would require assistance with transport, moving around the school building and going to the toilet (Leu et al. 2012). Unfortunately, most schools do not have the resources to accommodate such demands (Heffernan et al. 2021). Cast immobilisation often limits patient mobility, resulting in potential absences from daycare or school (Willimon et al., 2019). Also, Heffernan et al. (2021) conducted a study examining daycare policies regarding return to daycare (RTD) following orthopaedic immobilisation. They found significant restrictions on RTD for children with casts on their lower extremities. Daycare staff do not often receive specialised education on caring for children in spica casts, nor are they provided with cast care instructions upon discharge (Reed et al., 2011; DiFazio et al., 2011). Consequently, they may not be adequately informed about appropriate care procedures for children with casts. Despite the potential role of socioeconomic resources in supporting parents to manage daily tasks, the specific impact of these resources was not extensively explored in this study.

Additional concerns about environmental obstacles were highlighted by my participants, such as inadequate disabled parking spaces, limited car space for strollers, difficulties in physically carrying a child, and a shortage of diaper-changing facilities suitable for children over two years old(p,121) .The mothers I interviewed said that internal and external control factors were continuously affecting the family's ability to meet the caregiving requirements. In 2007, Bromley et al. conducted interviews to identify the challenges faced by individuals with disabilities in the UK when using public transportation. They noted that different areas in the city centre present varying degrees of difficulty, creating significant barriers for those with mobility impairments.the finding of Bromely's study has wider implications for the experiences of individuals with mobility impairments in general. For example, families with children who wear spica casts face mobility challenges due to the size and shape of the cast.

Understanding the challenges of caring for a child with a spica cast requires an assessment of strategies that vary according to factors that change with the complexity of the phenomenon.

Health professionals are encouraged to work together with families to identify their goals and priorities, reduce the physical and time demands of caregiving, and create personalized intervention plans to help children with their self-care. This can include making accommodations, modifying the environment, and using assistive technology to promote independence (Ryan et al., 2009; Clark et al., 2011).

III. Transition to Normal Life

When a child is fitted within a spica cast, their family may consider recovery as a return to pre-cast functionality. Recognising that there will be obstacles, parents try to return to normal life in two stages: acceptance and adaptation. This study has explored mothers' interpretations and experiences of taking care of children in a spica cast. The process of normalisation emerged from the participants' experiences and is a major aspect in my theory (see Chapter 9). Parents were found to move from defining and interpreting the event, to perceiving it and interacting with the surroundings (e.g., family circle , environment , and society), to accepting and adapting, as well as gaining control until a balance between demands and responsibilities is achieved.

I found that in these circumstances, mothers learned through trial and error, in harmony with the findings of Gallo and Knafl (1998) who reported that mothers seek to cope with the new situation by developing "tricks of the trade". Some studies reported a relationship between the disease duration and caregiver hardships. They showed that over time parents develop strategies for coping with care-related challenges (Hu et al 2016; Adib-Hajbaghery et al 2019). The Family

Adaptation and Response (FAAR) model, is particularly useful to explain my finding .It emphasises how families manage the challenges inherent in their caregiving roles by striving to maintain homeostasis through the use of internal resources and coping strategies.This is further shaped by the interpretations that families attribute to different events, influencing their responses over time. Through recurring cycles of adaptation, crisis, and readaptation, families overcome these stressors and try to achieve a harmonious balance in their caregiving duties.

Normalisation entails making adjustments to their environment to satisfy evolving shifting social, cognitive, and emotional demands (Moonpanane et al 2021). It involves treating the child as their peers or siblings would be treated and acknowledging the obstacles which prevent them from leading a ‘normal’ life. Normalisation reflects the child’s changing physical and emotional needs to become active members of society (Germeni et al 2018).

Parents in my study normalised life by using various strategies, e.g., establishing their version of ‘normal’ and making the spica cast part of their daily lives. While they initially believed that they lacked the necessary information to care for their child, they found that their caregiving process evolved. Efforts to return to normal daily routines when a child is wearing a spica cast required the entire family to make extra efforts. My study has reported that the participants’ roles and tasks were similar, but their experiences diverged. These divergent experiences reflected differences in the meanings that mothers attributed to the event due to predisposing factors in their lives, like early life experiences, other family responsibilities, and healthcare roles. For example, Beatrice’s mother had been treated for DDH as a child. Therefore, Beatrice learned from her mother’s experience.

By assessing potential stressors, individuals can select appropriate coping strategies. The acceptance subcategory, outlined in Chapter Seven, is characterised by two key themes, namely coping strategies and moving through, which seek to facilitate acceptance of new experiences. Over time, families transition from the acceptance stage to the adaptation phase. During the acceptance stage, the capacity to cope and adapt results from the parents' knowledge and the physical needs of the child.

It follows that the goal of normalisation remains unchanged; however, the caregiving approach applied changes as a result of trial and error. Normalisation takes parents out of their comfort zone, requiring them to make environmental social, temporal, financial, psychological, and emotional adjustments to make their children enjoy normal experiences. The environment and activities of children with a spica cast are changed and minimised. Therefore, caregivers should devote more time to assist their children in various activities.

Parents need to strike a balance between demands and responsibility to establish a version of normality. The Facebook posts and interview responses revealed that parents strive to keep their children busy and entertained through activities such as reading and playing with blocks. Some invited friends to play at their home, whilst others attended playgroups. However, some Facebook posts indicated that parents limited their children's activities because they were concerned that they might be harmed, particularly in the early stages of recovery. Other parents thought that the size of the cast would prevent children from participating fully. Both the Facebook posts and interviews suggest that parents regarded specialised equipment such as wheelchairs or spica tables as tools to facilitate their children's participation in social activities (refer back to 7.2.2 section)

IV. Mediating factors that affect acceptance and adaptation

My discussion focuses on the participants' different backgrounds and circumstances. Although I examined several factors impacting parental stress, there might be other factors causing stress, like parents' knowledge and ability, cultural and ethnic factors, family economic status, family composition, and sibling relationships, which fell beyond the scope of the present study.

Gendered nature of caring for children with a spica cast

In my study, most of the participants were mothers who shared their experiences of taking care of children in a spica cast in Facebook posts and in the interviews. When I looked for participants, I did not specify a preference for parents' gender. It was mainly mothers who responded the most to my post, whereas the men visible on the Facebook page did not appear to show any interest. This observation raises questions about unconscious biases or societal expectations that may contribute to this imbalance. The unexpected lack of father participation in this study aligns with previous research indicating limited involvement of fathers in paediatric research owing to factors such as time constraints, limited interest, restricted accessibility, and a lack of active engagement (Mitchell et al., 2007; Panter-Brick et al., 2014). Moreover, scholars noticed a higher prevalence of maternal involvement in research related to this topic, possibly indicating a proactive role or greater interest among mothers (Phares et al. 2005; Davison et al., 2017). These findings emphasise the importance of further investigation into gender dynamics in caregiving roles and understanding how societal expectations influence parental involvement in caring for children with health needs or disabilities.

The primary responsibility of caring for a child with health needs or disabilities often falls on mothers. As a matter of fact, women usually undertake the primary caregiving role for elderly family members and children due to cultural and socioeconomic factors, a trend that persists despite demographic shifts (Katz-Wise et al., 2010; Sharma et al., 2016). Maternal instinct and tendency to often prioritise their child's daily needs and family relationships result in mothers assuming a larger caregiving responsibility compared to fathers (Friedman et al., 2015), which in turn leads to increased caregiving burdens and psychological distress (Akpınar, 2011; del-Pino-Casado, 2012; Pöysti et al., 2012). In contrast, fathers may prioritise work and financial responsibilities.

The mothers interviewed stated that put in much effort to care for their children while they were in spica casts. This was due to their role as primary caregivers. In the adaptation subcategory "Need Interruption," the process was unveiled by posing questions about the phenomenon, including when, where, why, who, how, and the resulting consequences. For instance, a mother who took leave from her employment . This leads me to think about what motivated all those mothers to take on all caregiving responsibilities and to determine if any cultural and/or social community norms dictate that mothers should be the only caregivers of these children. Another important consideration is the extent to which other family members, such as siblings and parents, play a role in this situation.

Furthermore, my results corroborate other studies which indicated that despite the widespread use of the term ‘parents’ in research on DDH, a closer examination reveals a predominant focus on mothers as the primary caregivers, reflecting traditional caregiving norms (Theunissen, 2023; Sadeq and Al-Dujaili, 2023).

Socioeconomic characteristics

It is acknowledged that socioeconomic factors can exert a significant influence on the experience of motherhood. These factors can range from financial constraints to demographic characteristics of mothers and can affect not only the physical health of the mother but also her emotional well-being. While this study does not provide definitive conclusions on socioeconomic aspects, it suggests their potential relevance.

Throughout the study, participants emphasised the impact of being able to afford private healthcare, which resulted in better support for caring for their child in a spica cast. Additionally, informal support networks, support groups, and social media play a role in mitigating challenges, helping parents acquire costly equipment and thereby alleviating the burden of care(See section Equipment p135).

In this study, Angel is the mother of three-year-old twins, while Freya is the mother of two children, one aged 2.5 years old and the youngest is 18 months. The task was more challenging as the children were younger and required equal amounts of attention. Freya's mother discussed the exhausting complexities of her by stating example “I try avoiding taking her out to play for long enough that I'd have to do a nappy change in public because if I'm on my own particularly I then got to take me and her and her brother and a buggy into a disabled toilet “.The findings of Vatansever and colleagues’ study (2022) indicate that the size of a family may affect the quality of care given to children with DDH, as the effectiveness of therapy decreases as the size of the household increases. Demographic characteristics of mothers

During the interviews, the sample mainly consisted of mothers aged between 20 and 35 with higher educational levels. Most of them had given birth to their first child.. Mulpuri et al. (2016) stated that a mother's age can be an important aspect to consider. Perhaps younger mothers lack experience in managing their children's health, which could be a reason for some health-related issues among children. Freya's mother stands out as the youngest participant among the mothers in my study, bearing the brunt of challenges stemming from her youth and the responsibilities of her second childbirth. The demands of caring for her daughter resulted in the premature birth of her second child.

This study primarily attracted women with higher levels of education, indicating their potential inclination toward participating in interviews or research activities. Charlotte's mother described how her background as a nursery teacher influenced how she perceived her daughter's mood swings and different post-operative behaviour. These findings suggest that some mothers with higher education attainment appear to be better equipped to manage their child's behavioural changes and understand their child's health status. This confirms similar statements found in existing literature (Prickett and Augustin, 2016; Mensch et al., 2019; Paul et al., 2022).

In summary, the process began with defining a child's need (physical, psychological, or social), as we discussed previously, and that it is a new experience not like an experience to looking after a healthy child. In order to create meaning for this stage, there was a need to assess the demand and the available resources and capabilities to meet the new needs, followed by defining burdens and difficulties. Families with children with spica cast face both the normal pressures and tensions of family life and, in addition, adjustment to the presence of the child with a spica cast. This process ended with acceptance, adaptation, and attempts at normalization.

Next section will show the context, which is all the circumstances that contribute to the structure of the phenomenon under study. Additionally, the phenomenon always manifests within a particular context or under specific circumstances, which plays a crucial role in shaping the unique experiences of the parents involved.

10.3 Seeking control and empowerment

The previous sections have highlighted the multiple challenges and changes experienced by parents and the wider family following DDH surgery and the use of a spica cast. These changes affected the families to a certain extent. However, my discussion here shows how the parents managed to retain control, largely through being empowered with knowledge and support from others. The

outermost circle in my theory of "Being in Spica cast after DDH surgery from mother perspectives” is the "control" and "empowerment", which help families enhance their confidence and competence in managing their child in Spica cast (Figure 17). Parents in my study felt empowered when they accepted and took responsibility for the situation. This reflects Taylor et al.’s (2023) statement that empowerment equips families with the necessary resources and support to meet their child's needs, building upon each family's unique experiences, opportunities, abilities, and interests.

All mothers in this study reported feeling more in control and capable of navigating the caregiving journey when they had sufficient information and specialised hospital care. Meeting with supportive doctors who provided medical assistance and empathy further enhanced their experience. The mothers interviewed also showed a high level of empowerment, whether through sufficient social or medical support and demonstrated a more successful adaptive experience. However, parents’ sense of control and empowerment could be achieved through various other means, including enhancing knowledge, participation, and skills, as well as creating a supportive environment for the child's care.

Likewise, this finding is consistent with stress theory in the literature, which explains how families respond differently to similar stressors, as discussed by Phoenix et al. (2020).Coping resources, stemming from external social, individual or personal factors, facilitates a full and active adaptation to stressful conditions. These resources are crucial, as their availability affects how events are interpreted and determines which strategies individuals can use (Phoenix et al. 2020). Recent studies emphasise the importance of understanding the family context, dynamics and roles when dealing with a child with a chronic illness or disability (Phoenix et al., 2020; Moonpanane et al., 2021). If an individual lacks access to a specific resource, they are at a higher risk of vulnerability to stress. Conversely, if that resource is accessible, the individual becomes less vulnerable or more resistant to the negative effects of stress. Thus, subjective definitions can vary according to their interpretation of the event as challenging, difficult, different, or unmanageable. In line with these findings, mothers in this study who exhibited a high level of empowerment, whether through sufficient social or medical support,

demonstrated a more successful adaptive experience compared to mothers with lower levels of empowerment and control.

In the following section, I delve deeper into the factors that mothers identified as resources of control.

10.3.1 Information

The main challenge mentioned in the "Sources of Information" section in Chapter 8, as reported by participants, was the lack of practical information provided by healthcare professionals regarding where to purchase appropriate clothing, furniture and car seats, and how to change nappies . The participants also reported that worry and the emotional burden were notable challenges. With limited prior knowledge of DDH, they turned to online sources for information. Some even noted receiving inconsistent or inappropriate guidance from healthcare providers, such as recommending the use of double nappies or extended follow-up periods before surgical intervention. Instances of postponed treatment led some mothers to feel guilty, as early intervention might have averted the need for surgery. This finding is thus in line with Salisbury et al.’s (2007) observation that the primary need of parents is information.

Emotional burden and shock were also prevalent, stemming from uncertainty about treatment types, outcomes, and timelines. Parental fear and uncertainty can be mediated by connecting with other parents to learn about their experiences and to gain social support. The families have emphasized the importance of normalization and reassurance. They strongly believe that individuals who can personally relate to their experience are better positioned to provide these elements, as opposed to members of the medical team.According to Bettany-Saltikov et al. (2016), there is a consistent indication that establishing connections with other children and families who have previously underwent similar major surgery may provide this reassurance and normalization experience to families (Bettany-Saltikov et al., 2016).

10.3.2 Types of Support

The study has found that the types of support parents needed during the caregiving experience were emotional, practical, and informational. This support from formal and informal sources was found to relieve parents' stress and anxiety. This study indicated that caregiving responsibilities improve when parents accessed support from a range of sources, which is consistent with findings in existing literature (Hastings et al., 2002; Shin, 2002; Jones and Passey, 2004). The following are the types of support I will discuss.

I. Support from healthcare professionals

My theory in Chapter 9 explains that empowerment involves having the agency to control the situation. This empowerment cannot be achieved in these experiences without adequate information and support from healthcare providers. Healthcare professionals were expected to take responsibility for giving information and preparing the parents for the experience of caring for a child with DDH. However, the interviews revealed that some mothers received appropriate emotional and informational support from the staff, while a significant proportion of the respondents stated they did not feel supported either before or after their child was discharged (see Chapter 8). It is apparent from the current study that the day-to-day demands faced by families when caring for a child can soon become overwhelming, which may not be apparent to healthcare staff accustomed to managing young children in spica casts. According to several studies (Al-Masry et al., 2018; Fang et al., 2022; Phoenix et al., 2020), mothers think that nurses should provide comprehensive support, including emotional and practical assistance to assist them in navigating their emotions during this difficult time. Caregiving without adequate preparation and support adversely affects parents' emotional and physical health, as well as their financial resources (Elliott and Pezent, 2008).

Parents' perceptions in Support from health practitioners examples in finding of healthcare professionals' competency are not solely based on their skills but also on how supportive and caring they are .My findings in then suggest that guidance is important for the families of children in a spica cast as one of The impact of the theory in this study on health policy (see p, 223-224).An essential aspect of family empowerment is active participation of healthcare professionals with parents. This involves supporting and consulting parents as experts in their child’s care, as well as developing parents’ knowledge, skills and self-efficacy to provide care and manage situations of being a caregiver in child with spica cast. The literature supports this, emphasising that parental empowerment can be facilitated by healthcare professionals validating and respecting parents’ opinions and existing knowledge, actively listening to parents, and acknowledging parents as partners (Kokorelias et al., 2019; Reeder and Morris, 2021; Ang et al., 2023). Indeed, it is widely accepted that parents highly value a positive relationship with healthcare professionals, referred to as the therapeutic relationship (Reeder and Morris, 2021). Ashcraft et al.’s (2019) systematic review identified various factors that may facilitate empowerment, including positive relationships with providers characterised by effective communication, listening to parents, providing informational support, fostering trust, and ensuring that families feel like valued team members. Conversely, interactions with providers who are insensitive to family preferences or exhibit poor communication may contribute to feelings of disempowerment.

Reciprocal trust is essential as parents provide additional information about their child’s condition, serving as interpreters for their child’s needs (Aarthun et al 2020). The focus is often on patients’ trust in healthcare but there is a need for mutual trust. Mothers emphasised the importance of mutual trust with healthcare professionals, which is fostered by mutual understanding, respect for parental opinions and listening to their observations or inquiries. Trust is fostered when doctors provide reassurance and comfort to parents but doctors may be unaware of the complexity of the medical situation. One of the Facebook posts (post number 13) made by a participant in March mentioned that the doctor did not properly explain the surgical procedure or the duration of the child's stay in the hospital, causing a loss of trust. As a result, the parents got angry at the healthcare staff.

The study has revealed a significant concern raised by participants – healthcare professionals tend to disregard parents’ worries Another prevalent theme in the interviews were parents' frustration with nurses failing to acknowledge their concerns about delayed walking, pain during diaper changes or dressing their child. Furthermore, some reported that nurses' lack of knowledge about spica casts caused confusion., prompting them to take the initiative to understand what was delaying their child's movement. Seeking an alternative opinion from a different paediatrics specialist empowered some parents, enabling them to effectively advocate for their child's needs. Examples in the section "Lack of Knowledge from HCPs about Spica Casts" in Chapter 8 reflect one of the mothers' concerns about support from health practitioners(see p,161-162) .The failure of healthcare professionals to answer questions left many parents feeling dissatisfied. Continuous communication and collaboration between families and service providers are therefore crucial and should be considered about community resources. Patients emphasize the significance of effective communication and attentive listening as key components of a reliable patient-provider relationship.Therefore, healthcare providers need to exhibit patience and attentiveness toward their patients and their families to establish a robust relationship built on trust (Hong and Oh, 2019; Stroud et al., 2023). Recent studies conducted by Theunissen et al. (2022) and Gram et al. (2023) suggest that healthcare professionals who exhibit genuine concern for the well-being of sick children and their families offer a greater sense of reassurance and comfort to parents. In contrast to a narrow focus solely on the child, this holistic approach acknowledges and addresses parents' concerns, ultimately contributing to a more positive healthcare experience for all involved.

II. Social support

Social support can take various forms, including providing knowledge and emotional support and facilitating a sense of normality. The systematic review conducted by Fang et al. (2022) on situational factors associated with parenting stress suggests that certain factors, such as the level of social support, could serve as a preventive or support strategy for parents. However, there remains uncertainty regarding the specific interpersonal and psychological processes that enable social support to mitigate the adverse effects of stressful events.

In social support section in Chapter Eight , parents received support from various groups on Facebook and friends and family. While different forms of social support exist, it is the emotional support of friends and family that proves most effective in terms of helping carers deal with the stress of looking after a child in a spica cast. Angela's mother and Charlotte's mother are good examples of how support from a husband plays a crucial role in this experience (p 163). Studies in the UK show that informal support positively impacts parental well-being, irrespective of the child's characteristics or diagnosis (White and Hastings, 2004).

Geographical location and place of residence also significantly impact maternal well-being, with access to specialised health services and proximity to social support sources playing pivotal roles as highlighted by two mothers mothers, who felt fortunate to have family and friends in the same area as the hospital where the surgery was performed(p 163). Family social support, comprising both existing and additional resources available during crises, plays a pivotal role in well-being.

III. Role of Online Platforms

Effective support systems for parents are available on online platforms like Facebook's DDH support page, which offers parents opportunities to network, support each other emotionally, and exchange information like solutions to caregiving problems (Section 8.2.4 Informal support). The participants noted that caring for a child in a spica cast is an unpredictable experience that necessitates additional support. Faced with a need to alleviate their concerns about caring for their child, the mothers in this study stated that they relied on Facebook to supplement the formal support offered by their healthcare provider. They stressed the importance of peer support, expressing a preference for connections with others who share similar experiences. It is highlighted that interactions with other parents provide practical advice and emotional reassurance. In this regard, online communities offer a secure and supportive environment where parents can freely share their experiences and concerns, which in turn promotes solidarity and enhances their coping mechanisms (Para et al., 2021; Theunissen et al., 2023).

The use of social media reflects the shift towards the internet as the primary source of healthcare information. Indeed, it has been demonstrated that social networks can improve patients’ disease management and health outcomes, with the Internet emerging as a valuable resource for families seeking orthopaedic consultation for their children (Jildeh, 2019; Hecht et al., 2023). By nurturing a sense of community among parents, online forums greatly contribute to the overall well-being of families and effectively enhance their ability to navigate the challenges of caregiving for a child with any illness. While guidance and management decisions lie within orthopedic consultations, social media platforms play a significant role in offering information to families about, e.g., the disease process and treatment (Para et al., 2021; Theunissen et al., 2023)

IV. Impact of the COVID-19 Pandemic

Following the outbreak of the COVID-19 pandemic, immediate and stringent measures were taken that significantly impacted healthcare services, including DDH-related care. My findings of revealed that the lockdown measures affected the delivery of healthcare services, and mothers' experiences of accessing these services were significantly impacted (see p. 153). A considerable number of parents experienced feelings of isolation and abandonment as a result of the COVID-19 restrictions(see p.122). This finding is consistent with the results of recent research conducted by Theunissen et al. (2022). Following surgery, the burden of care was observed to have increased significantly for many parents. The situation was further compounded by lockdown restrictions, which impeded travel for appointments and adversely impacted cast treatment and management. International articles from various countries such as Turkey, Italy, Saudi Arabia, and Canada have also addressed the impact of the pandemic on DDH diagnosis and treatment. These articles span from the onset of the pandemic until January 2023 and support the findings about the challenges faced by parents of children undergoing DDH treatment during the pandemic (Guindani and De Pellegrin, 2021; Mert Doğan and Aslantürk, 2022; Aljamaan et al., 2023). However, it is noteworthy that no study has been conducted so far to specifically investigate this matter in the context of the United Kingdom.

Conclusion

Mothers interpreted the experience of having a child in a spica cast differently, and their circumstances influenced the challenges they faced when caring for their children. It is therefore crucial to understand context-specific perceptions to improve services, care, and support for caregivers. A sense of control including access to information, emotional support, and practical assistance can help alleviate mothers’ stress.

CHAPTER ELEVEN: CONCLUSION

Chapter overview

In this chapter, I summarise my key findings and the practical implications of my study on mothers' experiences of looking after children placed in a Spica Cast after a DDH surgery. The main aim of this study was to generate a theoretical understanding based on and informed by the experience of looking after a child in a spica cast from the parents' perspective. My emerging theory will be subjected to a thorough and rigorous evaluation. This research makes significant contributions to the existing body of knowledge and offers substantial practical implications, which are discussed in detail. Finally, this chapter assesses the strengths of the study and outlines possible avenues for future research.

11.1. Evaluating the emergent theory

My aim in this section is to evaluate the rigour of the constructivist grounded theory I developed in my study. To do this, I will rely on Charmaz's (2006) four evaluation principles, namely credibility, originality, resonance, and usefulness.

I. Credibility

The credibility of this study has been discussed in the following ways:

1. Participants selected for this CGT study were mothers who experienced taking care of children in a spica cast. These experiences gave me first-hand data to carry out my research. The existing body of literature which I reviewed also provided additional insights to understand the topic in question and to develop my emergent theory. The categories involved in my theory encompassed a spectrum of parental experiences spanning from activities of daily living to the profound philosophical process of meaning-making. This reflects the comprehensive breadth, depth, and complexity of their experiences as mothers of children in a spica cast. These categories encapsulate a diverse range of empirical observations, addressing not only the physical challenges parents encounter but also the emotional and social hurdles they face.

2. Constant comparison was used during each stage of analysis to compare the data, categories and concept ,so as ensure that theory generated was appropriately

supported by the data. Additionally, throughout the interview process, the questions were reviewed and updated to incorporate emerging concepts, new information and novel ideas. The semi-structured nature of the interviews was also advantageous because it enabled my participants to freely discuss the aspects of their experiences that were significant to them.

3. The recruitment of a sufficient number of participants is crucial for the development of my theory. The data collection process involved simultaneous analytical activities and memoing until theoretical saturation was achieved.

4. Achieving intimate familiarity with the topic, the theory offers legitimacy and acknowledgment for the mother's experiences documented in this research. It not only validates and recognises parents' experiences, but also acts as a valuable resource for future parents. By offering a comprehensive understanding of the expectations and intricacies associated with caring for a child in a spica cast, the theory provides a roadmap for navigating this caregiving journey.
5. To achieve credibility, it is necessary to explain the theory and describe the data so vividly that the reader can almost literally see and hear its people (Glaser and Strauss 1967), as I detailed in the Methodology Chapter. Furthermore, the use of tables, figures, and mind maps facilitated the comprehension of interpretations and the drawing of robust, logical connections between the collected data and subsequent analyses. Making use of Nvivo coding software enabled me to capture subtle nuances in meaning. Mothers' experiences reflected in the first-hand quotations they provided also helped to support this understanding.
6. The triangulation method I adopted also enhanced the credibility of this study. It is important to reiterate here that the Facebook post data was only used as raw material for discovering the topic, whereas the interviews offered rich and deep data that allowed for a deeper comprehension of the phenomenon being studied.

7. To check the codes and support the organisation of the data, which in turn helps develop the appropriate theory, I sought academic advice from specialists in qualitative research. I also sought support from a PhD graduate who used the same methodology.

8. Reflexivity was an essential component of the research process because it was used to recognise and describe my perceptions throughout the analysis process (see Appendix 14 and 15).

II. Originality

According to Charmaz (2006), originality refers to how search results are evaluated according to their novelty. The originality of my study was assessed by conducting a scoping review of the literature and comparing the results with the body of knowledge on mothers’ experiences of caring for children who underwent a DDH surgery and were placed in a spica cast. The literature has documented many aspects of these findings and the experience of caring for children with any disease has similarities to the study's findings. However, this study could be considered as the first of its kind in the UK context according to a scoping review that I conducted before undertaking this research. Moreover, the majority of studies have primarily concentrated on parents' experiences with alternative methods of treating DDH such as the Pavlik harness. The study aimed to enhance originality through the use of constructivist grounded theory to research the experiences of UK-based parents caring for children with congenital abnormalities..

This study has contributed to the limited body of literature existing on the significance of context in enhancing the experience and ease of care by providing insight into these experiences, as well as new theory supporting theoretical knowledge. Theory development provides legitimacy and acknowledgement of the experiences of parents which have been under-documented in the research. Socially, it provides a road map for future parents for what to expect and the phenomenology of caring for a child in a spica cast. Clinically, it guides HCPs, as will be elaborated below.

I. Resonance

A third criterion for evaluating a grounded theory is resonance. According to Charmaz (2006), resonance is concerned with whether the participants or those who share their experiences regard the theory as meaningful and whether it makes sense to them. Employing resonance as a criterion involves assessing the extent to which the theoretical model developed can "speak specifically for the population from which it was derived and apply back to them" (Strauss and Corbin, 1998, p.267).

It is acknowledged that parents possess a deeper comprehension of their children compared to external sources. This recognition forms the fundamental basis for incorporating their insights as a cornerstone within the study's methodology. The study's primary objective was to engage parents who have first-hand experience with their children through Facebook support groups to identify the features of the problem and give a foundation for the research. The posts were produced for purposes not directly allied to the researcher's interests but still enabled an emphasis on personal experiences that can inform about caring for children in spica cast. The interviews were designed to obtain feedback from the parents who are one of the most logical sources of information because they know about reality and can give more information about the categories that seem essential to the emerging theory, such as the activities that their child changed or discontinued during the casting. This approach had a two-fold effect: it enabled the gathering of viewpoints from relevant stakeholders and provided an all-encompassing outlook on the topic.

The findings of the study explore the experience of family-centred systems of care, satisfaction with services, and the burden placed on them. The majority of the respondents reported facing many barriers when trying to access appropriate healthcare services, highlighting the need for and benefits of quality care. Moreover, mothers are not provided with ongoing, timely support and services which can help them provide care on a day-to-day basis. In light of this, the findings cannot be representative of all children admitted for surgery and all hospital settings because the theory developed is specifically contextualised to mothers of children in a spica cast. The study also indicated the importance of understanding the roles of health practitioners among parents in terms of expectations and empowerment. It is possible that this study was limited by the absence of the opinions of health professionals, but this was outside the remit of this study which aimed to explore the experience of caring specifically.

To maintain authenticity when representing the experiences of the participants in this study, the research process was guided by a thorough literature review which provided a strong theoretical foundation. , A carefully planned sampling strategy was used, with the initial sample serving as raw material to understand various aspects of the topic in question. A detailed description of the methods I used for collecting and analysing the data in the Methodology Chapter further enhanced the validity of this research.

To better understand each case, I actively sought to grasp the context and narratives involved. However, my research approach was Constructivist Grounded Theory (CGT), which is based on the belief that knowledge is subjective. As a result, my understanding and documentation of reality may not have been entirely objective. Subjectivity means that researchers acknowledge the impossibility of complete objectivity and instead use collaborative knowledge (Mohajan and Mohajan, 2022).

Fundamentally, it constructs theory directly from lived experiences, grounding in and reflecting the actual voices, contexts, and experiences of families and mothers. Theory resonates with the people who have experienced this particular experience of caring for children. I was aware of the potential for my own beliefs and biases to influence my understanding of the parents' experiences and I worked to mitigate these biases through reflexive and transparent research practices. One of the main advantages of this approach was that I played a significant role in generating data and concepts. I acted as the main instrument in the data collection and analysis processes, interpreting and fully understanding the meaning of the participants' words and constructs. I described the perspectives of parents according to what was deemed to be the fundamental properties of child development. However, I sought to balance my philosophical position and the interpretation of the study, which I achieved by presenting all of the research activities to my supervisor who gave me feedback on the relevance of my research question. All axial and focus codes, and categories were also thoroughly reviewed by my supervisors, thereby enhancing confidence in my findings. In addition, some improvements were made to the code names or grouping, resulting in a more coherent and comprehensive classification of the data.

IV. Usefulness

A final criterion is usefulness, which Charmaz (2006) defines as a measure of how useful the research findings are and where further research is needed. The theory I developed can be useful to add knowledge to the everyday world of a child in a spica cast and their family. Furthermore, it provides interpretations that people can apply in their daily life. Health professionals may also be influenced by it and future research may be stimulated, as discussed below.

This study is highly relevant and applicable within the UK healthcare system, as it examines the specific challenges faced by parents caring for children in spica casts following DDH surgery. It provides valuable insights into the experiences of these parents, thus contributing to a better understanding of the unique needs of families in this context. Furthermore, the study's findings may have broader applicability beyond the UK. Similar studies conducted in other countries on DDH have produced comparable results, suggesting shared elements and potential generalisability across various aspects. The challenges parents encounter, such as toileting, diaper changes, positioning, and cast complications, indicate its relevance in understanding parental caregiving for children in spica casts globally.

Additionally, this theory sheds light on how certain parents accept and adapt to changes in care and needs, emphasising common elements such as finding meaning in altering caregiving requirements. This insight may also be transferable to other caregiving experiences involving children with chronic illnesses.

A comprehensive theory that resonates with real-life experiences is valuable for practical applications. Middle-range theories, being less abstract and more operationalised than grand theories, serve as practical guides for developing clinical interventions tailored to the needs of specific populations. Participants expressed a lack of awareness about DDH surgery and spica cast after surgery and discussed the difficulties of independently caring for their child with a cast, often resorting to online resources for support. Consequently, the findings indicate the necessity for knowledge dissemination initiatives targeting the public and parents to bridge informational gaps and address knowledge deficiencies during diagnosis, treatment, and caregiving. This thesis is dedicated to empowering families to effectively manage the stress associated with DDH surgery and caregiving for a child in a spica cast, aiming to foster balance and stability within family dynamics. Ultimately, it seeks to drive positive changes in how families navigate these challenging circumstances.

11.2 Contribution of theory of being a mother of a child in a spica cast.

This section explains the significance of the theory and what this theory brings to wider knowledge about this topic:

11.2.1 Contribution of the research findings to the body of knowledge

The key contribution of this study is the development of a theory about “Being in a Spica Cast after DDH Surgery from Mothers’ Perspective”, which comprises three main aspects:

Firstly, the theory explored the experiences of mothers of children in spica cast, a topic that has not been adequately researched. This study then sought to fill the gap existing in the literature reviewed in Chapter 2, and which highlighted the limited availability of contemporary studies specifically exploring the experiences of parents with a child in a cast in the UK. This theoretical framework holds particular relevance for parents whose children will undergo treatment for hip dysplasia and require a spica cast. By providing families with an honest portrayal of the immediate future, they can better anticipate and adapt to the challenges ahead. Thus, my research findings contribute to enhancing the understanding of parents’ experiences in caring for children with spica casts and underscore the significance of proactive support and preparation for families facing similar circumstances. They legitimise the experiences of these parents and provide clinicians and parents with further details about the recommendations which will be discussed separately later in this chapter.

Moreover, the theory delves into the experiences of parents in the British context. This is particularly noteworthy due to the distinctive nature of the UK’s healthcare system. While existing literature, such as the small-scale survey by Cox and Kernohan (1998), has touched upon the challenges parents face in acquiring appropriate mobility equipment for children undergoing late DDH treatment at home, my research takes a novel approach by employing CGT methods to delve deeper into these experiences. The previous survey, conducted approximately 30 years ago, fails to provide a comprehensive understanding of their experiences and lacks depth regarding the emotional, practical, financial, and social struggles faced by parents in the UK. This revealed a notable gap in understanding the daily challenges faced by families with children in spica casts. It becomes evident that hip dysplasia in children can impose a substantial burden, with families identifying significant gaps in their own needs compared to what healthcare providers offer. Addressing changes in family routines and the emergence of new demands due to the presence of a spica cast is imperative. Therefore, developing a thorough understanding of these changes and challenges in the caregiving experience during this crucial period of transition may help alleviate the difficulties faced by parents. This can highlight the importance of equipping and preparing families as early as possible to navigate through this phase effectively.

Research shows the value of Facebook posts as rich sources of data for researchers. The Facebook parent support pages offer a valuable and accessible avenue for collecting data and studying target populations, providing researchers with valuable insights into the lived experiences and perspectives of parents facing similar challenges. The convenience of accessing target families without the need to visit multiple clinics, which reduces researcher time and effort.

11.2.2 Clinical implications

The findings of this study have significant clinical implications, particularly in enhancing the support provided to families caring for a child in a spica cast. The developed theory emphasizes the interplay between parental adaptation, meaning-making, and contextual influences, highlighting the need for a more structured and supportive approach in healthcare settings. The following key implications emerge from this research:

1-Enhancing Parental Education and Support in Spica Cast Care

A key clinical implication of this study is the need for structured parental education and support programs to ensure a smoother transition from hospital to home care. Parents often face significant challenges due to a lack of clear guidance on essential caregiving tasks, including cast hygiene, mobility management, and adapting daily routines. Without adequate preparation, these challenges can lead to stress, uncertainty, and difficulties in maintaining the child’s well-being.

To address this, healthcare providers should:

- Develop structured preoperative and postoperative education sessions that cover both practical caregiving strategies.

Provide accessible educational materials, such as written guides, instructional videos, and digital resources, to ensure parents have reliable information available at all times. Developing comprehensive care toolkits and guidelines** that include step-by-step caregiving instructions, access to specialized equipment (e.g., adaptive seating, hygiene tools), and helplines for professional support.

- Implement follow-up consultations and helplines to offer continued support, answer questions, and reinforce learning after discharge.

2-Strengthen multidisciplinary collaboration by integrating orthopedic specialists, physiotherapists, occupational therapists, and social workers to comprehensively address the medical, physical, and emotional needs of both the child and the family.

The implementation of these strategies is essential for ensuring that families receive the requisite support and resources necessary to enhance the well-being of children in a spica cast.

11.2.3 The impact of the theory on health policy

The research findings presented in this study offer valuable insights into health policy in many ways.

1. Family-Centred Perspective – Contextualizing the Care Experience

A family-centred perspective provides insights into how the care demands of a spica cast affect the entire family unit, including coping strategies and caregiving roles. This approach acknowledges the challenges faced by parents and caregivers, documenting their meaning-making process as they navigate their child’s care. Understanding the family’s journey of acceptance and adaptation allows for tailored, empathetic support that considers the needs of all caregivers involved.

2. Structured Approach for Clinicians - Empowerment and Support

The theoretical framework offers a structured approach to understanding mothers' experiences and needs, enabling clinicians to gain insights into the daily lives of children in casts and their families. This understanding can inform health policies that promote holistic patient care, considering not only the child's symptoms but also the social, psychological, and environmental contexts of the family. Policies should encourage healthcare providers to adopt a comprehensive approach, addressing practical caregiving demands, emotional burdens, and the provision of adequate information and support. Recognising the importance of empowerment and support can help mitigate the psychosocial challenges faced by these families and promote their overall well-being.

Strengths and limitations of this research

The use of the grounded theory method in this study is one of its strengths. As there is limited evidence regarding the experiences of children with spica casts, utilizing constructivist grounded theory in this study allowed for a more thorough understanding of parents' experiences while caring for a child with a spica cast. It is essential to understand how parents approach their children's care. Doing so allows us to identify and address environmental barriers and provide helpful strategies to support families in managing and overcoming difficulties. It is hoped that this study will contribute to this debate. If we are about to treat a child patient, we must realise that, in addition to the patient, we are directly influencing the quality of life of their family as well. From this point of view, the health provider has to know and be able to evaluate the outcome of the treatment. Therefore, researchers should focus on the significant role of the family function, investigate additional strategies to strengthen the family function, assist families in effectively coping with various stressful events, and ultimately attain a balanced and stable state.

11.3.1 Methodological reflect

It is worth noting that this study utilized Facebook support pages for parents as a key strength, as parents generally know more about their children than any external source. The selection of posts as a raw data source was deemed advantageous as it offered a comprehensive initial insight into the problem. One of the major advantages of this data source is that the posts come with context, including comments, pictures, or other media that afford valuable depth of information that may help shed light onto the phenomenon and highlight the more important details and fundamental features of everyday life for children with DDH spica casts and their families.

This data source worked very well with the constructivist grounded approach, as grounded theory typically begins with purposive sampling and how the Facebook data supported the interview data collected, later in theoretical sampling and the development of emergent theory.

11.3.2 My 'outsider' perspective

As an international student meant that I had few preconceived assumptions about the experience of caring for a child in the context of the British setting.However, I believe that my perspective is a strength of this study as it allowed me to discover life experiences without any preconceived notions about the community. To support this perspective, I adopted a Constructivist grounded theory methodology, which prioritizes capturing the voices of parents regarding their experiences. This approach brings people and their perspectives into the foreground and helps to gain a deeper understanding of their experiences. While analysing my data, I moved between stories and analysis to strike a balance between rendering participants' experiences and interpreting reality instead of reproducing it (Charmaz 2017).

In terms of weaknesses, this study had a limited number of participants, making it difficult to generalise the findings to all children with spica casts. During the COVID-19 pandemic, hospitals had to postpone non-essential surgeries, which resulted in a shortage of eligible participants for medical studies. As a result, parents were reluctant to seek medical attention for their children, leading to delays in treatment by orthopedic surgeons or their families (Mert Doğan and Aslantürk, 2021). Another limitation of this study is that it primarily focuses on the experiences of mothers, as recruiting fathers was expected to be challenging at the outset of the research.

11.4 Recommendations

11.4.1 Recommendations for policy making

This study suggests the necessity of training healthcare providers to enhance their knowledge and ensure consistency in offering advice. This is achieved through the following steps:

a) Health professionals were identified as crucial sources of support. However, variations in treatment approaches and a lack of consistent, reliable information about DDH caused stress for parents. Developing evidence-based clinical practice guidelines and educational materials for healthcare providers, in collaboration with paediatricians, orthopaedists, nurses, and physical therapists can establish a consistent standard of care, preventing parental confusion and delays in care.

b) Nurses have a crucial role in teaching mothers necessary daily care skills. Therefore, it is essential to provide specialized training for home visitors on caregiving skills like cast care and diaper changing. All the mothers interviewed expressed that the health visitor could not provide answers to questions about the cast. Future research should focus on assessing nurses' knowledge and proficiency in DDH, including their education during undergraduate studies and skill development (Vuong et al., 2022).

c) As well as clinical skills, health practitioners specializing in DDH must enhance their interpersonal and communication skills to effectively convey empathy, offer psychological support, and increase parents' self-efficacy. Empathy training should be integrated into medical and nursing school curricula and offered to all healthcare professionals through workshops and training sessions. The training should include active listening, emotional recognition, perspective-taking, and compassionate communication. By implementing comprehensive empathy training and clear guidelines for empathetic support, healthcare organizations can foster a more empathetic and patient-centered environment.

11.4.2 Recommendations for practice

I. To enhance both the delivery of information throughout the DDH healthcare journey and parental education, attention can be directed toward several key areas:

Improvements are required in leaflets and NHS information websites to enhance the quality of information provided to parents regarding DDH. This information should include practical day-to-day care instructions, a facet currently lacking in the existing verbal and written materials. Insights gleaned from this research can guide the future development of DDH booklets tailored to address the specific concerns voiced by mothers. For instance, they expressed concerns about safe transportation methods for children in casts.

Another significant consideration involves how information is provided to parents. Enhancing home care instructions for parents can be achieved by providing visual training materials, such as images or short videos. Through my research, parents have expressed challenges with written instructions and have shown a preference for visual aids. For instance, they recommend visual guides for tasks like changing diapers, allowing them to refer to the material until they feel confident in mastering the skill.

It is noteworthy that certain mothers expressed confidence in using the Internet to find information. It is important for orthopaedic surgeons not to ignore online resources and to integrate them into their family interactions during clinic visits. They can recommend accurate and clear websites, and provide a printed list of reliable sources for easy access.

II. Establish peer-to-peer DDH parental support groups within hospital settings

Integrating peer-to-peer support groups into clinical care settings can offer valuable emotional, informational, and practical assistance for parents navigating the care of children with complex needs. This will be overseen by a healthcare professional, such as a practitioner, nurse, community nurse, or physical therapist. With proper implementation, these groups leverage the power of shared lived experiences to improve family confidence, skills, and access to services. This initiative, combined with offering DDH-related scientific books, articles, and journals within paediatric clinics. Promoting mothers' involvement in social activities and support groups aim to tackle social isolation and its profound impact on social life, as emphasised by participants in this study, thereby promoting social involvement for parents.

By reinforcing community education partnerships and implementing measures, the goal is to raise awareness of DDH, bolster mother resilience, and offer support to new parents.

11.4.3 Recommendations for Future Research

This study's findings leave several questions unanswered regarding the treatment of DDH, which warrants further investigation in the following areas:

- Recognising the impact of health professionals on parenting highlights the need for additional research that gathers their perspectives on caring for and looking after children, with a specific focus on developmental dysplasia of the hip (DDH). Such research would provide valuable insights that could enhance support and interventions for both parents and children.

- Future research should explore ethnographic or phenomenological methods to deeply understand the daily experiences and emotional nuances of caregiving. While this study effectively used a constructivist grounded theory approach, an ethnographic design—by immersing researchers in the realities of parental caregiving—could provide richer data and better clarify the dynamic processes involved in how parents create meaning and adapt to their roles.

- Another recommendation for future research is to implement longitudinal studies that track parental experiences before, during, and after treatment. These investigations would yield valuable insights into how parents' meaning-making and adaptation develop over time. Although our current findings are robust, a longitudinal approach would significantly deepen our understanding of these evolving processes

- This study acknowledges the lack of diversity in participant age groups and highlights the need for further research across different developmental stages to improve the theoretical framework. More research with a broader sample size is necessary to fully understand the experiences of parents caring for children in spica casts and to confirm how caregiving challenges vary across different age groups.

11.5 A brief conclusion to the thesis

This thesis has addressed the lack of research on mothers’ experiences of caring for children in spica cast. It has developed a comprehensive conceptual framework for better understanding the complexity of these experiences to support theoretical knowledge about this topic. To do so, I adopted a constructivist grounded approach informed by a triangulation of two data sources: Facebook posts and interviews with mothers-caregivers.

I collected this data to explore the postoperative challenges families face in managing daily routines and childcare, along with the strategies they employ to overcome these difficulties. I examined the various factors contributing to the complexity of this experience and found similarities in parents’ experiences during these challenging circumstances. This helped me to provide detailed insights into the immense responsibility faced when caring for a child with a spica cast, which goes beyond typical parental care demands. I showed that the impact of a spica cast extends beyond the child and influences various aspects of family life and dynamics, affecting the child's development depending on the family's interpretation and adaptation to the situation. I highlighted that taking care of a child with a spica cast is a daily responsibility that includes social, behavioural, and physical care. I also delved into how families perceive and engage with the changes associated with this situation, considering the available resources. Coping and adaptation were portrayed as dynamic processes, influenced by the family's interpretation and response to the new event.

It is worth noting that this was an explanatory study, as no standardised measures were used to provide additional information on health or coping. The combination of originality and credibility has significantly enhanced the resonance, utility, and rigour of my contribution.

An important aspect I highlighted in my study is the important role that healthcare providers played in empowering parents to look after children with spica casts in their everyday lives. I specifically underscored the importance of providing appropriate guidance and robust support from healthcare providers to parents in dealing with the practical aspects of caring for children with spica casts. By offering evidence and a conceptual framework, this research has the potential to help professionals, parents, and the public to better understand the factors influencing spica cast life experiences.

References

Aarthun, A., Øymar, K.A. and Akerjordet, K. (2019).Health professionals' involvement of parents in decision-making in Interprofessional Practice at the Hospital. *Journal of Interprofessional Care* **34**:297–306.

Aarvold, A., Schaeffer, E. K., Kelley, S., Clarke, N. M. P., Herrera-Soto, J. A., Price, C. T., and Mulpuri,K. (2019).Management of irreducible hip dislocations in infants with developmental dysplasia of the hip diagnosed below 6 months of age. *Journal of Pediatric Orthopedics*, *39*(1), p. e39.

Adams, A. J., Johnson, M. A., Ryan, K. A., Farrell, S. B., Morro, M., and Sankar, W. N. (2019).Safe Transportation in-Spica Following Surgical Treatment of Infantile DDH: Solutions and Threats. *Journal of Pediatric Orthopaedics*, *39*(7), pp. E488–E493.

Adib-Hajbaghery, M., and Mokhtari, R. (2018). Quality of care before, during, and after casting: A cross-sectional study. *Archives of Trauma Research*, *7*(4), pp. 155–160.

Addor, V., Santos-Eggimann, B., Fawer, C. L., Paccaud, F., and Calame, A. (1997). Enrollment of a population-based cohort of newborns at higher risk of developing a chronic condition: the EDEN study. Etude du Developpement des Nouveau-nés Study. *International Journal of Epidemiology*, *26*(2), pp. 340–348.

Ahmed, S., Haines-Saah, R. J., Afzal, A. R., Tam-Tham, H., Al Mamun, M., Hemmelgarn,B. R., and Turin, T. C.(2017).User-driven conversations about dialysis through Facebook: a qualitative thematic analysis. *Nephrology*, *22*(4), pp. 301–307.

Aitken, M. E., Mele, N., and Barrett, K. W. (2004).Recovery of injured children: parent perspectives on family needs. *Archives of Physical Medicine and Rehabilitation*, *85*(4),pp. 567–573.

Aitken, M. E., Tilford, J. M., Barrett, K. W., Parker, J. G., Simpson, P., Landgraf, J., and Robbins, J.M. (2004).Health Status of Children After Admission for Injury. *Pediatrics*, *110*(2), pp. 337–342.

Aksoy, M. C., Özkoç, G., Alanay, A., Yazici, M., Özdemir, N., and Surat, A. (2002). Treatment of developmental dysplasia of the hip before walking: Results of closed reduction and immobilization in hip spica cast. *Turkish Journal of Pediatrics*, *44*(2).

Ali, M. K., Kamachi, D. K. K., Burton, R., Hussain, A., and Utukuri, M. M. (2016).Dysplasia of the hip in children-earlier referrals: a key for better outcomes. *Int J Contemp Pediatr*, *3*, pp. 784–787.

AlQemzi, M., Maizen, C., De Pellegrin, M., and Alshryda, S.(2022).Early Detection of Hip Dysplasia. In *Developmental Dysplasia of the Hip: From Early Sonographic Diagnosis to Effective Treatment* (pp. 55–64). Springer.

Anderson, E. H., and Spencer, M. H. (2002). Cognitive representations of AIDS: A phenomenological study. *Qualitative Health Research*, *12*(10), pp. 1338–1352.

Anderson, S., Allen, P., Peckham, S. and Goodwin, N. (2008). Asking the right questions: Scoping studies in the commissioning of research on the organisation and delivery of Health Services. *Health Research Policy and Systems* **6**.

Andrew, T. (2006).The literature review in grounded theory: A response to McCallin (2003). *The Grounded Theory Review: An International Journal*, *5*(2/3), pp. 29–41.

Angliss, R. (2005). Surgical treatment of late developmental displacement of the hip: results after 33 years. *The Journal of Bone and Joint Surgery British Volume*, *87*(3), pp. 384–394.

Årestedt, L., Benzein, E. and Persson, C. (2015).Families living with chronic illness. *Journal of Family Nursing* **21**:206–231.

Arksey, H. and O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology* **8**:19–32.

Aroojis, A., Anne, R. P., Li, J., Schaeffer, E., Kesavan, T. M. A., Shah, S., Patwardhan, S., Karnik, A., and Thanawala, U. (2022).Surveillance for Developmental Dysplasia of the Hip in India: Consensus Guidelines From the Pediatric Orthopaedic Society of India, Indian Academy of Pediatrics, National Neonatology Forum of India, Indian Radiological and Imaging Association, Indian Fede. *Indian Pediatrics*, *59*(8), pp. 626–635.

Ataro, G. (2019).Methods, methodological challenges and lesson learned from phenomenological study about OSCE experience: Overview of paradigm-driven qualitative approach in medical education. *Annals of Medicine and Surgery (2012) .49*,pp. 19–23.

Atkinson, R., and Flint, J. (2001).Social research update. *Department of Sociology, University of Surrey*, *33*.

Atrey, P. K., Hossain, M. A., El Saddik, A., and Kankanhalli, M. S. (2010). Multimodal fusion for multimedia analysis: a survey. *Multimedia Systems*, *16*(6), pp. 345–379.

Aveyard, H. and Bradbury-Jones, C. (2019).An analysis of current practices in undertaking literature reviews in nursing: Findings from a focused mapping review and synthesis. *BMC Medical Research Methodology* **19** (1).

Auriacombe, C., and Mouton, J. (2007). Qualitative field research. *Journal of Public Administration*, *42*(6), pp. 441–457.

Austin, Z., and Sutton, J.(2014).Qualitative research: Getting started. *The Canadian Journal of Hospital Pharmacy*, *67*(6), p. 436.

Balch Samora, J., Samora, W. P., Dolan, K., and Klingele, K. E. (2018). A quality improvement initiative reduces cast complications in a pediatric hospital. *Journal of Pediatric Orthopaedics*, *38*(2), pp. e43–e49.

Barrera, C. A., Cohen, S. A., Sankar, W. N., Ho-Fung, V. M., Sze, R. W., and Nguyen, J.C. (2019).Imaging of developmental dysplasia of the hip: ultrasound, radiography and magnetic resonance imaging. *Pediatric Radiology*, *49*, pp. 1652–1668.

Barrouillet, P. (2015) . Theories of cognitive development: From Piaget to today. In *Developmental Review* (Vol. 38, pp. 1–12). Elsevier.

Beer, D. D. (2008). Social network (ing) sites… revisiting the story so far: A response to danah boyd and Nicole Ellison. *Journal of Computer-Mediated Communication*, *13*(2), pp. 516–529.

Bellevue, K. D., Bompadre, V., and Lindberg, A. W. (2019) . Comparison of management of developmental dysplasia of the hip in a Pavlik harness by orthopaedic surgeons, orthopaedic pediatricians, and advanced practice providers. *JBJS Journal of Orthopaedics for Physician Assistants*, *7*(3), p. e0007.

Benson, M. K. D., and Wainwright, A. M. (2004). Developmental dysplasia of the hip. *Surgery (Oxford)*, *22*(1), pp. 5–9.

Bettany-Saltikov, J. (2016) . EBOOK: How to do a Systematic Literature Review in Nursing: A step-by- step guide.

Biçimoglu, A., Ag, H., Ömeroglu, H., and Tümer, Y. (2003). Six years of experience with a new surgical algorithm in developmental dysplasia of the hip in children under 18 months of age. *Journal of Pediatric Orthopaedics*, *23*(6), pp. 693–698.

Booth, A., Sutton, A., Clowes, M. and Martyn-St James, M. (2022).*Systematic Approaches to a Successful Literature Review*. Los Angeles: SAGE.

Boyd, L. (2017) . *Problems faced by parents of mentally challenged children*.

Brady, E., and Guerin, S. 2010. “Not the romantic, all happy, coochy coo experience”: A qualitative analysis of interactions on an Irish parenting web site. *Family Relations*, *59*(1),pp. 14–27.

Broady, T.R., Stoyles, G.J. and Morse, C. (2015) .Understanding carers’ lived experience of stigma: The voice of families with a child on the autism spectrum. *Health andamp; Social Care in the Community* **25**:224–233.

Bromley, R. D. F., Matthews, D. L., and Thomas, C. J. (2007). City centre accessibility for wheelchair users: The consumer perspective and the planning implications. *Cities*, *24*(3), pp. 229–241.

Brown, S. C., Stevens, R. A., Troiano, P. F., and Schneider, M. K. (2002). Exploring complex phenomena: Grounded theory in student affairs research. *Journal of College Student Development*, *43*(2).

Bruce, B., Letourneau, N., Ritchie, J., Larocque, S., Dennis, C., and Elliott, M. R. (2002). A multisite study of health professionals’ perceptions and practices of family-centered care. *Journal of Family Nursing*, *8*(4), pp. 408–429.

Bruås, K. R., Aukland, S. M., Markestad, T., Sera, F., Dezateux, C., and Rosendahl, K. (2011) . Newborns with sonographically dysplastic and potentially unstable hips: 6-year follow-up of an RCT. *Pediatrics*, *127*(3), pp. e661–e666.

Bryant, A. (2002). Re-grounding grounded theory. *Journal of Information Technology Theory and Application (JITTA)*, *4*(1), p. 7.

Bryant, A., and Charmaz, K. (2007). *The Sage handbook of grounded theory*. Sage. Bryman, A. (2001). *Social Research Methods 4th ed.* Oxford university press.

Bryman, A. (2016) . *Social Research methods*. Oxford university press.

Busetto, L., Wick, W., and Gumbinger, C. (2020). How to use and assess qualitative research methods. *Neurological Research and Practice*, *2*, pp. 1–10.

Buxton, R. A., Humphreys, R., and Yeates, D. (2004). Neonatal hip surveillance and the early management of developmental dysplasia of the hip. *Current Paediatrics*, *14*(5), pp. 452– 458.

Bwanga, O. (2020). How to Conduct a Qualitative Systematic Review to Guide Evidence- Based Practice in Radiography. *International Journal of Sciences: Basic and Applied Research*.

Byrnes, J.P. (2008). Piaget’s cognitive-developmental theory. *Encyclopedia of Infant and Early Childhood Development*:543–552.

Calnan, M., Hutten, J., Tiljak, H., Saltman, R., Rico, A., and Boerma, W. (2006). The challenge of coordination: the role of primary care professionals in promoting integration across the interface. *Primary Care in the Driver’s Seat*, pp. 85–104.

Calnan, M., and Rowe, R. (2006). Researching trust relations in health care: conceptual and methodological challenges–an introduction. *Journal of Health Organization and Management*, *20*(5), pp. 349–358.

Causon, E. (20100. The nurses’ role in educating, counselling and preparing parents to care for a child with developmental dysplasia of the hip (DDH). *International Journal of Orthopaedic and Trauma Nursing*, *14*(1), pp. 40–47.

Cescutti-Butler, L., and Galvin, K. (2003). Parents’ perceptions of staff competency in a neonatal intensive care unit. *Journal of Clinical Nursing*, *12*(5), pp. 752–761.

Charenkova, J. (2023). “Parenting my parents”: Perspectives of adult children on assuming and remaining in the caregiver’s role. *Frontiers in Public Health* **11**.

Chao, M.-L., and Chiang, V. C. (2003). Impact on and coping behaviours of a Chinese mother with a child suffering from developmental dysplasia of the hip. *Journal of Orthopaedic Nursing*, *7*(4), pp. 176– 183.

Charmaz, K. (2001). *Grounded theory: Methodology and theory construction. International Encyclopedia of the Social and Behavioral Sciences,* pp. *6396–6399*.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. sage.

Charmaz, K. (2014). *Constructing grounded theory* (Second edi). SAGE.

Charmaz, K. (2017) . The power of constructivist grounded theory for critical inquiry.*Qualitative Inquiry*, *23*(1), pp. 34–45.

Charmaz, K., and Smith, J. A. (2003). Qualitative psychology: A practical guide to research methods. *Smith, Jonathan A. (Ed.)*, 81.

Chen, M., Gittings, D. J., Yang, S., and Liu, X. (2018). Total hip arthroplasty for Crowe type IV developmental dysplasia of the hip using a titanium mesh cup and subtrochanteric femoral osteotomy. *The Iowa Orthopaedic Journal*, *38*, p. 191.

Chichirez, C. M., and Purcărea, V. L. (2018). Interpersonal communication in healthcare. *Journal of Medicine and Life*, *11*(2), p. 119.

Chrenka, L. (2001). Misconstructing constructivism. *Phi Delta Kappan*, *82*(9), p. 694. Chun Tie, Y., Birks, M., and Francis, K. (2019) . Grounded theory research: A design framework for novice researchers. *SAGE Open Medicine*, *7*, 2050312118822927.

Clarke, A. E. (2003). Situational analyses: Grounded theory mapping after the postmodern turn.*Symbolic Interaction*, *26*(4), pp. 553–576.

Clarke, S. (2006). *An audit of spica cast guidelines for parents and professionals caring for children with developmental dysplasia of the hip*. pp. 128–137.

Clarke, S., and Dowling, M. (2003). Spica cast guidelines for parents and health professionals. *Journal of Orthopaedic Nursing*, *7*(4), pp. 184–191.

Clarke, S. and McKay, M. (2006). An audit of Spica cast guidelines for parents and professionals caring for children with developmental dysplasia of the hip. *Journal of Orthopaedic Nursing* **10**:128–137.

Clarke, Victoria., and Braun, Virginia.(2013). *Successful qualitative research: a practical guide for beginners*. SAGE.

Coad, J.E. and Shaw, K.L. (2008). Is children's choice in health care rhetoric or Reality? A scoping review. *Journal of Advanced Nursing* **64**:318–327.

Connolly, P. and Weinstein, S.L. (2007). The course and treatment of avascular necrosis of the femoral head in developmental dysplasia of the hip. *Acta Orthop Traumatol Turc* 41(. pp. 54–59.

Cooper, A. P., Doddabasappa, S. N., and Mulpuri, K. (2014). Evidence-based management of developmental dysplasia of the hip. *Orthopedic Clinics*, *45*(3), pp. 341–354.

Corbin, J., and Strauss, A. (2008). Qualitative research. *Techniques and Procedures for Developing Grounded Theory*, *3*.

Coughlan, M. and Cronin, P. (2021).*Doing a Literature Review in Nursing, Health and Social Care*. London: SAGE Publications.

Coulson, N. S., Buchanan, H., and Aubeeluck, A. (2007). Social support in cyberspace: a content analysis of communication within a Huntington's disease online support group. *Patient Education and Counseling*, *68*(2), pp. 173–178

Crespo, C., Santos, S., Tavares, A. and Salvador, Á. (2016).“Care that matters”: Family-centered care, caregiving burden, and adaptation in parents of children with cancer. *Families, Systems, andamp; Health* **34**:31–40.

Creswell, J. W. (2013(. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*.

Creswell, J. W., and Creswell, J. D. (2017) . *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications.

Cummings, E., and Borycki, E. M. (2011) . Grounded theory evolution and its application in health informatics. *ITCH*, pp. 286–292.

Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, *31*(6), pp. 1476–1484.

Cutcliffe, J. R. (2005). Adapt or adopt: Developing and transgressing the methodological boundaries of grounded theory. *Journal of Advanced Nursing*, *51*(4), pp. 421–428.

Dadkhah-Tehrani, M., Adib-Hajbaghery, M., and Abedi, A. (2022) . Cast-Related complications in patients with limb fractures: A cross-sectional study. *Archives of Trauma Research*, *11*(4), pp. 211– 217.

Dal-Ré, R. (2023). Waivers of informed consent in research with competent participants and the declaration of helsinki. *European Journal of Clinical Pharmacology* **79**:575–578.

Daudt, H.M., van Mossel, C. and Scott, S.J. (2013). Enhancing the scoping study methodology: A large, inter-professional team's experience with arksey and o'malley's framework. *BMC Medical Research Methodology* **13**.

David, A. M., Joanne, R. M., Colin, M. F., Reidy, M., Murray, A., and Wood, R. (2018). Enhanced detection services for developmental dysplasia of the hip in Scottish children, 1997–2013. *Archives of Disease in*

Childhood, *103*(11), pp. 1021–1026.

Davies, L., LeClair, K. L., Bagley, P., Blunt, H., Hinton, L., Ryan, S., and Ziebland, S. (2020). Face-to- face compared with online collected accounts of health and illness experiences: a scoping review. *Qualitative Health Research*, *30*(13), pp. 2092–2102.

Davies, R. M., Mace, J., Talbot, C., and Paton, R. W. (2016) . Evaluation of the six-to eight- week GP check for developmental dysplasia of the hip. *Orthopaedic Proceedings*, *98*(SUPP_15), pp. 5–6. Davison, K. K., Charles, J. N., Khandpur, N., and Nelson, T. J. (2017) . Fathers' perceived reasons for their underrepresentation in child health research and strategies to increase their involvement. *Maternal and Child Health Journal*, *21*, pp. 267–274.

De Hundt, M., Vlemmix, F., Bais, J. M. J., Hutton, E. K., De Groot, C. J., Mol, B. W. J., and Kok, M. (2012) . Risk factors for developmental dysplasia of the hip: a meta-analysis. *European Journal of Obstetrics and Gynecology and Reproductive Biology*, *165*(1), pp. 8– 17.

DeJonckheere, M., and Vaughn, L. M. (2019) . Semistructured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health*, *7*(2).

Del Rio-Roberts, M. 2010. A guide to conducting ethnographic research: a review of Ethnography: Step-by-Step by David M. Fetterman. *The Qualitative Report*, *15*(3), pp. 737–739.

Demir, S. G., Erden, S., Bulut, H., Carboga, B., and Elbas, N. O. (2015) . The problems experienced by parents providing postoperative home care following their child's surgery for developmental dysplasia of the hip. *Orthopaedic Nursing*, *34*(5), pp. 280–286.

Denzin, N. K., and Lincoln, Y. S. (2008). *Introduction: The discipline and practice of qualitative research.*

Denzin, N. K., and Lincoln, Y. S. (2011) . *The Sage handbook of qualitative research*. sage. Dey, I. (1999). Grounding grounded theory: Guidelines for qualitative inquiry. *(No Title)*.

Dezateux, C., and Rosendahl, K. (2007). Developmental dysplasia of the hip. *The Lancet*, *369*(9572), pp. 1541–1552.

DiFazio, R., Vessey, J., Zurakowski, D., Hresko, M. T., and Matheney, T. (2011) . Incidence of skin complications and associated charges in children treated with hip spica casts for femur fractures. *Journal of Pediatric Orthopaedics*, *31*(1), pp. 17–22.

DiPaola, M. J., Abzug, J. M., Pizzutillo, P. D., and Herman, M. J. (2014). Incidence and etiology of unplanned cast changes for fractures in the pediatric population. *Journal of Pediatric Orthopaedics*, *34*(6), pp. 643–646.

Dogruel, H., Atalar, H., Yavuz, O. Y., and Sayli, U. (2008). Clinical examination versus ultrasonography in detecting developmental dysplasia of the hip. *International Orthopaedics*, *32*, pp. 415–419.

Dorman, S., and Perry, D. (2020). Hip disorders in childhood. *Paediatrics and Child Health*, *30*(6), pp. 195–200.

Dombestein, H., Norheim, A. and Lunde Husebø, A.M. (2019).Understanding informal caregivers' motivation from the perspective of self-determination theory: An integrative review. *Scandinavian Journal of Caring Sciences* 34:267–279.

Durant-Law, G. (2005). The philosophical trinity, soft systems methodology and Grounded Theory. *University of Canberra*, pp. 2–30.

Easterby-Smith, M., Thorpe, R., and Jackson, P. R. (2012) . *Management research*. Sage.

Edmondson,C., and McManus, S. E. (2007). Methodological fit in management field research. *Academy of Management Review*, *32*(4), pp. 1246–1264.

Ekwall, A., Carlberg, E., Palmberg, G., and Sloberg, R. (2018). An audit of complications of fiberglass cast and hybrid cast for fractures of the foot, ankle and forearm in a Swedish emergency department. *International Journal of Orthopaedic and Trauma Nursing*, *31*,pp. 32–34.

Elbourne, D., Dezateux, C., Arthur, R., Clarke, N. M. P., Gray, A., King, A., Quinn, A., Gardner, F., and Russell, G. (2002). Ultrasonography in the diagnosis and management of developmental hip dysplasia (UK Hip Trial): clinical and economic results of a multicentre randomised controlled trial. *The Lancet*, *360*(9350), pp. 28)–(2017) .

Elkin, N. (2008). *How America Searches: Health and Wellness Scottsdale, AZ: iCrossing*. Elliott, T. R., and Pezent, G. D. (2008). Family caregivers of older persons in rehabilitation. *NeuroRehabilitation*, *23*(5), pp. 439–446.

Engesæter, I. Ø. (2013). *Hip dysplasia in young adults*. University of BERGEN.

Engward, H. (2013). Understanding grounded theory. *Nursing Standard (Royal College of Nursing (Great Britain): 1987)*, *28*(7), pp. 37–41.

Fabricant, P. D., Dy, C. J., Patel, R. M., Blanco, J. S., and Doyle, S. M. (2013(. Internet search term affects the quality and accuracy of online information about developmental hip dysplasia. *Journal of Pediatric Orthopaedics*, *33*(4), pp. 361–365.

Fairfax, A., Brehaut, J., Colman, I., Sikora, L., Kazakova, A., Chakraborty, P. and Potter, B.K. (2019).A systematic review of the association between coping strategies and quality of life among caregivers of children with chronic illness and/or disability. *BMC Pediatrics* **19**.

Ferreira, J. v, and Thomson, J. D. (2012) . Socioeconomic implications of spica casting: Commentary on an article by Dirk Leu, MD, et al.:“Spica casting for pediatric femoral fractures. A prospective, randomized controlled study of single-leg versus double-leg spica casts.” *JBJS*, *94*(14), p. e107.

Feudtner, C., Feinstein, J. A., Zhong, W., Hall, M., and Dai, D. (2014). Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation. *BMC Pediatrics*, *14*(1), pp. 1–7.

Finlay, L., and Ballinger, C. (2006). *Qualitative research for allied health professionals: Challenging choices*. John Wiley and Sons.

Flynn, J. M., Garner, M. R., Jones, K. J., D’Italia, J., Davidson, R. S., Ganley, T. J., Horn,D., Spiegel, D., and Wells, L. (2011) . The treatment of low-energy femoral shaft fractures: A prospective study comparing the “walking spica” with the traditional spica cast. *Journal of Bone and Joint Surgery*,*93*(23), pp. 2196–2202.

Flynn, J. M., and Schwend, R. M. (2004). Management of pediatric femoral shaft fractures. *JAAOS- Journal of the American Academy of Orthopaedic Surgeons*, *12*(5), pp. 347–359.

Fortier, M.A. and Kain, Z.N. (2015) . Treating perioperative anxiety and pain in children: a tailored and innovative approach. *Pediatric Anesthesia* 25(1), pp. 27–35.

Fowler, J. H., and Christakis, N. A. (2008). Estimating peer effects on health in social networks: a response to Cohen-Cole and Fletcher; Trogdon, Nonnemaker, Pais. *Journal of Health Economics*, *27*(5), p. 1400.

Furnes, O., Lie, S. A., Espehaug, B., Vollset, S. E., Engesaeter, L. B., and Havelin, L. I. (2001). Hip disease and the prognosis of total hip replacements: a review of 53 698 primary total hip replacements reported to the Norwegian arthroplasty register 1987–99. *The Journal of Bone and Joint Surgery British Volume*, *83*(4), p. 579.

Gallahue, D. L., and Ozmun, J. C. (2006). Understanding motor development: Infants, children, adolescents, adults. *(No Title)*.

Garcia, G. H., Taylor, S. A., Dy, C. J., Christ, A., Patel, R. M., and Dines, J. S. (2014). Online resources for shoulder instability: what are patients reading? *JBJS*, *96*(20), p. e177.

Gardner, F., Dezateux, C., Elbourne, D., Gray, A., King, A., and Quinn, A. (2005). The hip trial: psychosocial consequences for mothers of using ultrasound to manage infants with developmental hip dysplasia. *Archives of Disease in Childhood-Fetal and Neonatal Edition*, *90*(1), pp. F17–F24.

Gaysynsky, A., Romansky-Poulin, K., and Arpadi, S. (2015) . “My YAP Family”: analysis of a Facebook group for young

Gibbard, M., Zivkovic, I., Jivraj, B., Schaeffer, E., Robillard, J. M., and Mulpuri, K. (2021) . A global survey of patient and caregiver experiences throughout care for developmental dysplasia of the hip. *Journal of Pediatric Orthopedics*, *41*(6), p. e392.

Gjengedal, E., Rustøen, T., Wahl, A. K., and Hanestad, B. R. (2003). Growing up and living with cystic fibrosis: Everyday life and encounters with the health care and social services—A qualitative study. *Advances in Nursing Science*, *26*(2), pp. 149–159.

Glaser, B. G. (2001). The grounded theory perspective: conceptualization contrasted with description. *(No Title).*

Glaser, B. G. (2014)a. Choosing grounded theory. *The Grounded Theory Review*, *13*(2),pp. 3–19.

Glaser, B. G. (2014)b. *Memoing: A vital grounded theory procedure*. Sociology Press.

Glaser, B. G., and Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research, [e- book] Aldine de Gruyter*.

Glaser, B. G., and Strauss, A. L. (2017) . Discovery of grounded theory: Strategies for qualitative research. In *Discovery of Grounded Theory: Strategies for Qualitative Research*.

Glaser, B., and Strauss, A. (2014). Applying grounded theory. *The Grounded Theory Review*, *13*(1), pp. 46–50.

Grandcolas, U., Rettie, R., and Marusenko, K. (2003). Web Survey Bias: Sample or Mode Effect? *Journal of Marketing Management*, *19*(5).

Granger, J., Branney, P., Sullivan, P. and McDermott, S. (2021).Ethical considerations in post-GDPR Social Media-based research. *QMiP Bulletin* **1**:5–12.

Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science and Medicine*, *56*(3), pp. 631–642.

Greckhamer, T., and Koro-Ljungberg, M. (2005). The erosion of a method: Examples from grounded theory. *International Journal of Qualitative Studies in Education*, *18*(6), pp. 729–750.

Green, J. (2004). Is trust an under-researched component of healthcare organisation?*BMJ*, *329*(7462), p. 384.

Greisberg, J., Bliss, M. J., Eberson, C. P., Solga, P., and d’Amato, C. (2002). Social and economic benefits of flexible intramedullary nails in the treatment of pediatric femoral shaft fractures. *Orthopedics*, *25*(10).

Grissom, L. E., and Harcke, H. T. (2000). Ultrasonography and developmental dysplasia of the infant hip. *Current Opinion in Orthopaedics*, *11*(2), pp. 127–130.

Gruebner, O. et al. (2022) . Digital Platform Uses for Help and Support Seeking of Parents With Children Affected by Disabilities: Scoping Review. *Journal of Medical Internet Research* 24(12), p. e37972.

Guarniero, R. (2010). Dysplasia of hip development: update. *Revista Brasileira de Ortopedia (English Edition)*, *45*(2), pp. 116–121.

Guendouzi*, J. (2005). “I feel quite organized this morning”: How mothering is achieved through talk. *Sexualities, Evolution and Gender*, *7*(1), pp. 17–35.

Guerra, M., and Zuccoli, F. (2012) . Finished and unfinished objects: supporting children’s creativity through materials. *Procedia-Social and Behavioral Sciences*, *51*, pp. 721–727.

Guille, J. T., Pizzutillo, P. D., and MacEwen, G. D. (2000). Development dysplasia of the hip from birth to six months. In *The Journal of the American Academy of Orthopaedic Surgeons,* 8(4).

Gulati, V., Eseonu, K., Sayani, J., Ismail, N., Uzoigwe, C., Choudhury, M. Z., Gulati, P., Aqil, A., and Tibrewal, S. (2013). Developmental dysplasia of the hip in the newborn: A systematic review. *World Journal of Orthopedics*, *4*(2), p. 32.

Gusrianti, E., Winarni, T. I., and Faradz, S. M. H. (2018). Factors affecting parents’ acceptance towards children with familial intellectual disability (ID). *Journal of Biomedicine and Translational Research*, *4*(2), pp. 45–50.

Halanski, M., and Noonan, K. J. (2008). Cast and splint immobilization: complications. *JAAOS- Journal of the American Academy of Orthopaedic Surgeons*, *16*(1), pp. 30–40.

Haley, C. A., DeJong, E. S., Ward, J. A., and Kragh Jr, J. F. (2006). Waterproof versus cotton cast liners: a randomized, prospective comparison. *American Journal of Orthopedics (Belle Mead, NJ)*, *35*(3), pp. 137–140.

Hallström, I., Runesson, I., and Elander, G. (2002). Observed parental needs during their child’s hospitalization. *Journal of Pediatric Nursing*, *17*(2), pp. 140–148.

Hammersley, M. (2018). What is ethnography? Can it survive? Should it? *Ethnography and Education*, *13*(1), pp. 1–17.

Harry, A., Johnston, C., Twomey, S., and Wakely, L. (2022) . A Survey of Parents’ and Carers’ Perceptions of Parenting a Child With Developmental Dysplasia of the Hip. *Pediatric Physical Therapy*, *34*(3), pp. 328–333.

Hart, E. S., Albright, M. B., Rebello, G. N., and Grottkau, B. E. (2006). Developmental dysplasia of the hip: nursing implications and anticipatory guidance for parents. *Orthopaedic Nursing*, *25*(2), pp. 100–109.

Hassan, F. A. (2009). Compliance of parents with regard to Pavlik harness treatment in developmental dysplasia of the hip. *Journal of Pediatric Orthopaedics B*, *18*(3), pp. 111– 115.

Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., Krauss, M. W., Sayer, A., Upshur, C. C., and Hodapp, R. M. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development*, pp. 1–126.

Hedequist, D., Kasser, J., and Emans, J. (2003). Use of an abduction brace for developmental dysplasia of the hip after failure of Pavlik harness use. *Journal of Pediatric Orthopaedics*, *23*(2), pp. 175–177.

Heidegger, M. (2011) . *The concept of time: The first draft of being and time*. AandC Black. Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities*, *14*, pp. 159–171.

Herman, M. J., Abzug, J. M., Krynetskiy, E. E., and Guzzardo, L. V. (2011) . Motor vehicle transportation in hip spica casts: Are our patients safely restrained? *Journal of Pediatric Orthopaedics*, *31*(4), pp. 465–468.

Herring, J. A., and Tachdjian, M. O. (2002). Pediatric orthopaedics. *Benign Musculoskeletal Tumours*.

Herring, S. C. (2000). Gender differences in CMC: Findings and implications. *Computer Professionals for Social Responsibility Journal*, *18*(1).

Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., and Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, *50*(12), pp. 874–882.

Hessler, R. M., Downing, J., Beltz, C., Pelliccio, A., Powell, M., and Vale, W. (2003). Qualitative research on adolescent risk using e-mail: A methodological assessment. *Qualitative Sociology*, *26*,pp. 111–1

Hewson, C. (2017) . Research design and tools for online research. *The SAGE Handbook of Online Research Methods*, pp. 57–75.

Hinde, S. (2000). *The provision and availability of equipment for children in hip spicas and splints: a national survey*. STEPS. Cheshire: The National Association for Children with Lower Limb.

Holman, J., Carroll, K. L., Murray, K. A., MacLeod, L. M., and Roach, J. W. (2012) . Long- term follow- up of open reduction surgery for developmental dislocation of the hip. *Journal of Pediatric Orthopaedics*, *32*(2), pp. 121–124.

Hopia, H., Paavilainen, E., and Åstedt-Kurki, P. (2004). Promoting health for families of children with chronic conditions. *Journal of Advanced Nursing*, *48*(6), pp. 575–583.

Hopia, H., Paavilainen, E., and Åstedt-Kurki, P. (2005). The diversity of family health: constituent systems and resources. *Scandinavian Journal of Caring Sciences*, *19*(3), pp. 186–195.

Hughes, B. F., Sponseller, P. D., and Thompson, J. D. (1995). Pediatric femur fractures: effects of spica cast treatment on family and community. *Journal of Pediatric Orthopaedics*, *15*(4), pp. 457– 460.

Hummelinck, A., and Pollock, K. (2006). Parents’ information needs about the treatment of their chronically ill child: a qualitative study. *Patient Education and Counseling*, *62*(2),pp. 228–234.

Hunsinger, J., and Senft, T. M. (2013(. *The social media handbook*. Routledge.

Iarskaia-Smirnova, E., Romanov, P. and Yarskaya, V. (2015) . Parenting children with disabilities in Russia: Institutions, discourses and identities. *Europe-Asia Studies* 67(10), pp. 1606–1634.

Infante Jr, A. F., Albert, M. C., Jennings, W. B., and Lehner, J. T. (2000). Immediate hip spica casting for femur fractures in pediatric patients: a review of 175 patients. *Clinical Orthopaedics and Related Research®*, *376*, pp. 106–112.

Isaksen, J. H., Hertel, N. T., and Kjær, N. K. (2013). Semi-structured interview is a reliable and feasible tool for selection of doctors for general practice specialist training. *Dan Med J*, *60*, A4692.

Jacobsen, S., Sonne-Holm, S., Søballe, K., Gebuhr, P., and Lund, B. (2005). Hip dysplasia and osteoarthrosis: a survey of 4 151 subjects from the Osteoarthrosis Substudy of the Copenhagen City heart study. *Acta Orthopaedica*, *76*(2), pp. 149–158.

Jagosh, J., Boudreau, J. D., Steinert, Y., MacDonald, M. E., and Ingram, L. (2011) . The importance of physician listening from the patients' perspective: Enhancing diagnosis, healing, and the doctor–patient relationship. *Patient Education and Counseling*, *85*(3),pp. 369–374.

Jennings, H. J., Gooney, M., O'Beirne, J., and Sheahan, L. (2017) . Exploring the experiences of parents caring for infants with developmental dysplasia of the hip attending a dedicated clinic. *International Journal of Orthopaedic and Trauma Nursing*, *25*, pp. 48–53.

Johnson, B. S. (2000). Mothers' perceptions of parenting children with disabilities. *MCN: The American Journal of Maternal/Child Nursing*, *25*(3), pp. 127–132.

Johnson, P., Buehring, A., Cassell, C., and Symon, G. (2006). Evaluating qualitative management research: Towards a contingent criteriology. *International Journal of Management Reviews*, *8*(3), pp. 131–156.

Judd, J., and Wright, L. (2005). Joint and limb problems in children and adolescents. In *Orthopaedic and trauma nursing* (pp. 244–264). Churchill Livingstone, London.

Kelle, U. (2007). The development of categories: Different approaches in grounded theory.*The Sage Handbook of Grounded Theory*, pp. 191–213.

Khalil, H., Peters, M., Godfrey, C.M., McInerney, P., Soares, C.B. and Parker, D. (2016).An evidence-based approach to scoping reviews. *Worldviews on Evidence-Based Nursing* **13**:118–123.

Khan, K., Kunz, R., Kleijnen, J., and Antes, G. (2011) . *Systematic reviews to support evidence-based medicine*. Crc press.

Kietzmann, J. H., Hermkens, K., McCarthy, I. P., and Silvestre, B. S. (2011) . Social media? Get serious! Understanding the functional building blocks of social media. *Business Horizons*, *54*(3), pp. 241–251.

Kilicarslan-Toruner, E., and Akgun-Citak, E. (2013). Information-seeking behaviours and decision- making process of parents of children with cancer. *European Journal of Oncology Nursing*, *17*(2),pp. 176–183.

King, G. A. (2004). The meaning of life experiences: Application of a meta-model to rehabilitation sciences and services. *American Journal of Orthopsychiatry*, *74*(1), pp. 72–88.

Kocher, M., Ciarlo, M. L., Feroe, A. G., Dichtel, L. E., and Traver, J. L. (2022) . Impact on Family Functioning of Immediate Spica Casting for Pediatric Femur Fractures: An Ecological Study. *Journal of the Pediatric Orthopaedic Society of North America*, *4*(1),pp. 1–10.

Kocher, M. S., Sink, E. L., Blasier, D. R., Luhmann, S. J., Mehlman, C. T., Scher, D. M., Matheney, T., Sanders, J. O.,Kolovos, P., Kaitelidou, D., Lemonidou, C., Sachlas, A., and Sourtzi, P. (2015) . Patient Participation in Decision Making During Nursing Care in G reece—A Comparative Study. *Nursing Forum*, *50*(3),pp. 147–157.

Kotlarsky, P., Haber, R., Bialik, V., and Eidelman, M. (2015) . Developmental dysplasia of the hip: What has changed in the last 20 years? *World Journal of Orthopedics*, *6*(11), p. 886.

Kristensson- Hallström, I. (2000). Parental participation in pediatric surgical care. *AORN Journal*, *71*(5), pp. 1021–1029.

Lee, Y.-Y., and Lin, J. L. (2010). Do patient autonomy preferences matter? Linking patient- centered care to patient–physician relationships and health outcomes. *Social Science and Medicine*, *71*(10), pp. 1811–1818.

Lee, Y.-Y., and Lin, J. L. (2011) . How much does trust really matter? A study of the longitudinal effects of trust and decision-making preferences on diabetic patient outcomes. *Patient Education and Counseling*, *85*(3), pp. 406–412.

Levac, D., Colquhoun, H. and O'Brien, K.K. (2010). Scoping studies: Advancing the methodology. *Implementation Science* **5**.

Leu, D., Sargent, M. C., Ain, M. C., Leet, A. I., Tis, J. E., and Sponseller, P. D. (2012) . Spica casting for pediatric femoral fractures: A prospective, randomized controlled study of single-leg versus double-leg spica casts. *Journal of Bone and Joint Surgery*, *94*(14), pp. 1259–1264.

Lindmark, U., Bülow, P.H., Mårtensson, J. and Rönning, H. (2019).The use of the concept of transition in different disciplines within health and Social Welfare: An integrative literature review. *Nursing Open* **6**:664–675.

Liu, Q., Luo, D., Haase, J. E., Guo, Q., Wang, X. Q., Liu, S., Xia, L., Liu, Z., Yang, J., and Yang, B. X. (2020). The experiences of health-care providers during the COVID-19 crisis in China: a qualitative study.

The Lancet Global Health, *8*(6), pp. e790–e798.

Loder, R. T., and Skopelja, E. N. (2011) . The Epidemiology and Demographics of Hip Dysplasia. *ISRN Orthopedics*, *2011* , pp. 1–46.

López-Liria, R., Vargas-Muñoz, E., Aguilar-Parra, J.M., Padilla-Góngora, D., Mañas-Rodriguez, M.A. and Rocamora-Pérez, P. (2019).Effectiveness of a training program in the management of stress for parents of disabled children. *Journal of Child and Family Studies* **29**:964–977.

Lucchesi, G., Sacco, R., Zhou, W., Li, Y., Li, L. and Canavese, F. (2021).DDH in the walking age: Review of patients with long-term follow-up. *Indian Journal of Orthopaedics* **55**:1503–1514.

Maddock, C., Lewis, I., Ahmad, K., and Sullivan, R. (2011) . Online information needs of cancer patients and their organizations. *Ecancermedicalscience*, *5*(1), pp. 1–22.

Mak, S. and Thomas, A. (2022). An introduction to scoping reviews. *Journal of Graduate Medical Education* **14**:561–564.

Mahan, S. T., Katz, J. N., and Kim, Y.-J. (2009). To screen or not to screen? A decision analysis of the utility of screening for developmental dysplasia of the hip. *The Journal of Bone and Joint Surgery. American Volume.*, *91*(7), p. 1705.

Malik, S.H. and Coulson, N.S. (2013). Coming to terms with permanent involuntary childlessness: A phenomenological analysis of bulletin board postings. *Europe's Journal of Psychology* **9**:77–92.

Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *The Lancet*, *358*(9280), pp. 483–488.

Manning, J. (2017) . In vivo coding. *The International Encyclopedia of Communication Research Methods*, *24*, pp. 1–2. 14(2).

Manti, S. and Licari, A. (2018). How to obtain informed consent for Research. *Breathe* **14**:145–152.

Masarik, A.S. and Conger, R.D. (2017).Stress and child development: A review of The family stress model. *Current Opinion in Psychology* **13**:85–90.

Marsh, D., and Furlong, P. (2002). A skin not a sweater: Ontology and epistemology in political science. *Theory and Methods in Political Science*, *2*(1), pp. 17–41.

Marston, J. M. (2015) . The spirit of "Ubuntu" in children's palliative care. *Journal of Pain and Symptom Management*, *50*(3), pp. 424–427.

Masnari, O., Landolt, M. A., Roessler, J., Weingaertner, S. K., Neuhaus, K., Meuli, M., and Schiestl, C. (2012) . Self-and parent-perceived stigmatisation in children and adolescents with congenital or acquired facial differences. *Journal of Plastic, Reconstructive and Aesthetic Surgery*, *65*(12), pp. 1664–1670.

McCallin, A. (2003). Grappling with the literature in a grounded theory study. *Contemporary Nurse*, *15*(1–2), pp. 61–69.

McCann, T. V, Polacsek, M., and Lubman, D. I. (2019) . Experiences of family members supporting a relative with substance use problems: a qualitative study. *Scandinavian Journal of Caring Sciences*, *33*(4), pp. 902–911.

McGhee, G., Marland, G. R., and Atkinson, J. (2007). Grounded theory research: literature reviewing and reflexivity. *Journal of Advanced Nursing*, *60*(3), pp. 334–342.

McIntosh, C., Stephens, C. and Lyons, A. (2012).Young children's meaning making about the causes of illness within the family context. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* **17**:3–19.

Minnesota. Mehlman, C. T., Hubbard, G. W., Crawford, A. H., Roy, D. R., and Wall, E. J. (2000). Traumatic hip dislocation in children: long-term followup of 42 patients. *Clinical Orthopaedics and Related Research®*, *376*, pp. 68–79.

Meiser-Stedman, R. (2016) . Helping Children and Young People Who Experience Trauma: Children of Despair, Children of Hope By Panos Vostanis Radcliffe Medical .24.99 (pb). 304 pp*The British Journal of Psychiatry*, *208*(3), pp.302–303.

Melo, T. E. de, Resende, T. M., Silva, R. C. R. da, Cruz, S. A., and Oliveira, V. M. de. (2016) . Developmental dysplasia of the hip: do the responsible for screening know what to do? *Acta Ortopédica Brasileira*, *24*, pp. 312–317.

Mendelson, C. (2003). Gentle hugs: Internet listservs as sources of support for women with lupus. *Advances in Nursing Science*, *26*(4), pp. 299–306.

Mert Doğan, G., and Aslantürk, O. (2021) . Does the COVID-19 pandemic cause late diagnosis and delay in treatment in developmental dysplasia of hip patients? *International Journal of Clinical Practice*, *75*(10), p. e14572.

Mertens, D. M. (2009). Transforming research and evaluation. *New York, NY US: Guilford Press.*

Miles, M. S. (2003). Support for Parents During a Child's Hospitalization: A nurse's guide to helping parents cope. *AJN The American Journal of Nursing*, *103*(2), pp. 62–64.

Miller, L. M. S., and Bell, R. A. (2012) . Online health information seeking: the influence of age, information trustworthiness, and search challenges. *Journal of Aging and Health*, *24*(3), pp. 525– 541.

Mills, J., Bonner, A., and Francis, K. (2006). Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice*, *12*(1),pp. 8–13.

Mokkink, L. B., van der Lee, J. H., Grootenhuis, M. A., Offringa, M., Heymans, H. S. A., and Childhood”, D. N. C. C. “Chronic D. and H. C. in. (2008). Defining chronic diseases and health conditions in childhood (0–18 years of age): national consensus in the Netherlands. *European Journal of Pediatrics*, *167*(12), pp. 1441–1447.

Moreno, M. A., Kota, R., Schoohs, S., and Whitehill, J. M. (2013). The Facebook influence model: A concept mapping approach. *Cyberpsychology, Behavior, and Social Networking*, *16*(7), pp. 504– 511.

Morris, A. (2015) . A practical introduction to in-depth interviewing. *A Practical Introduction to In-Depth Interviewing*, pp. 1–160.

Morrow, S.L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of counseling psychology* 52(2), p. 250.

Morrow, S. L., and Smith, M. L. (2000). Qualitative research for counseling psychology. *Handbook of Counseling Psychology*, *3*, pp. 199–230.

Morse, J. M. (2007). Sampling in grounded theory. *The SAGE Handbook of Grounded Theory*, pp. 229–244.

Morse, J. M. (2010). Simultaneous and sequential qualitative mixed method designs. *Qualitative Inquiry*, *16*(6), pp. 483–491.

Mubarak, S. J., Frick, S., Sink, E., Rathjen, K., and Noonan, K. J. (2006). Volkmann contracture and compartment syndromes after femur fractures in children treated with 90/90 spica casts. *Journal of Pediatric Orthopaedics*, *26*(5), pp. 567–572.

Mulpuri, K., Song, K. M., Goldberg, M. J., and Sevarino, K. (2015) . Detection and nonoperative management of pediatric developmental dysplasia of the hip in infants up to six months of age. *JAAOS-Journal of the American Academy of Orthopaedic Surgeons*, *23*(3), pp. 202–205.

Mulugeta, B., Williamson, S., Monks, R., Hack, T., and Beaver, K. (2017) . Cancer through black eyes- The views of UK based black men towards cancer: A constructivist grounded theory study. *European Journal of Oncology Nursing*, *29*, pp. 8–16.

Munn, Z., Peters, M.D., Stern, C., Tufanaru, C., McArthur, A. and Aromataris, E. (2018). Systematic Review or scoping review? guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology* **18**.

Mussida, C. and Patimo, R. (2020). Women’s family care responsibilities, Employment and Health: A Tale of two countries. *Journal of Family and Economic Issues* **42**:489–507.

Murphy, N. A., Christian, B., Caplin, D. A., and Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child: Care, Health and Development*, *33*(2), pp. 180–187. Murphy, R. F., and Kim, Y.-J. (2016) . Surgical management of pediatric developmental dysplasia of the hip. *Journal of the American Academy of Orthopaedic Surgeons*, *24*(9), pp. 615–624.

Nelson, A. M. (2002). A metasynthesis: Mothering other-than-normal children. *Qualitative Health Research*, *12*(4), pp. 515–530.

Nemati, M., Ebrahimi, B., and Nemati, F. (2020). Assessment of Iranian nurses’ knowledge and anxiety toward COVID-19 during the current outbreak in Iran. *Archives of Clinical Infectious Diseases*, *15*(COVID-19).

Nettleton, S. (2004). The emergence of e-scaped medicine? *Sociology*, *38*(4), pp. 661– 679.

Newman, D. M. L. (2005). Functional status, personal health, and self-esteem of caregivers of children in a body cast: A pilot study. *Orthopaedic Nursing*, *24*(6), pp. 416–423.

O’Brien, M.R. and Clark, D. (2011).Unsolicited written narratives as a methodological genre in terminal illness. *Qualitative Health Research* **22**:274–284.

O’Connor, H., and Madge, C. (2000). Cyber-mothers: Online synchronous interviewing using conferencing software. *Sociological Research Online*, *5*(4), pp. 102–117.

Oledzka, M. M., Sweeney, J. K., Evans-Rogers, D. L., Coulter, C., and Kaplan, S. L. (2020). Experiences of parents of infants diagnosed with mild or severe grades of congenital muscular torticollis. *Pediatric Physical Therapy*, *32*(4), pp. 322–329.

Oltmann, S. M. (2016) . Public librarians’ views on collection development and censorship. *Collection Management*, *41*(1), pp. 23–44.

Oris, L., Rassart, J., Prikken, S., Verschueren, M., Goubert, L., Moons, P., Berg, C.A., *et al.* (2016).Illness identity in adolescents and emerging adults with type 1 diabetes: Introducing the Illness Identity Questionnaire. *Diabetes Care***39**:757–763.

.Østensjø, S., Carlberg, E. B., and Vøllestad, N. K. (2004). Motor impairments in young children with cerebral palsy: relationship to gross motor function and everyday activities. *Developmental Medicine and Child Neurology*, *46*(9), pp. 580–589.

Oudshoorn, A., Ward-Griffin, C., and McWilliam, C. (2007). Client–nurse relationships in home-based palliative care: a critical analysis of power relations. *Journal of Clinical Nursing*, *16*(8), pp. 1435– 1443.

Park, Y. S., Konge, L., and Artino, A. R. (2020). The positivism paradigm of research. *Academic Medicine*, *95*(5), pp. 690–694.

Patel, H., and Care, C. T. F. on P. H. (2001). Preventive health care, 2001 update: screening and management of developmental dysplasia of the hip in newborns. *Cmaj*, *164*(12), pp. 1669–1677.

Paton, R. W. (2005). Management of neonatal hip instability and dysplasia. *Early Human Development*, *81*(10), pp. 807–813.

Paton, R. W., and Choudry, Q. (2016) . Developmental dysplasia of the hip (DDH): diagnosis and treatment. *Orthopaedics and Trauma*, *30*(6), pp. 453–460.

Patton, M. Q. (2002). Qualitative research and evaluation methods. Thousand Oaks. *Cal.: Sage Publications*, *4*.

Peled, E., Eidelman, M., Katzman, A., and Bialik, V. (2008). Neonatal incidence of hip dysplasia: ten years of experience. *Clinical Orthopaedics and Related Research*, *466*, pp. 771–775.

Peng, F. B., Burrows, J. F., Shirley, E. D., and Rosen, P. (2018). Unlocking the doors to patient satisfaction in pediatric orthopaedics. *Journal of Pediatric Orthopaedics*, *38*(8),pp. 398–402.

Pennebaker, J. W., Mehl, M. R., and Niederhoffer, K. G. (2003). Psychological aspects of natural language use: Our words, our selves. *Annual Review of Psychology*, *54*(1), pp. 547–577.

Perry, D. C., and Paton, R. W. (2019) . Knowing your click from your clunk: is the current screening for developmental dysplasia of the hip fit for purpose? *The Bone and Joint Journal*, *101*(3), pp. 236–237.

Peters, M.D.J., Marnie, C., Tricco, A.C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., *et al.* (2020). Updated methodological guidance for the conduct of scoping reviews. *JBI Evidence Synthesis* **18**:2119–2126.

Piaget, J. (2003). Part I: Cognitive Development in Children--Piaget Development and Learning. *Journal of Research in Science Teaching*, *40*.

Picci, R.L., Oliva, F., Trivelli, F., Carezana, C., Zuffranieri, M., Ostacoli, L., Furlan, P.M., *et al.* (2015).Emotional burden and coping strategies of parents of children with rare diseases. *Journal of Child and Family Studies* **24**:514–522.

Pietrucin-Materek, M., van Teijlingen, E. R., Barker, S., Keenan, K. F., and Miedzybrodzka, Z. (2011) . Parenting a child with clubfoot: A qualitative study. *International Journal of Orthopaedic and Trauma Nursing*, *15*(4), pp. pp. 176–184.

Plantin, L., and Daneback, K. (2018). Fatherhood research on the Internet: methodological reflections from a literature review. *Fathers, Families and Relationships*, pp. 73–88.

Polit, D. F., and Beck, C. T. (2010). *Essentials of nursing research: Appraising evidence for nursing practice*. Lippincott Williams and Wilkins.

Pöysti, M. M., Laakkonen, M.-L., Strandberg, T., Savikko, N., Tilvis, R. S., Eloniemi- Sulkava, U., and Pitkälä, K. H. (2012) . Gender differences in dementia spousal caregiving. *International Journal of Alzheimer's Disease*.

Prescott, J., Rathbone, A.L. and Brown, G. (2020). Online peer to peer support: Qualitative analysis of UK and US Open Mental Health Facebook groups. *D* igital *H*ealth **6**.

Purtle, J., Nelson, K.L. and Gollust, S.E. (2021).Public opinion about adverse childhood experiences: Social stigma, attribution of blame, and government intervention. *Child Maltreatment* **27**:344–355.

Rabbitts, J. A., Aaron, R. V., Fisher, E., Lang, E. A., Bridgwater, C., Tai, G. G., and Palermo,T. M. (2017) . Long-Term Pain and Recovery After Major Pediatric Surgery: A Qualitative Study With Teens, Parents, and Perioperative Care Providers. *Journal of Pain*, *18*(7), pp. 778–786.

Ramani, N., Patil, M.S. and Mahna, M. (2014). Outcome of surgical management of developmental dysplasia of hip in children between 18 and 24 months. *Indian Journal of Orthopaedics* **48**:458–462.

Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., and Wong, M. (2004). Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC Pediatrics*, *4*, pp. 1–13.

Raymaekers, K., Prikken, S., Vanhalst, J., Moons, P., Goossens, E., Oris, L., Weets, I., *et al.* (2019).The social context and illness identity in youth with type 1 diabetes: A three-wave longitudinal study. *Journal of Youth and Adolescence* **49**:449–466.

Raysmith, B.P., Jacobsson, J., Drew, M.K. and Timpka, T. (2019).What is performance? A scoping review of performance outcomes as study endpoints in Athletics. *Sports* **7**:66.

Rebers, S., Aaronson, N.K., van Leeuwen, F.E. and Schmidt, M.K. (2016).Exceptions to the rule of informed consent for research with an intervention. *BMC Medical Ethics* **17**.

Reed, C., Carroll, L., Baccari, S., and Shermont, H. (2011) . Spica cast care: a collaborative staff-led education initiative for improved patient care. *Orthopaedic Nursing*, *30*(6), pp. 353–358.

Rhodes, A., and Aarvold, A. (2022) . Screening for developmental dysplasia of the hip: current UK practice and controversies. *Orthopaedics and Trauma*, *36*(6), pp. 317–321.

Riddell, R. P., and Racine, N. (2009). Assessing pain in infancy: the caregiver context. *Pain Research and Management*, *14*, pp. 27–32.

Rieger, K. L. (2019) . Discriminating among grounded theory approaches. *Nursing Inquiry*, *26*(1), p. e12261.

Roberts, L.D. (2015).Ethical issues in conducting qualitative research in online communities. *Qualitative Research in Psychology* **12**:314–325.

Robson, C. (2006). Real world research: A resource for social scientists and practitioner- researchers. *(No Title)*.

Rodriguez, A., and Smith, J. (2018). Phenomenology as a healthcare research method. In *Evidence-Based Nursing* 21(4), pp. 96–98.

Roposch, A., Liu, L. Q., Hefti, F., Clarke, N. M. P., and Wedge, J. H. (2011) . Standardized diagnostic criteria for developmental dysplasia of the hip in early infancy. *Clinical Orthopaedics and Related Research®*, *469*, pp. 3451–3461.

Roposch, A., Protopapa, E., Malaga-Shaw, O., Gelfer, Y., Humphries, P., Ridout, D., and Wedge, J.H. (2020). Predicting developmental dysplasia of the hip in at-risk newborns. *BMC Musculoskeletal Disorders*, *21*(1), pp. 1–8.

Rosendahl, K., Dezateux, C., Fosse, K.R., Aase, H., Aukland, S.M., Reigstad, H., Alsaker, T., *et al.* (2010). Immediate treatment versus sonographic surveillance for mild hip dysplasia in newborns. *Pediatrics* **125**.

Sah, L. K., Singh, D. R., and Sah, R. K. (2020). Conducting qualitative interviews using virtual communication tools amid COVID-19 pandemic: A learning opportunity for future research. *JNMA:Journal of the Nepal Medical Association*, *58*(232), p. 1103.

Saldaña, J. (2013). *The Coding Manual for Qualitative Researchers*. London: SAGE.

Saldaña, J. (2016) . The Coding Manual for Qualitative Researchers (No. 14). *Sage*.

Salisbury, M. H., LaMontagne, L. L., Hepworth, J. T., and Cohen, F. (2007). Parents' self- identified stressors and coping strategies during adolescents' spinal surgery experiences. *Clinical Nursing Research*, *16*(3), pp. 212–230.

Sanderson, T., Calnan, M., Morris, M., Richards, P. and Hewlett, S. (2011) . Shifting normalities: Interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis. Sociology of Health and Illness 33(4).

Sankar, W. N., Gornitzky, A. L., Clarke, N. M. P., Herrera-Soto, J. A., Kelley, S. P., Matheney, T., Mulpuri, K., Schaeffer, E. K., Upasani, V. V, and Williams, N. (2019) . Closed reduction for developmental dysplasia of the hip: early-term results from a prospective, multicenter cohort. *Journal of Pediatric Orthopedics*, *39*(3), p. 111.

Santos, F. M., and Eisenhardt, K. M. (2009). Constructing markets and shaping boundaries: Entrepreneurial power in nascent fields. *Academy of Management Journal*, *52*(4), pp. 643–671.

Savage, J. (2006). Ethnographic evidence: The value of applied ethnography in healthcare. *Journal of Research in Nursing*, *11*(5), pp. 383–393.

Sayers, S. L., Riegel, B., Pawlowski, S., Coyne, J. C., and Samaha, F. F. (2008). Social support and self-care of patients with heart failure. *Annals of Behavioral Medicine*, *35*(1), pp. 70–79.

Schaeffer, E. K., and Mulpuri, K. (2018). Developmental dysplasia of the hip: addressing evidence gaps with a multicentre prospective international study. *The Medical Journal of Australia*, *208*(8), pp. 359–364.

Schwandt, T. A. (2000). Three epistemological stances for qualitative inquiry: Interpretivism, hermeneutics, and social constructionism. In *Handbook of qualitative research* (pp. 189–213). SAGE Publishing.

Seçinti, D. D., Albayrak, Z. S., Demirdöğen, E. Ş., Albayrak, K., Akpınar,

Sewell, M. D., Rosendahl, K., and Eastwood, D. M. (2009). Developmental dysplasia of the hip. *Bmj*, *339*.

Sharma, N., Chakrabarti, S., and Grover, S. (2016) . Gender differences in caregiving among family-caregivers of people with mental illnesses. *World Journal of Psychiatry*, *6*(1), p. 7.

Sharpe, D., and Rossiter, L. (2002). Siblings of children with a chronic illness: A meta- analysis. *Journal of Pediatric Psychology*, *27*(8), pp. 699–710.

Shaw, B. A., Segal, L. S., Otsuka, N. Y., Schwend, R. M., Ganley, T. J., Herman, M. J., Hyman, J. E., and Smith, B. G. (2016) . Evaluation and referral for developmental dysplasia of the hip in infants. *Pediatrics*, *138*(6).

Shemshaki, H. R., Mousavi, H., Salehi, G., and Eshaghi, M. A. (2011) . Titanium elastic nailing versus hip spica cast in treatment of femoral-shaft fractures in children. *Journal of Orthopaedics and Traumatology*, *12*, pp. 45–48.

Shin, J. Y. (2002). Social support for families of children with mental retardation: Comparison between Korea and the United States. *Mental Retardation*, *40*(2), pp. 103– 118.

Shipman, S. A., Helfand, M., Moyer, V. A., and Yawn, B. P. (2006). Screening for developmental dysplasia of the hip: a systematic literature review for the US Preventive Services Task Force. *Pediatrics*, *117*(3), pp. e557–e576.

Shirley, E. D., Maguire, K. J., Mantica, A. L., and Kruse, R. W. (2020). Alternatives to Traditional Cast Immobilization in Pediatric Patients. *Journal of the American Academy of Orthopaedic Surgeons* 28(1), pp. E20–E27.

Shorter, D., Hong, T., and Da, O. (2013). *Screening programmes for developmental dysplasia of the hip in newborn infants (Review)*. *54*(9), pp. 11–54.

Shorter, D., Hong, T., and Osborn, D. A. (2013(. Cochrane Review: Screening programmes for developmental dysplasia of the hip in newborn infants. *Evidence-Based Child Health: A Cochrane Review Journal*, *8*(1), pp. 11–54.

Sink, E. L., Ricciardi, B. F., Torre, K. Dela, and Price, C. T. (2014). Selective ultrasound screening is inadequate to identify patients who present with symptomatic adult acetabular dysplasia. *Journal of Children's Orthopaedics*, *8*(6), pp. 451–455.

Smith, J. (2004). A literature review of the care of babies and young children in hip spicas. *Journal of Orthopaedic Nursing*, *8*(2), pp. 83–90.

Smith, L., and Daughtrey, H. (2000). Weaving the seamless web of care: an analysis of parents' perceptions of their needs following discharge of their child from hospital. *Journal of Advanced Nursing*, *31*(4), pp. 812–820.

Smith, M. (2004). Parental mental health: disruptions to parenting and outcomes for children. *Child and Family Social Work*, *9*(1), pp. 3–11.

Söderbäck, M., and Christensson, K. (2008). Family involvement in the care of a hospitalised child: A questionnaire survey of Mozambican family caregivers. *International Journal of Nursing Studies*, *45*(12), pp. 1778–1788.

Sparks, L., Ortman, M. R., and Aubuchon, P. (2004). Care of the child in a body cast. *Journal of Orthopaedic Nursing*, *8*(4), pp. 231–235.

Sparks, L., Ortman, M. R., and Aubuchon, P. (2005). Meeting the developmental needs of a child in a body cast. *Journal of Orthopaedic Nursing*, *9*(1), pp. 35–38.

Stommel, W. and Rijk, L. de (2021).Ethical approval: None sought. how discourse analysts report ethical issues around publicly available online data. *Research Ethics* **17**:275–297.

Storer, S. K., and Skaggs, D. L. (2006). Developmental dysplasia of the hip. *American Family Physician*, *74*(8), pp. 1310–1316.

Sugiura, L., Wiles, R. and Pope, C. (2016).Ethical challenges in online research: Public/private perceptions. *Research Ethics* **13**:184–199.

Swarup, I., Penny, C. L., and Dodwell, E. R. (2018). Developmental dysplasia of the hip: An update on diagnosis and management from birth to 6 months. In *Current Opinion in Pediatrics* 30(1).

Szostakowski, B., Smitham, P., and Khan, W. S. (2017) . Plaster of Paris–short history of casting and injured limb immobilzation. *The Open Orthopaedics Journal*, *11*, p. 291.

Talbot, C., Adam, J., and Paton, R. (2017) . Late presentation of developmental dysplasia of the hip.*Bone and Joint Journal*, *99B*(9), pp. 1250–1255.

Teddlie, C., and Tashakkori, A. (2003). Major issues and controversies in the use of mixed methods in the social and behavioral sciences. *Handbook of Mixed Methods in Social and Behavioral Research*, *1*(1), pp. 13–50.

Tedlock, B. (2005). The observation of participation and the emergence of public ethnography. *The Sage Handbook of Qualitative Research*, *3*, pp. 467–481.

Tekola, B., Kinfe, M., Girma, F., Hanlon, C. and Hoekstra, R.A. (2020). Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. *Social Science andamp; Medicine***256**:113034.

Thaler, M., Biedermann, R., Lair, J., Krismer, M., and Landauer, F. (2011) . Cost-effectiveness of universal ultrasound screening compared with clinical examination alone in the diagnosis and treatment of neonatal hip dysplasia in Austria. *The Journal of Bone and Joint Surgery British Volume*, *93*(8), pp. 1126–1130.

Theunissen, W. W. E. S., Van Der Steen, M. C., Van Veen, M. R., Van Douveren, F. Q. M. P., Witlox, M. A., and Tolk, J. J. (2022) . Parental experiences of children with developmental dysplasia of the hip: a qualitative study. *BMJ Open*, *12*(9).

Thom, D. H. (2001). Physician behaviors that predict patient trust. *Journal of Family Practice*, *50*(4),p. 323.

Thomlinson, E. H. (2002). The lived experience of families of children who are failing to thrive. *Journal of Advanced Nursing*, *39*(6), pp. 537–545.

Thornberg, R. (2012) . Informed grounded theory. *Scandinavian Journal of Educational Research*, *56*(3), pp. 243–259.

Timmers, T., Janssen, L., Kool, R. B., and Kremer, J. A. M. (2020). Educating patients by providing timely information using smartphone and tablet apps: systematic review.*Journal of Medical Internet Research*, *22*(4), p. e17342.

Tisherman, R.T., Hoellwarth, J.S. and Mendelson, S.A. (2018). Systematic review of Spica casting for the treatment of paediatric diaphyseal femur fractures. *Journal of Children's Orthopaedics* **12**:136–144.

Tomlinson, M., Swartz, L., Officer, A., Chan, K. Y., Rudan, I., and Saxena, S. (2009). Research priorities for health of people with disabilities: an expert opinion exercise. *The Lancet*, *374*(9704),pp. 1857–1862.

Tones, K., and Green, J. (2004). *Health promotion: planning and strategies*. Sage.

Toye, F., Williamson, E., Williams, M. A., Fairbank, J., and Lamb, S. E. (2016) . What value can qualitative research add to quantitative research design? An example from an adolescent idiopathic scoliosis trial feasibility study. *Qualitative Health Research*, *26*(13), pp. 1838–1850.

Trebble, T. M., Hansi, N., Hydes, T., Smith, M. A., and Baker, M. (2010). Process mapping the patient journey: an introduction. *Bmj*, *341*.

Turner, D. W. (2010). Qualitative interview design: A practical guide for novice investigators. *Qualitative Report*, *15*(3), pp. 754–760.

Ültanır, E. (2012) . *An epistemological glance at the constructivist approach: Constructivist learning in Dewey, Piaget, and Montessori* 5(2).

Urquhart, C., and Fernandez, W. (2006). Grounded theory method: The researcher as blank slate and other myths. *ICIS 2006 Proceedings*, 31.

Urquhart, C., and Fernández, W. (2013).Using grounded theory method in information systems: The researcher as blank slate and other myths. *Journal of Information Technology*, *28*(3), pp. 224–236.

van Douveren, F. Q. M. P., Pruijs, H. E. H., and Sakkers, R. J. B. (2003). Ultrasound in the management of the position of the femoral head during treatment in a spica cast after reduction of hip dislocation in developmental dysplasia of the hip. *The Journal of Bone and Joint Surgery British Volume*, *85*(1), pp. 117–120.

Vaquero-Picado, A., González-Morán, G., Garay, E. G., and Moraleda, L. (2019) . *Developmental dysplasia of the hip: update of management. EFORT Open Rev 4(9),* pp. *548–556*.

Velho, R., Holloway, C., Symonds, A., and Balmer, B. (2016) . The effect of transport accessibility on the social inclusion of wheelchair users: A mixed method analysis. *Social Inclusion*, *4*(3), pp. 24– 35.

Vitale, M. G., and Skaggs, D. L. (2001). Developmental dysplasia of the hip from six months to four years of age. *JAAOS-Journal of the American Academy of Orthopaedic Surgeons*, *9*(6), pp. 401– 411.

Vitaliano, P. P., Young, H. M., and Zhang, J. (2004). Is caregiving a risk factor for illness? *Current Directions in Psychological Science*, *13*(1), pp. 13–16.

Vitaliano, P. P., Zhang, J., and Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, *129*(6), p. 946.

Von Glasersfeld, E. (1995). *A constructivist approach to teaching. In. L. Steffe and J. Gale (Eds.), Constructivism in education (pp. 3-16). Hillside*. NJ: Lawrence Erlbaum.

Vostanis, P. (2021) . *Helping children and young people who experience trauma: children of despair, children of hope*. CRC Press.

Wakely, L., Easey, P., Leys, J., and Johnston, C. (2021) . Exploring the lived experience of parenting a child with developmental dysplasia of the hip. *Physical and Occupational Therapy In Pediatrics*, *41*(5), pp. 503–514.

Wakely, L. T., Rae, K., and Cooper, R. (2010). Stoic survival: the journey of parenting a premature infant in the bush. *Rural and Remote Health*, *10*(3), pp. 1–10.

Wakely, L., Rae, K., and Keatinge, D. (2015) . Fragile forgotten families: parenting a premature infant in a rural area, where is the evidence? *Neonatal, Paediatric and Child Health Nursing*, *18*(3), pp. 8–17.

Walker, D., and Myrick, F. (2006). Grounded theory: An exploration of process and procedure.*Qualitative Health Research*, *16*(4), pp. 547–559.

Wang, T.-M., Wu, K.-W., Shih, S.-F., Huang, S.-C., and Kuo, K. N. (2013).Outcomes of open reduction for developmental dysplasia of the hip: does bilateral dysplasia have a poorer outcome? *JBJS*, *95*(12), pp. 1081–1086.

Weinstein, S. L., Mubarak, S. J., and Wenger, D. R. (2004). Developmental hip dysplasia and dislocation: Part II. *Instructional Course Lectures*, *53*, pp. 531–542.

Wenger, D., Düppe, H., and Tiderius, C. J. (2013). Acetabular dysplasia at the age of 1 year in children with neonatal instability of the hip: a cohort study of 243 infants. *Acta Orthopaedica*, *84*(5), pp. 483–488.

Whittingham, K., Wee, D., Sanders, M. R., and Boyd, R. (2013). Sorrow, coping and resiliency: parents of children with cerebral palsy share their experiences. *Disability and Rehabilitation*, *35*(17), pp. 1447–1452.

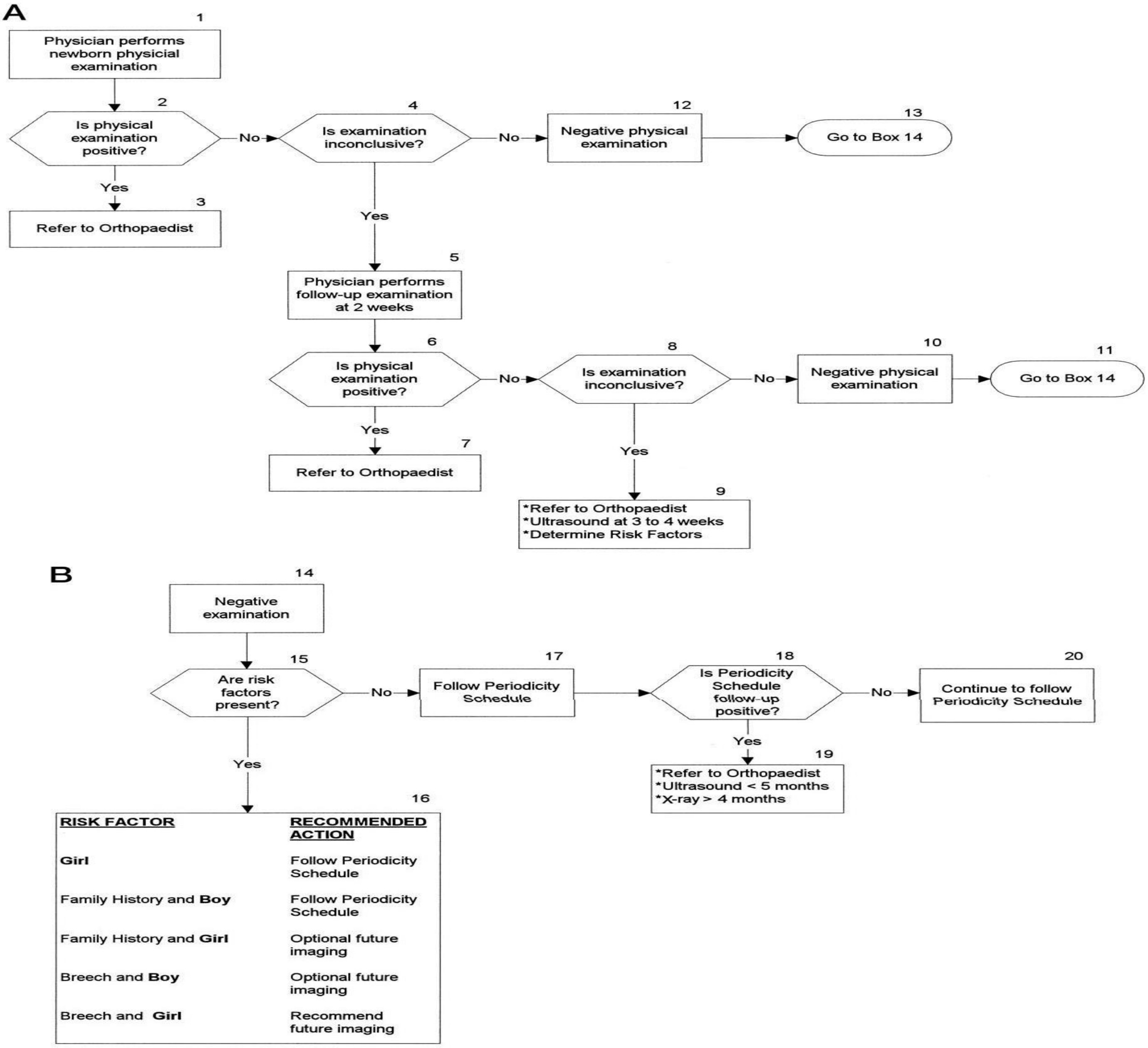
Wicart, P., Seringe, R., Glorion, C., Brassac, A., and Rampal, V. (2018). Closed reduction in late- detected developmental dysplasia of the hip: indications, results and complications. *Journal of Children's Orthopaedics*, *12*(4), pp. 317–322.

Witt, C. (2003). Detecting developmental dysplasia of the hip. *Advances in Neonatal Care*, *3*(2), pp. 65–75.

Yagmurlu, M. F., Bayhan, I. A., Tuhanioglu, U., Kilinc, A. S., and Karakas, E. S. (2013). Clinical and radiological outcomes are correlated with the age of the child in single-stage surgical treatment of developmental dysplasia of the hip. *Acta Orthop Belg*, *79*(2), pp. 159–165.

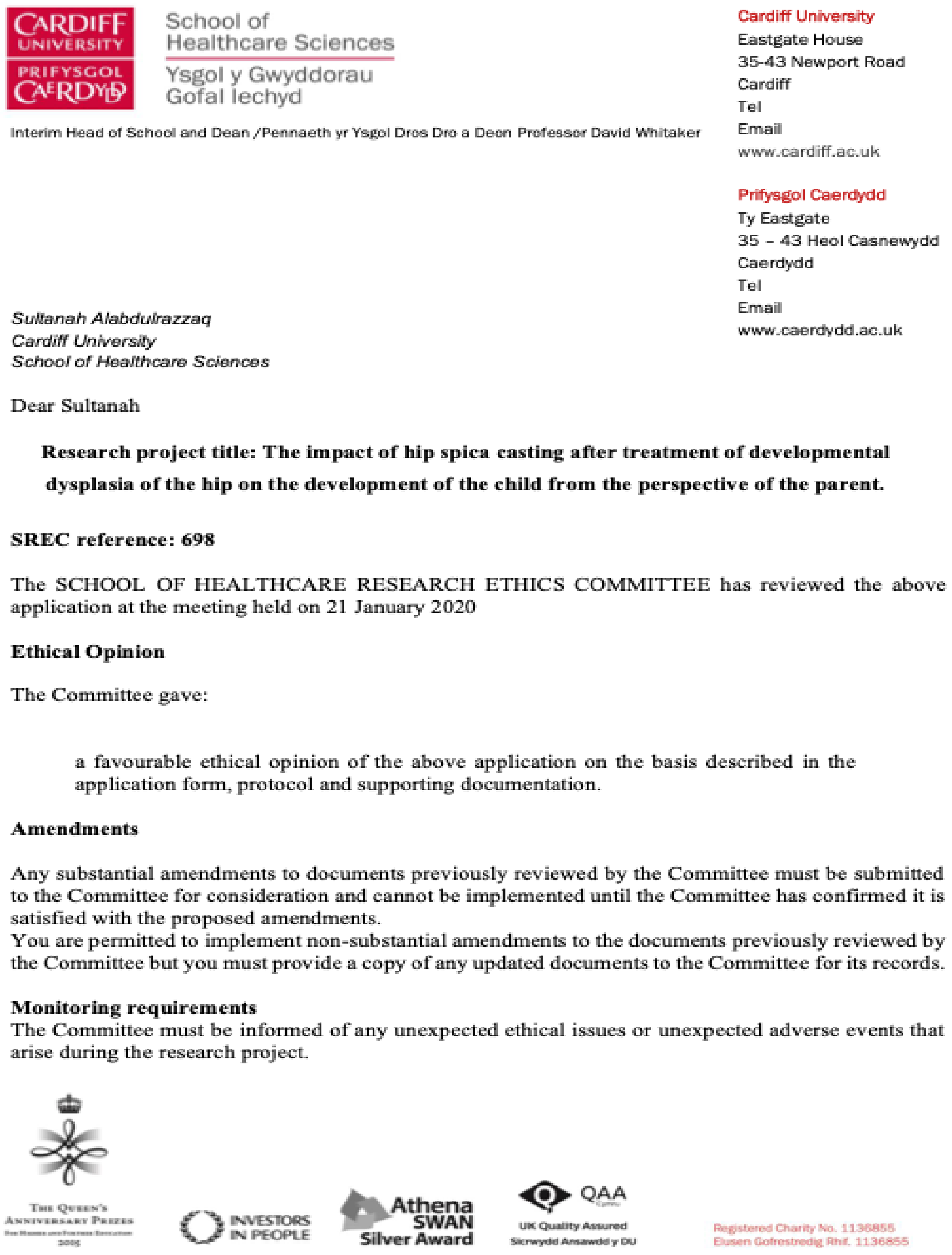
Appendix 1 ;Treatment Algorithm

The treatment algorithm used in the present study was defined to be consistent with the current standard as practiced by most of the members of the Pediatric Orthopaedic Society of North America (POSNA), the principal group treating developmental dysplasia of the hip in the United States. There remains, however, some variability in treatment from clinician to clinician. At the 2005 POSNA Annual Meeting, a “Specialty Day” focusing on developmental dysplasia of the hip was held, during which this treatment algorithm was developed this treatment algorithm also reflects the algorithm outlined originally by Graf.



RISK FACTOR	RECOMMENDED ACTION
Girl	Follow Periodicity Schedule
Family History and **Boy**	Follow Periodicity Schedule
Family History and **Girl**	Optional future imaging
Breech and **Boy**	Optional future imaging
Breech and **Girl**	Recommend future imaging

Appendix 2 ;Ethics Approval from the School of Healthcare Sciences, Cardiff University



CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD
School of Healthcare Sciences
Ysgol y Gwyddorau Gofal Iechyd

Interim Head of School and Dean /Pennaeth yr Ysgol Dros Dro a Deon Professor David Whitaker

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Sultanah Alabdulrazzaq
Cardiff University
School of Healthcare Sciences

Dear Sultanah

Research project title: The impact of hip spica casting after treatment of developmental dysplasia of the hip on the development of the child from the perspective of the parent.

SREC reference: 698

The SCHOOL OF HEALTHCARE RESEARCH ETHICS COMMITTEE has reviewed the above application at the meeting held on 21 January 2020

Ethical Opinion

The Committee gave:

> a favourable ethical opinion of the above application on the basis described in the application form, protocol and supporting documentation.

Amendments

Any substantial amendments to documents previously reviewed by the Committee must be submitted to the Committee for consideration and cannot be implemented until the Committee has confirmed it is satisfied with the proposed amendments.
You are permitted to implement non-substantial amendments to the documents previously reviewed by the Committee but you must provide a copy of any updated documents to the Committee for its records.

Monitoring requirements
The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.

Appendix 3 ;Facebook moderator

Dear Mrs. Natalie Trice,

My name is Sultanah Alabdulrazzaq. I have been working in Saudi Arabia for 15 years as a Paediatric Physiotherapist. Now, I am a Ph.D. student studying at Cardiff University and my current research study is titled 'The impacts of hip spica casting on the development of the child from the perspective of the parent'. I have received Ethics Approval from the School of Healthcare Sciences, Cardiff University (attached a copy). My supervisors are Dr. Tina Gambling and Dr. Alison Seymour.

I would like permission to access the Hip Dysplasia Support Group Facebook page. You do not need to do anything, other than grant permission. There are two stages to the research (see further information below).

First, I would like analyse posts of conversations between parents regarding the casting life. Posts may play an important role in understanding and analysing the context of the problems being studied. They can draw attention to more important details and fundamental features of everyday life of child with DDH spice cast.

Second, I would like to use the page to advertise the study and invite parents to participate in Facebook messenger or Skype interviews. If any members of your community are interested in sharing their experiences, they can get involved in interviews. The objective of the interview is to obtain an understanding of the participant's perspectives and experiences about the activities that their child changed or discontinued during the casting. Young children develop rapidly, and so being immobilized can mean a trauma during childhood, as well as a delay, or even cause, interruption in the growth and development process.

Data will be generated through two stages:

a) Gathering data posted from a Facebook group.

b) Online Interviews via Facebook messenger or Skype through phone or video calls.

Could you post an advert on the site on the researcher's behalf asking for volunteers for an online interview? Potential participants will respond to the advert through e-mail or the private message function on the site, and then they will receive an information sheet and consent form.

I hope to get a response as soon as possible to start collecting the data and please if you have, any questions do not hesitate to contact me.

Your cooperation will be highly appreciated, Yours faithfully, Sultanah Alabdulrazzaq, AlabdulrazzaqS@cardiff.ac.uk

Appendix 4;Anatomy of Facebook page:

Anatomy of Facebook page:

"Wall posts" are comments made by group members on a central group webpage and serve as a way to query or communicate with all group members. The more conversational "discussion groups" represent topic-based threads initiated by a single member and continuing to allow other group members to respond to the initial comments and any subsequent comments in the discussion topic (Figure 1).

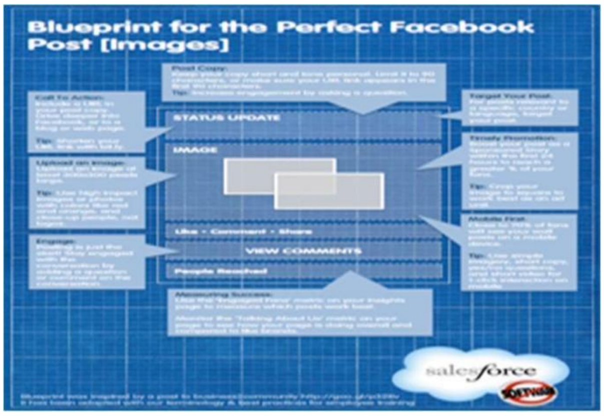


Figure 1; Anatomy of Facebook page

How to Find Old Posts on Facebook

https://www.wikihow.com/Find-Old-Posts-on-Facebook (Figure 2).

POSTS FROM
● Anyone
○ You
○ Your Friends and Groups

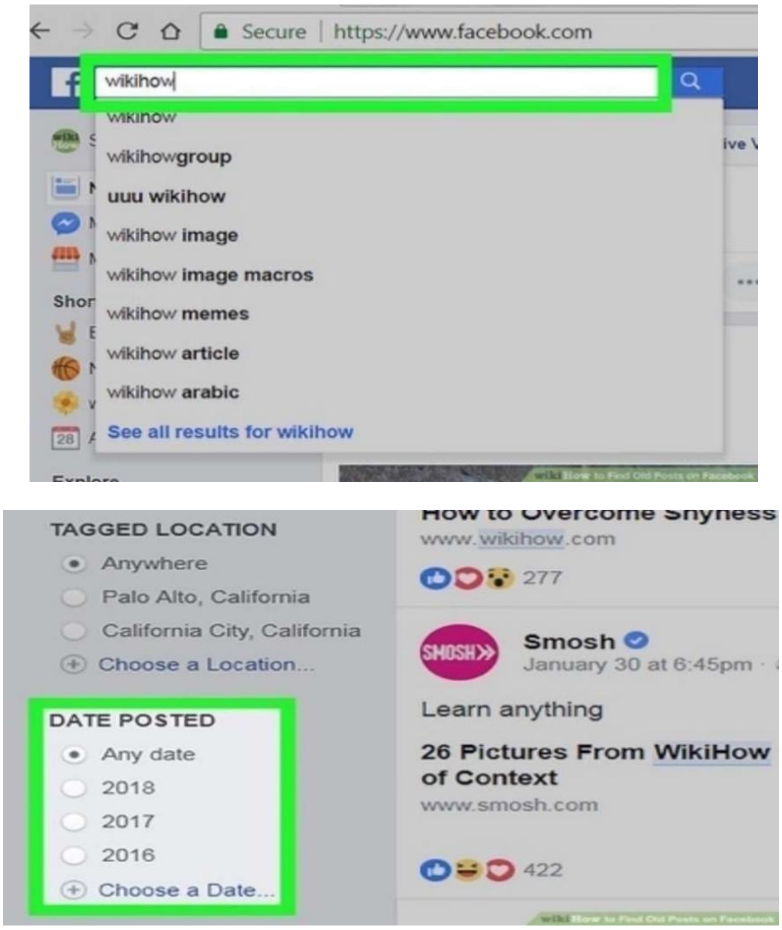
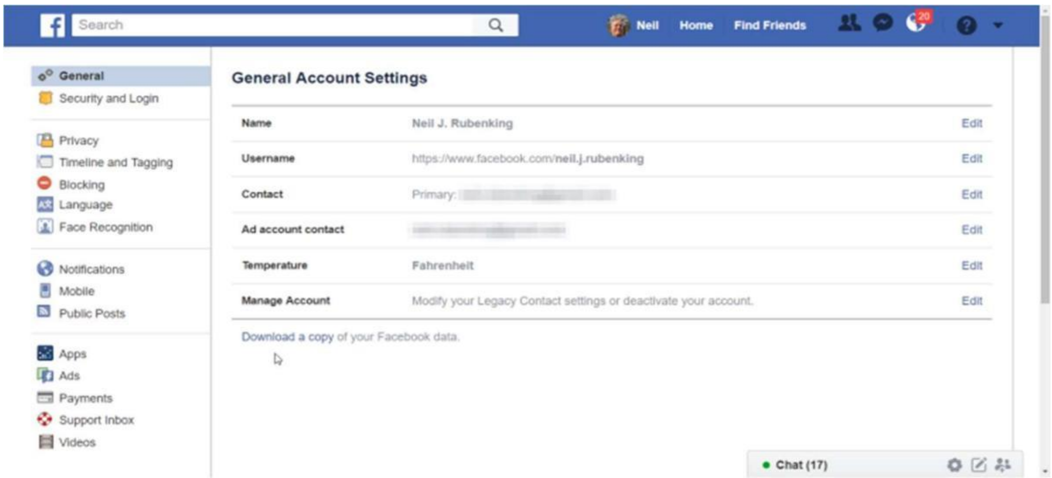


Figure 2; How to Find Old Posts on Facebook

Download your Facebook archive.

1. Log into Facebook click the down-triangle icon at top right and choose Settings.
2. On the General Settings page, click the last item, the link to download a copy of your data.
3. Facebook warns that collecting data may take a while. Click Start My Archive.
4. On the next page, click Start My Archive again, and wait for a notification that it's done.
5. Download your Facebook archive.

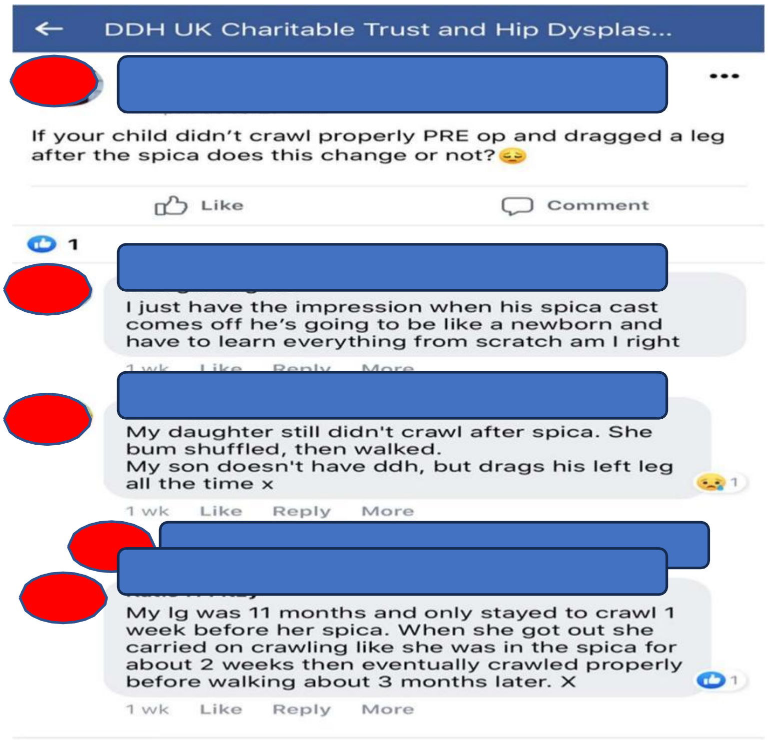


General Account Settings

Name	Neil J. Rubenking	Edit
Username	https://www.facebook.com/neil.j.rubenking	Edit
Contact	Primary: [redacted]	Edit
Ad account contact	[redacted]	Edit
Temperature	Fahrenheit	Edit
Manage Account	Modify your Legacy Contact settings or deactivate your account.	Edit

Download a copy of your Facebook data.

Figure 3; Download Facebook archive


DDH UK Charitable Trust and Hip Dysplas...

[redacted] [redacted]

If your child didn't crawl properly PRE op and dragged a leg after the spica does this change or not?😔

[redacted] [redacted]

I just have the impression when his spica cast comes off he's going to be like a newborn and have to learn everything from scratch am I right

[redacted] [redacted]

My daughter still didn't crawl after spica. She bum shuffled, then walked.
My son doesn't have ddh, but drags his left leg all the time x

[redacted] [redacted] [redacted] [redacted]

My lg was 11 months and only stayed to crawl 1 week before her spica. When she got out she carried on crawling like she was in the spica for about 2 weeks then eventually crawled properly before walking about 3 months later. X

Figure 4; Wall posts from DDH UK Facebook group

Appendix 5 :Advertisement flyer

Would you like to take part in a research study?

Who am I looking for?

Parent(s) of a child who has developmental dysplasia of the hip (DDH)

What will happen if I take part?

You will given further information about the study and if you are happy to consent, you will be interviewed about your experiences of being a parent of a child with DDH. You can decide on how the interview will be conducted; phone or Zoom

What are the benefits of taking part?

To help healthcare professionals understand the reality of having a child with DDH particularly during the period of time they spend in a spica cast or Pavlik harness

To take part or find out more:

Please leave a reply to this post and I will contact you directly via Messenger to arrange a chat. Alternatively, you can contact me on AlabdulrazzaqS@cardiff.ac.uk

About me:

My name is Sultannah and I have worked as a paediatric physiotherapist for many years. I am currently studying for a PhD at Cardiff University. You can contact my supervisor if you wish for confirmation and more information about me: Dr Jane Harden, hardenj@cardiff.ac.uk

Appendix 6;Participant information sheet for parents

Interview

The impact of hip spica casting after treatment of developmental dysplasia of the hip on the development of the child from the perspective of the parent.

Invitation

My name is Sultanah Alabdulrazzaq and I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. You may wish to talk to others such as family and friends about the study before deciding whether to volunteer.

Please do ask me if there is anything that is not clear or if you would like more information (my contact details are at the end of this information sheet).

What is the purpose of the study?

Childhood is a significant period for human development, both in the biological and in the psychosocial aspects. Developmental dysplasia of the hip (DDH) is the most common congenital deformity in newborns, and it can cause disability in childhood. Children's activities after DDH surgery are limited because they must remain in a hip spica cast for a long period. Moreover, some studies have reported that children in the cast experience motor, cognitive, and social problems.

The purpose of the study is to explore the impact of hip spica casting on the development of the child from the perspective of parents. This study will describe the parent's experience of looking after a child in hip spica casting. Also, it will investigate the impact of hip spica casting on the child development. The reason I am doing this study is to establish a clear picture of life experience of young children and parents with spica cast. Looking at family experiences will facilitate developing knowledge of an under-researched area and its impact. It could also help physiotherapists develop support for families with the complex needs of children to ensure that their standard of health, comfort, and happiness is as best as possible despite having a body cast.

This research is being conducted as part of a PhD project at Cardiff University.

Why have I been invited to participate?

You have been invited to take part in the study because you are looking after a child in hip spica casting. Parents are placed at the heart of the ongoing care of the child with complex needs. Therefore, it is appropriate that their views and experiences should be central to this research.

What will happen to me if I take part?

Interviews will take place online via Zoom Meetings program audio or video calls, depending on whether

you would like to stay visually anonymous or not. If you decide to take part, you will be invited to an online interview. I would like to record the discussions with a digital audio recorder if you give your permission. This will enable me to accurately record the things we discuss. I will also be able to go back over the recording to make sure I have noted down accurately what was said. The interview will be as short or long as you wish however most interviews would take between 40 minutes to an hour.
You may choose to have a friend or partner with you while being interviewed if this helps you feel more comfortable. It is also possible to interview both parents at the same where this is desired by a couple.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

If you withdraw from the study, we will destroy all data about you that has been collected during the study.

What do I have to do?

First of all, you will be asked to sign a consent form for interviewing. You will then be given an information sheet about this study. At the beginning, you will make online interview which includes questions about your child's activities that changed or stopped doing after cast and limitations of healthy development and how you as parents are coping with immobilization.

What are the possible benefits of taking part?

You will receive no direct health benefits from participating in this research study. However, your responses may help us learn more about Hip Dysplasia. The information that is generated from this study will be develop knowledge of health professionals and the impact it could help paediatric physiotherapy to develop interventions to support families with child’s complex needs to ensure that their child’s life is as healthy as possible despite having a spica cast.

What are the possible disadvantages and risks of taking part?

This study does not involve any intervention, participation in the study has no or minimal risk

What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the School of Healthcare Sciences Director of Research Governance

Dr Kate Button

buttonk@cardiff.ac.uk

02920687734

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against Cardiff University but you may have to pay your legal costs.

What will happen if I don’t want to carry on with the study?

If you become upset or decide that you would rather stop the discussion, the interview will be ended immediately. Moreover, we will destroy all data about you that has been collected during the study.

Will my taking part in this study be kept confidential?

At the time you consent all the information given at any point of this study will be confidential. All personal details if given will be removed in the data analysis so that no one could identify you. Pseudonyms will be used in any oral or written reports or presentations from the study, including any direct quotations from your questionnaire. All electronic data will be kept on a password-protected server at Cardiff

University. Any paper-based material will be kept in a locked filing cabinet. The original data collection sheets will be kept under lock and key in accordance with the Data Protection Act and will only be accessible to the research team and regulatory authorities. Data will be kept for five years and then disposed of securely.

What will happen to the results of the research study?

The results from the study will be reported in a thesis and submitted for examination for a PhD. Results will also be used as part of one or more articles submitted for publication in professional journals and reporting at professional conferences. You will not be identifiable in any of these reports or publications.

Who is organising and funding the research?

The research is organised by Sultanah Alabdulrazzaq as part of my study for a PhD. I am not being paid to do this research. The research is being supervised within the normal supervision arrangements for PhD students within Cardiff University

Who has reviewed the study?

This study has been reviewed and given favourable opinion by Cardiff University School of Healthcare Sciences Research Ethics Committee.

Contact for further information

If you would like more information or would like to agree to be interviewed, please contact. Sultanah Alabdulrazzaq

AlabdulrazzaqS@cardiff.ac.uk Tele: +44 (0)74 21878808

Cardiff University Eastgate House

Newport Road Cardiff

CF24 0AB

You may also contact the study supervisors, Dr. Jane Harden hardenj@cardiff.ac.uk Or Dr.Alison Seymour (SeymourA@cardiff.ac.uk) to learn more about the study. Thank you for taking the time to read this information.

Appendix 7;CONSENT FORM

CONSENT FORM

The impact of hip spica casting after treatment of developmental dysplasia of the hip on the development of the child from the perspective of the parent.

Name of Researcher: Sultanah Alabdulrazzaq

AlabdulrazzaqS@cardiff.ac.uk

Please initial box

1. I confirm that I have read the information sheet dated.................... (version ....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐

3. I agree to be audio-recorded during the study. ☐

4. I confirm that data from the study can be used in the final report and other academic publications. I understand that these will be used anonymously and that no individual respondent will be identified in such report. ☐

3. I understand that the findings and potentially secondary analysis of the findings and associated data from the study may be presented at conference and in scientific journals. I understand that these will be used anonymously and that no individual respondent will be identified in such report. ☐

5. I agree to take part in the above study. ☐

______________________ ______________________ ______________________

Name of Participant Date Signature

______________________ ______________________ ______________________

Name of Person Date

Signature taking consent

Appendix 8 ;Pilot study

A pilot study is defined as a "small study to test research protocols, data collection, sample recruitment strategies, and data analysis in preparation for a larger study" (Lancaster et al, 2004; Kraemer et al, 2006; Zailinawati et al, 2006). In this case, such a study was an important stage to identify a potential problem and help me to become familiar with the procedures required for recruitment of participants. It also provided me with a better understanding of how to execute analysis and thus helped me to move forward with my work.

In order to collect the necessary data for the pilot study, I collected posts covering three months (Autumn 2019) from the archives of the selected support group; I then evaluated the comments by reading all posts in the sample and noted how these were presented. The barriers that emerged included failure to gather sufficient information from posts if a specific month of the year was selected; for example, posts from December reflected contributions from few member participants and had no useful information. The experimental study suggested that the study protocol would be better served by randomly selecting one month from every three or four months and collecting all posts in the chosen month. A major reason for conducting a pilot study is to select the most appropriate methods to collect data, and it was important to determine what information is contained in these posts and how rich it is, as will have a direct impact on planning sampling to gather sufficient data for the study. Hence, to make the sample more representative of the problem, more than one method for collecting data was indicated, a need met by the addition of an interview stage.

First Cycle Coding Methods:	It carried out by collecting posts covering one-month period (November 2019) from the archives of a support group. The following example of initial line-by-coding of posts in word document shows six codes identified during the initial coding phase that have special meaning and significance within this study.
Procedures:	. Collected posts covering one-month period (November 2019) from the archives of a support group. . Posts were manually copied from Facebook and pasted into a Google Docs. . In step one, I read and reread the posts line by line to familiarise myself with the material. Moreover, it is a way of identifying important words, or groups of words, in the data and then labelling them with phrases that describe what is going on in data. . In step two, the initial codes were generated: I noted anything important and related to the research objectives. These codes explain the child's activities or parents' feelings. I highlighted the hardcopy of the documents manually by using colored pencils.

Colour codes	Indication
Blue	Patient info
Yellow	Motor development
Pink	Social problem
Green	Psychological problem.
Grey	Child activities
Red	***Parents feeling***

Appendix 9 Analysis of Posts

November facebook post number 9

POSTS NUMBER 9	INITAIL CODING
PARENT 1: So after 4 major reconstruction surgeries and from the age of 11 months to 2.5 years in numerous casts tomorrow I have to collect a wheelchair for my 3 year old. I should be getting her measured for school shoes but instead she was measured for a chair. I hate DDH our journey is far from over and my little girl still hasn't took her first step. I don't post very often as our little girl has severe hip dysplasia but I am just so upset and angry that DDH is stealing my daughters childhood. Sorry for the vent but just needed to get it out!	She has severe DDH and numerous invasive surgery and casting. She was an infant when she started treatment. The patient evaluated for an assistive device, but the mother wants a normal life for her by comparing her achievements with her same-age peers. Sever developmentally delayed (Delayed milestone), she does not do what others are doing at the same age. She missed the normal chronological development. The mother needs to support, which includes ''venting'' to deal with upset and angry. Mother has a strong negative emotion against disease because she is watching her child struggle with DDH. Eliciting emotional support was the sole intention of this post.
PARENT 2: Our son uses a wheelchair in school and out and about. It took awhile to get used to as well as the acceptance that he isnt 100% the same as his peers. Simple things like P.E., playtime.it gets easier. He has had 8 ops at	Engaging in everyday activities. Before he accepted being disabled, he first suffered from lost his mobility by comparing himself with peers.

the age of 8 with more to come x I know how you might feel x	Parents feeling accepts and get it easier. He has *many surgeries* through his age. Emotional support.
PARENT 3: My little girl is in a wheelchair full time, she's 6. They can give them some absolutely amazing independence! My little girl absolutely loves her chair. Other kids are so kind, they mother her so much and always look after her, she loves doing wheelies and most of all she loves racing.	The wheelchair gives her independence. Acceptance *and* adaptation. She has friends and behaves in a socially accepted manner. Participation levels of disabled child in physical activities.
PARENT 4: Vent away. Big hugs to you all and the guys are right our little warriors are so resilient. I totally know how you feel about stealing childhood I have to stop my little girl joining in sometimes with her friends and it breaks my heart.	Facebook has a highly supportive environment in which parents can share feelings. It is important to let them know you care and they are not alone. *Parental rejection.* Avoiding placing her child in situations where disability might appear which resulted in gradual withdrawal from activities. Mother may appear stuck in a pattern of grieving over her daughter condition.
PARENT 5: It's good to vent and this is the best place to do it! Sometimes you just need to say it ... DDH sucks big time Thinking of you. Take care.	The potential of Facebook page to be a source of social support. Parents provide emotional support in a positive tone. Parents suffered as much as the child did, although in a different way.

Visual presentational to posts analysis result.

1.Pain *management.*	1. Characteristics of pain; quality, severity, timin 2. *Pain management problem.* 3. Muscles cramping.
2. Healthcare	1. Doctor 2. HCPs role role 3. Difficulty to access services
3. **Social aspect**	1. Doing daily or enjoyable activities. 2. Limited ability to travel. 3. Using a car. 4. *Impact on Day*-to-*day routine*. 5. Social activity. 6. Lockdown. 7. Killing time. 8. Environment around a child
4. The psychological aspect	1. struggling with DDH 2. Parents' suffering and feeling. 3. The ability of a child to tolerate such treatment 4. Sleeping disorder. 5. Acceptance and adaptation. 6. Aggressive behavior 7. Behavior changes. 8. Bad habits or odd behavior. 9. Resist stopping bad behavior. 10. Environment around the child. 11. Child’s experiences and reactions. 12. The psychological impacts of the casting experience
5. Parents Perspective	1. Expectations, information or sight of delaying. 2. DHH is not the cause of the development delayed 3. Delayed depending on the child himself. 4. Needing a reference and enough information. 5. Expectations after the cast is remove. 6. A doctor's words. 7. The parents’ expectations. 8. Overprotective parents.
6.Delayed in motor development	1. Delayed milestone. 2. Use Assistive device. 3. The change in the activities before and with Spica cast. 4. Posture. 5. Compared with another normal child. 6. The cast restricts the normal motor development.

Social exclusion of the child and the parents

Quote	Sub-category	category
"Hello! Random question but does anyone know about flying while in a spica. My family live in Scotland and Spain (I live in Essex) and while I have time off with her post surgery they have asked if we would like to come to either place to see them and have a bit of a break. I don't want to drive so flying would be our best option but not sure_if it would affect swelling etc. Thank you!" *April Participant(1) Post number 4*	Transportability Car Flying Train	Limited mobility (Cast impact on Day-to-day routine)
" the airline may not be insured to take somebody in plaster. There is also the risk of DVT on flights. My daughter couldn't sit comfortably in a car for more than half an hour when she was in spica. Could you not drive with rest breaks?" *April Participant(2) Post number 4*		
"My daughter could only do half hour max in the car in her spica and that was pushing it. They really can't sit comfortably She would have managed on my knee in a train fine." *April Participant(3) Post number 4*		
"I don't think airlines allow it I'm afraid. You would have to check individually with the airline but I think I've seen on here before that it's rare to allow it." *April Participant(4) Post number4*		
"I had to go to Scotland after my hip replacement and not allowed to fly so went on the train. Went 1st class for the better seating and more space." *April Participant(7)Post number4*		
"Check with consultant and airline as we were allowed to fly as it wasn't a fracture" *April Participant(5) Post number4*		
"Check with the airline about the cast though, most say no due to the swelling that can occur during air travel." *April Participant(9) Post number4*		
"We are stuck as to what kind of things can help her be amused as she's not able to completely sit up? " *March Participant* (1) *Post number13*	Struggling to adjust to the new situation	

“She did lots of arts and crafts, playdoh etc. Stickers were a big winner and jigsaws too! Also, we have one of those magnetic white/blackboard sets which killed a few hours!!!” *March Participant (2) Post number13*		Full time (Pushing child to keep occupied in spica)
“I know you say he can’t draw but what an adult defines as drawing isn’t the same as a toddler/baby. They still gain skills and enjoyment from playing/exploring with pens/crayons/paint. One of the few things that keeps my daughter occupied in her spica is messy play, kinetic sand, playdough, cornflour, scribbling with pens or paintpens”. *March post Participant (6) Post number10*		
“You can go outside for a walk. Just keep a distance from other people. Unless you have underlying health issues”. *March post Participant (2) Post number10*	Lockdown and feel social isolation	
“*Advice needed please!!!!* *Ok my 18 month old son is in week 4 of the spica tomorrow. I am sick of just letting him watch tv but cannot for the life of me think of what else to do (I READ BOOKS. mainly at nighttime) but what else? He CANT draw talk colour. And I cannot go outside due to this virus and being put in self isolation. Please help me guys.“* *March post Participant (1) Post number13*		
“Me and family yesterday down at beach. Gutted Alexandra couldn't do anything but she loved being down at beach but was upset she couldn't go on any rides at fair. 8 days till cast off can't wait now”. *April Participant (1) Post number2*	Normal versus abnormal child	Powerlessness (the cast sometimes prevents the child from doing daily activities or enjoyment).
So after 4 major reconstruction surgeries and from the age of 11 months to 2.5 years in numerous casts tomorrow I have to collect a wheelchair for my 3 year old. I should be getting her measured for school shoes but instead she was measured for a chair. I hate DDH our journey is far from over and my little girl still hasn’t took her first step. I don’t post very often as our little girl has severe hip dysplasia but I am just so upset and angry that DDH is stealing my daughters childhood. Sorry for the vent but just needed to get it out! *November Participant (1) Post number 9*		
“Vent away. Big hugs to you all and the guys are right our little warriors are so resilient. I totally know how you feel about stealing	withdrawal from activities.	Parental rejection

childhood I have to stop my little girl joining in sometimes with her friends and it breaks my heart.” *November Participant(4) Post number9*		(avoid potential problems or dangers).
One mother shared her daughter's experience using an adaptive skil to move l *Post number12 March Participant (3)* *Participant (1) respond* wow! That is amazing! I just darent let her down and sit on the floor because I’m scared it’ll hurt her.	The overprotective parents protect their children from hurt when moving freely at spica cast.	
oh wow! I’m definitely trying this then! She’s had the femur shortened and then pinned and I think because it’s pinned we’ve been scared it’ll pop back out *March Participant (1) Post number13*		
“My little girl is in a wheelchair full time, she’s 6. They can give them some absolutely amazing independence! My little girl absolutely loves her chair. Other kids are so kind, they mother her so much and always look after her, she loves doing wheelies and most of all she loves racing.” *November Participant (3) Post number 9*	re-adjusting	Level of socially adaptive
"Our son uses a wheelchair in school and out and about. It took a while to get used to as well as the acceptance that he isn’t 100% the same as his peers. Simple things like P.E., playtime.it gets easier. He has had 8 ops at the age of 8 with more to come x I know how you might feel.” *November Participant(2) Post number9*		

Appendix 10 ;Interview guide questions

Open-Ended Questions	*1.Can you describe your child's journey with DDH? Tell me about what happened 2.Can you tell me more about the cast and what the period was like?* *3. How is it being a parent during the casting time?* *4. How would you describe the child he/she /was then?* *5. What contributed to change?* *6. What are your main concerns about your child?* *7. What was going on in your life then? How would you describe the child's care before surgery and cast? How, if at all, has your view of caring is changed?*
Structured Questions	1. *Could you tell me about your thoughts and feelings when you learned about the surgery and cast?* 2. *What happened next?* 3. *Who, if anyone, was involved? When was that? How were they involved?* 4. *In some posts, parents express regret over the surgery they had on their child - how do you feel about the decision to have the surgery?* 5. *What are some of the ways you dealt with problems after surgery and cast?* 6. *Could you describe a typical day for you when you are looking after your child without cast? Now tell me about a typical day when you are looking after your child with cast ?* 7. *Do you observe any specific changes or issues in your child during this time?* 8. *What do you perceive as different in your child's development? Why? And what did that feel like having cast?* 9. *What aspects of your child life do you think would be different without cast?* 10. *What aspects of your life and that of your child do you think could be improved?* 11. *What do you think about the care your child receives from the health system?And what kind of things did / did not they do for your child?* 12. *What helps you to manage this period ? What problems might you encounter? Could you tell me the sources of these problems?* 13. *Who has been the most helpful to you during this time? How has he/she been helpful?* 14. *Has any organization been helpful? What did it help you with? How has it been helpful?*
Probing Questions or Spontaneous follow-up questions:	1. *Tell me more about that* 2. *And how did you feel about that?* 3. *How did that make you feel?* 4. *What do you mean when you say.....?* 5. *Can you give me more details?* 6. *What is your experience with ...?*
A General Last Question	1. *What do you think are the most important ways to take care of a child with a cast ? How did you discover [or create] them?* 2. *How has your experience before the operation and the cast affected how you handle the new situation?* 3. *Can you tell me about how the experience of parenting has changed since you had a child with a cast?* 4. *After having these experiences,what advice would you give to parents who has just discovered that he or she will look after child with cast ?* 5. *Is there something that you might not have thought about before that occurred to you during this interview?* 6. *Thank you for all that information, is there anything else you'd like to add before we end?*

Appendix 11; Piloting the Interviews

Piloting the Interviews

Pilot interviews were needed to gain experience conducting interviews, using the interview guides, and understanding any practical issues or problems which may occur in subsequent transcription and data- analysis (Doody and Doody 2015). The purpose of these pilot interviews was to determine the length of the interview, the suitability of the interview guides, and whether any changes were needed. Furthermore, I used pilot interviews to uncover any potential technology issues that could impede the interview. I conducted two pilot interviews, one with a postgraduate student and one with a parent, which were not included in the actual study. During the pilot interview with parent, I realized during the pilot interviews that, in practice, it can be difficult to control the flow of interviews. This is because participants sometimes speak outside the subject matter of the study. I realized that if I listed too many details or she didn't focus on the main topics of the study, I would have to interrupt and ask a direct question during the interview. Furthermore, there were frequent and detailed questions that I didn't need in the first draft from Interview guide questions. From here it was realized the importance of adjusting interview guides to ensure that important questions for the study are not missed. After conducting the pilot interviews, I began thinking about how to ask more probing questions, paraphrase some, and delete others .

Conducting Interviews:

All the interviews are scheduled after I contacted the parents via Facebook messenger, and together we agree on the time. I then asked them to send an email address to send the consent form, participate information and Zoom invitation. Except for two participants, contact me directly via my email that found in the flyer on the Facebook page. One of them was interviewed but was eventually excluded. The day before each interview, I sent a reminder to the participant to ensure that the interview took place; They were also asked to test their webcam and audio equipment, if appropriate, as well as to confirm the timing of the interview. A signed consent form was obtained from the mother prior to the start of the interview. In some cases, obtaining consent from mothers was challenging due to the fact that they did not possess a computer, therefore, I advised them to take a photo of the consent form by phone and edit it with editing features to ensure their consent, since I did not want to lose them because of difficulty in obtaining others.

I had placed the flyer weekly on DDH UK Charitable Trust and Hip Dysplasia Support Group from 17 December 2021 to 21 March. The time between the first and last interview was approximately 6 weeks,including a pause. After the first three interviews, I realized I needed to stop and do an analysis to determine if I needed any additional or new questions to ask in subsequent interviews. As soon as I put the post on Facebook page, I got comments or likes.

Appendix 12 : Child characteristics

Child characteristics	Angela	**Beatrice**	Charlotte	**Daisy**	Elizabeth	Freya
Age of the Child	Three years	six years	Five years	Five years	11 months	Two and half years
Birth order of the child in the family	She is one of twins	First	First	First	Second	First
Number of children	2	2	0	0	2	2
Types of delivery	Caesarean Section premature at and she was breech	Caesarean Section	Caesarean Section she was breech	Normal Vaginal Delivery	Caesarean Section she was breech	Caesarean Section premature
Primary knowledge about DDH	she started walking with limping	she couldn’t shuffle across the floor because she couldn't move her left leg	Immediately after birth, the doctor automatically referred her for a hip examination because she was in breech position	When she was six months old, her mother noticed that she couldn't move her legs in the same way as other children.	The mother expressed concern that something wasn't quite right with her child's hips, as she experienced pain during diaper changes and movements. Despite this, she was repeatedly told that hip dysplasia doesn't cause pain.	When she was a baby, her mother expressed concern about delayed movement and repeatedly requested hip checks from the paediatrician. However, the paediatrician reassured her, stating that there was nothing wrong and that her child was just slow.
Healthcare provider	private sector	private sector	private sector	NHS health provider.	NHS health provider, Orthopaedic hospital	NHS health provider
Walking age	Before surgery 18 months	After surgery she took 22 months to walk after four months of being cast off	Before surgery, her movements were fairly normal, and nobody suspected anything was wrong unless the parent informed them.	A year after casting off to walk independently	She is young	she didn't start walking until she was 17 months.
Diagnosed with DDH	She waited three months after she began walking before her initial X-ray, which	At her six-week checkup, the doctor didn't notice anything unusual. However,	She had been in the breech position for a significant period, leading to an	The GP assessed her and noted that she wasn't as flexible as other children but did not detect DDH at	During the newborn examination, her hips were initially checked, but no abnormalities were	As her walking badly she started to swing one of her legs to the side when she walked.

	occurred when she was 21 months old, to receive a diagnosis.	due to her mother's DDH history, she underwent a scan.	automatic referral for a hip scan.	that point. She was then referred to the children's hospital for orthopaedics	detected. However, during a scan at six weeks old, prompted by her being breech, they discovered that her hip was subluxed. After a two-week wait, another scan was conducted at the General Hospital. Subsequently, when she was about 10 weeks old, she was referred to the Orthopaedic Hospital. Monitoring continued until she reached six months old, at which point an X-ray was performed.	Eventually, her mother insisted on having an X-ray done.
Treatment journey	The surgery was booked within four weeks from the diagnosis, when she was 23 months old. It involved a closed reduction procedure followed by six months in a spica cast. Due to her sensitive skin, there was an early cast change as her skin was breaking down.	Pavlik harness for six weeks until she was around 10 months old, followed by open reduction surgery and a spica cast for six months. After that, she used a broomstick for another few months until she was about 18 months old.	She was referred to a consultant, and at six months old, she had a close reduction with spica cast for about five months.	At 11 months old, she underwent an open reduction and spica cast for six weeks.	At 10 weeks old, she was in double nappies. Then, at six months, she wore an abduction brace for six weeks. Following that, she underwent a reduction procedure with a 12-week spica cast, which was changed midway through.	From the moment her mother raised concerns about her motor delay until we finally obtained the X-ray, it took about a year. Subsequently, after being referred to an orthopaedist, it only took about three or four weeks from the X-ray appointment to the surgery. The procedure involved a closed reduction and a spica cast for 12 weeks, with a change in the middle.
Schooling	During the cast period, preschools refused to accept the child	During the cast period, preschools refused to accept the child	school did allow her to go back	During the cast period, preschools refused to accept the child	No school	No school

Appendix 13 ;Interviews analyse example.

A source of information	
Need to know	it was just getting through it was taking each day I just came home and cried it was especially when We told was going into surgery. We didn't know if she'd been the cast for three months or six months. So until she had the operation and we didn't know what was closed or open reduction, so when we found out it's going to be six months in a cast I just literally did not know how I would cope.
Source of information	We had a name nurse, it was amazing so with Chelsea westminster, we had a name nurse to source for out and did lots of checkup appointments and I had his email and phone number, so I could contact him anytime. And he helped the cast and things and you just give lots of advice, but I found the parent forum was the best one because other parents had tips and advice for going through things so. Nurse laurie was amazing, but he hadn't got a child doing it, so you could tell you what this is what to do, met at three o'clock in the morning, when the cast is soaking wet. You want someone else to say don't worry about it and. it's a case I think other parents were. Your biggest source of hints and tips and practical ideas, I think the nurses was fantastic and reassurance medically giving advice. I think they said they got hints and tips, so this is, this is what hospice had been actually keeping the cost dry this works really well or this carrier is really good for carrying and. This this bike works well, or this highchair works well, they would people who could say in our cast this is what helped yeah.
Internet	I would google things as well, I do google things, but there wasn't that much I could find on Google, especially for long periods of time in the cast, I found it quite frustrating. That everyone be talking about oh we've got six months six weeks in a cast this is the renders like six weeks is nothing we've got this for six months so in some ways, like what are you complaining about 7-6 weeks for you we've got a whole six months of this.

Appendix 14;Personal reflections on completing a PhD journey.

Completing the journey to obtain a PhD has been a profound and transformative experience, one that has tested my determination and perseverance like never before. Throughout this challenging pursuit, my unwavering belief in my abilities, coupled with the invaluable guidance of my supervisor, has been instrumental in seeing this project through to its conclusion. These years of rigorous research have not only yielded valuable insights but have also shaped me as an individual in every respect. This academic odyssey has left an indelible mark on my personal and intellectual growth. It has been a journey that stretched not only my knowledge but also my emotional resilience. I have come to understand the true value of persistence and resilience, realising that overcoming obstacles is an essential part of achieving meaningful goals. This process has taught me more about myself than I could have ever imagined, deepening my self- awareness and fostering a greater appreciation of the importance of perseverance in achieving meaningful goals.

Throughout this research process, I often encountered phases of writing fatigue which proved to be incredibly frustrating. Deconstructing the grounded theory analysis process presented another challenge, especially because this approach is not commonly used in my field and the available literature on it varied significantly. Nevertheless, I managed to overcome these hurdles reasonably well, thereby making the process even more rewarding. Furthermore, a multitude of challenges were encountered, predominantly during the sample collection phase, with additional complexities surfacing during the interview phase (see Appendices for a detailed description of these challenges 9 &12).

As I contemplate my role in research, I am acutely aware that my journey as a mother of a high-risk infant who was born prematurely and conceived through IVF goes beyond the typical experience of motherhood. This unique path has brought me face-to-face with the challenges of navigating medical care and grappling with the dearth of information from healthcare professionals concerning the specific issues related to caring for such children. Recognising the value of my own experiences, I approached this research with a sense of responsibility and a desire to co-construct meaning. My role goes beyond being a passive participant; I see myself as an active collaborator in shaping the narrative. By infusing my personal insights and understanding into the study, I aim to foster a richer and more empathetic comprehension of the challenges faced by mothers in similar circumstances.

This process has been the most isolating and lonely experience I have ever had. It was also a period in my life when my personal circumstances underwent several changes. It was the second year of my PhD, at the time of the coronavirus pandemic (COVID-19), when I almost thought of quitting because of the anxiety I experienced. It was the frequent lockdowns, the social isolation and stopping going to university that was a life changer during my PhD years. I did not have the opportunity to take full advantage of the university's learning environment. During my PhD years, I therefore lost out on the discussions and group learning I would have cherished. Additionally, all of the interviews were conducted online via video call due to contact and travel restrictions. While these Zoom interviews provided a rich dataset, they also posed limitations. Conducting qualitative interviews online restricted the potential to gain implicit, personal and contextual insights that are typically obtained in a face-to-face setting, often in a natural environment.

Throughout the research process, I actively engaged in self-reflection, maintaining a record of memos and notes to capture my thoughts and emotions at various stages. These reflexive constructs played a crucial role in challenging my thinking and promoting self-awareness of my personal assumptions during the research journey. I kept a diary- like record, documenting the challenges I faced during the coding and sample collection stages .

Regarding the timeline for this study, I had to take into account the changes in the supervision team which added some complexity. One significant challenge that I encountered was the unfortunate departure of one of my supervisors, whose influential guidance greatly contributed to the formation of my research trajectory and the cultivation of my abilities as a scholar during the initial phases. However, I found strength in my unwavering determination to learn and grow continually, overcoming the obstacles that came my way.

As I look back on this journey, I realise that the true measure of success in pursuing a PhD lies in the impact it can have on the lives of others through valuable research findings and practical applications. This mission has been my guiding light, giving purpose and meaning to my research beyond academic accomplishments.

In conclusion, the completion of a PhD has been a transformative and rewarding experience. It has enriched my resilience, fuelled my intellectual curiosity and instilled essential research skills. As I reflect on this journey, I carry with me valuable lessons and a deeper sense of self. This experience has not only enriched my academic pursuits but has also empowered me to embrace future challenges with confidence and flexibility.

Appendix15; Extracts from Memos

Memo about; **Being vs Becoming **

Being describes an event but becoming describes the dynamics of that event.

“Being in a state of existence does not need a future because it already exists. Then it became and it is a different kind of action that results from it.” The term 'being,' as found in dictionaries, is defined using words such as 'existing,' 'living,' 'nature,' and 'essence.' The dictionary meaning of 'becoming' as a noun is described as '... a coming to be .

Heidegger’s existential analytic of Dasein focused on the human being’s existence in their world as an individual and within their social context (Heidegger, 1927/2011cite in Wilcock 1998). Also, he introduced the concept of Dasein reflecting the notion of a ‘‘living being’’ through their activity of ‘‘being there’’ and being in the world (Heidegger, 1927/20112011cite in Wilcock 1998).

Furthermore, according to Eriksson (1997), health and suffering encompass various dimensions and levels. The human relationship with health and suffering (illness) can be characterized as a transition across three distinct dimensions: health as doing, as being, and as becoming.

Memo about; ** Being in spica cast **

Being an individual and being part of a social context are two aspects of existence. Heidegger's definition that ‘being’ does not need a future because it already exists (Heidegger, 1927/2011). According to Eriksson (1997), health and suffering have various dimensions and intensities. A person's relationship to health and suffering (illness) can be characterized as a transition between three different dimensions: health as doing, as being, and as becoming. The state of being means already present or exist as well as being an individual or part of a social context (Maslow 1968).

This is the definition of "being in a spica cast" in describing the exist of child in spica cast after surgery for period extend between 6-12 weeks.

Memo about; **Interview**

Facing challenges accessing caregivers beyond a Facebook page and dealing with bureaucratic hurdles as an international student in a UK hospital, I adopted an innovative approach. Utilizing social media groups, I successfully reached a rare and difficult-to-access sample of children with spica cast. This method yielded valuable insights from parents, diversifying the data and enhancing variance in the research project. The interview questions were designed to be open-ended and adaptable to focus on *the study aims. The semi-structured format allowed participants to share their unique lived experiences and discuss important DDH issues (Gray 2014).*

However, the advent of the COVID-19 pandemic posed an additional layer of complexity. Regrettably, the constraints imposed by the pandemic prevented me from conducting face-to-face interviews with the parents, leading to some uncertainty about their comparability.

Memo about; **Cast Impact on Children's Mobility**

Children's movement is restricted by the cast since it applies a heavy, and bulky mass from the chest downward to the feet. Yet, an important revelation highlights that movement is closely tied to the cast's shape and length. This revelation prompted a focused inquiry during interviews centered around the topic of motor development. The question of what the cast looked like surfaced as a pivotal aspect to explore. Interestingly, two interviewees pointed out that a cast that extends from the mid-chest to just above knees for both of legs, allows the child to move more freely.The shape of the cast had positive effects on the activities and care of the child from the mother's perspective, confirming that the shape of the Spica cast is one of the dimensions of "Becoming inactive".

Memo about; ** Exploring Changes in a Child's Identity During Cast Period**

The majority of mothers who engaged in the process of contrasting their child's condition before and during the time in the cast were essentially attempting to find a new identity for their children during this time.

Memo about; **Anticipating Child Behavior**

Among the issues raised by parents were how to manage the child's emotional and psychological issues after surgery and the cast period. This was due to the difficulty in imagining or understanding the child's behaviour after the surgery, as children's reactions sometimes varied from sleep disturbance to aggressive behaviour. This behavioral change appears to be related to different expectations of parents and how this change was perceived. It was discovered that feelings of guilt regarding the decision to proceed with surgery were experienced by many parents, coupled with a sense of shock at the observed alterations in their child's behavior post-surgery. Conversely, this change was embraced by some parents, who interpreted the newfound aggressive behavior in their children as a mechanism for articulating feelings of immobility, but it is temporary, and the child adapts later.

Memo about; ** "Being on the Spica cast" negatively affected the well-being of the child and his family. **

It can be challenging to travel with children of any age. So, how is it going to be to travel with a child in a cast? because of the cast's shape and nature. This was the question asked by one of the families in a Facebook group on 21 April about the transportation options available during the cast period and whether there would be any side effects. The responses agreed that the plane seat is not suitable for the cast. Also, the airline may not be insured to take someone in a cast. There is also a risk of complications as DVT while travelling by air. In other words, parents faced challenges in maintaining a normal life with limited mobility that required major adjustments in nearly every aspect of their lives. Through this example, we learned how the experience of “being on the Spica team” negatively affected the quality of life and well-being of the child and his family.

Memo about; ** Status of participant selection **

Are there any noteworthy criteria for study participants, such as socioeconomic status or educational level?

My sample selection was neutral, and I did not condition the educational level criterion for selecting parents participating in the sample to generalize the results. In my mind, I wondered whether knowledge or education could affect the quality of care? Charlotte's mother expressed how her educational background enabled her to manage her daughter's behavioural changes during this transition period. As a result, the more knowledge and education parents have, the greater their chances of success and ease of care for their children.