Department of Nursing and Healthcare

Waterford Institute of Technology

Doctoral Thesis

TITLE:

Exploring the detection and care of infants with Developmental Dysplasia of the Hip.

BY

Heather Jennings

STUDENT NUMBER

00134167

Academic Supervisors

Dr. Linda Sheahan

Dr. Martina Gooney

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Contents

Abstract

Developmental dysplasia of the hip (DDH) represents a spectrum of anatomic abnormalities in which the femoral head and the acetabulum are aligned improperly or grow abnormally. It is generally acknowledged that the rationale behind screening for DDH is that earlier diagnosis will lead to simpler treatments resulting in better outcomes and minimising the need for open surgery. Additionally, the condition and subsequent treatment for DDH poses significant challenges for parents and impacts on many aspects of parent, child and family lives. To date, there are no national guidelines or algorithms in relation to the screening or management of DDH.

The aim of this research was to explore the detection and care of infants with developmental dysplasia of the hip. A mixed methods sequential explanatory design was utilised over three phases. Data collection involved a retrospective chart review (*n*=372), a survey (*n*=100), and semi-structured interviews involving parents (*n*=11) and health care professionals (*n*=8). Data analysis used the Statistical Package for Social Sciences (SPSS) and semi-structured interviews were subjected to thematic analysis.

The study revealed that despite a high late referral and diagnosis rate of DDH in the region, treatment in a specialist consultant led DDH clinic provided successful outcomes. A further significant finding of the study was the general lack of awareness regarding the condition DDH and the lack of hip health related information given to parents. Findings also identified that more formal training is needed by health care professionals to facilitate the development of their knowledge and skills in relation to the examination and screening of DDH.

Recommendations include the need for a National Integrated Care Pathway in relation to DDH while also supporting collaboration between Primary and Secondary Care. Consequently, this will promote a family centred approach to how health care professionals practically and psychologically support families through the diagnosis and treatment of DDH.

Keywords: Developmental dysplasia of the hip; consultant; parents; health care professionals; late referral; screening; treatment.

Declaration

I, Heather Jennings, declare that this thesis is submitted in partial fulfilment of the requirement for the degree of Doctor of Philosophy (PhD) and is entirely my own work except where otherwise accredited. It has not at any time either in whole or in part been submitted for any other educational award.

Signed:  (Candidate)

Heather Jennings

Date 15th June 2018

List of Publications

Jennings H., Gooney M., O'Beirne J. & 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, 48-53.

Dedication

This Thesis is dedicated to Frankie. Everything I do, I do for you.

To my father Frank and sister Maureen who made sure Frankie was delivered safely into my arms. I know they would be very proud of how far we have come as a family.

To see far is one thing, going there is another. Constantin Brâncuşi (1876-1957)

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Abbreviations used

AAOS American Academy of Orthopaedic Surgeons

AAP American Academy of Paediatrics

AI Acetabular Index

AMO Area Medical Officer

CASP Critical Appraisal Skills Programme

CDH Congenital Dislocation of the Hip

CEO Chief Executive Officers

CHC Child Health Care

CME Continuous Medical Education

CSO Central Statistics Office

DDH Developmental Dysplasia of the Hip

DoHC Department of Health and Children

FCC Family-Centred Care

GP General Practitioner

HCP Health Care Professional

HER Electronic Health Record

HSE Health Service Executive

IFPCC Institute for Patient and Family-Centered Care

NCP National Clinical Programme

NMBI Nursing and Midwifery Board of Ireland

NPV Negative Predictive Value

OPD Outpatient Department

OR Odds Ratio

PCC Person-Centred Care

PCN Person-Centred Nursing

PHN Public Health Nurses

PHR Personal Health Record

PPV Positive predictive Value

RCN Royal College of Nursing

RCR Retrospective Chart Review

RCT Randomised Control Trial

RR Risk Ratio

SHO Senior House Officer

SPSS Statistical Package for Social Sciences

UIN Unique Identifier Number

UK United Kingdom

UN United Nations

UNCRC United Nations Convention on the Rights of the Child

US Ultrasound

USPSTF United States Preventative Services Task Force

WHO World Health Organisation

Index of Tables

Table Number Page

Index of Figures

Index of Appendices

Chapter 1 Introduction

1.0 Background to the proposed research

Developmental dysplasia of the hip (DDH), formerly termed congenital dislocation/dysplasia of the hip (CDH), describes an array of anatomic abnormalities in which the femoral head and the acetabulum are aligned improperly or mature abnormally (United States Preventative Services Task Force 2006; Cooper et al. 2014). DDH is a poorly understood disorder as evidenced by the abundance of literature, both recent and historical, on the topic. The very name of the condition has evolved over time. Since clinical screening for neonatal hip abnormalities began in the 1950's it has been recognised that the disorder is not always congenital but an evolving process that may develop with growth and altered development of the hip (Klisic, 1984), occurring in utero, perinatally or during infancy and childhood (American Academy of Paediatrics 2000). As a result, a normal physical examination of the hips after birth does not preclude a subsequent diagnosis of DDH (Kotlarsky et al. 2015).

Additionally, the hip may be anatomically abnormal (dysplastic) while not being dislocated (Tomlinson *et al*. 2016). Therefore, the traditional term Congenital Dislocation of the Hip (CDH) has been gradually replaced by DDH, to include in the disorder, infants who subsequently develop hip dysplasia or dislocation despite having had a normal neonatal screening examination at birth (Shipman *et al*. 2006).

The precise definition of DDH is controversial as it has been described as not just one single condition but as a spectrum of pathologies which can on one end overlap with normal hip maturation (Bracken *et al*. 2012). From a clinical examination perspective DDH includes hips that are unstable, subluxated or dislocated. In an unstable hip, the femoral head (rounded top of the thigh bone) moves back and forth slightly out of the acetabulum (cup-like hip bone socket) with passive stimulation. A subluxated hip joint is where the femoral head is not centred in the acetabular cavity (partially dislocated); and complete dislocation is where the femoral head is completely out of the acetabulum (Agarwal & Gupta 2012). Radiologically, DDH extends to include acetabular dysplasia. Dysplastic hips demonstrate deficient formation of the acetabulum and may include rounding, flattening and loss of depth of the bony acetabulum and flattening or eversion of the acetabular labrum, see Figure 1.1 (AAP 2000). Dysplasia is generally too subtle to be picked up on clinical examination (Mahan *et al*. 2009). As a result, routine ultrasound (US) evaluation of newborns is becoming widespread but remains

controversial; the primary concern is the over-diagnosis (increased false-positive results) of DDH (McCarthy *et al*. 2005). The great variation of terms used for a single phenomenon may reflect the uncertainty related to the condition, making it difficult to define a truly pathologic hip (Raposch & Wright, 2007).

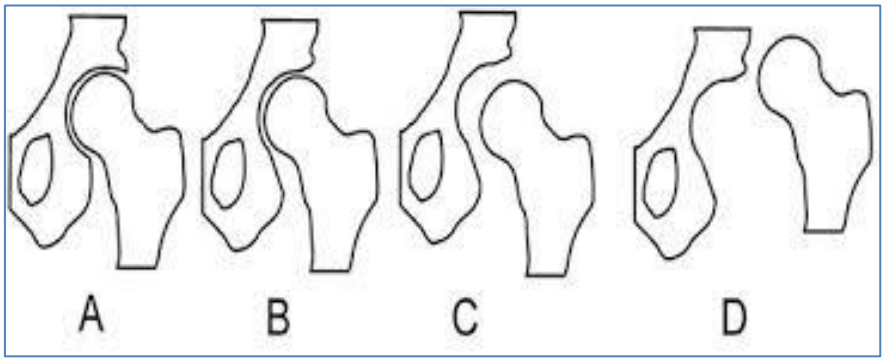

Figure 1.1 Schematic representation of DDH. A = normal, B = mild dysplasia, C = subluxation, D = dislocation Adapted from http://medicinembbs.blogspot.com/

Following on from this, one of the current difficulties is the limited consensus on what degree of abnormality in a newborn hip should be treated (Dezateux & Rosendahl 2007; Shorter *et al*. 2011).The natural course of DDH is largely unknown and different definitions for when treatment is considered necessary persist (Shorter *et al*. 2011). Consequently, some advocate treatment where others recommend surveillance or no follow up (Raposch *et al*. 2011). Numerous observational and retrospective studies report that 60% - 80% of the hips of newborns identified as abnormal or as suspicious for DDH by physical examination and over 90% of those identified by ultrasound in the newborn period resolve spontaneously during the maturation process of the neonatal acetabulum in the first six weeks of life and require no intervention (USPSTF 2006; Wenger *et al*. 2013; Bin *et al*. 2014). This lends itself to the belief that many infants who may just in fact be displaying signs of an immature hip, are being treated for DDH unnecessarily (Mahan *et al*. 2009), which in turn leads to unnecessary follow-ups and parental anxiety. A recent audit of referral time frames for ultrasound screening of DDH in neonates with a normal antenatal clinical examination carried out by Burnett *et al*. (2018) in Australia identified 41% of the cohort scanned at or before 4 weeks of age were classed a Graf type 2a on US scan compared with 20.5% of babies who were scanned after 5 weeks of age. This showed a twofold increase in babies diagnosed with abnormal hips when scanned before 5 weeks of age. It was suggested in the study that DDH screening ultrasounds be performed at

6 weeks of age to allow for neonatal acetabular maturation; thus decreasing the rate of over diagnosis of DDH, avoidable orthopaedic review and parental anxiety (Burnett *et al*. 2018).

What is largely agreed across the literature is that if DDH is referred promptly, correctly diagnosed and treated early, the risk of significant morbidity is reduced; moreover, uncorrected or persistent DDH is increasingly recognised as a leading cause of significant long term morbidity including: impaired walking, chronic pain and premature degenerative joint disease requiring joint replacement in later life, (Holroyd & Wedge 2009; Sewell *et al* 2009; Sewell & Eastwood 2011; Clarke *et al* 2012). DDH can be accounted for 29% of all hip replacements being performed on patients under the age of 60 (Engesaeter *et al*. 2011). However, despite best practise, young adults will still present with hip dysplasia that was not detected at birth (Schwend *et al*. 2014). As a result, a much debated question is what the optimal form of treatment for DDH should be (Cooper *et al*. 2014).

Once DDH has been accurately identified, it is generally agreed that early identification and treatment leads to optimum development of the hip and reduces the number of children who eventually require surgery for the condition which is associated with more long term problems (Gardner *et al*. 2005). Concerns have been expressed that the incidence of late diagnosis of DDH appears to be particularly high in Ireland (Gul *et al*. 2002), but evidence is lacking as to whether this is due to a high natural incidence of the condition in the Irish population, or to poor screening and early management. It has been suggested that clinical practice in Ireland in this area is under developed and requires significant research (O'Grady *et al*. 2010).

Health Care Practitioners (HCPs) not only play a valuable role in the early screening of DDH but also in the support of parents who have received a diagnosis of DDH and are caring for a child/infant being treated for the condition. DDH poses tremendous challenges for caregivers and impacts on nearly every aspect of parent and family lives such as skin care, feeding, work and transportation (Gardner *et al*. 2005). In order to provide family-centred care, HCPs must step into the role of a family advocate, preparing families for the challenges that often arise, with a focus on decreasing the stress and anxiety often involved in caring for their child. Parents lived experiences are not widely researched in an Irish context and present a void in relation to identifying suffering and priorities in meeting children's needs. Additionally, there are no nationally agreed screening or treatment protocols in place or recognised training, or development programmes for best practice for HCPs and parents in Ireland.

1.1 The aim of the research project

The proposed research aim was to explore and analyse the DDH services in South East Ireland. In Phase One, a chart review of DDH referrals from babies born in 2012 and 2013 was analysed to identify incidence rates of DDH and assess the effectiveness of treatment and screening methods in the region. Phase Two involved parents of infants with DDH completing a questionnaire regarding their experiences using the DDH clinic and their experiences of caring for a child with DDH. Phase Three involved the parents and participating in a semi structured interview in order to gain further knowledge into their experiences of caring for a child with DDH. It was anticipated that Phases Two and Three would help identify how we can improve services and care for infants with DDH and their families.

1.2 Objectives of the research project

1. Identify the true incidence of DDH and early/late diagnosis of the condition in the South Eastern region of Ireland.
2. Assess the effectiveness of current screening and treatment methods in the region.
3. Explore the experiences of parents in caring for a child with DDH and identify their needs to in order to develop appropriate care packages for service improvements.
4. Explore the viewpoints of General Practitioners (GPs) and Public Health Nurses (PHNs) who screen and refer suspected DDH in the community setting
5. Identify scope for the improvement of care in DDH diagnosis and treatment.

1.3 Significance of the research project

This research is significant as it is the first time that issues surrounding the detection and care of infants with DDH have been explored from an Irish perspective. The findings from the project could make a very significant contribution to the enhancement of care for infants with DDH and their families. The outcomes of the research project can provide directions for family centred care and presents important suggestions for future policy, practise and research. The findings could be of considerable value to a wide constituency of healthcare professionals, parents, child health stakeholder groups nationally and internationally, educators and policy makers.

1.4 Organisation of the Thesis

This PhD dissertation is composed of seven chapters. Chapter 1 introduces the background and study rationale in the context of what is already known about DDH. Chapter 2 provides a critical account of the literature in relation to what is known about DDH both from an Irish and international perspective. The various screening practices that have been adopted worldwide will be explored and their success rates critically evaluated. The experience of receiving a diagnosis of DDH and caring for a child in treatment is also investigated in relation to the impact these experiences have on parents. Finally, the value of adopting a family centred approach to how health care professionals, practically and psychologically, support families through the diagnosis and treatment of DDH will be explored. Chapter 3 presents the research methodology used to conduct this study. The types of data analysis used in the different phases of the research study design are outlined and discussed in relation to the impact on the overall outcome of the research project. Chapter 4 presents the key findings from Phase I which was a retrospective chart review of all infants who were referred to the DDH clinic who were born in 2012 and 2013. Chapter 5 presents the findings of Phases 2 and 3. The findings from the questionnaire in Phase 2, which included parents who were attending the DDH clinic with their infants, informed the topic guides for the semi-structured interviews in Phase 3 with the parents and HCPs involved in the screening and referral of infants with suspected DDH in the community. A discussion and integration of the results of the three phases is provided in

Chapter 6, where the results are interpreted in light of the evidence from the literature. Chapter 7 considers the clinical and theoretical implications of the study in the context of the current body of evidence. It also addresses key strengths and limitations of the study and makes clear recommendations for clinical practice and future research directions.

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1.5 Chapter Summary

The first chapter has introduced the research problem by providing an overview of the topic within a practical and theoretical context. Justification for the research is presented and an outline plan for the dissertation is also provided. Chapter 2 provides a more in depth contextual background for the research study.

Chapter 2 Literature review

2.0 Introduction

The aim of this literature review was to evaluate the evidence and to identify gaps in relation to the current provision of care to infants with DDH and their families. Evidence on the various different screening and diagnostic pathways in Ireland, the UK, Europe and internationally is appraised in order to gain an appreciation of what is currently considered best practice with a view to investigate if any aspects could be adapted for use in the future organisation of DDH services in Ireland. The literature review begins by outlining the search strategy in Section 2.1. It will then give a brief overview of the history of DDH followed by a review of international and Irish incidence rates for DDH in sections 2.2 and 2.3. Section 2.4 examines the risk factors for the condition followed by section 2.5 which explores the various aspects of screening for DDH including the different methods used to identify DDH and the controversies that surround the different screening programmes adopted internationally and here in Ireland. Section 2.6 summarises the forms of non-operative treatment used in the management of DDH. The views of parents that have received a diagnosis of DDH for their infant and are in receipt of treatment for the condition are explored at length in section 2.7 while the final section 2.8 examines aspects of a family centred model of care which can be beneficial for families under the care of DDH services.

2.1 Literature searching strategy

A critical review of the literature was undertaken and the principles of a systematic approach enabled a logical format to the organisation of the review (Grant and Booth, 2009). The researcher undertook a comprehensive review to address the research objectives. This review provided the opportunity to undertake critical appraisal of the evidence to date about the provision of care to infants with DDH and their families.

2.1.1 Identification of the literature

The search was structured in line with the principles of systematic reviewing as advocated by the Cochrane Collaboration (Higgins *et al.*, 2011). A systematic review attempts to collate all empirical evidence that fits pre-specified eligibility criteria in order to answer a specific research question. It is envisaged that research will promote the development of new

understanding that can be used to inform clinical practice and improve standards of care within DDH services.

Whilst it is recommended by the Cochrane guidelines (Higgins *et al.*, 2011), that research papers be graded according to the level of evidence, this was not incorporated in this review. Instead, this review focused on examining the nature of the study, the methodologies and methods used and the findings, all of which formed part of the critical appraisal of this literature review. In addition, there were papers which did not fit the eligibility criteria, for example grey literature, but which were utilised to add important contextual information to the review.

2.1.2 Selection and critical appraisal

The literature concerning DDH screening, diagnosis and parental experiences consisted mainly of peer reviewed articles found in the electronic databases CINAHL with Full Text; Science Direct; Wiley Online Library; Ovid and Pubmed

In addition, reference lists in retrieved publications were reviewed. A combined free-text and thesaurus approach was adopted using both UK and US spellings for key-word selection with mesh terms. 'DDH' search terms included the following: 'Congenital Dislocation of the Hip', 'DDH management', 'DDH screening', 'DDH diagnosis', 'DDH late diagnosis' 'DDH epidemiology', 'DDH risk factors', 'DDH management', 'DDH treatment', 'DDH referral pathways' DDH parental experiences', patient-centred care' and 'family-centred care' as can be visually examined in the following table. The data sources were interrogated using a multitude of search terms as displayed and the search was refined using Boolean operators – 'AND', 'OR' and 'NOT' (Ely and Scott, 2007). The literature search and results are outlined in Table 2.1.

Web-based searches regarding DDH care and health services provision were performed, including websites for The Irish Government, The World Health Organisation (WHO), Health Service Executive (HSE), and the Department of Health and Children (DoHC) websites of Ireland and the United Kingdom. Citation searches were conducted on key papers and the reference lists of included studies were checked for additional references.

In excess of 112 studies were considered potentially relevant to the review. Further assessment for relevance was made according to the abstract content. The titles were scanned and the relevant abstracts were read and sorted according to the inclusion and exclusion criteria. This resulted in a final selection and appraisal of the full text of 29 papers to represent the literature.

Critical appraisal refers to a balanced scrutiny of a research paper, highlighting its strengths and weaknesses (Downe-Wamboldt, 1992).

2.1.3 Inclusion and exclusion criteria

The search revealed that DDH and associated words received considerable attention in the last decade. To sharpen the focus, inclusion and exclusion criteria were adopted to identify as many relevant research papers as possible.

Inclusion criteria:

- Published and unpublished research reports,
- Government papers,
- Clinical guidelines,
- Discussion papers
- Primary research articles in the English language between years 2008-2018.
- Seminal studies which fell outside this constraint were also reviewed, and research studies using any approach were accepted.

Exclusion criteria:

- Non-English language data outside years 2008-2018.
- Non peer reviewed studies.

The searching strategy employed and results obtained are outlined in Figure 2.1

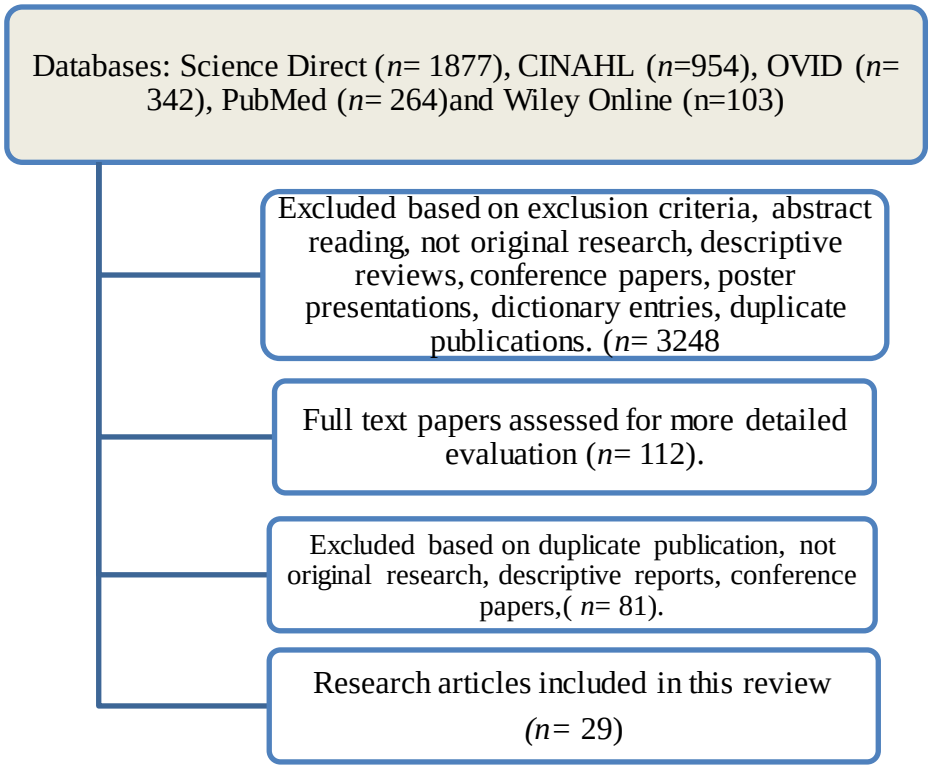

Figure 2.1 Literature Searching strategy

2.3 Incidence of DDH

DDH is one of the most common congenital defects in newborns and is a leading cause of childhood disability (Gelfer & Kennedy 2008). However, determining the incidence can be difficult. The reported incidence of DDH varies widely from 1.4 to 35.0 cases per 1000 live births (Mahan *et al*. 2009), the higher incidence rate applies to hips that are dysplastic while approximately 1in 1000 hips are diagnosed as being dislocated at birth (Storer 2006) The epidemiologic literature regarding DDH is vast and confusing due to different definitions of hip dysplasia, different methods of diagnosis, different ages of the population studied, clinical experience of the examiner, different ethnicities/races in the examined population and different geographic locations within similar ethnic populations (Bracken *et al*.2012). Bialik *et al*. (1999) argued that the confusion in determining the incidence of DDH is due to the uncertain definition of the term DDH and as a result of the variety of inclusion and exclusion diagnostic criteria used by health professionals. A decade later, this uncertainty is still echoed by The American Academy of Pediatrics (AAP, 2000) who argued that the true incidence of DDH can only be estimated as there is no "gold standard" for diagnosis during the newborn period. In Barlow's (1962) classic study, an incidence of hip instability found at newborn examination was reported

as high as one in 60. However, over 60% of these hips became stable by one week and 88% by two months (Barlow, 1962).

These findings suggest that the timing of diagnosis can have a major impact on the cited incidence rates of DDH and begs the question whether all neonates with slight hip abnormalities or immaturity can be considered as having DDH or does it apply only to those hips that will remain pathologic if not treated (Eli *et al*. 2014). Measuring specificity and false-positives is difficult because in most prospective studies carried out, all infants who have a positive screening test are treated with non-surgical intervention; the great majority of infants improve, and it is impossible to say how many infants 'responded' and how many of them resolved spontaneously thus did not have DDH in the first place (Shipman *et al*. 2006).

However, a clinical study carried out by Kokavec & Bialik (2007) in Slovakia aimed to identify those neonatal hips which, if left untreated, would develop any kind of dysplasia and, therefore, are to be included in the determination of DDH incidence. Clinical and ultrasound examinations for DDH were performed on 4356 neonatal hips. Hips that featured any type of sonographic pathology were re-examined at 2 or 6 weeks, depending on the severity of the findings. Only hips in which the initial pathology was not improved or had deteriorated were treated; all others were examined periodically until the age of 12 months. Three hundred and one instances of deviation from normal were detected during sonographic screening of the 4356 hips, indicating a sonographic DDH incidence of 69.5 per 1000. However, only 21 hips remained abnormal and required treatment, indicating a true DDH incidence of 4.8 per 1000 hips. All others evolved into normal hips, and no additional instances of DDH were found on follow-up throughout the 12 months. The authors concluded that these findings enable HCPs to distinguish two categories of neonatal hip pathology; one that eventually develops into a normal hip (sonographic DDH); and another that most likely deteriorate into a hip with some degree of dysplasia, including full dislocation (True DDH), thus giving a more appropriate determination of its incidence.

In order to explain the reasons behind the significant variances in the incidence rates, Bialik *et al*. (1999) described three eras in modern medicine when the incidence of DDH has been determined. Period I (1920s to 1950s) was when the incidence was arbitrarily estimated. Period II (1950s to 1980s) was when the incidence was determined based on the detection of unstable hips on clinical examination plus the addition of late diagnosed patients. Period III (1980s to present) incorporates hip ultrasonography and clinical screening. Until the 1950s, before the

introduction of routine screening programmes for detecting DDH, incidence was estimated at 0% to 40%. Until the 1980s when routine screening for DDH was performed clinically, the incidence was 0.41% to 16.8%. Since the 1980s, after the introduction of sonographic techniques for the investigation of paediatric hip and neonatal screening, the incidence rose to between 4.4% and 52% (Eli *et al*. 2007).

In an attempt to update the current knowledge of the epidemiology and demographics of paediatric hip disease, Loder & Skopelja (2011) conducted a systematic medical literature review regarding DDH focusing on etiology, epidemiology and diagnosis. They found a significant variability in incidence between different racial groups by geographical location. The incidence of DDH per 1000 live birth ranges from 0.06 in Africans in Africa to 76.1 in Native Americans. The incidence of DDH was found to be most high in Native Americans, likely due to a combination of genetics and swaddling. In the Arizona Fort Apache Indians for example, the incidence was reported as 31 per 1000. In the Navajo tribe of New Mexico, the incidence of DDH was 67 per 1000. These high incidence rates may be associated with the Native American culture of marrying within their own bands, thus creating a very tight gene pool. Using weighted averages, Loder & Skopelja (2011), found the overall average incidence of Native American Indians to be 76.1 per 1000 live births.

A strong correlation has been found between swaddling and DDH, most likely due to the Native American culture of strapping the infant to a cradle board with the hips extended and adducted. The physiologic hip position in a newborn infant is flexion and abduction. This aids hip development in enlocated hips by maintaining contact between the femoral head and the acetabulum. Swaddling in such a way where the legs are extended and adducted may exacerbate the dysplasia and alter the natural course of hip development (Mahan & Kasser, 2008). Loder & Skopelja (2011) found in their study of 2300 Navajos, that hip dislocation was more prevalent in adults than children. It was postulated that the decrease in dislocation was due to the steady decrease of the use of the cradleboard in modern times. Similarly, there was a ten-fold increase in DDH in Canadian Native Americans who have continued to use the cradleboard.

On the other end of the spectrum, DDH was found to be extremely rare in Africans. There were no signs of hip dysplasia at 3 months of age in one study of 16678 Sub-Saharan Bantu African children. While in another study, only 2 cases of typical DDH were described in the Bantu. This so called 'immunity' of the African infant from DDH is assumed to be due to deeper

acetabulae, genetic factors, and the absence of swaddling in African cultures. Instead, the African population more commonly carry their infants in an abducted position on their backs, which naturally encourages the acetabular roof to form correctly around the femoral head, therefore protecting against DDH.

2.3.1 Ireland's incidence rates of DDH

The situation in Ireland is even more uncertain, and the literature contains only a small number of papers from the Irish setting. While it is believed that there is a high incidence of late diagnosis of DDH in Ireland (Gul *et al.* 2002; Phelan *et al.* 2015), evidence is sparse as to whether this is due to a high natural incidence in the Irish population, or to poor screening and early management of the condition. Late diagnosis is regarded as a missed opportunity to have dealt appropriately with DDH after 3 months of age (Duppe & Dannielsson 2002; Myers *et al.* 2009).

In Northern Ireland, Maxwell *et al.* (2002) carried out a comparative retrospective study from January 1991 to December 1997 in order to compare rates of late diagnosed DDH requiring surgery in the region to a previous study which found an incidence rate of 1.75 per 1000 during 1983 to 1987 in the same province. Results showed that by putting an increased emphasis on staff training, introduction of a centralised nurse led clinic to improve faster access to orthopaedic surgeons and an increased use of ultrasound, the incidence of DDH diagnosed after 6 months that required surgery fell to 0.59 per 1000 presumably due to improved early detection. Interestingly, 29 (16%) of the affected hips were not diagnosed when the child was first referred within the first 3 months of life. It is worth noting that infants that were treated non-surgically for DDH were not included in the study.

Thirteen years later, Donnelly *et al.* (2015) carried out a retrospective review of all infants born in Northern Ireland between 2008 and 2010 who were diagnosed with DDH after 1 year of age. Of the 75,856 live births during the study period, 645 infants were treated for DDH (8.5 per 1000). Of those, 32 infants were diagnosed after their first birthday (0.42 per 1000). Interestingly, they found that 287 children were diagnosed with DDH between the ages of 3 and 5 months (3.78 per 1000), which many in the field believe to be a late diagnosis (Myers *et al.* 2009; Sanghrajka *et al.* 2013; Woodacre *et al.* 2014).

Gul *et al.* (2002) carried out a retrospective study of all cases of late presenting DDH from 1988 to 2000 in Cork. Late presentation was defined as 'DDH not identified at the initial

newborn screening and later diagnosed at 6 months of age or more'. The aim was to identify the reasons of late presentation of DDH in the presence of a screening programme. A total of 49 cases of late presenting DDH were diagnosed over the 12 year period. Among the cohort, 46 were female (94%) (female: male ratio 46:3) and had at most one risk factor, highlighting the absence of multiple risk factors in the majority and the mean age of diagnosis was 14.8 months. Conclusions drawn by the authors were that despite screening, children continued to present with late DDH, however, there was an overall reduction in the incidence of late presentation from 10 in 1988 to 2 in the year 2000, most likely due to increased public awareness of the condition and more stringent screening and surveillance.

The current overall incidence of DDH in the Republic of Ireland is unknown, however, Phelan *et al.* (2015) carried out a retrospective study of all cases of DDH in children born between 1st of January and the 31st of December 2009 in the South Eastern Region of Ireland. The aim of the study was to determine the incidence of DDH, including the incidence of late diagnosis of DDH and also to examine the treatment outcomes of infants diagnosed with DDH. They defined an early and late diagnosis as those treated before or after 3 months. There were 8317 live births in the Southeast region in 2009, of which 56 cases of DDH were diagnosed giving an incidence rate 6.73 per 1000 live births. Results showed that 58.9% (n=33) were referred to the clinic and began treatment early, while 41.1% (n=23) presented late. This gave an early incidence rate of 3.97 per 1000 and late diagnosis rate of 2.77 per 1000. Fourteen patients required referral to a tertiary centre, with 9 of those having open surgery. While the overall incidence rate of 6.73 per 1000 live births in 2009 is similar to other studies , the incidence of late presentation and diagnosis of 2.77 per 1000 is 3 times higher than the findings of the Northern Ireland study from the late nineties (Maxwell *et a.* 2002). The authors concluded that there is a need for the development of a national screening programme in Ireland as, compared with similar studies in other countries which have universal ultrasound screening, the results of this study show a higher incidence of late diagnosis and surgical interventions. The authors advocate the incorporation of the greater use of ultrasound and clinical examination by those experienced in DDH assessment as currently many examinations in Ireland are performed by paediatricians in training with variable experience.

Bracken *et al.* (2012) also highlighted the importance of the clinical examination of the infant hips being performed by experienced, trained personnel. In a study involving each of the maternity units in Ireland, O'Grady *et al.* (2010), carried out a two-pronged prospective and retrospective study to ascertain current screening approaches for DDH in 2006. A postal

questionnaire was administered anonymously to Consultant Paediatricians and Neonatologists attached to all 19 maternity units in Ireland to determine screening practises. Results showed that most units (84%) were still dependant on x-rays at 4-6 months of age for imaging hips, while only 2 units primarily used ultrasound (10.5%). The authors estimated that neonatal hip examinations were performed by an experienced examiner in less than 30% of newborn examinations. While the Randomised Control Trial (RCT) and recent Cochrane review mentioned earlier (Holen *et al.*2002; Shorter *et al.* 2011), were unable to recommend an optimal screening method, it is noteworthy that the results of O'Grady *et al.* (2010) study fall short of the Cochrane Group's recommendation that all newborn examinations for DDH should be carried out by an experienced examiner. It was suggested following this study that national guidelines were required to develop continuity of practise across all maternity units in the Republic of Ireland.

A review carried out by the National Clinical Programme for Paediatrics and Neonatology three years later in 2013 found that approximately 50% of the units now have access to hip ultrasound, at 6 weeks of age, while the remainder rely on X-rays at 4-6 months of age, for detection of DDH (HSE 2013). While this is an improvement, there is still a marked variation in practise with regard to screening for DDH. As a result the National Clinical Programme for Paediatrics and Neonatology are progressing with a project to develop a national targeted screening programme for infants at risk of DDH which is in the process of being finalised and rolled out nationally in 2018 (HSE 2017).

2.3.2 Late incidence of DDH

The main aim of modern screening programmes for DDH is to reduce the number of patients presenting late with the condition and to avoid frequent and costly treatment (Wirth *et al.* 2004). Late diagnosis is considered to be DDH which has not been detected in the first 3 months of life (Sharpe *et al.* 2006;Woodacre *et al.* 2014); however, interpretation of rates of late diagnosis can often be difficult in relation to the strict definition and age of diagnosis (Sharpe *et al.* 2006). However, despite efforts to detect and screen for DDH soon after birth, delay in diagnosis in some infants remains an issue, resulting in less favourable outcomes (Kotlarsky *et al.* 2015). At present there is no general consensus on screening strategies, ultrasound techniques or specific indications for treatment which may reduce the number of late presenting cases of DDH (European Society of Paediatric Radiology's Task force group on DDH, 2011).

While there is no general consensus as to the most effective screening programme to combat late diagnosis of the condition (Shorter *et* al 2011), there is soft evidence that suggests that ultrasound screening tends to reduce the rate of late DDH and the need for surgical interventions (Holen *et al*. 2002, von Kries *et al*. 2012). Different screening strategies including universal or selective ultrasound screening have been established in several European countries and centres during the last decade to try to reduce the rates of late diagnosis.

Some authors recommend universal ultrasound screening to decrease the incidence of late presentation of the condition (von Kries *et al*. 2012; Sink *et al*. 2014). To determine the long term effects that general/universal neonatal sonographic hip screening had on the evolution of late presenting DDH, Wirth *et al*. (2004) compared children who needed treatment based solely on the type of hip found on ultrasound from 1985 to 1998. The first group (n=604) diagnosed by ultrasound were compared to a second group of children who were treated conservatively and/or surgically for DDH under the age of 16. The second group (n=73) did not receive sonographic screening of the hip. Femoral and pelvic osteotomies were almost entirely restricted to the unscreened group (n=25). In the screened group, only4 patients required surgery. There was a decline in late presentations in the screened group from 3 or less per year from 1990 to 1994, no late presentations between 1995 and 1998 and 1 or 2 late presentations per year from 2000. The authors concluded that general ultrasound screening significantly reduced surgical procedures, hospitalisation and late presentation of DDH.

It is also suggested that the criteria for selective screening for DDH does not identify all patients that will go on to develop DDH later in life (Thaler *et al*. 2011; Sanghrajka *et al*. 2013). Sink *et al*. (2014) used a prospective hip registry to identify 68 consecutively skeletally mature patients undergoing corrective hip surgery for symptomatic hip dysplasia after skeletal maturity. Risk factors for DDH were evaluated in all patients including sex, family history of DDH, breech and method of delivery. No patients were previously diagnosed with DDH or received treatment for their hips as infants. The majority of patients (85.3%) did not meet selective ultrasound screening criteria had they been born today. Selective ultrasound screening is described in section 2.3.6.

An 8 year prospective targeted ultrasound screening program for instability and at-risk hip joints in DDH trial was undertaken by Paton *et al*. (2002) in the UK between 1992 and 2000. in an attempt to clarify if a selective ultrasound programme could reduce the rate of late diagnosis of DDH. This study was undertaken between May 1992 and April 2000. There were 28,676 live births. Unstable and at-risk hips were routinely targeted for ultrasound examination.

One thousand eight hundred six infants underwent ultrasound examination (6.3% of the birth population). Twenty-five children (18 with dislocations, 7 with dysplasia) required surgical intervention in the form of open reduction of the hip or pelvic or femoral osteotomy (0.87 per 1,000 births for dysplasia, 0.63 per 1,000 births for dislocation). The authors concluded that targeted ultrasound screening does not reduce the overall rate of surgery compared with the best conventional clinical screening programmes performed by skilled practitioners; and argued that the development of a national targeted ultrasound screening program for at-risk hips cannot be justified on a cost or result basis.

Conversely, Roovers *et al*. (2005) reported no significant difference in rates of late detection in their large prospective cohort study which compared two groups of children in the Netherlands. The first intervention group of children (n= 5170) comprised of children who were screened by ultrasound at 1, 2 and 3 months of age. The control group of children (n=2066) was screened by routine physical examination as part of the programme for child health surveillance at child health care centres (CHC) in the Netherlands. For evaluation purposes both groups of children received an ultrasound reference examination after 6 months of age to detect any abnormality that might have been missed by screening. Comparison of ultrasound and CHC screening found that the sensitivity of the ultrasound screening programme was 88.5% compared with 76.4% for the routine CHC screening programme in the Netherlands, therefore showing that ultrasound screening detects more children with DDH than CHC screening. Additionally more children were detected at an earlier age (67% v 29%). However, universal ultrasound screening did not eradicate late cases of DDH as 11.5% of cases of DDH were not picked up until the ultrasound reference examination at eight months of age. The higher treatment rate in the control group points to overtreatment as a consequence of the screening.

2.4 Risk Factors

It is generally accepted that there are genetic, hormonal and mechanical factors that are involved in the aetiology of DDH. In case control and observational studies, family history of DDH, breech presentation at delivery and female gender have been shown most consistently to have an association with the diagnosis of DDH (Shipman *et al*. 2006). The prevalence is higher in firstborn children and DDH is three times more common in the left hip, likely because of the left occiput anterior position that infants tend to adopt in-utero, which places the left hip against the mother's spine and limits its abduction (Delaney & Karmazyn, 2011); yet these risk

factors tend not to be used in screening programmes (Sewell *et al*. 2009). Additional risk factors include high birth weight, oligohydramnios and congenital foot deformities.

Breech presentation may be the most important single risk factor, with DDH reported in 2% to 27% of boys and girls presenting in the breech position (Imrie *et al*. 2010). Frank breech presentation in a girl (sacral presentation with hips flexed and knees extended) appears to have the highest risk. (Bache *et al*. 2002). Family history is the second most commonly recognised risk factor (Paton 2017). It has been suggested that by having one affected sibling increases the DDH risk to 6%, one affected parent a 12 % risk and if both one parent and one sibling are affected the risk of DDH to the neonate is 36 % (Tomlinson *et al*. 2016).

Two recently conducted meta-analyses reported on the common risk factors associated with DDH. Ortiz-Neira *et al*. (2012) examined 31 studies and reported a relative Risk Ratio (RR) for each risk factor in newborns. Their findings were: breech presentation had a RR of 3.75, female sex had a RR of 2.54, left hip side had a RR of 1.54, first born had a RR of 1.44 and a positive family history had a RR of 1.39. These findings suggest that the most significant risk factors associated with DDH include: those presenting in a breech position at birth, being female, being firstborn, having an affected left hip or having a family history of DDH. Similarly, De Hundt *et al*. (2012) identified 30 studies and looked at the association between risk factors and DDH using a common Odds Ratio (OR) to quantify factors that indicate a risk for DDH. The risk was strongly increased in cases of infants born in breech presentation who had an OR of 5.7, female infants had an OR of 3.8, infants with a positive family history had an OR of 4.8 and clicking hips found at clinical examination had an OR of 8.6. These findings, while slightly different to those of Ortiz-Neira *et al*. (2012), suggest that those with a suspected abnormality on clinical examination, babies born in a breech position at birth, positive family history and female infants have an increased risk of developing DDH.

Although the presence of these risk factors has been shown to confer an increased risk of DDH, most infants with DDH (73-90%) have no identifiable risk factors, with the exception of female gender, while the prevalence of DDH in infants with risk factors is 1-10% (Bracken *et al*. 2012). Therefore, risk factors should be considered an adjunct to guide clinical suspicion, rather than a substitute for universal clinical examination of the newborn (Shipman *et al*. 2006). The AAP (2000) recommend using risk factors to identify newborns whose risk of DDH may influence the paediatrician to perform confirmatory evaluations such as an ultrasound, regardless of a normal newborn clinical examination.

2.5 Benefits of a Screening Programme

Internationally, there are no agreed guidelines or standards in relation to the screening for DDH. There is debate about the usefulness of screening for DDH and whether it improves outcomes. (AAP 2000) concluded in their review that the evidence is insufficient to recommend routine screening for developmental dysplasia of the hip in infants as a means to prevent adverse outcomes. In its conclusion, the AAP therefore did not recommend screening for DDH. However, There was acknowledgement that there is evidence that screening leads to early identification but it was also stated that a high percentage of those identified as abnormal or suspicious of DDH by physical examination and those identified by ultrasound in the newborn period resolve spontaneously and require no intervention. The USPSTF (2006) continue to recommend serial clinical examinations of the hips with ultrasound imaging for female infants born of the breech position or with a positive family history of DDH.

In 2013, the Cochrane Collaboration undertook a review of screening programmes for DDH with a view to determining the effect of these programmes on the incidence of late presentation of the condition (Shorter *et al*. 2011). The review ultimately concluded that there was insufficient evidence to give clear recommendations for practice as neither universal nor selective ultrasound screening strategies had demonstrated to improve clinical outcomes including late diagnosed DDH and surgery.

There is very little debate, however, in suggesting that delay in diagnosis of persistent DDH results in more serious sequale with the potential of higher failure rates, so early diagnosis and prompt, appropriate treatment are essential (Holroyd & Wedge 2009; Sewell *et al* 2009; Afaq *et al*. 2011; Clarke *et al* 2012). Early screening for DDH has the potential to prevent long term hip dysplasia and arthritis requiring hip replacement (Shorter *et al* 2011). There is general agreement that the key to effective management of the problem and the avoidance of long term adverse outcomes is thorough screening, early diagnosis and treatment starting from the initial newborn period (Clarke *et al*. 2012)

2.5.1 Methods of screening

The main aim of screening is to reduce the prevalence of late diagnosis as early detection allows early treatment, reducing the need for surgical treatment and the risk of residual dysplasia (Sewell *et al*. 2009). As already mentioned, there still remains considerable uncertainty surrounding the optimal method of screening and the choice of population to be screened for

DDH as illustrated by the different recommendations and policies adopted by various national bodies (AAP 2000, Patel 2001). Some form of neonatal screening for developmental dysplasia of the hip is practised in most developed countries throughout the world since the 1950's and generally involves clinical examination, ultrasound examination (universal or targeted to high risk groups) or a combination of the two. X-ray screening appears to be in the process of being phased out internationally (Shorter *et al*. 2011), but is still used as a method of screening in Ireland so will be covered by this study. Risk factors for DDH that may prompt targeted screening include breech presentation, female gender, a first degree relative with DDH, metatarsus adductus, congenital torticollis, talipes, high birthweight and oligohydramnios (Wynne-Davies 1970; Bache *et al*. 2002). In Ireland, identified risk factors are: positive immediate family history and breech presentation at or following 36 weeks gestation. With very few randomized control trials and a recent Cochrane review being unable to recommend an ideal screening method, it is difficult to recommend which of the methods should be used in Ireland (Phelan *et al*. 2015).

2.5.1.1 Clinical screening

Clinical screening for DDH includes ascertainment of a medical history (family history, pregnancy) and a clinical examination involving reductive and provocative tests such as the Ortolani and Barlow manoeuvres (Bracken *et al*. 2012). It is generally performed in the immediate newborn period by a Senior House Officer (SHO), within 72 hours of birth on the postnatal ward and then again at 6 weeks of age by a GP. The Barlow test is performed by adducting a flexed hip with gentle posterior force to identify a dislocatable hip. The Ortolani examination is performed by abducting a flexed hip with gentle anterior force to relocate a dislocated hip. In other words, the Barlow test attempts to identify a dislocatable hip (Barlow 1962) whereas the Ortolani test attempts to identify a dislocated hip (Ortolani 1976). Both tests have been shown to have a low level of sensitivity at 60% and a high degree of operator dependence, needing a skilled practitioner to differentiate between a true dislocation clunk from a benign click (Gelfer & Kennedy 2008, Tafazal & Flowers 2015). O'Grady *et al*. (2010) highlight the importance of these manoeuvres being performed by an experienced clinician in order to obtain the most accurate diagnosis. The detection of clinical abnormalities, such as limited abduction or hip instability will depend on the experience and skill of the health care professional carrying out the examination (Pollet *et al* 2017). Although screening with clinical examination has been performed in the UK and Ireland for over 3 decades and has a high specificity, the sensitivity of clinical examination is low. In the postnatal setting in Ireland, the

majority of hips are examined by the (SHO). Traditionally for SHO's, the training for the newborn examination has been to observe a more senior doctor performing the examination once before being expected to take on the sole responsibility of performing it themselves.

A qualitative study by Bloomfield *et al.* (2003) exploring junior paediatricians', midwives, GPs' and mothers' experiences and views of the examination of the newborn highlighted this poor practice and suggested that SHO's would prefer to have more training in the area of newborn examination. Feedback from GP's regarding the newborn examination and in particular the examination of the hips was generally negative. GP's reported little or no supervised training with a general belief that the 'hip examination is done badly' as a result. The overall consensus from the GP's in the study was that more formal training is needed alongside time spent working withe more experienced registrars to facilitate the development of their knowledge and skills in the examination.

False positives can lead to over diagnosis and over treatment, and high false negatives can lead to late detection of DDH (Dezateux & Rosendahl 2007). A meta- analysis by Lehmann *et al.* (2000) found the incidence of DDH revealed from examination by a paediatrician to be 8.6/1000, from examination by an orthopaedic surgeon to be 11.5/1000 and from ultrasound examination to be 25/1000.

The Barlow and Ortolani tests while useful in neonates, becomes difficult by 2-3 months of age. In children 3-6 months, the hip laxity reduces and the hip may remain in a dislocated position outside the acetabular socket. Thus the utility of the Barlow and Ortolani tests wane (Agarwal & Gupta 2012). Limited hip abduction, asymmetric skin folds and shortening of the thigh are more sensitive signs in children older than 3 months (Clarke & Taylor 2011). The top set of slides below in Figure 2.3 demonstrate the Barlow manoeuvre while the bottom set of slides demonstrate the Ortolani Manoeuvre

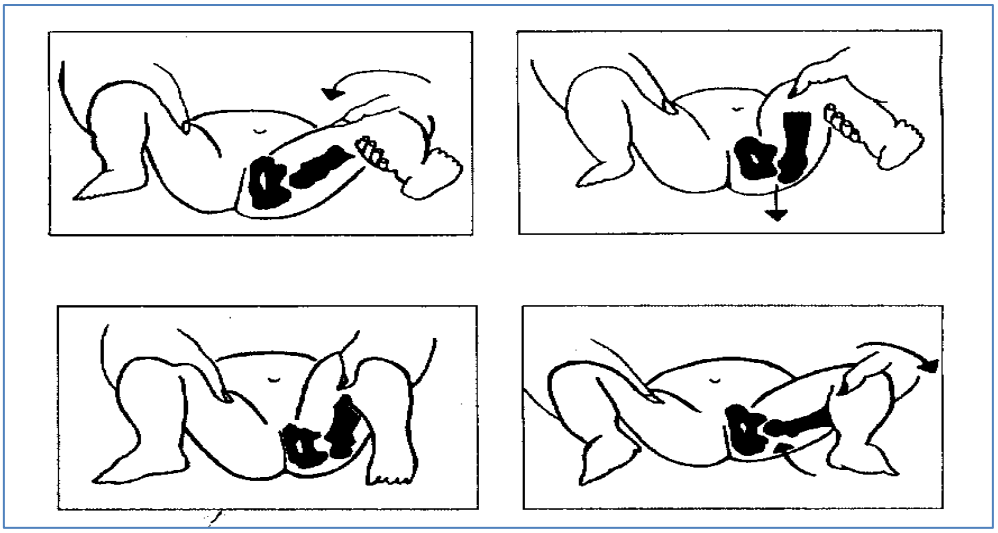

Figure 2.3 Barlow & Ortolani Manoeuvres

Adapted from http://www.cssd.us/body.cfm?id=512.

2.5.1.2 Ultrasound screening

Despite the advent of newborn screening programmes based on the Barlow and Ortolani tests, the prevalence of late cases warranting surgery remained stable at approximately 1 per 1000 internationally (Dezateux & Rosendahl 2007). As a result, the use of ultrasound in the detection of DDH was first proposed by Graf in the 1980's (Sewell & Eastwood 2011). Consequently, neonatal hip ultrasound (US) has been used as an additional test in the evaluation of DDH (Dezateux & Rosendahl 2007). Graf's own Index is widely used in interpreting US findings (Graf *et al*. 1984) and is described below. Ultrasound is more sensitive and specific than the clinical tests of Ortolani and Barlow (Clarke *et al*. 2012). However, an experienced sonographer should perform the US as it is highly operator dependant (Tomlinson *et al*. 2016). Ultrasound screening practises vary and debate continues as to the timing of ultrasound screening and to what degree of ultrasound abnormality in a newborn hip should be treated (Raposch *et al*. 2014). Not every abnormal finding on ultrasound may require treatment. Correct diagnosis is essential, as it is used to determine if no further assessment is needed, if an infant should be followed up or if immediate treatment is required (Raposch and Wright, 2007). Raposch and Wright (2007) also highlight if an incorrect decision is made, the patient may face future negative consequences if left untreated when treatment was in fact warranted or conversely complications of treatment if the patient's hip may have spontaneously resolved without treatment. The financial and emotional strain on families going through lengthy

treatment for DDH needs to be considered when caring for infants who have been diagnosed with DDH.

Ultrasound is the primary imaging technique for evaluation of DDH in the first 4 to 6 months of life because it is a non-invasive procedure that enables direct visualisation of the cartilaginous femoral head position and assessment of the acetabular fossa shape (Delaney & Karmazyn 2011). After this point, plain antero-posterior pelvic radiographs are more useful. The rationale is that ultrasound can identify those hips in need of treatment even in the absence of clinical signs of instability, as well as monitoring subsequent progress and management and determine treatment duration (Thaler *et al*. 2011).

2.5.1.3 The Graf's Index

The Graf method is the most widely used ultrasound system throughout Europe (Sewell & Eastwood 2011). This static evaluation method assigns hips to one of four groups on the basis of the bony acetabular roof development (α- angle), cartilaginous roof (β-angle) and the bony rim. These morphological appearances represent a continuum from normal to severe dysplasia.

- Graf type I: α-angle of more than 60 degrees, the bony roof cover is satisfactory. These hips identified in the neonatal period are likely to remain normal.
- Graf type IIa: α-angle of more than 50 degrees where infant is less than 3 months of age, these hips are usually considered as immature rather than abnormal but warrant close observation radiologically.
- Graf type IIb: α-angle of 50-59 degrees where infant is more than 3 months of age, generally considered abnormal and demonstrate ossification delay with progressive flattening of the acetabulum.
- Graf type IIc: α-angle of 43-49 degrees at any age, generally considered abnormal and demonstrates ossification delay with progressive flattening of the acetabulum.
- Graf type IId: α-angle of 43-49 degrees at any age generally considered abnormal and demonstrates highly deficient bony modelling with a flattened bony rim, displaced cartilage roof and everted labrum.
- Graf type III: α-angle of less than 43 degrees is considered abnormal and demonstrates a subluxated hip, very shallow acetabulum with labral eversion and partial displacement of the femoral head.
- Graf type IV: in this situation the femoral head is dislocated and all of the hyaline cartilage has now been pushed downwards.

An α-angle of 60 degrees (Type I) or above is normal and what you would expect a hip to measure after 3 months of age. At the other extreme, an α-angle of 43 degrees or less (Type III and IV) indicates that the bony cover is so poor that it cannot keep the femoral head in place. In between are the Type II hips (43-60 degrees). Originally, Type II was regarded as abnormal and any infant regardless of age who was found to have a Type II hip was treated with abduction splintage, increasing the treatment rate, leading to accusations of over-diagnosis. As a result, a distinction was made between Types IIa, IIb & IIc based on morphology, signifying that a Type IIa hip in a child under the age of 3 months is simply displaying an immature hip that should spontaneously resolve. Once this was recognised, the treatment rate began to fall, see Figure 2.4.

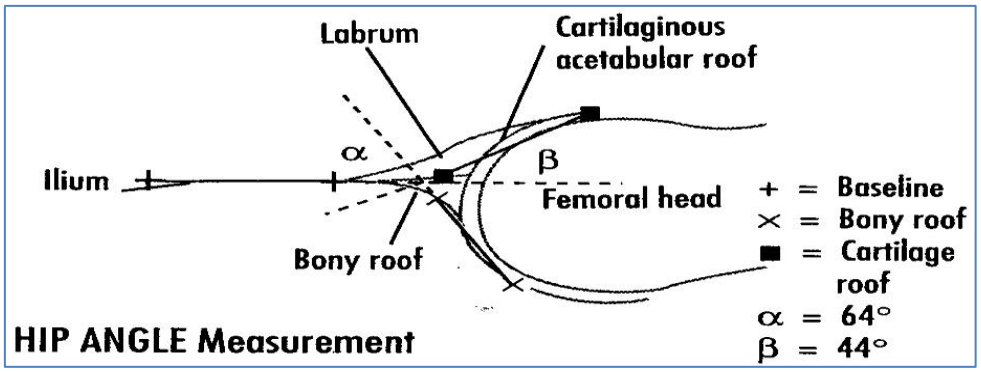

Figure 2.4 Hip angle measurements **Adapted from** https://kriznanultrasoundimages.com/

2.5.1.4 X-ray screening

Plain radiographs are only useful in the detection of DDH after 4-6 months of life when the femoral head and acetabulum are no longer cartilaginous and have ossified (Rosenfeld 2013); so should be used as a useful adjunct in the assessment of stability and adequacy of reduction following treatment for DDH (Clarke & Taylor, 2011). However, approximately 50% of the 19 maternity units in Ireland do not have access to hip ultrasound for diagnostic purposes at 6 weeks of age. They rely on x-rays at 4-6 months of age, for detection of DDH (HSE 2013). This suggests that there is still excessive reliance on X-rays for diagnosis of DDH in Ireland (O'Grady *et al.* 2016). This in turn means that infants are being diagnosed late with DDH.

With regards to the DDH clinic that this study is focused on, x-rays are used in three types of clinical situations: assess acetabular index after six months of age during routine follow-up of infants who have required Pavlic Harness treatment, as a form of surveillance for infants who

have been identified as having risk factors or clinical suspicion but have had a normal clinical examination and hip ultrasound and as an initial investigation in some late presentations (Phelen *et al.* 2015) It is worth noting that one of the recommendations of the DDH Subgroup of the National Child Health Review Steering Group is to limit the Universal National Screening Programme to 2 screening contacts - at birth and at 6 weeks (HSE 2017). The rationale for this recommendation was influenced by evidence based clinical practise guidelines endorsed by the American Academy of Orthopaedic Surgeons (AAOS 2014) who state that there is only limited evidence that performing serial examinations will detect additional children with DDH. See Figure 2.5 for example of x-ray findings of DDH.

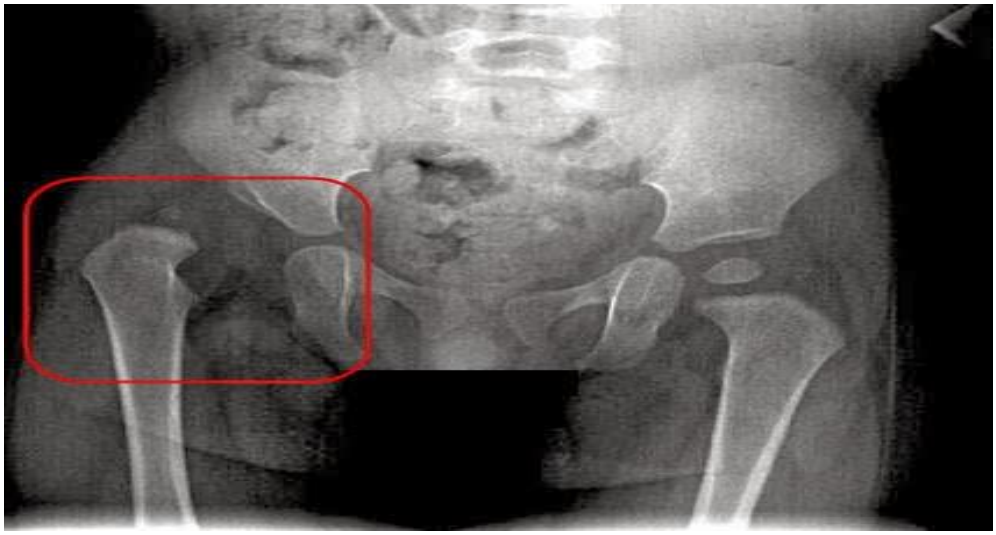

Figure 2.5 Plain film x-ray of right sided DDH **Adapted from https://hipdysplasia.org/**

2.5.2 When to utilise ultrasound screening

One of the most significant current discussions regarding ultrasound is whether infants identified with DDH by US in the first few days or weeks of life will go on to develop clinical disease that will result in some degree of disability if left untreated (Shorter *et al.* 2011). Observational studies have shown that ultrasound imaging at, or shortly after birth, identifies a high number of immature and abnormal hips, most of which are 'false positives'; and if left untreated would go on to develop normally (Bialik *et al.* 1999, Woolacott *et al.* 2005). This view is supported by Rosendahl *et al.* (2010) who conducted a single centre blinded randomised control trial in Norway from February 1998 to April 2003. A total of 128 newborns with mild hip dysplasia in one or both hips, were identified by ultrasound. The group were randomly assigned to receive either 6 weeks of abduction treatment (Immediate treatment group) or follow up alone (Active sonographic surveillance group). The main outcome measured was the

acetabular inclination angle, measured by radiograph at one year of age. Results were that active sonographic surveillance halved the number of children requiring treatment, did not increase the duration of treatment, and yielded similar results at 1 year follow up.

2.5.2.1 Universal/selective screening

Despite the controversy, ultrasound has been widely incorporated into DDH screening programmes in many developed countries in conjunction with universal clinical examination (Shipman *et al*. 2006). Ultrasound screening can be 'selective' for high risk groups or 'universal' for all neonates (Sewell & Eastwood, 2011). Support for universal screening where every baby born is offered an ultrasound after birth is particularly strong in Germany and Austria and German speaking areas of Switzerland, where it is believed it's use allows early identification of all babies in need of treatment, so that as a result very few babies require surgery (Wirth *et al*. 2004; Thaler *et al*. 2011). The American Academy of Pediatrics (AAP) highlights the resource implications on screening all infants for DDH (Shipman *et al*. 2006), however, views have been expressed that such an approach justifies the cost (Elbourne *et al*. 2002, Gray *et al*. 2005, Thaler *et al*. 2011). Additionally, concerns have been expressed that such a policy can lead to overtreatment, with possible risks such as avascular necrosis (Elbourne & Dezateux 2005; Roovers *et al*. 2005; O'Grady *et al*. 2010).

In 2012, von Kries *et al*. conducted a case control study in Germany of a population in which general US screening supplementing clinical screening was recommended and offered free of charge to all children. The objective was to assess the effectiveness of universal US screening to prevent first operative procedures of the hip. First operative procedures for DDH (n=446) were compared with control subjects (n=1173), (children not needing an operative procedure for DDH) for whether they had been exposed to the recommended ultrasound screening or not. Results showed that effectiveness of ultrasound screening to prevent first operative procedures for DDH was estimated as 52% (95% CI, 32-67). However, the introduction of universal screening was associated with a 5% to 7% early treatment rate, compared to 2% of newborns treated with clinical screening alone, which suggests a connection between universal ultrasound screening and overtreatment (Duppe & Danielsson, 2002).

In recent years, there has been an increasing amount of literature advocating the use of selective ultrasound screening (Gray *et al* 2005; Paton *et al*. 2005; Rosendahl & Toma 2007; Mahan *et al*. 2009; Clarke *et al*. 2012). Currently, selective ultrasound screening is practised in Australia,

North America and most European countries (Bracken *et al*. 2012). In this particular type of screening, ultrasound is offered to babies where hip instability has been detected clinically or where recognized specific risk factors for DDH, such as breech delivery or a positive first degree family history have been identified (Dezateux & Rosendahl, 2007).

Holen *et al*. (2002) carried out a RCT in the Hospital University of Trondheim in Norway between 1988 and 1992. A total of 15,529 infants were randomized to either clinical screening and US examination of all hips or clinical screening of all hips and US examination only of those at risk of DDH. The aim of the study was to evaluate whether universal or selective screening of hips should be recommended at birth. The effect of the screening was assessed by the rate of late detection of DDH in the two groups, which was defined as that diagnosed after one month of age, including dislocation, subluxation and acetabular dysplasia of the hip. During the follow up period of 6 to 11 years (mean 8.5), one late detected hip dysplasia was seen in the universal group, compared with five in the selective group, representing a rate of 0.13 and 0.65 per 1000, respectively. The difference in late detection between the two groups was not statistically significant (p=0.22). It is unfortunate that late detection was defined in this study as DDH detected after one month of age as this presumes that it is essential to detect and treat DDH within a month of life. As a result, the clinical validity of this outcome appears to be debatable since DDH identified at 1 month is often not true DDH (Woolacott *et al*. 2005). While the study found no statistical difference when comparing universal US to clinical screening, they do recommend an US for infants with hip instability or with risk factors, and that clinical screening needs to be of high quality to reduce the rate of late diagnosed DDH.

The USPSTF also reviewed the published literature on screening for DDH (Shipman *et al*. 2006). The USPSTF determined that the quality of evidence supporting different screening approaches was variable and that evidence is insufficient to recommend routine screening for DDH in infants as a means to prevent adverse outcomes (Shipman *et al*. 2006). A recent Cochrane review was carried out by Shorter *et al*. (2011) of screening programmes for DDH. Their objective was to determine the effect of different screening programmes for DDH on the incidence of late presentation of DDH. Their review found that targeted US of infants at high risk of DDH did not significantly increase the risk of treatment but also did not significantly reduce the rate of late detected DDH or surgery. They, therefore, found it was not possible to give clear recommendations for practise. Following the review by USPSTF (2006), the AAP issued recommendations including: serial clinical examinations of all hips, hip US for all

female infants born in the breech position and optional hip US for male breech infants or female infants with a family history of DDH.

2.5.3 Current screening situation in Ireland

As it currently stands, there are no nationally agreed care and treatment protocols or guidelines in relation to the screening and treatment of DDH in Ireland. As a result, there still remains a widespread inequity in how infants are screened ant treated for DDH nationally (O'Grady *et al*. 2010). From a screening perspective, findings from O'Grady *et al.'s* (2010) study found that the first neonatal hip exanimation an infant has is carried out by a Senior House Officer (SHO), alone, in 13 out of 19 of the maternity units in Ireland. One department had an orthopaedically trained registrar who was designated to examine hips while a consultant paediatrician examined all hips in 6 other units. These study findings highlight that the most effective way of screening for DDH: examination by an experienced clinician and selective ultrasound are not widely practised in Ireland (O'Grady *et al.* 2010).

After birth and discharge home, the next clinical examination of the hips is performed by a GP at the 6 week postnatal check-up in the community (Groarke *et al*.2017). As well as criteria obtained from utilising the Barlow and Ortolani manoeuvres and patient history, a GP must assess for limitation of abduction, asymmetric skinfolds, hip clicks or limb shortening (Raposch *et al.* 2014). Groarke *et al*. (2017) performed a multi-centre retrospective review in Ireland over a 12 month period of all referrals by GP's to two local orthopaedic Outpatient Departments (OPD) for DDH. All patients who were less than 36 months of age who were referred for the first time with suspected DDH were included in the study. The objective of the study was to determine among GP's the most common clinical findings that raised concern for DDH and necessitated an orthopaedic outpatient referral. In addition, the sensitivity and specificity of the most common of these clinical findings was assessed. The Acetabular Index (AI) from pelvic radiographs was used as a reference test to assess the accuracy of the clinical examination in diagnosing DDH. Sensitivity and specificity of each clinical sign was calculated.

Findings revealed that 26 of 174 infants referred over the 12 month period were diagnosed with DDH. The most common indication for referral, per the GP letter was asymmetrical skin folds (97 patients, 45.8%), followed by hip click (42 patients, 19.8%), and limb shortening (34 patients, 16%). None of the clinical findings by the GP's showed an acceptable level of

sensitivity. Logistic regression analysis found no clinical sign to be a statistically significant indicator of an abnormal AI. In conclusion, the authors suggested that clinical examination by GPs does not reliably detect DDH. As well as bringing into question the effectiveness of GPs screening for DDH in the community, these findings highlight how poorly understood the disorder remains (Bracken *et al*. 2012) and why it continues to be a source of much debate throughout the literature with no universally agreed criteria for its diagnosis and no accepted gold standard diagnostic test (Cooke & Kiely 2011).

Public Health Nurse (PHNs) practitioners are also notified of all births and interact with families at prescribed times up until children reach 3½ years of age. PHNs provide a number of important elements such as physical examination, eliciting parental concerns, assessment of risk, health education, support and guidance through the Child Health Programme (HSE 2005). PHNs raise the developmental nature of DDH with parents at the first postnatal visit at 1 week of age and check for DDH at three months and 7-9 months. This assessment entails examination of any symmetry of appearance of skin folds; assessing Galeazzi's sign and assessing any limitation in abduction . Children aged over one year should be observed by the PHN for any problems in relation to gait or leg length. Referrals are made for second tier services and/or specialist assessment on the basis of clinical findings and/or parental concern (HSE 2015).

Mulcahy *et al*. (2016) used a case study approach to illustrate the complexities of public health nursing practice when screening, intervening and managing DDH. The case originated from one interview in a larger qualitative study, which sought to understand the experiences of parents who had child growth or development concerns about their preschool children (Mulcahy and Savage 2015). This case study focused on a mother who herself had a history of DDH and her daughter. The mother noted that her daughter's leg started to 'go in' and had gotten quite 'clumsy' at the age of 42 months. The mother relayed her concerns to her own mother but did not verbally express her concerns to a PHN until her daughter was 48 months of age. A physical examination by the PHN was unremarkable but in view of parental concerns and the strong family history of DDH, the PHN referred the child to the second tier clinic where the child was seen and examined by an Area Medical Officer (AMO) who arranged a hip X-ray. DDH was out-ruled but it was diagnosed that Arianna's hip was 'overly flexible' and a further referral was made for physiotherapy which was commenced a month later. Additionally, the mother also expressed worries about the fact that she had not received an

appointment for a younger daughter's hip X-Ray, even though she was then seven months old and had a family history of DDH.

While in this case, the eldest daughter was not diagnosed with DDH, the case study highlights how PHNs may be the first health professional to be alerted to a missed case of DDH. Mulcahy *et al*. (2016) maintains that's PHNs must make sure that their knowledge about DDH is up to date and complete; and that they are sensitive to the developmental nature of DDH.

Another important aspect that the case study draws our attention to is the importance of adopting a person or family- centred approach to provided care. In the case example, the mother was aware of the family history and thus attuned to the possibility of the risk for DDH and had concerns in relation to her child's unsteady gait. Despite this, she did not raise any concerns with the PHN for another 6 months. As the case example shows PHNs cannot rely on parents to raise concerns immediately (Mulcahy *et al*. (2016). While there was no physical evidence of DDH, there was sufficient rationale on the basis of parental concern and family history of DDH to warrant a referral to the second tier clinic. While effectively identifying and managing DDH in the community involves having a sound knowledge of the condition and carrying out a thorough assessment; PHNs also have to assess the family's understanding of the condition, listen carefully to the ways in which parents articulate their concerns. Even if no abnormalities are immediately evident then a strategy needs to be put in place in collaboration with parents to monitor for a specific period of time and then review and/or refer. It is vital for HCPs to facilitate parents in expressing concerns at an early stage to expedite early intervention for child growth or development concerns (Mulcahy and Savage 2015).

2.5.3.1 Evaluation of screening practises at national level

The National Clinical Programme (NCP) for Paediatrics and Neonatology was established in June 2011 by the Clinical Strategy and Programmes Directorate of the HSE and the Faculty of Paediatrics, Royal College of Physicians of Ireland. Over the course of the following 2 years, the team engaged in an extensive consultation process, visiting every paediatric and neonatal unit in the country. A report called '*The Review and Framework for Future Development'* was devised following on from the visits. The main aims of the report was to help pave the way to develop a national model of care for all Irish children and was the first phase in the process of improving the services that are available to children and their families (HSE 2013). It advocates

that all children should have equal rapid access to medical and surgical care when needed. The objective is 'right child, right place, right care, right time'.

Based on their discussions with healthcare professionals throughout the country coupled with best practice internationally, the following are some of the pillars/ principles that were suggested would help underpin the future care of children and young people in Ireland:

1. *Involve and empower parents and patient groups in decisions*.

The doctor-patient relationship is changing. Doctors have always worked for sick children and their families but not necessarily with them. The development of partnerships between doctors and parents for the best care of the child is still evolving and there is now a unique opportunity to advance this accordingly. Healthcare professionals need to listen to patients and their families to understand their needs and develop a culture of partnership which promotes shared decision making in health care.

2. *Focus on health promotion, prevention and screening*

Children and their parents, and the wider societal environment should be aware that there is much that can be done to protect the health of children. Health promotion campaigns and supports that ensure the best possible outcome from pregnancy are vitally important. Immunisation programmes, injury prevention programmes, screening and early detection of existing conditions with timely intervention can make a significant difference to the health and wellbeing of children.

In relation to DDH, the NCP made several recommendations for the Neonatology Services:

- Imaging for all infants at increased risk of DDH.
- The early detection of developmental dysplasia of the hip requires a national approach to improve early detection.
- The training of SHOs in paediatrics should be enhanced including the examination of newborns. Senior staff must ensure that all the doctors are proficient at the task of newborn examination.

- The hidden pitfalls in the examination must be constantly emphasised.

Following on from this, in June 2014 the Health & Wellbeing Division of the HSE established a Child Public Health Group to commence a programme of work to review and update the existing child health programme '*Best Health for Children'*. An evidence review was completed by the Child Public Health Group. Since October 2014 the National Steering Group for the Revised Child Health Programme, working through a number of subgroups, has taken the evidence presented to develop the new National Healthy Childhood Programme (HSE 2017).

The Developmental Dysplasia of the Hip Subgroup developed recommendations for an Irish National DDH screening programme. They were developed with reference to the literature, the current practice in a number of other Western countries and Ireland, available Irish data and the expertise and experience of the subgroup members. It was the recommendation of the National Clinical Programme for Paediatrics and Neonatology (HSE 2013) and the DDH Subgroup of the National Child Health Review Steering Group (HSE 2017) that a targeted ultrasound screening programme utilising the Graf Method of Sonography be officially implemented. The Irish National DDH Screening Programme consists of:

- Universal Clinical examination at birth and six weeks
- Universal assessment of risk factors at birth
- A Selective Ultrasound screening programme for babies with the eligible risk factors

The recommended risk factors for the Irish National DDH Screening programme to decide which babies require a screening ultrasound examination at six weeks are:

1. A first degree family history of DDH
2. The baby has been a breech position after 36 weeks gestation.

This screening programme has been signed off by the National Healthy Childhood Programme and is currently being rolled out in several regions around the country and is hoped to be rolled out nationwide this year.

2.5.3.2 Evaluation of screening practices at International level

The American Academy of Pediatrics (AAP, 2014) also suggested similar recommendations in order to promote high quality early development surveillance and screening. Their strategy included the following recommendations:

- Commit to better and earlier evaluation of children who are at risk, both developmentally and medically.
- Be prepared to work together across disciplines, identifying and bringing together key stakeholders.
- Address potential shortages or lack of availability of early intervention resources.
- Seek out valid and reliable screening tools.
- Identify optimal times and locations of screening.
- Plan and provide professional training and education.
- Standardise simple and effective processes for referral and feedback between primary and secondary healthcare providers who serve young children.
- Expand evidence on the effectiveness of developmental surveillance.

Together, these reports highlight the need for national standardised guidelines and algorithms for the referral, screening and treatment of DDH in Ireland.

2.6 Treatment options for DDH

The treatment for DDH is currently not governed by any international or national guidelines or algorithms, which results in varied practice (Feeley e*t al*. 2014), this has led to widespread uncertainty relating to the exact definition of DDH, screening methods and what the 'gold standard' for treatment should be (USPSTF 2006, Nakamura *et al*. 2007, Shorter *et al*. 2013). The management strategy for DDH depends on the child's age and the severity of the disease (Dwan *et al*. 2017). Treatment for DDH is initially conservative (Nakamura *et al*. 2007), with children under 6 months of age treated with an abduction splint, such as the Pavlic Harness (Wada *et al*. 2013), while infants over 6 months are commonly treated with a hard shelled brace called a Boston Brace.

Successful treatment, defined as reduction of a dislocated hip or maintenance of a reduced but dysplastic hip, has been reported at rates of 80.2% to 100% (Cooper *et al*. 2014). However, the earlier diagnosis is made and treatment commences, the higher the success rate, with statistically significant improvements seen if treatment commences before 7 weeks of age (Atalar *et al*. 2006). The Pavlic Harness is considered to be the gold standard in terms of dynamic orthosis for the outpatient treatment of children with developmental dysplasia of the hip below the age of 6 months (Hassan 2009). It is a relatively simple, effective and practical form of treatment, see Figure 2.6. When wearing a splint, an infant's hips are placed into a position of abduction and flexion which promotes healthy growth of the acetabular roof around the femoral head. The treatment principle is active movement. By using it, spontaneous repositioning, spontaneous centralization of the femoral head and correct anatomic and functional healing is achieved (Mubarak & Bailik, 2003). Allowing infants to remain free to move their legs within the range permitted by the splint, provides a more gentle reduction than other splints that fix the legs in a predefined position, thereby potentially lowering the risk of complications (Dwan *et al*. 2017). Opinions vary regarding optimal duration of treatment in Pavlik Harness. Pavlik (1989) recommended a 'few months' while some sources recommend a treatment range from several weeks to 6 months (Van der Sluijs *et al*. 2009).

Figure 2.6 Pavlic Harness**. Adapted from https://www.rch.org.au/**

The use of a Boston Brace has become popular for infants who are diagnosed over the age of 6 months or for those infants where the Pavlic harness has not achieved full stabilization of the dysplastic hip (Hedequist *et al*. 2003). Spontaneous resolution of this residual dysplasia without intervention is unlikely in children over 6 months of age (Vitale & Skaggs, 2001). For those infants who have some degree of residual dysplasia or have just been newly diagnosed the utilization of an abduction brace can, in some cases, avoid the need for a closed reduction in

the operating room with the application of a spica cast (Gan *et al*. 2013). Dornacher *et al*. (2013) found that up to 30% of DDH patients treated successfully with Pavlic Harness may have residual acetabular dysplasia at the time of their first x-ray of the pelvis which usually occurs around 6 months of age. Residual acetabular dysplasia treated with abduction bracing can significantly improve the acetabular index in infants between 6 and 12 months of age (Gan *et al*. 2013). See Figure 2.7

Figure 2.7 Boston Brace **Adapted from https://musculoskeletalkey.com/**

2.7 Parental experiences with DDH

The relationship between a newborn diagnosis of DDH, parental experiences and coping strategies is not well described in the literature, particularly from an Irish perspective. One of the aims of this study was to elicit the experiential stories of parents who have received a diagnosis of DDH, paying particular attention to the diagnostic process and parental coping efforts during treatment thereafter.

The psychosocial consequences for parents regarding the screening and treatment policies of DDH are potentially important and should help guide the management of DDH (Gardner et al. 2005). Parents will often feel overwhelmed when a new diagnosis of DDH is made, or when a treatment is initiated. A lot of information is given to them regarding diagnosis, treatment, possible failure of treatment and possible surgery if early treatment fails which can be a lot for parents to absorb (Causon 2010). Furthermore, coming to terms with the diagnosis of DDH

and the need for treatment may invoke feelings of guilt and stress that their child has been affected (Causon 2010).

As previously highlighted, there are no definitive national guidelines in relation to the screening and treatment of DDH in Ireland. Until recently, some hospitals treated any abnormality found on clinical examination during the initial newborn period, other treatment centres utilize ultrasonographic surveillance to screen and sometimes observe hips that may resolve without treatment during the first weeks of life. Although most infants with neonatal hip instability (NHI) are not at increased risk of developing DDH, it is, in practise difficult to identify those who are, thus some receive an unnecessary diagnosis, treatment with the possibility of iatrogenic risks for the child and psychosocial consequences for the family (Gardner *et al*. 2005, Rosendahl *et al*. 2010).

2.7.1 Parental experience of newborn examination

A qualitative study by Bloomfield *et al*. (2003) exploring junior paediatricians', midwives, GPs' and mothers' experiences and views of the examination of the newborn found that while most mothers were on the whole satisfied with the newborn examination being performed by a doctor, the view was expressed that examiners should explain what they were doing and what they were looking for during the examination, and some suggested that written information about the examination in the form of a leaflet would be very useful. Reassurance that everything was all right was considered important for nearly all mothers. Most parents in the study reported not knowing the content of the newborn examination or that some abnormalities might present later (Bloomfield *et al*. 2003). This finding highlights the general lack of awareness regarding DDH, the dynamic nature of the condition and the possibility that it may not present during the immediate newborn period.

These findings are supported by the Review of Paediatric and Neonatology Services and Framework for Future Development (HSE 2013) report which draws attention to criticisms made by medical and non-medical personnel regarding the failure of junior medical staff to detect or identify conditions or anomalies during the newborn examination at a stage when treatment could be more effective. DDH was identified as one of the conditions of frequent concern.

2.7.1.2 Parental experience of Ultrasound screening

Witting *et al*. (2012) attempted to measure parental satisfaction with US hip screening in preventative child health care in the Netherlands. Parental satisfaction was measured using a questionnaire devised by the authors. Between November 2007 and April 2009, 4,099 infants were screened for DDH during a special visit to 2 CHC centres in the Netherlands. All infants with suspected DDH, based on the screening were referred to a medical specialist for additional diagnostic procedures and, if necessary, treatment. A total of 1,140 parents participated in the screening and received the questionnaire. Overall parental satisfaction was measured on a 10 point scale ranging from 1 'bad' to 10 'excellent'. A total of 703 questionnaires were returned (response rate 61.7%). Overall, parents reported positive scores on all factors. The competence, friendliness and carefulness of the ultrasound screener influenced satisfaction significantly. Satisfaction was also significantly influenced by the time offered to parents to ask questions. Satisfaction was also influenced by the burden of the screening on the infant. The unpleasantness of the crying of an infant during screening proved to be a significant predictor of satisfaction. Overall conclusions drawn were that good information provision before US screening and communication during the screening are means by which parental satisfaction can be influenced positively.

2.7.2 Impact of diagnosis on parents

Few studies have investigated the psychological impact that the diagnosis and subsequent home care of an infant with DDH can have on parents. Pregnancy and the transition to parenthood without any complications is major adjustment period within a family, particularly for first time parents (Deave *et al*. 2008). The expectation surrounding the birth of a child is linked to the idea of bringing a healthy baby home, however, when parents receive a newborn diagnosis, this fact is not realised and the normal transition into parenthood is interrupted (Ballantyne *et al*. 2017). When a situation like this happens, parents often experience mixed feelings resulting from the loss of idealised dreams, the insecurity of an uncertain reality, permeating with various feelings, including grief as well as loneliness and isolation (Stube & Stumm 2017, International Hip Dysplasia Institute 2018). When an infant is diagnosed with an illness, parents quite often undergo multiple transitions; transfers from one healthcare setting to another, becoming an unanticipated caregiver to their ill infant, concern related to the health outcomes of their child while also transitioning to parenthood (Ballantyne *et al*. 2017). Parents need to develop expertise in a range of technical skills and knowledge of health care issues, while also coming

to terms with the uncertainty of a condition with an unpredictable trajectory (Swallow & Jacoby 2001).

The time around diagnosis of chronic or serious conditions is a key milestone for parents (Baird *et al*. 2000, Mooney-Doyle *et al*. 2017); the manner in which a diagnosis is disclosed is very important and should reflect sympathy, honesty and openness. Baird *et al*. (2000) encourage health care professionals to talk with clarity about medical details and give parents as much time as they wish to ask questions. A qualitative study performed by Rahi *et al*. (2004) in Great Ormonde Street Hospital in London, which evaluated a pioneering key worker and specialist clinic programme to meet the needs of parents around the time of diagnosis of a disability identified some key generic components which helped parents at the time of diagnosis. The dedicated link team who worked within a specialist outpatient setting was considered to be an important source of information for parents and facilitated access to specific services, while providing emotional and social support and facilitating meetings with other families of children with similar conditions. The findings of their study on the whole indicated that the greatest needs for parents during the critical time of diagnosis of a chronic health condition is for family-professional collaboration in the form of verbal and written information together with emotional support from health care professionals and information regarding formal and informal social networks and support groups. As well as increasing parents early transition experiences, psychosocial wellbeing and parent satisfaction with healthcare services, this type of family-professional collaboration can have a positive impact on parent engagement with services, intervention outcomes and overall health outcomes of their children (An & Palisano 2014, Ballantyne *et al*. 2017).

There have been very few studies exploring the impact of diagnosis of DDH on parents and certainly none from an Irish setting where there does appear to be a very high natural incidence rate of the condition. A case study carried out by Chao & Chiang (2003) focused on the impact and coping behaviours of a Chinese mother whose child was diagnosed at the age of 17 months and treated for DDH. Through participant observation and follow-up telephone interviews over the course of 6 months, the study revealed that the impact on the mother fell into 5 categories: shock of diagnosis, fear of potential risk of surgery, feelings of loss and anger for the unexpected, uncertainties and anxiety about the future and excessive and incontrollable emotions. Several coping behaviours were also identified from the case study such as seeking out of family and peer support, additional knowledge relating to DDH and the care of an infant

with DDH, meeting the child's special needs, enlisting appropriate spouse participation and maintaining a positive outlook. The authors conclude that health care professionals need to provide greater opportunities for mothers to express their concerns regarding the condition and any negative feelings they may be harbouring following the diagnosis. It was also suggested by the authors that by acknowledging and recognising when parents are managing the care of their infant in treatment for DDH, that this would increase self-confidence and possible acceptance of the condition. Health care providers are uniquely positioned to assist parents in meeting challenges and to promote parent competency and confidence in their child's care (Kratz et al 2009). Parent to parent support has also been highlighted in the literature as an important factor which enables parents the opportunity to share their feelings, worries and anxieties with other parents in similar situations as them, and has been shown to improvement emotional and psychosocial well-being for parents caring for an ill child (Bray *et al*. 2017).

2.7.3 Impact of treatment options on parents

While there have been numerous studies assessing the reliability, effectiveness and cost-effectiveness of the different types of policies regarding the screening and treatment of DDH, there has been limited research looking at the psychosocial effects for parents in relation to the effects varying policies have on their day to day lives caring for an infant with DDH. Moreover, it has yet to be evaluated within a solely Irish context. Families report they often live in a state of hyper-vigilance, heightened anxiety and emotional exhaustion when caring for a child with any sort of special health needs (Kratz *et al*. 2009).

Gardner *et al*. (2004) reported on the psychosocial consequences for mothers and the developing mother-child relationship of ultrasound, and associations between abduction splinting and maternal psychosocial distress. The multicentre randomised controlled trial involved 629 infants from thirty three hospitals in the United Kingdom and Ireland. The mothers were given a postal questionnaire to fill out when their babies were age 8 weeks and 1 year. The main outcome measures were anxiety, postnatal depression, parenting stress and maternal concerns about hip problems which were assessed using the Infant Hip Worries Inventory. At 8 weeks, there was no difference between US and non-US groups of the trial in maternal anxiety, depression or parenting stress. However, interestingly the study showed that early intervention with a splinting device was related to increased maternal anxiety and hip worries compared with the non-splinted group. Conclusions drawn from this study indicate that

although early splinting is associated with maternal anxieties, US was not shown to be associated with any increase or reduction in psychosocial effects on mothers.

Bergo & Rosendahl (2013) more recently, carried out a cross-sectional study over a period of 16 months from 2010 to 2011 in a hospital in Norway. This was to determine whether treatment for mild hip dysplasia instigated in the immediate newborn period was preferred over a delayed treatment by parents of infants with DDH, as delayed treatment for mild hip dysplasia detected in newborns is an acceptable policy. Parents attending the paediatric radiology outpatient clinic with their infants were invited to fill in a questionnaire on parent satisfaction on information provided, and on follow up and treatment given. A total of 91 parents were included, of which 66 (72.5%) had their babies treated from birth, while 25 (27.5%) had their child treated from 5 weeks onwards. Results showed that parent satisfaction with information given by health-care personnel providing follow ups and treatment of their child with DDH was good and did not differ between the early and delayed treatment group. Those in the delayed treatment group were less satisfied with timing of the treatment than those in the early treatment group, but overall total satisfaction did not differ. When the parents were sub grouped into those receiving treatment between 5 and 8 weeks (n=17) and those starting at 9 weeks or later (n=8), no differences were seen to total satisfaction scores. However, those starting at week 9 or beyond were less content with timing than those starting between 5 and 8 weeks of age. This may indicate that these parents had a perception of the diagnosis being missed, despite their child being sonographically surveyed from birth. Equally, it was noted by the authors that infants at this age are becoming increasingly mobile, with a higher level of activity, which is more awkward and less compatible with immobilization in an abduction brace.

The study indicated that parents having their baby treated from birth found the treatment slightly more cumbersome than those starting at age 5 weeks or later, the authors conclude that this may reflect that parents highly value the initial weeks together with their new baby without having to deal with an abduction device. There was no difference in total satisfaction between parents having their first child treated and parents having their second or subsequent child treated, although the first group seemed to experience the treatment as more distressing to the baby. Similarly, no difference in total satisfaction score was seen between parents having had a previous child treated for DDH and those having their first child treated, except that the treatment seemed more cumbersome for the latter group. Overall this study showed that parent satisfaction did not differ according to whether treatment was instigated at birth or later in

infancy, based on the US appearance of the joint and that good communication from health care providers was essential.

A prospective analysis was carried out by Hassan (2009) of the views of 160 parents of children with a diagnosis of DDH and treated with a Pavlic harness to assess compliance. Ninety-six percent of parents claimed that they had received adequate information regarding instructions, application and care of the harness while 48% of parents would have preferred written instructions and drawings as a parent's guide to the harness. Thirty-one percent of parents reported various difficulties while using the harness. Moreover, 88% of parents reported significant emotional difficulties with the child being uncomfortable in the harness. Sixty-one percent of parents reported concerns about leaving the child 1 week without proper bathing.

Caring for a child in a spica cast can be especially difficult for parents. Hip spicas are a plaster of Paris splint which starts at the waist and continues down to the ankles. It holds the child's hips in a position of flexion and abduction. It is used after open surgery on the hips if non-surgical treatment has failed or if there has been late diagnosis of the condition. Going to hospital for surgery can be particularly daunting for parents and children (Healy 2013), resulting in stress and anxiety caused by anticipation of the unknown, lack of control over events and unfamiliarity with the environment. One of the few studies done in relation to parental experiences caring for a child being treated for DDH was a study by Newman and Fawcett (1995) confirmed that having a child in a spica cast posed tremendous challenges for the caregiver, involving major adjustments in almost every aspect of the parent's lives, including household activities, social and community activities, child care activities, occupational activities and educational activities (Newman & Fawcett, 1995). The treatment may seem basic for a health care professional, but for the family of the child, it can be very overwhelming. Teaching about the care involved with the cast and preparing the family for the challenges that often arise can greatly decrease the stress and anxiety that is commonly seen in the post-operative period (Smith 2004).

Newman and Fawcett's (1995) work is complemented by Smith's (2004) literature review on the care of babies and young children in hip spicas. Two common themes emerged from the review including:

2.7.4 Information needs, both verbal and written.

Smith (2004) found that much of the related literature surrounding parental care of a child at home following discharge from hospital paid particular attention to the lack of specific information available to parents, even in specialist units. The importance of clear written instructions as a follow up to verbal instruction was also highlighted in the literature search. This view is further supported by Hassan (2009) and Causon (2010), who suggest that the provision of written information along with active engagement of the mother by nursing staff and the opportunity to ask questions can contribute to a shorter period of treatment in Pavlic Harness.

2.7.5 Support needs: practical, emotional and social.

Practical problems of mobility were notable in the literature, particularly relating to car seating, static seating and the general immobility of the child, some of whom were previously walking (Smith 2004). These difficulties may lead to social and emotional disjointedness, with feelings of isolation for the mothers in particular emerging as a recurrent theme throughout the literature. Similarly, Demir *et al.* (2015) found that families, especially mothers, can suffer psychological and social problems such as anxiety, guilt, fatigue, depression and social isolation during home care following treatment for DDH.

2.7.6 Parental satisfaction with DDH clinics

Health provision for children in an outpatient setting has many advantages to parents, most significantly of which is the reduction of stress caused by the admission to the hospital (Matziou *et al*. 2013). Parental satisfaction from this particular type of care is high, since they report that their children experience less fear and anxiety when they are not taken away from their families (Koren-Karie *et al*. 2001). Satisfaction is known to be associated with patient behaviour, including adherence to treatment plans and use of preventative health services (Halfon *et al*. 2004). Satisfaction is, in turn, considered to be an important predictor of health related behaviour, by, for example, influencing parents' commitment to, and effectiveness of recommended treatment for DDH (Witting *et al*.2012).

Lee (2005) carried out a satisfaction survey in order to assess the acceptability and effectiveness of a nurse led paediatric outpatient clinic in Reading in the UK, for hip dysplasia in infants from the patient and family perspective. A purposive sample of 100 infants was identified between May 2003 and March 2004. A self- administered tick box questionnaire was

developed and contained 12 questions relating to waiting times, appointment and quality of service. Sixty six questionnaires out of a possible 100 were returned giving a return rate of 66%. Results showed that the dedicated nurse led clinic was able to see 80% of infants referred within 2 months, with only 6% waiting longer than 3 months. There was a significant level of acceptance for the service with a 100% of participants being either very satisfied (67%) or satisfied (33%). The majority of parents (80%) were completely satisfied with the service and felt nothing more needed to be added.

Treatment for DDH is effectively a partnership between the multidisciplinary team and the child's carers (Causon 2010). Nurses in particular play a pivotal role in providing education and support to parents who are caring for an infant with DDH. The condition poses tremendous challenges for caregivers and impacts on nearly every aspect of parent and family life such as skin care, feeding, work and transportation, (Gardner *et al*. 2005, Hart *et al*. 2006). Additionally, non-compliance of correct harness care and maintenance can lead to failure of treatment, so education of parents regarding these issues is paramount to the success of the treatment (Hart *et al*. 2006). Nurses have the potential to work as strong family advocates preparing families for the challenges that often arise, with a focus on decreasing the stress and anxiety often involved in caring for their child. Parents' experiences do not appear to be widely researched in an Irish context and this presents a void in relation to identifying suffering and priorities in meeting children's' needs. Additionally, it seems there is no recognised training or development programme for best practise for health professionals and parent/caregivers in relation to the newborn diagnosis of DDH and the transition to home of their infants receiving treatment for DDH.

2.8 Family-Centred Care

Family-Centred Care (FCC) means working with families, rather than just doing *to* or *for* them (Johnson & Abraham 2012). The concept of "family-centeredness" is being increasingly emphasised in the area of childhood health, in recognition of the importance of collaborative care-giving, with professionals working in partnership with families to develop, implement, and evaluate services (Jugnoo *et al*. 2004) The fundamental approach to the philosophy of FCC can be described as: a philosophy of care that helps families whose baby is in hospital or in poor health to cope with the stress, anxiety and altered parenting roles that accompany their baby's condition. It puts the physical, psychological and social needs of both baby and their

family at the heart of all care given (Kelly 2018). The Institute for Patient and Family-Centered Care (IFPCC) developed core concepts of family-centered care (Johnson & Abraham 2012). These core concepts are described in Table 2.1.

Table 2.1 Core Concepts of Family Centred Care (FCC)

Core Concepts of Family Centred Care (FCC)
Respect and dignity Health care practitioners listen to and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.
Information Sharing Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
Participation Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
Collaboration Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education as well as in the delivery of care

From Johnson & Abraham (2012)

A number of positive outcomes of family centred care have been identified in the literature: it can shorten a baby's length of stay in hospital and reduce re-admission rates, as well as improve bonding between parents and their baby and help parents to feel more confident and able to care for their baby both in hospital and at home (O'Brien *et al*. 2013). FCC has also been shown to provide significant benefit not only in terms of infant medical outcomes, but it can also reduce stress, anxiety and depression in the family; improve their ability to cope and through structured competency based educational programmes will result in true partnership with parents (Kelly 2018).

In today's health care culture, parents are critical members of their child's health care team, especially when the child has ongoing health concerns. Effective collaboration between the parent and health care professional is the cornerstone to successful outcomes (Kratz *et al*. 2009). Parents play a pivotal role in the doctor-parent-child relationship, where parents are relied upon as the source or voice of information about their child's health status (Tates *et al*. 2002).

Essential components of this collaborative approach to family centred health care are: mutual trust; respect for the expertise each brings to the relationship; and the ability to engage in shared

decision-making (Baker 2001). Providing a quality service to patients is more than treating them in a safe and clinically sound way. It is about listening to patients and their families to understand their needs and develop a culture of partnership which promotes shared decision making in health care (Bitzer *et al*. 2012). The need for families and professionals to coexist successfully is recognized as critical to the successful management of chronic illness (Swallow & Jacoby 2001).

In 1996 in Ireland, the Chief Executive Officers (CEO's) of all Health Boards commissioned a national review of the child health services for the 0-12 year age group in Ireland. The findings and recommendations resulting from this process were published in 1999 in the form of a strategic report called Best Health for Children-Developing a Partnership with Families (HSE 1999). Amongst its recommendations was the emphasis of the importance of parental observation and concern and the need to continuously strengthen the role of health promotion and parent support in all areas of child health, taking cognisance of the broad determinants of child health and the pivotal role of parents and other primary caregivers in influencing child health outcomes (HSE 2005).

Against this background, The Children's and Parents Reference Group was established in November 2011 for the Paediatric and Neonatal Clinical Programmes in order to help the successful development of policy and establishment of the programmes (HSE 2013). Stakeholders from advocacy organisations, the Department of Children, researchers, special interest groups and parents with experience of health services were invited to participate on this Reference Group. The remit of the group was to:

- Ensure that children's voice / experience of health care is central to identifying health needs and improving their experience of services
- Inform the design, delivery and evaluation of the paediatric and neonatal programmes.

Based on their review following visits and discussions with healthcare staff in every paediatric and neonatal site nationally coupled with best practise internationally, ten pillars/principles were proposed in their report to help underpin the future care of children in Ireland. They mirror many of the concepts suggested by the IPFCC earlier. They included:

- Involving and empowering parents and patient groups in decision making. Health care professionals need to listen to patients and their families to understand their needs and develop a culture of partnership which promotes shared decision making in health care.
- Focus on quality improvement. Health services should aim to provide high quality, equitable and safe care to children and their families that is comparable with best international and national practice, providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.
- Improve access to scheduled care for children. There is a need to ensure that children and young people access the necessary generalist or specialist paediatric care as appropriate, in a timely manner, and as close to home as possible, in an appropriate environment. This requires primary care practitioners, paediatricians and health care managers working together to ensure that the model of care is developed with children and young people at the centre.
- A consultant delivered service. A consultant-delivered paediatric service is a key element for delivering better patient care in Ireland. In a consultant-delivered service the consultant paediatrician is clinically responsible for the care the patient receives during the course of treatment. In essence it means that the consultant will either provide hands-on care or closely supervise, in the clinical setting and in all aspects of the care received by the child.
- Improve primary care of children. The vast majority of care children receive is in primary care. Our primary care services should be able to provide for the management of acute and chronic childhood conditions, health surveillance, health promotion and disease prevention. General practitioners and their staff need appropriate training for providing a practice based quality child health service for the 21st century. Primary care should be appropriately resourced to provide this service.
- Develop a national model of care for newborns. There are 19 neonatal units in the country, operating at different levels of complexity. There is a need to group the various units into appropriate networks to ensure that the newborns most in need are managed by appropriately trained neonatologists. The early detection of developmental dysplasia of the hip in particular requires a national approach to improve early detection. Improved access to diagnostic tests for example.

- Focus on health promotion, prevention and screening. Children and their parents, and the wider societal environment should be aware that there is much that can be done to protect the health of children. Health promotion campaigns and supports that ensure the best possible outcome from pregnancy are vitally important. Immunisation programmes, injury prevention programmes, screening and early detection of existing conditions such as DDH with timely intervention can make a significant difference to the health and wellbeing of children.

2.9 Conclusion

It can be concluded from the literature search that DDH remains a poorly understood disorder despite a great deal of research being carried out on the subject. Controversy remains as to what the ideal screening method is for DDH (McCarthy *et al*. 2005) and what degree of hip abnormality should be treated (Dezateux & Rosendahl 2007). A Cochrane review concluded that there was insufficient evidence to give clear recommendations for practice as neither universal nor selective ultrasound screening strategies had demonstrated to improve clinical outcomes including late diagnosed DDH and surgery (Shorter *et al*. 2006)

Currently, there is no national ultrasound screening programme for DDH in Ireland, although a recently agreed upon protocol should be rolled out within the coming year (HSE 2017). While there are no national figures for DDH In Ireland; what the literature review has shown is that DDH is an important condition in Ireland with a high incidence of late diagnosis leading to poorer outcomes for children in the country (Phelan *et al*, 2015). What is also apparent is the widespread inequity in how infants are screened ant treated for DDH nationally (O'Grady *et al*. 2010). There is a need for the establishment of national guidelines in relation to the screening and management of DDH.

The review of the literature in relation to the parents of infants with DDH has shone a light on the psychological impact of DDH on their day to day lives. The condition poses tremendous challenges and caring for a child with DDH can often lead to stress and anxiety for the parents (Hart *et al*. 2005). However, there remains a lack of research from an Irish context in relation to the experiences of parents utilizing a regional dedicated DDH clinic and caring for a child who is receiving treatment for DDH and hence the need for this research.

Chapter 3 Methodology and Methods

3.0 Introduction

As discussed in chapters 1 and 2 the evidence signals a critical need to develop national guidelines in relation to the screening and treatment of DDH in Ireland (Phelan *et al*. 2014). Previous research has emphasized the psychosocial consequences for parents managing the care of their infants with DDH (Gardner *et al*. 2005; Hart *et al*. 2006). Given the recommendations of The National Clinical Programme for Paediatrics and Neonatology (HSE 2011) to involve and empower parents and patient groups in decisions relating to their children's health, it is timely to investigate the effectiveness of DDH services in the South East of Ireland and explore the perceptions of the parents whose children are in receipt of care from the clinic.

This chapter outlines the research design, methods and procedures used in the study. Section 3.1 presents a description of the aims, objectives and outcomes. Justification of the particular choices of research design adopted is presented in section 3.2. Section 3.3 looks at the target population for the study, while sections 3.4 and 3.5 detail the study parameters for Phases 1, 2 and 3 of the study, the approach to the data collection and problems encountered with data collection. In addition, relevant ethical considerations pertaining to the study and issues regarding reliability and validity are addressed.

3.1 Aim of the study

The study aimed to explore and analyse the DDH services in South East Ireland. In Phase 1, a retrospective chart review of all infants who were referred to the DDH clinic who were born in 2012 and 2013 were analysed to identify incidence rates of DDH and assess the effectiveness of treatment and screening methods in the region. Phase 2 involved parents of infants with DDH completing a questionnaire in order to determine their satisfaction rates utilizing a dedicated DDH clinic and explore their experiences of caring for a child with DDH. In Phase 3, semi-structured interview approach was adopted for the first strand of the 3rd phase to allow a deeper understanding of the experiences of parents and discover their principal concerns caring for an infant undergoing treatment for the condition; and semi structured interview was utilised for the 2nd strand via a telephone conversation in order to evaluate the effectiveness of the screening and referral pathways utilised by GPs and PHNs in the community.

3.2 Objectives of study

In order to achieve the aim a number of objectives were developed over three phases:

1. Identify the true incidence of DDH and early/late diagnosis of the condition in the South-eastern region of Ireland.
2. Assess the effectiveness of current screening and treatment methods in the region.
3. Explore the experiences of parents in caring for a child with DDH and identify their needs to in order to develop appropriate care packages for service improvements.
4. Explore the viewpoints of GPs and PHNs who screen and refer suspected DDH in the community setting
5. Identify scope for the improvement of care in DDH diagnosis and treatment.

3.4 Research process

Researchers find it useful to provide a visual model to display the processes, procedures and outputs involved with mixed methods studies (Tashakkori & Teddlie 1998, Creswell 2009). Table 3.1 shows an overview of the research process, aims, study populations, outcomes, designs and analysis.

Table 3.1 Overview of research process

Aim	**Phase 1**	**Phase 2**	**Phase 3 (2 Strands)**
	Retrospective chart review of DDH screening methods, treatments and outcomes. (Incidence, screening and effectiveness).	To identify factors that impact on parents and families as caregivers and their views on provision of services to DDH children.	To explore the views of parents caring for a child who has been diagnosed with DDH and utilising the dedicated DDH clinic. To explore the viewpoints of GPs and PHNs who screen and refer for suspected DDH
Study population	Retrospective and prospective records of children born in 2012 and 2013 who have attended the DDH clinic	Parents of infants with DDH across a range of treatment stages.	Parents of infants with DDH across a range of treatment stages. GPs and PHNs
Data collection	Clinical records of babies born in 2012 and 2013 who attend the DDH clinic	Questionnaire	Semi-structured interview for parents and for GPs and PHNs
Main outcome	Incidence rates, rates of early/late diagnosis, successful treatment rates of Pavlic harness and Boston brace. Referral rates to tertiary clinics for further treatment/surgery.	Experiences of parents caring for a child with DDH. Evaluation of DDH services	Illuminate and describe the experiences of parents caring for a child with DDH. Elicit the viewpoints of GPs and PHNs in order to evaluate DDH services
Analysis	Descriptive and inferential statistics.	Descriptive statistics and thematic analysis.	Thematic analysis

3.5 Research Paradigm and Design

A paradigm may be regarded as philosophical beliefs about the world, a foundation upon which all research is based (Polit and Beck 2008). It represents a world view which defines the nature of the world, the individuals' place within it and the range of possible relationships within that world (Guba and Lincoln 2005). Each paradigm offers a unique perspective and it is important to choose one which can address the research question and guide the research study (Burns and Grove 2003).

For the purpose of the study a mixed methods approach was adopted. Mixed methods research is concerned with bringing together numbers and narratives, description and understanding of meaning and context to provide greater transportability of the phenomenon under study (Stange *et al*. 2006).

The research design encompasses the strategies for collecting, analysing, interpreting and reporting data in research studies. It guides the decisions made during the study and reflects on the philosophical and theoretical basis of the study, and sets the logic for the enquiry (Parahoo 2006, Creswell & Plano Clark 2011).

The research questions asked in this study are:

- What are the incidence rates of DDH in the South-east of Ireland?
- How effective is screening and treatment of the condition?
- What is the parent's experience of caring for a child with DDH and of utilizing a dedicated DDH clinic in their region?
- What are GP's and PHN's experience of screening and referring for suspected DDH in the community?

3.6 Mixed Methods Research

Mixed methods research is now being recognised as the third research paradigm in educational research (Johnson & Onwuegbuzie 2004). Since the turn of the century, there has been a growth of interest in mixed methods research, including the advocacy of mixed methods research as a separate design in its own right (Stange *et al*. 2006). The need for mixed methods research in the health sciences is crucial for the exploration of contemporary public health issues (Creswell *et al*. 2007; Mertens 2011). The potential to contribute to social change exists in a more defined way if mixed methods are viewed as a tool for such change (Mertens 2011). It involves integrating quantitative and qualitative approaches to generate new knowledge and can involve concurrent or sequential use of these two classes of methods to follow a line of inquiry (Stange *et al*. 2006).

Mixed methods research is increasingly being used as a methodological standpoint in health sciences to gain a more complete understanding of issues and hear the voices of participants (Guetterman *et al*. 2015). A priority exists in health science research to develop new methodologies to improve the quality and scientific power of data that is leading to an extraordinary surge in methodological diversity; this diversity reflects the nature of the problems facing the health service such as poor adherence to treatment thought to be effective and the use of multi-level approaches to investigate complicated health problems and the patient's point of view (Creswell *et al*. 2011).

3.6.1 Justification for a Mixed Methods design

The fundamental rationale behind mixed methods research is that more can be learned about the research topic if the strengths of qualitative research with the strengths of quantitative research are utilised while compensating at the same time for the weaknesses of each method (Johnson & Onwuegbuzie 2004). The process enables a multi-faceted understanding of nursing phenomena (Creswell 2009, Chiang-Hanisko *et al*. 2016).

Following a review of the literature and with consideration of the research questions involved, it was deemed that this study is better situated within the methodological approach of a mixed methods framework, integrating quantitative and qualitative tools to foster a greater understanding of the experiences of parents attending a DDH clinic with their infants.

Using a mixed methods approach, the research aims to build on the knowledge on pragmatic grounds (Creswell 2003). Pragmatists accept the problem solving function of human beliefs. All human activity arises from the need to solve problems (Andrews & Halcomb 2009). Pragmatists further choose approaches which are most appropriate for finding an answer to the research question (Tashakkori and Teddlie, 2010). A major view of pragmatism is that quantitative and qualitative methods are compatible and therefore quantitative and qualitative data collected concurrently or sequentially can enhance comprehension of the research problem (Andrews & Halcomb 2009). The design type chosen is the sequential explanatory design according to the Creswell *et al*. (2003) classification table for Mixed Method designs (Tashakkori and Teddlie, 2003 p.224).

Caracelli & Greene (1997) identified three typical uses of a mixed methods study: (1) testing the agreement of findings obtained from different measuring instruments, (2) clarifying and building on the results of one method with another method, and (3) demonstrating how the results from one method can impact subsequent methods or inferences drawn from the results. A sequential explanatory design was felt to be the approach best suited to this study as this design method is characterized by the collection and analysis of quantitative data followed by the collection and analysis of qualitative data. The purpose of this design is to use qualitative results to assist in explaining and interpreting the findings of a quantitative study (Creswell & Plano Clark 2011). The sequential explanatory design can be used when the findings of a quantitative study could be further explained and interpreted by using a qualitative method (Chiang-Hanisko *et al*. 2016). The sequential explanatory design for this study consists of three

distinct phases: a clinical review of referrals to the clinic, questionnaires and semi-structured interviews. The findings from phase 1 of this study highlighted the need to explore the experiences of parents caring for a child with DDH and to explore the provision of DDH services from the perspectives of the parents of the infants in receipt of care from the clinic. The results from the questionnaire demonstrated that receiving a diagnosis of DDH had a profound impact on parents; and caring for a child being treated for DDH was a difficult transition for the parents that needed further exploration. A semi-structured interview approach was chosen for the first strand of the 3rd phase to allow a deeper insight into parental experiences; and the semi-structured interview was utilised for the 2nd strand via a telephone conversation in order to elicit the viewpoints of GP's and PHN's who screen and refer for suspected DDH in the community. The decision tree as visually displayed in Figure 3.1 provided the structure with regard to getting 'the right fit' with regard to the choice of mixed method design.

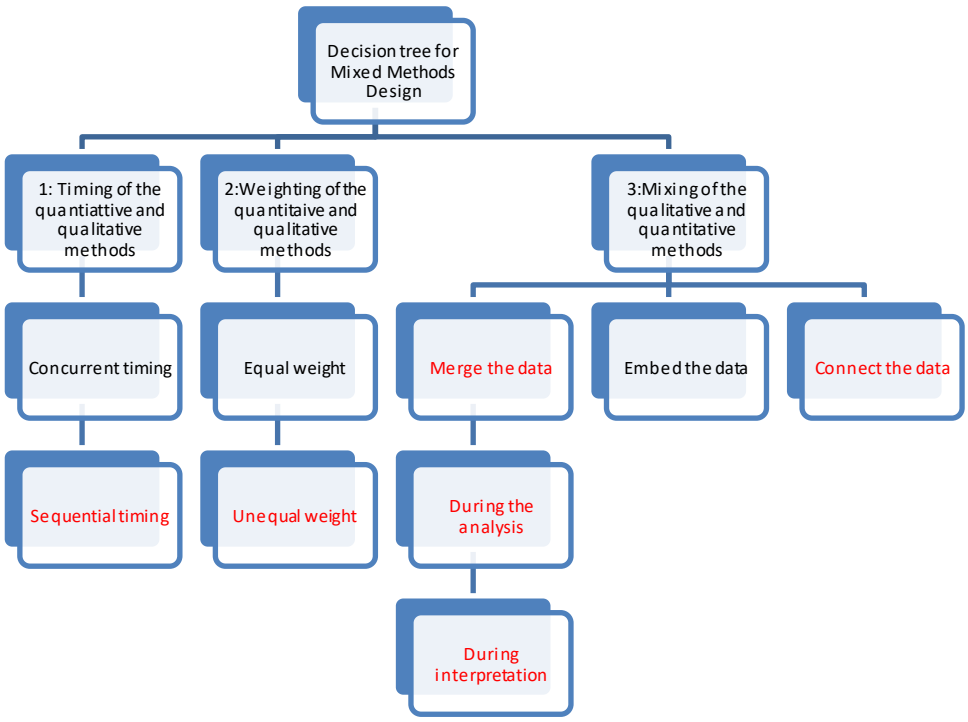

Figure 3.1 Decision tree regarding mixed methods design (Creswell, et al. 2003; Creswell *et al*. 2007).

3.7 Conceptual Framework

The use of a theoretical framework has the potential to increase credibility in research and promotes application in practice as it allows the researcher to consider the study and its findings within the existing body of knowledge (Polit and Beck 2004). A conceptual framework outlines graphically or narratively the key concepts to be studied and the relationship among them; it gives focus to the data collection and analysis (Miles and Huberman 1994). This study in essence incorporates the exploration of the quality of healthcare outcomes and parental experiences surrounding DDH. While no specific conceptual framework for this particular area was discovered, the recent emphasis on health-care systems and organizations looking to improve health system performance through the implementation of a person-centred care (PCC) model was used as a starting point in researching a suitable conceptual framework for the study.

By seeking perspectives on care, we can measure the quality of our health services (Heaney & Hahessey 2011). Quality of care is a multi-factorial concept. The World Health Organisation (WHO) defines quality of care as the extent to which health care services provided to individuals and patient populations improve desired health outcomes. The need for greater reliability and less variation in the quality of Irish healthcare has been well accepted (Health Information and Quality Authority 2012). In relation to DDH, the discrepancy in the detection and management of such a common condition as DDH has been highlighted and addressed by the National Clinical Programme for Paediatrics and Neonatology (HSE 2013). In a follow up HSE study, the DDH Subgroup of the National Child Health Review Steering Group (HSE 2017) argue that services that are not tailored to the needs of the population they serve, risk introducing inequalities by allowing differential engagement with services.

The Expert Advisory Group on the Early Years Strategy recommend that services and supports to children in particular, and their families should be of high quality, affordable, and accessible to all, while recognising that some children may have additional needs (Department of Children and Youth Affairs (2013). Furthermore, the same group recommend the strengthening of child and family supports in their Right from the Start report (2013), advocating a dedicated health

service led by 'child and family' spanning across the antenatal period through to the early years with particular focus on PHN's and Primary Care Teams. Health care needs to be safe, effective, timely, efficient, equitable, and family-centred. Therefore, a framework with important domains of measurement and pathways to achieve the desired health outcomes is required to identify the action points to improve the quality of care.

3.7.1 Existing frameworks and theory

In order to develop a framework in relation to DDH, literature surrounding the general ideas of person PCC was reviewed. PCC means putting people and their families at the centre of decisions and seeing them as experts, working alongside professionals to get the best outcome (Health Innovation Network South London, 2016). The Person-Centred Nursing (PCN) Framework, developed by McCormack and McCance (2010) comprises four constructs 1) *Prerequisites,* which focuses on the attributes of the provider; 2) *The care environment,* including supportive systems, effective staff relationships, and organizational systems; 3) *Person-centred processes*, including working with patient's beliefs and values, engagement, having sympathetic presence, sharing decision-making and providing for physical needs. These activities influence the fourth construct, *person-centred outcomes*, such as satisfaction and involvement with care. However, this framework does not show how PCC relates to clinical care (Sudhinaraset *et al*.2017).

The World Health Organization's (WHO) Quality of Care framework (2015) for maternal and newborn health helps to address this aspect, as it describes how person-centred outcomes relate to clinical quality. The framework describes quality of care in terms of provision of care and experiences of care. In addition, it illustrates how broader health systems lead to the quality of care at departmental level, ultimately impacting individual and health-care outcomes (Tuncalp *et al*. 2015). This framework, however, fails to address how women may experience disparity in their treatment based on factors such as social status, influences of communities and women's perceived role in society (Sudhinaraset *et al*.2017).

The Person-Centred Care Framework for Reproductive Health Equity (Sudhinaraset *et al*.2017), builds on these existing frameworks. Within the framework, there are three levels of interrelating environments that lead to achieving reproductive health equality. The three levels include: 1) societal and community determinants of health equity; 2) women's health-seeking

behaviours; and 3) facility-level factors, including the provision of care and the person-centred aspects of care. Sudhinaraset *et al*. (2017) suggest that there are bidirectional links between the decision to seek care and the experience of care, and the quality of care also influences communities and individuals' perceptions of care, needs for care, expectations of care and ultimately seeking of care. The framework also assumes that there is a bidirectional link between provision of care and PCC.

3.7.2 Family Centred Care for Infants with DDH

According to Miles and Huberman (1994), a conceptual framework "lays out the key factors, constructs, or variables, and presumes relationships among them" (p. 440). Integration of the three models into one comprehensive model suitable for this population of children with DDH and their parents was developed to meet the study's aims and objectives. Building on the constructs identified in the previous studies mentioned, this framework conceptualizes FCC as a key outcome of three levels of interacting constructs. The three constructs included in the proposed model are: national and community determinants of early childhood care; parental determinants of successful screening and treatment of DDH and quality of care which is further subdivided into two interlinked dimensions of provision of care and experience of care. Each construct categorizes separate factors influencing family centred care for infants with DDH, and is described in detail below, with reference to the existing literature These constructs were selected based on what was considered to be most relevant and grounded on the available literature surrounding DDH. The framework is illustrated in Figure 3.2 below

3.7.2.1 National and community determinants of early childhood care

The national and community determinants of early childhood care construct addresses the broader issues within the national health care system that affect the quality of care at departmental level in hospitals and in the community. The WHO's Quality of Care Framework (2015) describes the health care system as the foundation that creates the structure that can facilitate access to quality care. There are over 331,000 children aged 0-4, representing 11% of the national population in Ireland (CSO 2016). The United Nations Convention on the Rights of the Child (UNCRC) is an internationally binding agreement on the rights of children, adopted by the UN General Assembly in 1989 and ratified by Ireland in 1992. It emphasizes that every child has the right to survival, development, protection and participation, and that the role of the State is to be the guarantor and enabler of these rights. Parents are viewed as being responsible for caring and protecting their children and the importance of providing

resources to meet the needs of parents is recognised (Children's Rights Alliance, 2010). For this reason high-quality services that promote the health and well-being of children and families that encompass ante-natal services and education, access to primary health care is essential. These services must also support families through public health promotion to ensure that there is an awareness of access to their GP's and PHN's. Children also need strong community-based health services with immunisation, development and nutrition assessment and screening. Health screening programmes are efficient and effective ways to improve outcomes for children because they provide for early identification of health risks and are an important route by which parents receive information about their child's health, as well as being one of the few services that connect with all families in the State (Department of Health, 2010). Any disparities or lack of cohesion between sources of care can have a detrimental effect on the quality of early childhood care in Ireland. While a national selective ultrasound screening programme for DDH has just been agreed upon in Ireland in 2018, there are currently, no nationally agreed treatment protocols or guidelines in relation to the treatment of DDH in Ireland. Therefore, this is an area of concern.

3.7.2.2 Parental determinants of successful screening and treatment of DDH.

Parents and guardians have the primary responsibility for children's health and upbringing. There are strong associations between the health and education of mothers and the overall health of their young children (Department of Children and Youth Affairs, 2013). All parents need access to high quality information on children's health and development. This access to information should ideally start during pregnancy. Culturally-appropriate written and verbal information regarding DDH should be incorporated into the antenatal and postnatal health promotion programme. (HSE 2017). Increased awareness of the incidence of DDH, known risk factors for the condition and awareness of what support services are in place if there are any parental concerns should be discussed. By the inclusion of parents in the decision making process concerning their child's health, better parental satisfaction can be achieved; which in turn, can lead to improved healthcare outcomes for their children (Health Information and Quality Authority 2012, Witting *et al*.2012). Within the scope of DDH, parental education and support during diagnosis and treatment of DDH is paramount to the success of the treatment (Hart *et al*. 2006).

3.7.2.3 Quality of Care

This construct describes quality of care in terms of provision of care and experiences of care, which ultimately leads to outcomes of FCC and optimum child health. Both dimensions are interlinked. The way in which parents and their children are treated in healthcare settings will have a direct impact on how they perceive the quality of their child's care (Flynn & Whitehead, 2006, Heaney & Hahessey 2011). Each domain within the dimensions are not mutually exclusive, for instance, development of partnerships with parents depends on the cultivation of effective communication skills. Nonetheless the domains provide a comprehensive map for developing measures that capture the key aspects of FCC. This framework acts as a lens to offer greater insights and understanding of family-centred practise within the DDH setting, and so for this reason was considered to be a suitable framework to provide the theoretical underpinning for the study.

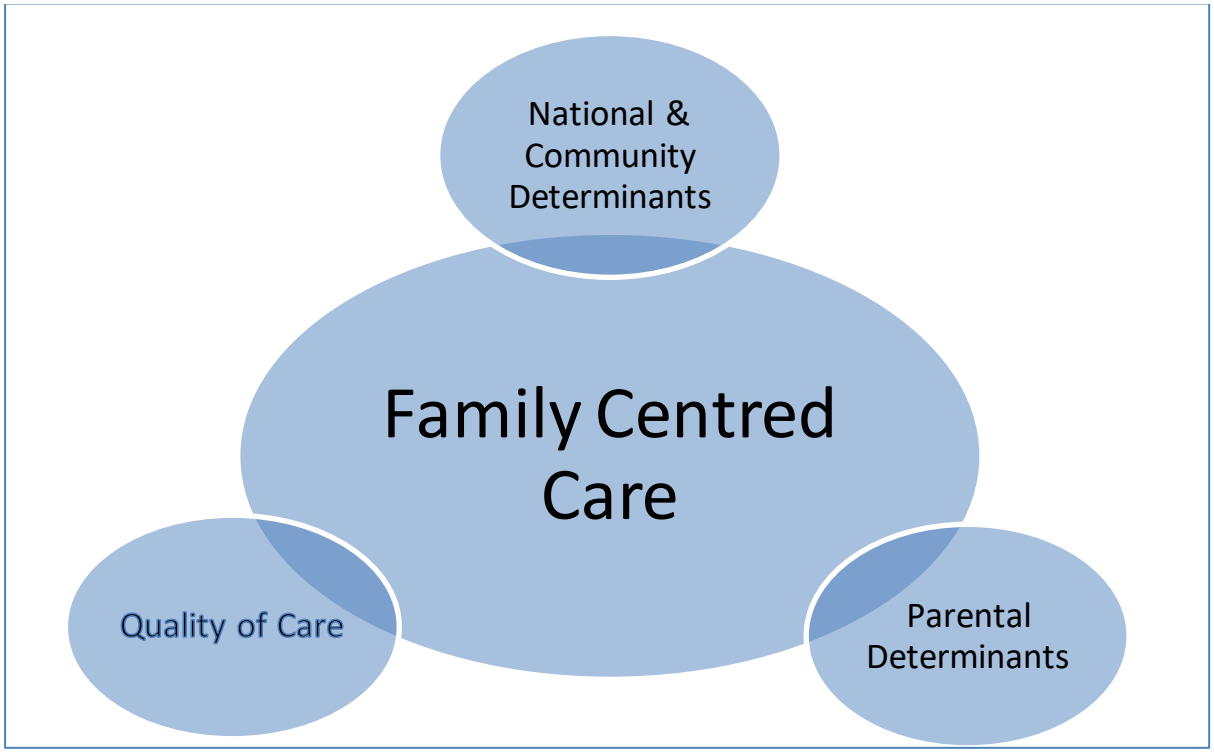

Figure 3.2 Adapted Family Centred Care Conceptual Framework. (Adapted from McCormack and McCance 2010; Tuncalp *et al*. 2015 & Sudhinaraset *et al*.2017).

3.8 Quantitative -Phase 1

Quantitative research is concerned with the collection and analysis of data in numeric form (Guba and Lincoln, 2005), focusing on relatively large-scale sets of data, often presented as the gathering of *'facts'*. This scientific approach viewed as the positivist paradigm has been

proposed as having shaped the development of both medicine and nursing as scientific disciplines (Easterby-Smith and Bartunek 2009). The traditional scientific method aspired to objectivity and detachment of the researcher from the field of study. The quantitative paradigm offers an effective way to produce factual, reliable outcome data by using methods including statistical techniques to determine if and to what extent predetermined study variables are causally related (Steckler *et al.* 1992)

3.8.1 Benefits of a chart review

A retrospective chart review (RCR) of DDH referrals of infants born in 2012 and 2013 who have attended the DDH clinic was undertaken to determine data regarding incidence rates of DDH, late diagnosis rates, screening methods and successful treatment rates in the South East of Ireland. The RCR, also known as a medical record review, is a type of research design in which pre-recorded, patient-centred data are used to answer one or more research questions (Worster & Haines 2004). The retrospective chart review is a widely applicable research methodology that can be used by healthcare disciplines as a means to direct subsequent prospective investigations (Vassar & Holzmann 2013). Observational studies such as cohort studies using patient records can have a considerable impact on health care provision and are performed more often than randomised controlled trials because of the relative ease of collecting data and the low costs of collecting such data (Grimes & Schulz 2002). Data were collected through the evaluation of the patients' medical charts. Data extraction was conducted by the researcher.

3.8.2 Target population and recruitment procedure - Phase 1

A population is defined as the total number of units from which data can be potentially collected and may include individuals, organisations, events or artefacts (Polit & Beck 2008). The population covered were from the regional centre and three rural centres. The target population of this study comprised of the infants and parents attending the DDH clinic who had been referred from either the Regional centre or one of three rural centres.

Woods and Roberts (2003) acknowledge that planned, diplomatic negotiated access to research participants and sites is crucial to the research process. Ethical approval was granted from the HSE Research Ethics Committee, South East and the Waterford Institute of Technology Local Research Ethics Committee (Appendices I & II). In addition, prior to the commencement of this study, a letter requesting permission to carry out the chart review accompanied by

information regarding the study was sent to the clinical director, hospital managers and directors of nursing (Appendix III). In addition, the co-operation and support from nursing managers and orthopaedic doctors was sought and received.

3.8.3 Sampling technique and sample size - Phase 1

Sampling involves the process of choosing representative units of a population that are included in a study and includes selecting a subset of the target population or sample frame (Polit & Beck 2006). Convenience sampling refers to using the most conveniently available people as participants (Polit & Beck 2006). Convenience sampling is the most widely used form of sampling in quantitative studies; however it is the weakest, due to the risk of introducing bias (Polit & Beck 2006). Due to restricted resources, it was deemed the most appropriate method of sampling for this study. The sample that was selected for Phase 1 of the project included all infants born in 2012 and 2013 (n = 372) that were referred to the DDH clinic for observation or treatment.

3.8.4 Inclusion and exclusion criteria - Phase 1

An inclusion list to determine eligibility to the study was established and approved following consultation with: ethics committees, hospital stakeholders, OPD clinic guidelines and academic supervisors. The overall profile of the parents who were eligible to participate in the study included:

Inclusion criteria:

- Any child referred to the DDH clinic who was born between 1st of January 2012 and 31st of December 2013
- Any child diagnosed with DDH by a Consultant Orthopaedic Surgeon by clinical examination or with ultrasound by a Consultant Radiologist
- Early and late diagnosed infants are those diagnosed and treated before and after 12 weeks of age.

Exclusion criteria:

- Any child who was not born in 2012 or 2013.

3.8.5 Data collection Phase 1

The retrospective data collection was conducted from the patient records of all infants attending the DDH clinic who were born in 2012 and 2013. Data were extracted by the researcher and all patient details collected in the study were coded to protect confidentiality; the only person that was able to convert the coded data to identifiable data was the researcher. The data were recorded into a clinical database.

Data collected in the study was standardized for each patient. Standardization of the data is important for the internal validity of the study, but is also essential for the reproducibility of the research data (Jansen *et al*. 2005). Categorical variables were extracted from the patient charts as outlined in Table 3.2. Data were collected for both hips regardless of whether both were affected or not.

Retrospective research often requires the analysis of data that were originally collected for reasons other than research (Hess, 2004; Jansen et al., 2005). It was critical to ensure good data management techniques to facilitate data analysis and accurate reporting of results. Data cleaning or data scrubbing deals with detecting and removing errors and inconsistencies from data in order to improve the quality of data (Gerrish & Lacey 2010). A manual inspection of the data was carried out in order to identify any incomplete, incorrect or inaccurate parts of the data. Missing data was then retrieved from the medical records where possible. However, the researcher found that the availability of data was lacking from a number of charts and because the data was mainly retrospective it was impossible to retrieve the information in some cases.

Table 3.2 Data collected from medical notes

Demographic Details	**Delivery Details**	**Risk factors**
Place of birth Year of birth Gender	Presentation: Breech/Normal/Other Mode of delivery: Vaginal/Caesarean Section	Family history/ Foot deformity/ Torticollis/Oligohydramnios/Breech presentation /Other
Referral Details	**Age**	**Clinical Examination Details**
Source of referral: Postnatal ward/ GP/ Paediatric clinic/ Other Reason for referral: Instability/ Limited abduction/ Risk factors identified/ Clinical suspicion/ Abnormal findings on US or X-ray	Age at referral Age at attendance	Clinical findings left/right hip: Unstable/ Limited abduction/ Click/ No definite abnormality/ N.A.
Ultrasound Details	**Pavlic Harness**	**X- ray Details**
Diagnostic US: Yes/ No Findings of US left/ right hip: Normal/ Dysplastic/ Dislocated/ Subluxed/ NA	Pavlic Harness: Yes/ No Duration of treatment Outcome of Pavlic Harness treatment: Successful/ Unsuccessful	Age at first X-ray X-ray of left/ right hip: Normal/ Dysplastic/ Dislocated/ Subluxed Action: None/ Brace/ Refer
Boston Brace	**Appointment Details**	**Outcome Details**
Boston brace: Yes/ No Duration of Boston brace	Follow through appointments: How many Situation at final appointment left/ right hip: Normal/ Dysplastic/ Dislocated/ Subluxed	Discharge/ Refer to tertiary unit Total number of visits

3.8.6 Problems encountered with data collection Phase 1

Additionally, because infants with DDH are observed for a number of years following treatment prior to being fully discharged, the outcome details cannot be finalised for some infants at this time.

The findings from Phase 1 are displayed in Chapter 4 and discussed in Chapter 5 with the integration of findings from the other phases. Phase 1 informed the subsequent phase of the research study.

3.8.7 Data analysis Phase 1

Data were entered into the Statistical Package for Social Sciences, SPSS Version 21 and coded for analysis. Data were systematically entered into the computer and double-checked to ensure consistency of information. Descriptive statistics in the form of percentages and frequencies

for the categorical variables were calculated including: demographic information, delivery and referral details (type of delivery, source of referral, reason for referral, risk factors specified and age at first presentation). To estimate incidence rates, data were used from the Report on Vital Statistics 2012 and 2013 published by the Central Statistics Office (CSO 2012, CSO 2013). The number of live births by area of occurrence was identified and the number of live births in the four regions which refer infants for DDH assessment in the clinic in this study was estimated.

Chi-square tests ($\chi 2$) for independence explored the relationship between categorical variables within the dataset. The evaluation of the accuracy of key risk factors associated with the detection of DDH and the validity of screening methods used in diagnosing DDH was evaluated by calculating sensitivity, specificity, positive and negative predictive values, using the final clinical diagnosis as the gold standard. The $\chi 2$ test was used to compare the observed frequencies between each of the 3 screening methods for DDH and the detection of the condition. The $\chi 2$ test was used to compare the observed frequencies between diagnostic ultrasound and treatment type. Algorithms were developed in order to evaluate the effectiveness of diagnostic ultrasounds and follow up x-rays on final outcomes in the clinic. The source, indications, total number of referrals and subsequent number of treated cases of DDH were explored using descriptive statistics in the form of frequencies. Cross tabulations were used to examine the relationship between referral type and type of treatment required.

Bivariate analysis and logistic regression analysis was used to determine the effects of key characteristic variables on the likelihood that a positive diagnosis of DDH would be made. Bivariate analysis and logistic regression analysis was also used to determine the effects of key characteristic variables on the likelihood that a late diagnosis of DDH would be made. The association between age at first referral and treatment types, the association between age at first referral and final outcomes and finally the association between early/late referrals and final outcomes were also determined.

3.9 Quantitative - Phase 2

Phase 2 adopted a questionnaire approach in order to elucidate the experiences of parents in receipt of treatment for their infants in the dedicated DDH clinic.

3.9.1 Benefits of a questionnaire

A twenty-three question parent satisfaction survey was administered to parents to obtain relevant demographic and DDH related information (see Appendix I). The questionnaire was modelled on Lee et al. (2005) satisfaction survey and Gardner et al.'s (2005) Hip Worries Inventory, and following permission, both instruments were modified to suit this study (See Appendices II & III).

Questionnaires are a structured approach to data collection and analysis, which are suitable for providing factual, descriptive information. Another advantage of questionnaires is that participants are more likely to feel that they can remain anonymous and thus may be more likely to express controversial opinions (Brink & Wood 2001). In order to improve cost-effectiveness, reliability and validity, it is advisable to use validated instruments that are well designed and easy to use (Parahoo 2014).

3.9.2 Selection of the survey instrument

Lee *et al*. (2005) highlighted the need for improved child and family centred care within orthopaedic services in the UK. The authors argued that the needs of the child and their families were not always clearly identified and, therefore, not always met. The authors designed a parent satisfaction survey in order to identify whether their nurse-led paediatric DDH clinic in a hospital in the UK, was providing an acceptable alternative for children/infants as opposed to the traditional orthopaedic consultant led clinic and to ascertain whether parents were happy with the service. The self-administered tick box questionnaire contained 12 questions that related to: waiting times, appointment and quality of service. However, the instrument did not address demographic details and details regarding the treatment their infant received so a further 11 tick box questions were added for the purposes of this study.

Similarly, Gardner *et al*. (2005) carried out a multi-centre randomised controlled trial consisting of thirty three hospitals in the UK and Ireland. One of the authors' aims was to report on the association between abduction splinting and maternal psychosocial distress. A Likert Scale was developed with a set of twelve hip specific questions (The Infant Hip Worries Inventory) devised to directly reflect maternal concerns relating to caring for a child in abduction splintage. For the purposes of this study, ten of the questions from the Infant Hip Worries Inventory were used, with a further seven questions devised following consultation

with project supervisors and medical and nursing staff in the DDH clinic to give a more detailed picture of concerns that a parent may have caring for a child in abduction splintage.

3.9.3 Description of the study questionnaire

The questionnaire for this study was divided into five sections and contained 22 questions and 17 statements. The questions consisted of a combination of multiple choice questions and one open ended question. Participants were asked to score the 17 statements using a Likert Scale. The questionnaire examined the following 5 areas: demographic details, waiting times, appointments, infant hip worries and overall impression of the hip clinic service.

The first section of the questionnaire consisted of eleven questions that related to demographics of the sample: age, gender of child, treatment child was undergoing, age at diagnosis of DDH, type of delivery, whether child was born breech, if child had undergone ultrasound of hip x-ray for DDH, what type of health professional referred the child to the DDH clinic, length of time attending the clinic and finally, knowledge as to why the child was referred to services.

The second section of the questionnaire consisted of two questions regarding length of time the child waited for the first appointment from time of being told the appointment was needed and whether the parent found this waiting time acceptable.

The third section comprised of seven questions relating to appointment times and lengths, what health professionals were seen, explanations given as to why the child was being examined, the opportunity to ask questions about the child's care, and if further treatment was required. The parent was asked if this was explained, and if parents were made aware of a contact number they could use if any concerns regarding the child's care arose.

The fourth section consisted of 17 statements which the respondents were asked to score using a Likert scale. The scale asked parents to rate how strongly the agreed or disagreed with certain worries related to the day to day care of their child with DDH.

The fifth section comprised of two questions, one being an open ended question, relating to the parents overall perception of the DDH service and whether they had any suggestions on how the service could be improved.

3.9.4 Target population - Phase 2

The target population of this phase comprised of the parents attending the DDH clinic with their infants who were either in receipt of treatment for DDH or were under observation for the condition.

3.9.5 Sampling technique and sample size – Phase 2

Nonprobability convenience sampling was used to select study participants in Phase 2 (Polit & Beck 2006). In probability sampling, every unit of the target population has a more than zero chance of being selected for study participation (Polit & Beck 2006). Probability sampling was not achievable in this study; therefore, nonprobability sampling was adopted. This type of sampling is useful when the purpose of the study is to learn about individuals in the population (Saks & Allsop 2007). Furthermore, this method of sampling is acceptable when the findings of the study are intended to add to the body of knowledge, rather than generalisation (Burns & Grove 2001). Therefore, further justification for the use of nonprobability sampling is the exploratory nature of the study as it is hoped to contribute to knowledge pertaining to the care of a child with DDH.

Well conducted surveys with a small sample size of communicative and well informed participants will obtain high quality data therefore the point of data saturation will be reached quickly and the small sample size will be sufficient (Burns and Grove 2003). For the purpose of this study, data collection continued until nothing new was learned (n = 100). This sample size was justified using an online survey sample size calculator (Creative Research Systems, 2012) which is available as a public service of Creative Research Systems survey software. The quantitative strand of the research question was addressed using a sampling frame with a 95% confidence level. The 'Sample Size Calculator' can be used to determine how many people are required to survey in order to get results that reflect the target population as precisely as required in the study. The calculation was based on the number of infants diagnosed with DDH being 200 per annum. If using a confidence level of 95%, and a confidence interval of 10, the recommended sample size is 65 participants. Therefore, the sample size used for this survey (n=100) was considered appropriate and adequate

3.9.6 Inclusion and exclusion criteria - Phase 2

The overall profile of the parents who were eligible to participate in the study in included:

Inclusion criteria:

- Parents of infants who were currently engaged in observation or treatment in the DDH OPD clinic.
- Parents 18 years and older.
- Parents who were English-speaking: able to speak, read and write in English.

Exclusion criteria:

- Parents of infants who had clinically or sonographic normal hips
- Parents under the age of 18 years
- Parents who are not English-speaking: able to speak, read and write in English.

3.9.7 Pilot testing of the questionnaire

A pilot study is a preliminary trial of the research study that is designed to test and check the viability of the planned research approach. The pilot study is designed to test the suitability of the instruments to be used, to identify potential and actual problems with data collection and to examine analytical strategies (Polit & Beck 2014). The pilot study has the potential to provide additional knowledge which leads to an improved main study by insuring enhanced reliability and validity (Lancaster *et al*. 2004).

Prior to carrying out the pilot study, an expert panel consisting of the consultant orthopaedic surgeon and nursing staff in the DDH clinic were consulted regarding the questionnaire and critical feedback was provided. As there was no previous study of this nature, a pilot study was undertaken in October 2014 involving ten parents of infants with DDH in the DDH clinic to assess the acceptability of the questionnaire, to check for ambiguities in relation to the understanding of the questions and to investigate the length of time for completion of the questionnaire. The researcher met with the parents following their clinic visit in order to discuss how appropriate the questionnaire was to complete.

3.9.8 Refinements undertaken as a result of the pilot study

All pilot study participants could understand and complete the questionnaires easily and they said the questionnaire appeared to be straightforward to complete. Further evaluation of the pilot questionnaire and conversations with parents revealed that most of the suggested changes from the pilot study referred to minor editing changes with word changes and revision of the overall layout which were amended prior to the main study.

The questionnaire was deemed acceptable by the multidisciplinary team and the parents. The pilot group participants were excluded from the subsequent major study. The final questionnaire was agreed between the researcher and two supervisors and the survey commenced following incorporation of the minor amendments suggested by the pilot study.

3.9.9 Data collection - Phase 2

The questionnaires were distributed by the researcher. Prior to the launch of the survey an information session was provided for all of the staff in the DDH clinic by the researcher. Data collection was carried out over three months, November 2014 to January 2015, involving ten DDH clinics. Eligibility for invitation into the study was assessed by the researcher the morning of the DDH clinic by checking the outpatient list for the day. Parents of infants who had attended the clinic on more than one occasion and whose child had been given a diagnosis of DDH or who were under observation for suspected DDH were eligible. The list was triaged using the inclusion/exclusion criteria to identify participants who were suitable. The clinic receptionist informed the parents of the research study when they checked in. The parents were approached by the researcher after they had checked in and while they were waiting to be seen. The parents who met the inclusion criteria were given oral information about the study. Eligible parents were informed that the research aimed to examine their experiences caring for a child with DDH and their experiences using the DDH services. A questionnaire was given to each parent at the time of recruitment. The parents were given the opportunity to read the questionnaire prior to consent. Participants were assured that participation in the research was voluntary and that their views were anonymous. The completed questionnaires were returned to a sealed box at the reception desk to which only the researcher has access. Completion of the questionnaire implied consent to participate. One hundred questionnaires were administered to the parents attending the DDH clinic with their infants over the course of ten weeks. It was noted that data saturation was reached at (n=100) due to the fact that many of

the same parents were returning on a weekly or fortnightly basis to the clinic, it was therefore decided to discontinue data collection. A response rate of 100% was achieved as one hundred questionnaires were returned to the researcher.

3.9.10 Data analysis - Phase 2

Data were entered into the Statistical Package for Social Sciences (SPSS) Version 21 and coded for analysis. Data were systematically entered into the computer and double-checked to ensure consistency of information.

The final section of the questionnaire contained 17 closed-ended statements which asked respondents to rate their worries in relation to the diagnosis and daily care of an infant with DDH using a Likert scale. The data were treated as continuous and for the convenience of analysis each category was recoded to indicate positive or negative agreement with each of the statements. In keeping with the original hip worries inventory (Gardner *et al*. 2005), the scoring was reversed, this produced a scale of 1 to 5 where 1 showed the strongest disagreement and 5 indicated the strongest agreement. Neutral responses were scored as 3.

Adjoining categories within these items were also collapsed; strongly disagree and disagree were combined, neutral was treated as a separate category and finally, agree and strongly agree were also merged. Each of these variables now had 3 categories and not the original 5. The percentage agreement and frequencies were then presented in most cases, as an indication of the overall level of agreement with the statements. Statistical analysis included the Mann Whitney *U* test in order to compare results between those that were diagnosed early and late. The above test was carried out using a two-tailed significance of 5%.

3.10 Qualitative – Phase 3

While quantitative health research addresses concrete quantitative questions of treatment efficacy, qualitative health research addresses questions pertaining to the experience of illness and of receiving care (Morse 2012). Phase 3 is the qualitative component of the study. One common held view is that the hallmark of qualitative research lies in its ability to provide in-depth descriptions. Thus, one marker of adequacy is the richness of the picture that such research produces (Popay *et al*. 1998). Individual interviews enable deep exploration of individual perspectives about an experience or phenomenon, the interviewee is the sole focus

allowing the researcher to obtain optimum detail and clarification throughout data collection (Spencer *et al*.2003). Data collection requires careful consideration and should allow the researcher to meet the aims and objectives of the study.

In this study, the findings from the questionnaire in Phase 2 provided the basis for the focus of the topic guide for semi-structured interviews that involved the parents of infants diagnosed with DDH in Strand 1 (See Appendix IV); while the findings from Phase 1 also informed the topic guide for semi-structured interviews with the GP's and PHN's who screen and refer infants to the DDH clinic in Strand 2 (See Appendices V & VI).

3.10.1 Benefits of a semi-structured interview

Semi-structured interviews provide structure to provide the qualitative information required to meet the demands of the aim and objectives of the study but also allow opportunities for the participant to talk openly and freely (Streubert and Carpenter 2011). Another reason the semi-structured approach was chosen was to capture the complexities of a parent receiving a newborn diagnosis of DDH for their child and to gain a detailed understanding of the level of care involved in the management of a child undergoing treatment for the condition.

3.10.2 Development of the interview guide for parents

The questions were developed from the key themes from the literature review about DDH and the findings of Phase 1 and Phase 2. In the 1st strand of Phase 3, nineteen questions consisting of demographic details in relation to: age, gender, firstborn, delivery, family history, hip exanimation, DDH information/education received, referral type and treatment received in the DDH clinic were included. Fourteen open style questions were developed which explored perceived prior knowledge of DDH; perceived level of information/education provided by maternity and paediatric services in relation to DDH awareness; the understanding of the purpose of the newborn examination; the experience of receiving a diagnosis of DDH and the subsequent commencement of treatment of the condition from the perspectives of the parents.

3.10.3 Development of the semi-structured interviews for GP's and PHN's

In the 2nd strand of Phase 3, twenty questions were developed for the GP's and PHN's in order to gain information on the DDH screening and referral practises utilised in the community as part of the Healthy Childhood Programme and to determine any potential barriers to the successful referral and management of infants with potential DDH. The topic guides was

determined based on the issues highlighted in the literature and the findings from Phase 1 of the study.

Five questions related to demographic details such as: age, gender, number of years in their chosen profession, place of work and academic qualifications. Fifteen open style questions were developed which explored the number of years each HCP had experience in screening for DDH; what training they received in order to screen for DDH; details of how each HCP screens for DDH in their practise; what information they give parents when DDH is suspected; what procedure they adopt to refer suspected cases of DDH and questions related to how effective they find the screening process in their own opinion.

3.10.4 Target population - Phase 3

The target population of strand 1 of Phase 3 comprised of parents attending the DDH clinic with their infants who were either in receipt of treatment for DDH or were under observation for the condition. The target population of strand 2 of Phase 3 comprised of GP's and PHN's who screen and refer for suspected DDH in the Regional Centre or one of the 3 Rural Centres.

3.10.5 Sampling technique and sample size – Phase 3

Sample sizes in qualitative studies are small, unlike quantitative studies the aim is not to determine incidence, prevalence or statistical significance, qualitative research uses a small sample size to facilitate deep exploration and the generation of data that has depth of understanding (Ritchie *et al*. 2003). Well conducted interviews with a small sample size of communicative and well informed participants will obtain high quality data therefore the point of data saturation will be reached quickly and the small sample size will be sufficient (Burns and Grove 2003). For the purpose of this study, data collection continued until nothing new was learned (n = 11).

Nonprobability convenience sampling was used to select the participants in both strands of Phase 3. On completion of the questionnaire in Phase 2 of the study, participants were asked to supply their name and phone number if they were interested in being interviewed at a future date regarding their experiences of DDH. Twenty-three parents expressed an interest in taking part in an interview. Of those 23, 11 parents when contacted a year later, agreed to participate in an interview.

Four GP's and four PHN's, from the Regional centre area and from each of the rural centre areas respectively were selected for the second Strand of Phase 3. They were followed prospectively and selected consecutively. One GP and 1 PHN were selected from the phone directory from each of the four centres as per the inclusion criteria described below.

Informed consent remains a significant issue for all research studies and according to Rees (1997), showing respect to the person is achieved through informed consent. All participants were given both written and verbal information about the study in the form of an information sheet (Appendix VII). Participants made their choice to participate or not, free of any coercion or undue pressure. At each phase of the research, continuous negotiation of participation was safeguarded by verbally discussing the implications of participation with the research study. Participants were informed that they had the right to withdraw from the research process at any stage, to decline to answer a question during the interview process without having to offer an explanation. Participants were reassured that there were no anticipated risks of potential discomfort or harm as a result of the study.

3.10.6 Inclusion and exclusion criteria - Phase 3

The overall profile of the parents who were eligible to participate in the 1st Strand of Phase 3 were:

Inclusion criteria:

- Parents of infants who have been engaged in treatment and care in the DDH OPD clinic.
- Parents 18 years and older.
- Parents who were English-speaking: able to speak, read and write in English.

Exclusion criteria:

- Parents of infants who had clinically or sonographic normal hips
- Parents under the age of 18 years
- Parents who are not English-speaking: able to speak, read and write in English.

The overall profile of GPs and PHNs who were eligible to participate in the 2st Strand of Phase 3 were:

Inclusion criteria:

- Qualified GPs or PHNs working in either the Regional Centre or one of the Rural Centres within the remit of the south-eastern region.
- Have direct experience screening and referring infants to the DDH clinic in the South-eastern region of Ireland.

Exclusion criteria:

- Qualified GPs or PHNs who did not work in either the Regional Centre or one of the Rural Centres within the remit of the south-eastern region.
- Have no direct experience screening and referring infants to the DDH clinic in the South-eastern region of Ireland.

3.10.7 Pilot testing of the interview guide

A pilot study of the interview guide was undertaken with 2 parents in September 2017. Their feedback and participation was subsequently excluded from this phase of the study. Based on the pilot it was noted that parents appeared to have very little knowledge regarding DDH prior to their first attendance in the DDH clinic. Following consultation with academic supervisors, the interview questions assessing prior knowledge regarding DDH were increased from 1 to 5, giving a total of 14 open ended questions. This was done in order to provide a more detailed and explicit exploration of the reasons why there appears to be a general lack of awareness surrounding DDH.

3.10.8 Data collection Phase 3

Data were collected for Strand 1 of Phase 3 between October and November 2017. Written information regarding the study was sent out to the 11 interested participants in October 2017 prior to the commencement of interviews. All 11 participants were happy to proceed with the interview following receipt of the information leaflet. The participants were asked to sign the informed consent that was also enclosed (Appendix VIII) if they wished to proceed with the interview. Participants were given a choice of time and location. Three interviews were carried out face to face in the parent's own home, while the remaining 8 interviews were carried out over the phone. All participants were advised they could stop the interview at any time. The

interviews lasted from 15 to 20 minutes, which allowed sufficient opportunity for all participants to respond to the questions. In order to enhance the accuracy of data and the potential validity of data analysis, all interviews were digitally recorded with permission form the parents, then the verbal data was digitally transcribed verbatim in Microsoft Word in order to conduct a thematic analysis.

Data were collected for Strand 2 of Phase 3 between February and March 2018. GP's and PHN's were chosen from the phone directory from each of the specific regions that are involved in the DDH clinic. Telephone contact was made with each potential participant and verbal information regarding the research study was given. Once verbal consent was obtained from each potential candidate, written information was sent out prior to commencement of the telephone interview. All eight participants were happy to proceed with the interview following receipt of the information leaflet. The participants were asked to sign the informed consent that was also enclosed. Participants were given a choice of time for the phone call. The phone conversations lasted approximately 10 to 15 minutes. All interviews were digitally recorded with permission form the candidates, then the verbal data was digitally transcribed verbatim in Microsoft Word in order to conduct a thematic analysis. Thematic saturation occurs when fewer surprises, patterns or themes emerge from the data (O'Reilly and Parker 2013). As a result, sampling of data was discontinued when the sample size of HCP's was 8.

3.10.9 Data Analysis Phase 3

Clarity on process and practise of method is vital; otherwise it is difficult to evaluate research and to compare/synthesise it with other studies on a particular topic (Attride-Stirling 2001). Thematic analysis, which was adopted in this phase, through its theoretical freedom, provides a flexible and useful research tool which can potentially provide a rich and detailed yet complex account of data (Braun & Clarke 2006).

All interviews in Strand 1 were analysed thematically using a theory and data driven approach (Braun & Clarke 2006). This qualitative approach was based on a mixed inductive (themes grounded in the data) and theoretical approach (themes influenced by the literature). The data was analysed in 6 steps (See Table 3.3). The transcription of the data, which in itself is argued to be a 'key phase of data analysis within interpretive qualitative methodology' as it is an excellent way to become familiar with the data (Bird 2005) The transcripts were read several times in order to become accustomed with the data and the overall patterns of meaning and

issues of potential interest in the data. Initial ideas and potential coding themes were written down in this first phase.

In the second stage, a more formal coding process began (Braun & Clarke 2006). Data were organised into meaningful groups thus generating the initial codes. The coding was performed manually by writing notes on the texts that were being analysed. Once initial codes were identified, all matched data extracts that demonstrated the code were collated together within each code in separate computer files. All potential themes/patterns were coded and saved.

Stage 3 of the thematic analysis involved sorting the different codes into potential overarching themes, and collating all the relevant coded data extracts within the identified themes. A visual representation of the different codes in the form of mind maps were utilised to sort the different codes into themes. Some initial codes went on to form some of the main themes of the study, while others formed some of the sub-themes identified.

Stage 4 involved the refinement of the themes. The collated extracts for each theme were re-read in order to determine whether the themes adequately capture the essence of the coded data (Braun & Clarke 2006). Then, the validity of themes in relation to their reflection of the data set as a whole was considered carefully. This was achieved by re-reading the entire data set in order to ascertain whether the themes worked in relation to the data set. Some re-coding of the data set was done at this time.

In stage 5, a detailed analysis of the data within each of the individual themes was conducted. Each theme was considered within itself, and also in relation to the other themes. Further sub-themes were identified at this point of the analysis. Sub-themes can be useful for demonstrating the hierarchy of meaning within the data (Braun & Clarke 2006). The goal at the end of this phase was to generate final names and clear definitions for each theme.

Finally, stage 6 involved the final analysis and write-up of the findings. It was paramount that the analytic narrative illustrated the *story* of the data; that it went beyond description of the data and made an *argument* in relation to the research question being asked in the study (Braun & Clarke 2006).

Confirmability is concerned with establishing that data and interpretations of the findings are not figments of the inquirer's imagination, but clearly derived from the data. It is the degree to

which the findings of the research study could be confirmed by other researchers (Korstjens & Moser 2018). Consultation with academic supervisors was undertaken during each stage as a means of a quality control check for confirmability. By consulting regularly with academic supervisors in relation to coding, analysis and interpretation decisions (investigator triangulation), credibility of the research data was also ensured (Korstjens & Moser 2018). See Table 3.3 below.

Table 3.3 Phases of Thematic Analysis (Braun & Clarke 2006)

Stage	**Description of the process**
1: Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2: Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3: Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4: Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis
5: Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6: Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

3.11 Establishing rigour

Methodological rigor in quantitative research refers to the thoroughness and accuracy with which research is conducted and involves elements such as empirical validity, statistical significance, and the generalizability of results" (Flickinger *et al*. 2014). Qualitative studies however, are more complex in many ways than a quantitative investigation. Quantitative research follows a structured, rigid, preset design with the methods all prescribed. In naturalistic inquiries, planning and implementation are simultaneous, and the research design can change or is emergent (Cypress 2017). Rigour in qualitative research requires that researchers attempt to be fully accountable for their data collection, analysis, and interpretive

methodologies (Tashakkori and Teddlie 2003). Researchers continually need to strive to assess and document the legitimacy of their findings in order to reach an acceptable level of accountability, such as validity, credibility, trustworthiness, dependability, conformability, and transferability (Onwuegbuzie and Teddlie, 2003). It has been stated that a credible qualitative study will contribute to the body of knowledge and enhance the quality of practice (Vivar 2007). It is, therefore, important to establish rigour in qualitative research so that findings are accurate and credible in order to make an impact (Creswell 2013).

3.11.1 Reliability – Phase 1 and 2

The reliability of an instrument is the degree of consistency that it measures (Polit and Beck 2008). It means that the measurement is consistent and accurate (Polit and Hungler 2008; Polit and Beck 2014). The reliability of an instrument can also be defined in terms of accuracy, consistency and the predictability of specific research findings (Chisnall 2001).

In relation to Phase 1, the scientific and systematic investigation of existing health records is an important and valued methodology in health care research, specifically in epidemiology and quality assessment studies (Gearing *et al.* 2006). Chart reviews offer the opportunity to research the rich readily accessible existing data that was originally collected for reasons other than research (Worster and Haines 2004).

The most widely accepted statistical measurement of internal consistency is Chronbach's Alpha co-efficient. To establish internal consistency and reliability of the research questionnaire in this study, the coefficient alpha was calculated. The result (0.80) indicated the questionnaire as an accurate measuring tool.

3.11.2 Validity

Validity refers to whether a measurement instrument accurately measures what it is supposed to measure (Polit and Hungler, 2008). Content validity refers to the data collection instrument and that the data collected meets the research aims and objectives. The questionnaire underwent close scrutiny of the content and the full range of factors under study to fulfill the research aim. Content validity pertaining to the questionnaire items was sought from two supervisors (one with extensive research experience and the other with extensive nursing and research

experience), and 2 local ethics committees. The experts reviewed the questionnaire in order to assess whether the questions were relevant to the subject it aimed to measure.

Face validity, a subtype of content validity, is a rudimentary type of validity and refers to whether the instrument appears valid and looks as though it is measuring the appropriate construct (Polit and Hungler, 2008). Face validity in this study was established through expert opinion and through an examination of the questionnaire that identified the variables involved with the research topic.

Construct validity was based on a review of the literature regarding parents experiences of attending DDH services and caring for a child being treated for DDH. This informed the questionnaire and processes for this data collection. The addition of relevant topic areas to the original questionnaire was essential to capture the areas for exploration of the parent's views.

Internal validity refers to unwanted factors internal to the study which can interfere with the results (Parahoo 2006). Bias is an influence that can produce estimate or inference errors and can be present at every stage of the study. It is a key concern and can threaten the study's validity and trustworthiness and warrants the application of rigorous research methods (Parahoo 2006). One potential bias in the study was the fact that the majority of the interviews that took place in Phase 3 were telephone interviews. Telephone interviews are often depicted as a less attractive alternative to face-to-face interviews in qualitative research due to the lack of visual cues via telephone resulting in the loss of contextual, nonverbal data and have the possibility of compromising rapport (Novick 2008). However, it was felt that given the fact that the majority of the sample set in strand 1 were busy parents, a telephone interview was realistically an easier fit into their daily schedule. It was verbalized by most of the parents that were interviewed that this was indeed the case and they were appreciative of not having to interrupt their normal routine to participate in the study. This versatility, as well as the decreased cost and increased access to geographically disparate participants have been noted in the literature as some of the advantages of telephone interviews (Sweet 2002, Sturges and Hanrahan 2004). No issues with rapport with any of the parents was noted by the researcher. In terms of the 2nd strand of Phase 3, telephone interviews were also the only practical way of making contact with HCP's during their busy working schedule. Another potential bias and threat to the internal validity of this study was that the researcher worked in the DDH clinic as discussed in the next section.

3.12 Reflexivity and transparency – Phase 3

In Phase 3, there was a potential issue where the researcher may be known to the participants. Therefore, strategies were adopted to minimise the effect of the facilitator being known to the participants. Reflexivity is considered an essential characteristic of qualitative research (Priest and Roberts 2010) and is characterised by an ongoing analysis of personal involvement that helps to make the process open and transparent (Dowling 2006). 'Empathic Neutrality' is essential in conducting a qualitative study because it is the acceptance that the researcher cannot be value free but that there is acknowledgement of the researcher's beliefs on data collection and analysis (Ritchie and Lewis 2003). Ritchie and Lewis (2003) highlight that the researcher must, therefore, take an 'emic perspective' where the researcher looks at the perspective of the individual and making sense of their views maintains neutrality and a non-judgemental or influential position. Reflexivity incorporates aspects of reflection but is a more active process, it allows the readers of the researcher to be aware of all influences the researcher has had on the study (Snape and Spencer 2003).

For the purpose of this research project the researcher acknowledges that working in the DDH clinic is considered a bias within the study. The researcher will continue the process of reflexivity throughout this research study. Therefore, it was considered advisable for this study that the researcher clarified her thoughts, ideas, suppositions or presuppositions about the topic, as well as personal biases prior to undertaking the interviews. Exploration of personal beliefs made the researcher more aware of the potential judgments that could have occurred during data collection and analysis based on the researcher's belief system of being a midwife and nurse. This process was used to separate personal views and preconceptions from the phenomenon under study. In addition, the construction of a 'decision trail' explaining the choices made during the research process was employed. The following table provides an account of the strategies used in this study.

Table 3.4 Points used to assist promotion of reflexivity in this study

Promotion of reflexivity
The following points were employed at the interviews which assisted in promoting reflexivity
• Maintenance of a research diary to record what influences could have affected interpretation of the data.
• Ensuring that participants had freedom to speak in interviews
• Provision of an analysis of the research context and ongoing attention to same.
• Careful recording and transcription of the interview data, with on-going attention to details.
• Participant's perceptions were validated at the end of each interview.
• Construction of a decision trail explaining how the choice of participants and questions evolved. This helped to acknowledge the researcher's effect on the research process.
• Qualitative findings were derived from the participants' perspective but interpreted by the researcher.
• Findings were reviewed with peers
• Constant reflection on the role of the researcher involved.

Adapted from Jootun *et al.* 2009

3.13 Ethical considerations

The ethical implications of all research must be considered to ensure the protection of human rights of research participants (Polit and Beck 2004). Ethics are principles of right conduct, their purpose being to ensure the rights and welfare of the research participants are upheld at each stage of the research process (World Health Organisation, 2004). The protection of the participant is the obligation of every nurse researcher (Brink & Wood 2001). In Ireland, nurses' responsibility when undertaking research is indicated in the NMBI's (Nursing and Midwifery Board of Ireland *Ethical Conduct in Research (*Nursing & Midwifery Board Ireland, 2017 p.6) as follows:

> *"The principles underpinning the scope of nursing and midwifery practice include respecting the dignity and rights of patients, promoting and maintaining patient safety, providing quality care, facilitating patient autonomy, informed choice and evidence-based decision-making. These principles apply equally to research activity. The Scope of Practice framework is also relevant to the nurse's or midwife's role in research. The framework takes cognisance of the overall benefit to the patient, legislation, local national, and international evidence-based clinical practice guidelines*

guidelines/policies and the concepts of responsibility, accountability and autonomy, and competency".

3.13.1 Ethical Approval Phases 1, 2 and 3.

Prior to commencing this research, the study received full ethical approval from the College Ethics Committee and HSE South Research Ethics Committee (See Appendices IX & X.). Permission was sought in writing of the hospital ethics committee and all members were furnished with a copy of the research proposal. The researcher attended a committee meeting in order to respond to any queries that the committee had in relation to the research proposal. The permission of the ethics committee was withheld pending the rewording of a particular question in Phase 2 which enquired about the types of health professional that the children see at each clinic appointment. The wording was changed in order to make it clear that the question was related to what type of health professional they saw rather than an enquiry to name the health professional. This was to protect the anonymity of the staff in the clinic. Permission was then granted to continue with the study.

3.14 Informed consent Phase 2 and 3

All participants were invited to participate on a voluntary basis to the study, by the researcher as described in the different recruitment procedures involved with the last 2 phases of this study. The right not to participate and the right to withdraw from the study at any time were fully explained. All participants were given both written and verbal information about the study in the form of an information sheet (Appendix VII)

Parents of children with an illness are a vulnerable research population and obtaining informed consent for participation in research is a key issue. The principle of informed consent arises from the subject's right to freedom and self-determination (Ledward 2011). It involves the following 3 threshold elements: information, competence and voluntariness (Ledward 2011). Informed consent is a complex issue in all research especially when dealing with vulnerable groups and the NMBI (2017)) supports the premise that if vulnerable groups remain invisible in research they will be further disadvantaged. The researcher was aware that the participants were in a vulnerable position and, therefore, it was essential to negate any feelings of coercion (Cohen *et al.*, 2007; LoBiondo-Wood and Haber 2008).

Gaining informed consent entails using skills of listening, attending, clarifying, making explicit the implicit and genuinely attending to the person and fostering a consent dialogue throughout the research process (Roberts *et al*, 2004). The researcher has vast experience in her professional nursing and midwifery career of engaging with the public and using appropriate interpersonal skills, which greatly assisted in establishing a rapport with participants and with the ongoing process of negotiating consent throughout all aspects of the current study.

A professional and moral duty was necessary to ensure fair treatment of the infants and uphold sound ethical principles in conducting research with the parents of infants with DDH as participants. Safeguarding measures were introduced such as the use of posters in the waiting area informing potential participants of the research study. The secretary informed the parents of the research study when they checked in. This avoided the perception of any coercive measures to persuade parents to take part in the research project. Parents of infants with DDH were then later approached by the researcher and asked if they would like to participate in the study. All participants were assured that participation was voluntary and that they could withdraw from the study at any time without penalty. Contact details of the researcher were provided in the questionnaire. Particular care was taken by using these measures to ensure that their consent was both informed and voluntary.

Implied consent for participation was accepted when a parent who was eligible completed a questionnaire before leaving the clinic. The completed questionnaires were then deposited by the parent into a locked box at the clinic desk. The box was emptied and completed questionnaires were collected at the end of each clinic by the researcher.

On the back of the questionnaire was a tick box asking participating parents if they were willing to be interviewed at a future date regarding their experiences of caring for an infant with DDH. They were asked to supply their name and phone number if they were interested in being interviewed. All participants who agreed to be interviewed in both strands of Phase 3 were given both written and verbal information about the study in the form of an information sheet and consent from to sign if they wished to proceed with the interview (Appendices VII & VIII).

3.15 Protection of confidentiality and anonymity Phase 1

The gathered data was protected abiding by the Data Protection Act (Government of Ireland 1988) and the Data Protection Amendment Act (Government of Ireland 2003). Training was undertaken in the local college to ensure statutory compliance with regard to the protection of

data. All data collected in this study was coded to protect confidentiality; the only person that was able to convert the coded data to identifiable data was the researcher. The anonymised computerised data was stored on the researcher's own personal laptop which was password protected. The physical security of this laptop was ensured at all times as nobody else had access to it. Back-up USB copies of research data were made and stored in a locked filing cabinet in an office. Computerised results were also protected under the Data Protection Act (Government of Ireland 2011) and will be held in a locked office press to be destroyed five years following completion of this study (Government of Ireland 2011).

3.15.1 Protection of confidentiality and anonymity Phases 2 and 3

The concept of confidentiality is central to the role of the researcher and upholding this principle helps to protect and maintain a participant's psychological well-being (The Irish Medical Council 2004). Throughout this study, measures were implemented to protect parents, children and hospitals identity.

All data collected in this study was coded to protect confidentiality; the only person that was able to convert the coded data to identifiable data was the researcher. Participants were informed that as a subject of the research they would remain anonymous in matters regarding publication of the findings and in preparation of reports. Participants were informed that summary data would be disseminated to the professional community, but in no way would it be possible to trace responses to individuals.

Appropriate security measures were taken to ensure unauthorised access to, or alteration, disclosure or destruction of data and against accidental loss or destruction was avoided. All information gathered was securely stored in a locked filing cabinet in the Post Graduate Student office in the local college and will be destroyed in keeping with the Data Protection Act (Irish Government 2003) and the local college's Data Protection policy.

3.16 Conclusion

This chapter described the methodological structure for this study. It gave a general overview of the theoretical approach to the study and the rationale for using a mixed methods design. The research processes involved in phases 1, 2 and 3 were made explicit. It described the data collection and data analysis of the Phase I chart review which was undertaken to determine data regarding incidence rates of DDH, late diagnosis rates, screening methods and successful treatment rates in the South East of Ireland. It explained the development and analysis methods for the questionnaire utilised in Phase 2 to illuminate and describe the experiences of parents in receipt of treatment for their infants in the DDH clinic the findings of which provided the basis of the topic guide for the semi-structured interviews that involved the parents in Phase 3. Finally attention was drawn to the ethical issues raised in the study as were issues of reliability and validity. Central to this study was the objective of maintaining the highest standards of scientific rigour in answering the research questions and, in so doing, to ensure an ethically sound and robust research endeavour. Chapter 4 will present the findings from all the study phases.

Chapter 4 Presentation of Quantitative Findings Phase 1

4.0 Introduction

This chapter reports the findings of the retrospective chart review of all infants who were referred to the DDH clinic who were born in 2012 and 2013. The purpose of Phase 1 was to identify incidence rates and assess the effectiveness of screening and treatment rates. Sections 4.1 – 4.2 describes the demographics information and incidence rates of DDH in the South-eastern region. Section 4.3 valuates the diagnostic value of the three screening pathways utilised in the DDH clinic. Sensitivity and specificity of each screening method is calculated. The association between diagnostic ultrasounds and treatment types and algorithms identifying final outcomes following diagnostic ultrasounds and follow up x-rays are presented in sections 4.4 and 4.5. Section 4.6 describes the source and indications for referral to the DDH clinic, total number of referrals diagnosed with DDH and type of treatment required based on referral type. Section 4.7 discusses the risk factors identified by referring practitioners and the evaluation of the accuracy of those risk factors associated with the detection of DDH. Sensitivity and specificity of each key risk factor are calculated. Negative and positive predictive values are also tabulated. Bivariate analysis and logistic regression analysis is used to determine the effects of key characteristic variables on the likelihood that a positive diagnosis of DDH would be made. The association between risk factors and treatment type is also discussed. Section 4.8 explores age at first referral, regional differences in age at first referral, regional differences compared to the regional centre and associations between region of birth and early/late referrals. The association between age at first referral and treatment types, the correlation between age at first referral and final outcomes and finally the correlation between early/late referrals and final outcomes are also discussed in section 4.8.

4.1 Demographic information

This section presents the results of the descriptive analyses: percentages and frequencies for the categorical variables including: demographic information, delivery and referral details (type of delivery, source of referral, reason for referral, risk factors specified and age at first presentation).

The population of interest was all infants born in 2012 and 2013 who attended the DDH clinic. The total number of participants over the two years was 372. The majority of infants in both

years attending the clinic were female (71%, *n*=134 in 2012 and 79%, *n*= 144 in 2013). Of the 190 infants referred in the 2012 group, the majority (33%, *n*= 62) were referred from Rural 2. Of the 182 participants in the 2013 group, the highest numbers of referrals were from Rural 1 (32%, *n*= 59). In both 2012 and 2013, approximately two thirds of participants were born by vaginal delivery (62%, *n*=118; 65%, *n*= 119).

In terms of age at first referral, in 2012, 34% (*n*= 63) of infants attended the service by 12 weeks of age; while in 2013, 28% (*n*= 51) of infants attended by 12 weeks. Referral by 12 weeks of age is often considered as an early referral, while any referral over 12 weeks of age is deemed a late referral. Eight percent (*n*=18) and 9% (*n*=19) of participants respectively were seen between 13 and 26 weeks of age in 2012 and 2013. The majority of infants were between 27 and 52 weeks of age at first presentation in 2012 and 2013 (48%, *n*=99; 57%, *n*=106). Of the participants, 10% (*n*=10) and 6% (*n*=6) respectively were seen for the first time when they were over 1 year of age in 2012 and 2013. The results are presented in Table 4.1.

Table 4.1 Demographic information for infants born in 2012 & 2013.

Demographic Information	**2012 (n=190)**		**2013 (n=182)**	
	Frequency (n)	**Percentage (%)**	**Frequency (n)**	**Percentage (%)**
Gender				
Male	56	29%	38	21%
Female	134	71%	144	79%
Place of Birth				
Regional Unit	54	28%	41	23.5%
Rural 1	49	26%	59	32%
Rural 2	62	33%	53	29%
Rural 3	23	12%	28	15%
Other	2	1%	1	0.5%
Type of delivery				
Vaginal	118	62%	119	65%
Caesarean Section	72	38%	63	35%
Age at First Presentation				
1-12 weeks of age	63	34%	51	28%
13-26 weeks of age	18	8%	19	9%
27-52 weeks of age	99	48%	106	57%
Over 1 year of age	10	10%	6	6%

4.2 Incidence Rate

One of the objectives of this study was to establish the overall incidence rate as well as the early and late incidence rates of DDH in the South East of Ireland. There were 14,887 live births in the South-east region in 2012 and 2013 (CSO 2012, CSO 2013). Two hundred and sixty-one diagnosed cases of DDH were identified from a cohort of 372 infants with a date of birth of 2012 or 2013. This gave an overall incidence rate of 17.5 per 1000 live births.

4.2.1 Early/late incidence rates

In 30% of these newborns (*n*=78), the diagnosis was made within 12 weeks of age giving an early incidence rate of 5.23 per 1000 live births. Seventy percent of the newborns diagnosed with DDH (*n*=183), were diagnosed over 12 weeks of age giving a late diagnosis rate of 12.29 per 1000 live births in the region. Figure 4.1 shows early and late incidence rates for each of the 2 years.

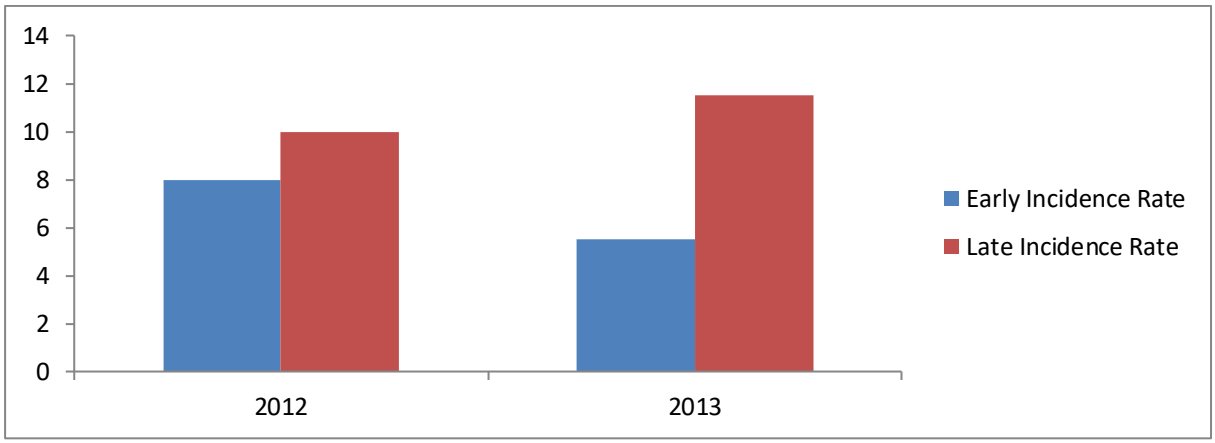

Figure 4.1 Early/Late Incidence Rates of DDH / 1000 live births 2012 2013

4.3 Screening Pathways

The next section will evaluate the diagnostic value of the screening pathways utilized in the DDH clinic. Sensitivity and specificity of each screening method will be calculated. Negative and positive predictive values will also be tabulated.

4.3.1 Evaluation of diagnostic value of clinical examination of the hips.

A Chi-square test for independence indicated a strong significant association between Clinical Examination of the Hips and the detection of DDH χ^2 (1) = 117.044, p = 0.000. Further

information that gives insight into the nature of the association is given in Table 4.2 below. There was 76% sensitivity that clinical examination of the hips in the DDH clinic would correctly diagnose an infant as having DDH. There was 85% specificity that clinical examination of the hips in the DDH clinic would correctly identify normal hips in those who did not have DDH. A clinical examination positive predictive value was calculated to be 92% while the negative predictive value was calculated to be 60%.

4.3.2 Evaluation of diagnostic value of ultrasound screening.

A Chi-square test for independence indicated a strong significant association between diagnostic ultrasound of the hips and the detection of DDH χ^2 (2) = 45.134, p = 0.000. Two hundred and twenty infants (59%) underwent an ultrasound of the hips for diagnostic purposes. Fifty-four percent (*n*=79) of those who had a diagnostic ultrasound were found to have a normal ultrasound screen while, 46% (*n*=68) had an abnormal ultrasound screen. Thirty percent of those who had a normal ultrasound screen, following further surveillance, ultimately went on to be treated for DDH while 61% following further surveillance were found not to have DDH. There was 47% sensitivity that diagnostic ultrasounds would correctly diagnose an infant as having DDH. There was 97% specificity that diagnostic ultrasounds would correctly indicate a negative screen in those who did not have DDH. A diagnostic ultrasound positive predictive value (PPV) was calculated to be 97% while the negative predictive value (NPV) was calculated to be 46%. (Table 4.2).

4.3.3 Evaluation of diagnostic value of x-ray screening.

A Chi-square test for independence indicated a strong significant association between x-ray screening of the hips and the detection of DDH χ^2 (2) = 120.941, p = 0.000. There was 71% sensitivity that an x-ray of the hip would correctly indicate an abnormal screen in those who did have DDH. There was 90% specificity that an x-ray of the hips would correctly indicate a normal screen in those who did not have DDH. An x-ray positive predictive value was calculated to be 94% while the negative predictive value was calculated to be 57%., see Table 4.2).

Table 4.2 Sensitivity and specificity of each screening method

	Clinical Examination of the Hips	Diagnostic Ultrasound Screening	Diagnostic X-ray Screening
Sensitivity	76%	47%	71%
Specificity	85%	97%	90%
Positive Predictive Value	92%	97%	94%
Negative Predictive Value	60%	46%	57%

4.4 Diagnostic ultrasound and treatment type

A Chi-square test for independence indicated a strong significant association between diagnostic ultrasound of the hips and treatment type χ^2 (4) = 19.160, p = 0.001. Out of the total of 220 patients who received a diagnostic ultrasound, 19% were treated with a Pavlik Harness and 33% were treated with a Boston Brace. Seven percent required treatment with both a Pavlik Harness and a Boston Brace while 9% were referred to a Tertiary Unit. Thirty-two percent did not require any treatment. See Table 4.3 below.

Table 4.3 Diagnostic ultrasound and treatment type

Diagnostic Ultrasound	Treatment Type									
	Pavlik		Brace		Both		No Tx		Tertiary	
	n	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)
Yes	43	(19)	72	(33)	15	(7)	70	(32)	20	(9)
No	14	(9)	69	(46)	3	(2)	41	(27)	25	(16)

4.5 Algorithms of Diagnostic Ultrasound and Follow up x-ray Findings

In the 2012 cohort, of the 99 who had a diagnostic ultrasound, 48% had normal results while 52% had abnormal findings. Of the 48 infants who were radiologically normal on ultrasound, 58% went on to have a normal routine follow up x-ray, while 42% went on to have an abnormal follow up x-ray. Of those that had an abnormal x-ray result, 75% went on to be subsequently treated and discharged while 25% required referral to a Tertiary Unit. See Figure 4.2 below. In the 2013 cohort, of the 121 who had a diagnostic ultrasound, 82% had normal results while

18% had abnormal findings. Of the 99 infants who were radiologically normal on ultrasound, 41% went on to have a normal routine follow up x-ray, while 59% went on to have an abnormal follow up x-ray. Of those that had an abnormal x-ray result, 88% went on to be subsequently treated and discharged while 12% required referral to a Tertiary Unit. See Figure 4.3 below.

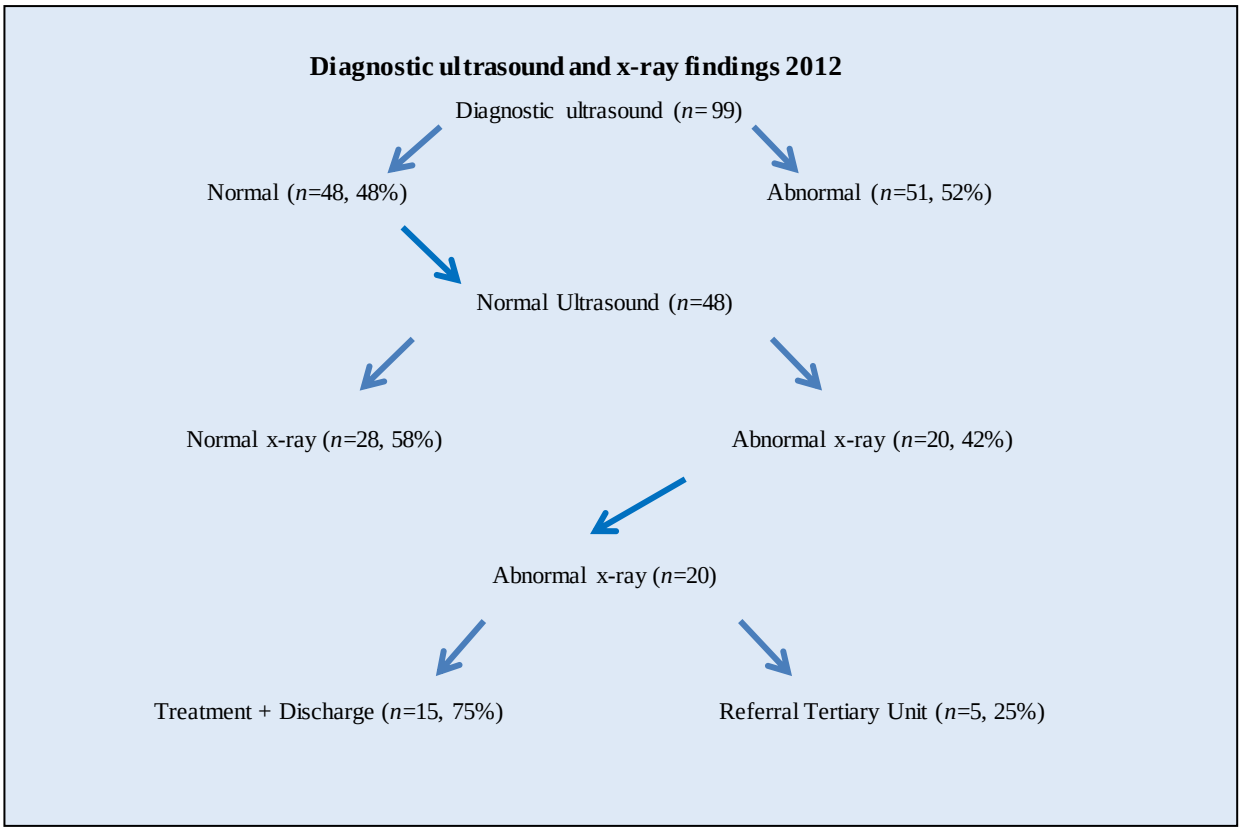

Figure 4.2 Diagnostic ultrasound and x-ray findings 2012

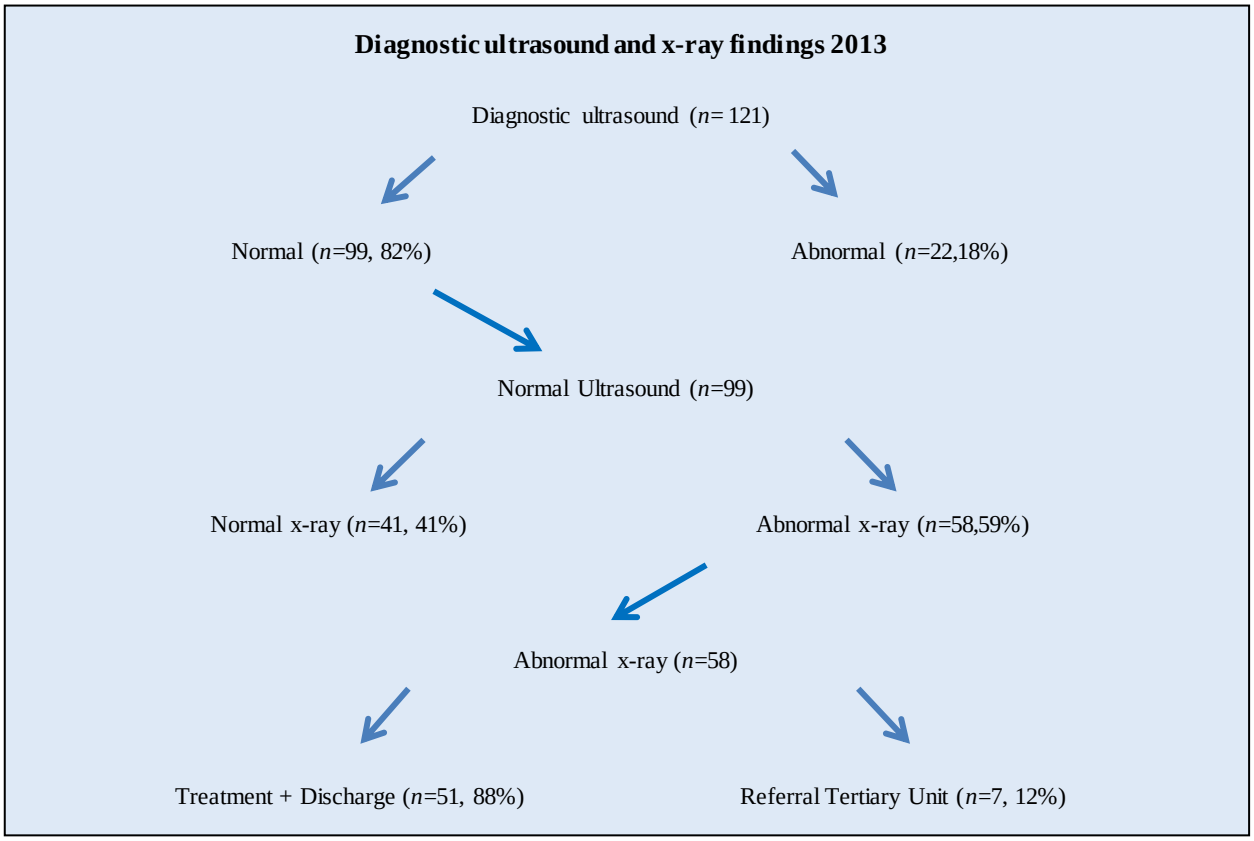

Figure 4.3 Diagnostic ultrasound and x-ray findings 2013

4.6 Source and Indications for Referrals

The majority of participants in both 2012 and 2013 were referred from the paediatric clinic 55% (*n* = 106) and 58% (*n* = 105) respectively, while the postnatal clinic referred 19% (*n* = 35) of the participants in 2012 and 14% (*n* = 26) in 2013. The Public Health Nurse referred 18% (*n* = 33) of the participants in 2012 and 13% (*n* = 24) in 2013, while the GP referred 9% (*n* = 16) and 13% (*n* = 24) in 2012 and 2013 respectively.

In both 2012 and 2013 the most common indication for referral were abnormal findings on Ultrasound or X-ray 29% (*n* = 56) and 42%, (*n* = 77) while the next leading reason for referral was from clinical suspicion 27% (*n* = 51) and 26% (*n* = 47). The least occurring cause for referral in both years was for instability at 7% (*n* = 14) and 10% (*n* = 19) respectively. See Table 4.4 below.

Table 4.4 Source and indication for referral

Source of Referral	**2012 (n=190)**		**2013 (n=182)**	
	Frequency (n)	**Percentage (%)**	**Frequency (n)**	**Percentage (%)**
Postnatal Clinic	35	19%	26	14%
GP	16	9%	24	13%
Paediatric Clinic	106	55%	105	58%
Public Health Nurse	33	18%	24	13%
Indication for Referral				
Instability	14	7%	19	10%
Limited abduction	24	13%	16	9%
Risk factors identified	45	24%	23	13%
Clinical suspicion	51	27%	47	26%
Abnormal findings on X-ray or US	56	29%	77	42%

4.6.1 Total number of referrals diagnosed with DDH

In total, 70% of referrals made to the clinic were diagnosed with DDH. Table 4.5 shows the number of referrals and the subsequent number of treated cases. Out of the 33 cases referred for suspected instability, 28 were diagnosed with DDH and treated (85%). Of the 40 infants who were referred due to limited abduction on clinical examination, 27 went on to be diagnosed and treated for DDH (68%). Thirty-eight infants (56%) out of a total of 68 who were referred because they had risk factors were diagnosed with the condition while 61 out of 98 infants referred because of a clinical suspicion were found to have DDH (62%). Out of the 133 infants referred because of abnormal findings on ultrasound or X-ray, 107 (62%), were diagnosed and treated for DDH. A Chi-square test for independence indicated a strong significant association between referrals made for DDH and the detection of DDH χ^2 (4, n=372) = 19.8, p = 0.001

Table 4.5 Referrals and cases of DDH

Indication for referral	**Referrals**		**Treated**	
	(*n*)	**(%)**	**(*n*)**	**(%)**
Instability	33	(9)	28	(85)
Limited abduction	40	(11)	27	(68)
Risk factors identified	68	(18)	38	(56)
Clinical suspicion	98	(26)	61	(62)
Abnormal findings on X-ray or US	133	(36)	107	(62)
Total	372	(100)	261	(70)

4.6.2 Type of treatment required based on referral indication

The most common indications for referral for those treated with a Pavlic Harness were the identification of risk factors and abnormal findings on ultrasound or X-ray (Identification of risk factors (25%, n=14). Abnormal findings on ultrasound or X-ray were also the most common indication for referral for those who were treated with a Boston Brace (53%, *n*=74). Infants that required treatment with both a Pavlik Harness and Boston Brace were most commonly referred due to abnormal findings on ultrasound or X-ray (39%, *n*= 7). The majority of those who ultimately were not diagnosed with DDH but were kept under surveillance were referred because of clinical suspicion (33%, *n*=37), which was also the most common indication for referral for those who required referral to a Tertiary Unit (36%, *n*=16). Table 4.6 below.

Table 4.6 Indication for referral and treatment types

Treatment Type	**Indication for referral**									
	Instability		**Limited abduction**		**Risk factors identified**		**Clinical suspicion**		**Abnormal findings on US/X-ray**	
	n	**(%)**	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**
Pavlik	12	(21)	10	(17)	14	(25)	7	(12)	14	(25)
Brace	6	(4)	9	(6)	15	(11)	37	(26)	74	(53)
Both	4	(22)	3	(17)	3	(17)	1	(5)	7	(39)
Surveillance	5	(5)	13	(12)	30	(27)	37	(33)	26	(23)
Tertiary Unit	6	(13)	5	(11)	6	(13)	16	(36)	12	(27)

4.7 Risk factors

Table 4.7 summarizes the risk factors that were noted to be present in each of the 2012 and 2013 groups as well as those who had no risk factors that were referred to the DDH clinic. The leading risk factor identified in both years was female gender 41%, 44%) followed by a positive family history (29%, 24%) Breech presentation was identified as a risk factor in 11% of the 2012 group and 2013 group. However, 17% of the 2012 group and 19% of the 2013 group had no risk factors present.

Table 4.7 Risk factors.

Risk factors	2012		2013	
	n	**(%)**	***n***	**(%)**
Family history	94	(29)	78	(24)
Foot deformity	1	(1)	2	(1)
Oligohydramnios	1	(1)	2	(1)
Breech presentation	36	(11)	37	(11)
Female	134	(41)	144	(44)
No risk factors	58	(17)	63	(19)

4.7.1 Evaluation of the accuracy of risk factors associated with the detection of DDH

Table 4.8 summarizes the evaluation of the accuracy of risk factors that present to the DDH clinic. Coexisting risk factors were detected in the medical history of 529 infants with a distribution of 172 family histories of DDH, 3 foot deformities, 3 oligohydramnios, 73 breech presentations, 278 female genders while 121 had no risk factors present. Three quarters (75%, *n*= 129) of those who had a positive family history of DDH were subsequently diagnosed with DDH. Sixty-six percent (*n*=48) of those infants who were born in a breech position were diagnosed with DDH while 77% (*n*=214) of the referrals who were female were diagnosed with DDH. However, 66% (*n*=80) of infants who had no identifiable risk factors received a diagnosis of DDH.

4.7.2 Sensitivity and specificity of key risk factors

Female gender had a sensitivity of 82% and a specificity of 42%. Breech presentation had a sensitivity of 23% and a specificity of 77%. Caesarian section delivery had a sensitivity of 37% and a specificity of 65%. Positive family history had a sensitivity of 49% and a specificity of 63%. A chi-square test indicated that female gender and positive family history were statistically significant indicators of DDH (Table 4.9).

Table 4.8 Distribution of risk factors according to final diagnosis

Risk factors	DDH		No DDH	
	n	**(%)**	***n***	**(%)**
Family history	129	(75)	43	(25)
Foot deformity	2	(67)	1	(33)
Oligohydramnios	2	(67)	1	(33)
Breech presentation	48	(66)	25	(34)
Female	214	(77)	64	(23)
No Risk Factors	80	(66)	41	(34)

Table 4.9 Validity of key risk factors in the detection of DDH

Risk factors	Sensitivity	Specificity	Positive Predictive Value	Negative Predictive Value	*p* Value
Female	82%	42%	77%	50%	0.000*
Breech presentation	23%	77%	68%	30%	0.759
Family History	49%	63%	76%	35%	0.036*

4.7.3 Bivariate analysis of key characteristics associated with DDH diagnosis

Among those diagnosed with DDH, 82% were female, 22% were of breech presentation and 495 had a family history of DDH. Thirty-five percent were referred from the Regional Centre, 23% from Rural 1, 31% from Rural 2 and 10% from Rural 3.

Bivariate analysis determined that female infants were significantly more likely to be diagnosed with DDH. Those who had a positive family history of DDH were also significantly more likely to be diagnosed with DDH. See Table 4.10 below.

Table 4.10 Bivariate analysis of key characteristics associated with DDH diagnosis

Risk factors	DDH (%) *n*=261	No DDH (%) *n*=111	*p* value
Female	82	58	0.000*
Breech Presentation	22	24	0.759
Family History	49	37	0.036*
Place of Birth			0.065
Regional Centre	35	21	
Rural 1	23	36	
Rural 2	31	29	
Rural 3	10	14	

4.7.4 Logistic regression analysis of key characteristics associated with DDH diagnosis

A logistic regression model was used to determine the effects of the key characteristic variables on the likelihood that a positive diagnosis of DDH would be made. The model contained 4 independent variables female gender; breech presentation at birth; positive family history and place of birth. The full model containing all predictors was statistically significant χ^2 (6, n=372) = 31.45, p<0.001 indicating that the model was able to distinguish between infants who were diagnosed with DDH and who were not. The model as a whole explained between 8.1 % (Cox and Snell R square) and 11.5 % (Nagelkerke R square) of the variance in DDH diagnosis and correctly identified 72% of cases.The logistic regression identified female gender (p=.000) and family history (p=0.019) as being significant indicators of a DDH diagnosis. (Table 4.11).

Table 4.11 Logistic regression of key characteristics associated with DDH diagnosis

Key Characteristics	**OR**	**SE**	**95% Confidence Interval**		***p* value**
Female	3.373	0.259	2.030	5.605	0.000*
Breech Presentation	1.243	0.296	0.696	2.219	0.462
Family History	1.837	0.259	1.106	3.050	0.019*
Place of Birth					0.491
Rural 1	1.522	0.330	0.797	2.907	0.203
Rural 2	0.977	0.308	0.535	1.787	0.941
Rural 3	1.223	0.392	0.567	2.638	0.567

4.7.5 Bivariate analysis of key characteristics associated with late diagnosis DDH

Among those diagnosed late with DDH, 80% were female, 19% were of breech presentation and 48% had a family history of DDH. Twenty-one percent were referred from the Regional Centre, 36% from Rural 1, 29% from Rural 2 and 14% from Rural 3.

Bivariate analysis indicated no significant difference in the effect of each key characteristic on the late diagnosis of DDH. See Table 4.12 below.

Table 4.12 Bivariate analysis of key characteristics

Characteristics	Early (%) *n*=78	Late (%) *n*=183	*p* value
Female	85	80	0.586
Breech Presentation	30	19	0.093
Family History	53	48	0.598
Place of Birth			0.065
Regional Centre	35	21	
Rural 1	23	36	
Rural 2	31	29	
Rural 3	10	14	

4.7.6 Logistic regression analysis of key characteristics associated with late diagnosis DDH

A logistic regression model was used to determine the effects of these key characteristics on the likelihood that a late diagnosis of DDH would be made. The model contained 4 independent variables female gender; breech presentation at birth; positive family history and place of birth. The full model containing all predictors was statistically significant χ^2 (6, n=261) = 12.790, p<0.005 indicating that the model was able to distinguish between infants who were diagnosed with DDH late and who were diagnosed early. The model as a whole explained between 4.8% (Cox and Snell R square) and 6.8 % (Nagelkerke R square) of the variance in late DDH diagnosis and correctly identified 71% of cases.The analysis identified breech presentation (*p*=0.034) and Rural 1 (*p*=0.011) as being significantly associated with receiving a late diagnosis of DDH. Table 4.13

Table 4.13 Logistic regression of key characteristics associated with late diagnosis DDH

Risk factors	OR	SE	95% Confidence Interval		*p* value
Female	0.663	0.379	0.315	1.337	0.279
Breech Presentation	0.489	0.337	0.253	0.947	0.034*
Family History	0.705	0.293	0.397	1.252	0.233
Place of birth					0.071
Rural 1	2.529	0.367	1.232	5.190	0.011*
Rural 2	1.609	0.358	0.797	3.249	0.184
Rural 3	2.217	0.484	0.859	5.721	0.100

4.7.7 Risk factors and treatment type

Sixteen percent (n=28) of those that had a positive family history needed to be treated with a Pavlik Harness while 41% (*n*=70) needed to be treated with a Boston brace. Five percent (*n*=8) required treatment with both the Pavlik Harness and the Boston Brace. Twenty-five percent (*n*=43) did not require any treatment but were kept under surveillance while 13% (*n*=23) required referral to a tertiary unit. Of the infants that were born in a breech presentation, 25% (*n*=18) were treated with a Pavlik Harness, while 37% (*n*=27) were treated with a Boston Brace. Thirty-four percent (*n*=25) did not require treatment but underwent surveillance. Within the group of infants that had no risk factors, 7% (*n*=9) required treatment with a Pavlik Harness and 36% (*n*=43) were treated with a Boston Brace. Seven percent (*n*=9) required treatment with both the Pavlik Harness and the Boston Brace. Thirty-four percent (*n*=41) did not require any treatment while 16% (*n*=19) were ultimately referred to a tertiary unit. These findings are presented in Table 4.14 below.

Table 4.14 Risk factors and treatment type

Risk Factors	**Treatment type**									
	Pavlik		**Brace**		**Both**		**Surveillance**		**Tertiary**	
	n	**(%)**	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**
Female	48	(18)	112	(40)	17	(6)	64	(23)	37	(13)
Family History	28	(16)	70	(41)	8	(5)	41	(25)	23	14)
Breech Presentation	23	(27)	31	(37)	3	(3)	25	30)	3	(3)

4.8 Age at First Referral

In terms of age at first referral, 31% (*n*=114) of infants were referred to the clinic by 12 weeks of age, while 10% (*n*=37) of infants were referred for the first time between 13 and 27 weeks of age. The majority of infants were referred between 28 and 52 weeks of age (55%, *n*=205), while 4% (*n*=16) were referred to the clinic for the first time at over 1 year of age. This means that overall, 31% of infants (*n*=114) were referred early (<12 weeks) to the DDH clinic, while the majority were referred late (*n*=258, 69%). The overall mean (±SD) age at first referral over the 2 year period was 25.92 weeks (18.29). Figure 4.2 shows the distribution of infants

presenting to the DDH clinic according to their age at first referral over the 2 year period. (Figure 4.4).

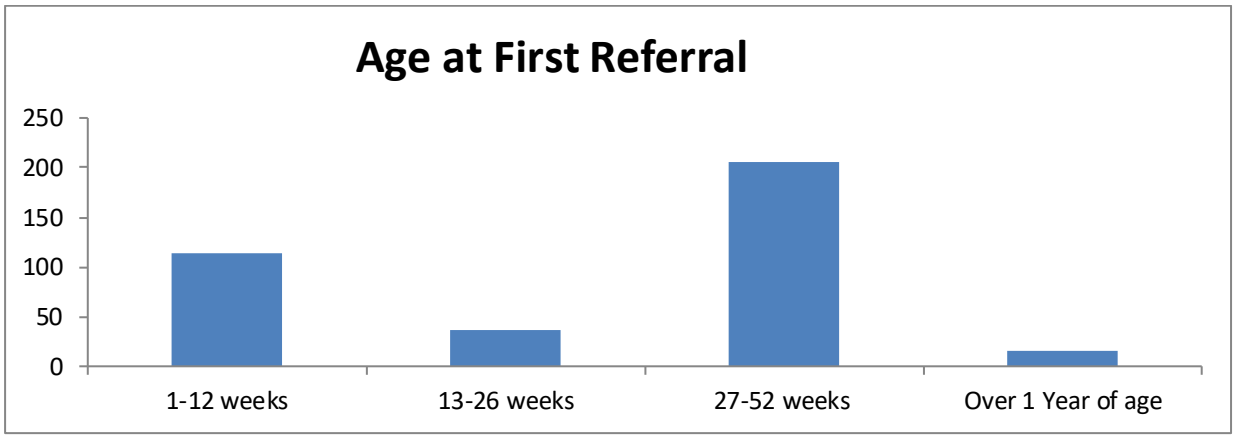

Figure 4.4 Distribution of age at first referral to DDH clinic.

4.8.1 Regional Differences in Age at First Referral

The majority of infants who were first referred within 1-12 weeks of age were born in the Regional Centre (41%, *n*=47), while the majority of infants who were referred within the ages of 13-26 weeks were born in the Rural 2 (51%, *n*=19). The highest numbers of referrals within the 27-52 week age bracket were babies born in the Rural 1 (34%, *n*=70), while the majority of infants referred over the age of 1 were referred from Rural 2 (38%, *n*=6). See Table 4.15.

Table 4.15 Regional Differences in Age at First Referral

Age at first referral	**Place of Birth**							
	Regional Centre		**Rural 1**		**Rural 2**		**Rural 3**	
	n	**(%)**	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**
1-12 weeks	47	(41)	25	(22)	31	(27)	11	(10)
13-26 weeks	4	(11)	10	(27)	19	(51)	3	(8)
27-52 weeks	41	(20)	70	(34)	59	(29)	34	(16)
Over 1 year	3	(19)	3	(19)	6	(38)	3	(19)
Total	95	(26)	108	(29)	115	(31)	51	(13)

Some percentages calculated using denominator less than stated total due to missing data.

A *Kruskal-Wallis* test measured regional differences in the average age of first referral. This revealed a statistically significant difference between places of birth in relation to age at referral χ^2 (n=372) = 26.640, p = 0.000. (GP1, *n*=95: Regional Centre, GP2, *n* = 108: Rural 1, GP3, *n* =115: Rural 2, GP4, *n* = 51: Rural 3). See Table 4.16 below.

Table 4.16 Median Values for Age at First Referral in each region

Place of Birth	Mean	SD	Median
Regional Centre	19.14	17.11	20.00
Rural 1	27.66	14.80	31.00
Rural 2	26.93	20.77	29.00
Rural 3	32.08	18.03	33.00

4.8.2 Regional differences in Age at First Referral compared with the Regional Centre

Further analysis was carried out using a non-parametric Mann-*Whitney U* tests (employing Bonferroni correction) to examine the difference between the ages at first referral in each of the different counties versus the Regional Centre. Rural 1 (*Md* = 31, *n* = 108), *U* = 3377, *z* = -4.202, *p* = 0.000, *r* = .40, Rural 2 (*Md* = 29, n = 115), U = 4316, z = -3.029, *p*= 0.002, r = .28, Rural 3 recorded a higher median score than the other regions (*Md*= 33, n = 51), U = 1437, z = -4.053, *p* = 0.000, r = .57, see Table 4.17.

Table 4.17 Regional differences in Age at First Referral compared with the Regional Centre

Rural Centres vs Regional Centre	*r* value	*p* value
Rural 1 v Regional Centre	0.40	0.000*
Rural 2 v Regional Centre	0.28	0.002*
Rural 3 v Regional Centre	0.57	0.000*

4.8.3 Association between Region of Birth and Early/Late Referral.

A Chi-square test for independence indicated a strong significant association between early and late referrals and region of birth χ^2 (4) = 22.741, *p* = 0.000. The majority of infants who were referred early to the clinic were referred from the Regional Centre (41%) while the majority of infants who were referred late were born in Rural 2 (33%). See Table 4.18 below.

Table 4.18 Association between Region of Birth and Early/Late Referrals

Early/Late Referral	Regional Centre		Rural 1		Rural 2		Rural 3	
	n	(%)	*n*	(%)	*n*	(%)	*n*	(%)
Early	47	(41)	25	(22)	31	(27)	11	(10)
Late	48	(18)	83	(32)	84	(33)	40	(16)

Some percentages calculated using denominator less than stated total due to missing data.

4.8.4 Age at first referral and treatment type

In the 2012 group, the majority of those who were referred for the first time in the 1-12 week bracket were successfully treated with a Pavlik Harness (62%). In the 13-26 week age bracket, the majority of infants were also treated with a Pavlik Harness (44%). In the 27-52 week age range, 59% of infants were successfully treated with the Boston Brace, while in the over 1 year of age group, the majority of infants attending for the first time required no treatment and were discharged following surveillance . In total, the most common form of treatment in the 2012 group was the Boston Brace (35%). Figures are presented in Table 4.1

Table 4.19 Age at first referral and treatment type 2012

Age at first referral	**Treatment Type**							
	Pavlik		**Brace**		**No Treatment**		**Refer**	
	n	**(%)**	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**
1-12 weeks	39	(62)	2	(3)	18	(29)	4	(6)
13-26 weeks	8	(44)	5	(28)	3	(17)	2	(11)
27-52 weeks	1	(1)	58	(59)	27	(27)	13	(13)
Over 1 year of age	0	(0)	1	(10)	7	(70)	2	(20)
Total	48	(25)	66	(35)	55	(29)	21	(11)

In the 2013 group, of those who were referred for the first time within 1-12 weeks of age, the most common form of treatment was the Pavlik Harness (47%). Within the 13-26 week age range, the majority of infants required no treatment (58%). Of those who attended for the first time between 27-52 weeks of age, 63% were successfully treated with a Boston Brace. Of those who attended for the first time at over 1 year of age, 67% required no treatment; however, 33% required referral to a Tertiary Unit. See Table 4.20.

Table 4.20 Age at first referral and treatment type 2013

Age at first referral	**Treatment Type**							
	Pavlik		**Brace**		**No Treatment**		**Refer**	
	n	**(%)**	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**
1-12 weeks	24	(47)	6	(12)	18	(35)	3	(6)
13-26 weeks	3	(15)	2	(11)	11	(58)	3	(16)
27-52 weeks	0	(0)	67	(63)	23	(22)	16	(15)
Over 1 year of age	0	(0)	0	(0)	4	(67)	2	(33)
Total	27	(15)	75	(41)	56	(31)	24	(13)

4.8.5 Age at first referral and final outcomes

Over the 2 year period, the majority of infants who were referred to the DDH clinic by the time they were 12 weeks of age were successfully treated and discharged (*n*=71, 62%) while 36 of the infants (32%) were ultimately discharged having required no active treatment. Six percent

however, required referral to a tertiary unit. Within the 13 -26 week age group, 48% of infants were successfully treated and discharged while 39% of infants were ultimately discharged having required no active treatment. Thirteen percent required referral to a Tertiary Unit. Within the 27-52 week age bracket, 126 (62%) required treatment and were successfully discharged while 50 infants (24%) were ultimately discharged having required no active treatment. Twenty-nine infants however (14%), were referred to a tertiary unit. The majority of infants (*n*=11, 69%) who were referred over the age of 1 year were successfully discharged following regular surveillance, however 4 infants (25%) required referral to a tertiary unit. See Figure 4.5 below.

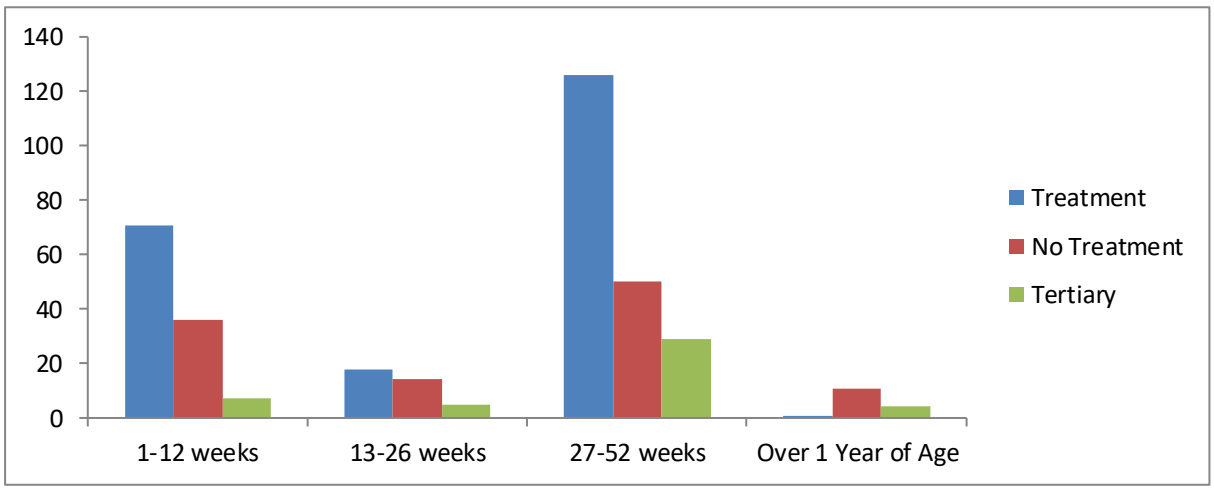

Figure 4.5 Proportion of infants successfully treated, referred and not requiring treatment according to age at first referral over the 2 year period.

4.8.6 Age at first referral and final outcomes year by year

In 2012, within the 1-12 week age bracket, 92% of infants were successfully treated and discharged. Eight percent required referral to a Tertiary Unit. In the 13-26 week age bracket, 89% were successfully treated and discharged while 11% required referral to a Tertiary Unit. Eighty-seven percent of those in the 27-52 week age bracket were successfully treated and discharged, while 13% required referral to Tertiary Unit. Of those that were over 1 year of age at first referral, 80% were treated and discharged while 20% required referral to a Tertiary Unit. In total, 88% of infants seen in the DDH clinic were successfully treated while 12% were ultimately referred to a Tertiary Unit. (Figure 4.6)

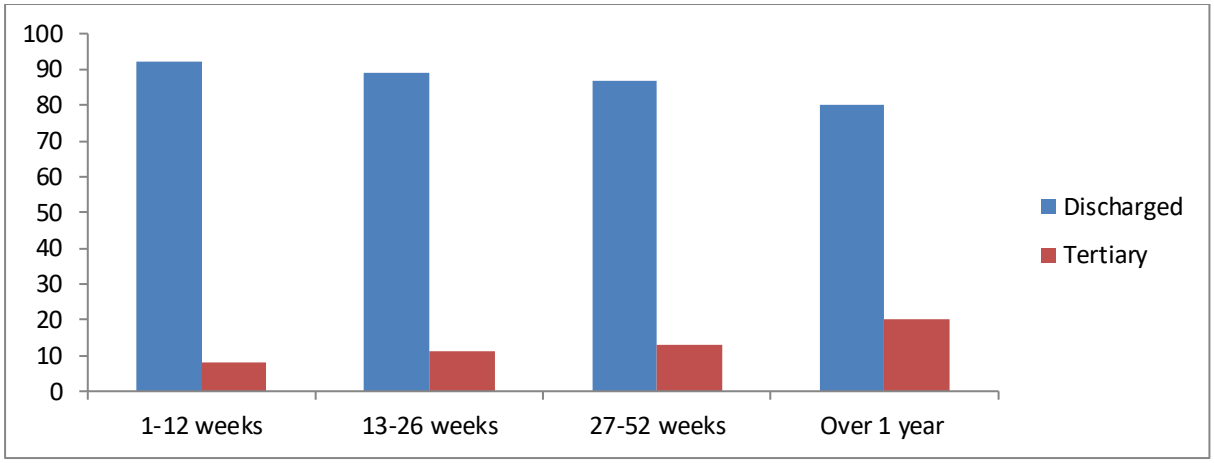

Figure 4.6 Final Outcomes based on Age at First Referral 2012.

In 2013, within the 1-12 week age bracket, 94% of infants were successfully treated and discharged. Six percent required referral to a Tertiary Unit. In the 13-26 week age bracket, 84% were successfully treated and discharged while 16% required referral to a Tertiary Unit. Eighty-four percent of those in the 27-52 week age bracket were successfully treated and discharged, while 16% required referral to Tertiary Unit. Of those that were over 1 year of age at first referral, 67% were treated and discharged while 20% required referral to a Tertiary Unit. In total, 88% of infants seen in the DDH clinic were successfully treated while 33% were ultimately referred to a Tertiary Unit. (Figure 4.7).

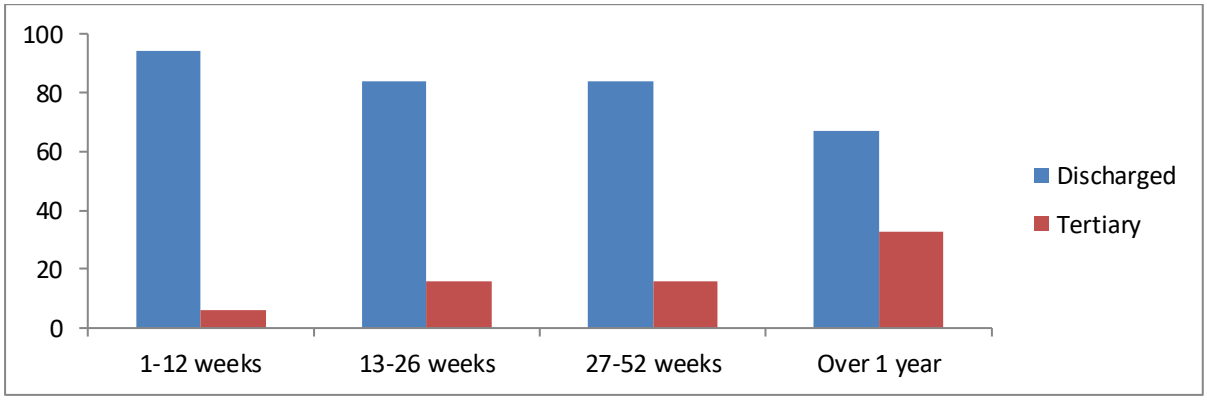

Figure 4.7 Final Outcomes based on Age at First Referral 2013.

4.8.7 Early/late referral and final outcomes

Ninety-two percent of those referred early within 12 weeks of age in 2012 were successfully treated and/or discharged while 8% required referral to a Tertiary Unit. Of those who were referred late, 87% were successfully treated and/or discharged while 13% required referral to a Tertiary Unit. See Figure 4.8 below

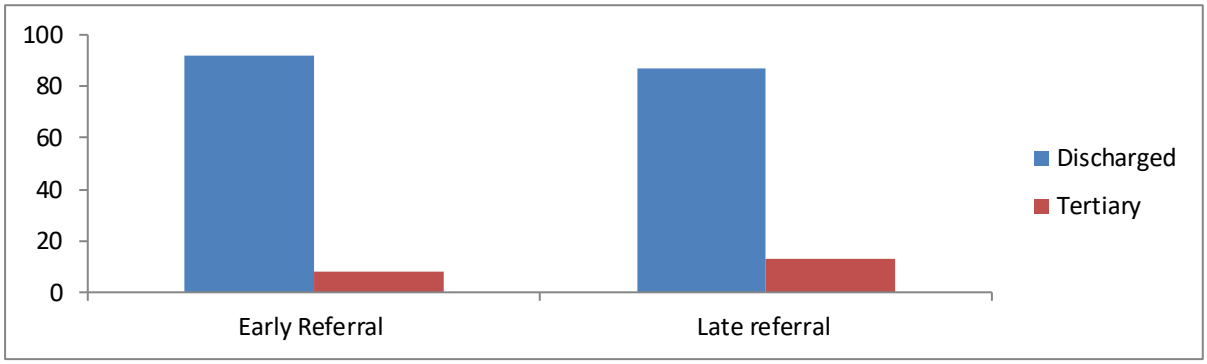

Figure 4.8 Final outcomes based on early/late referrals

In 2013, 94% of those referred early were successfully treated and/or discharged and 6% required referral to a Tertiary Unit. Of those referred late in 2013, 83% were successfully treated and/or discharged while 17% required referral to a Tertiary Unit. See Figure 4.9 below

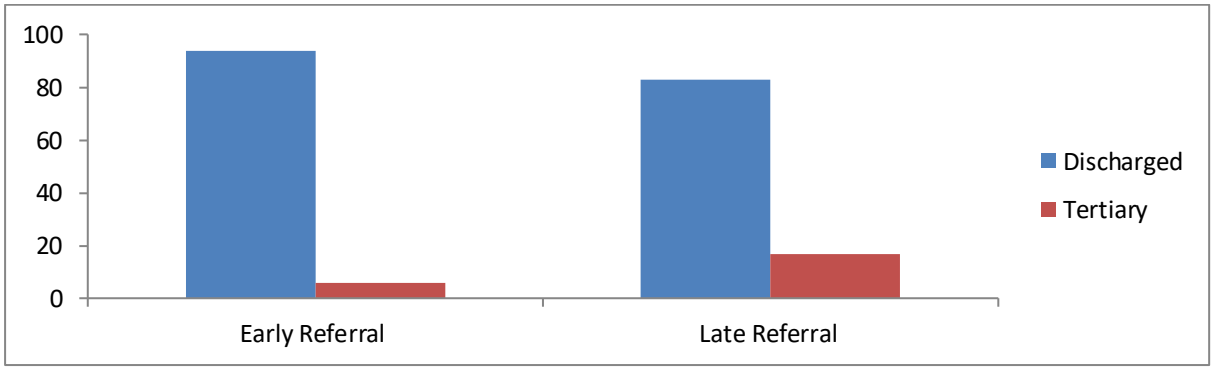

Figure 4.9 Final Outcomes base on Early/Late Referral 2013.

4.9 Summary of Phase 1 Findings

In summary, 372 infants who were born in 2012 and 2013 were referred to the clinic. The majority of infants who attended in both years was female (71%, *n*=134 in 2012 and 79%, *n*= 144 in 2013). An overall incidence rate of 17.5 per 1000 live births was established. In 30% of these newborns (*n*=78), the diagnosis was made within 12 weeks of age giving an early incidence rate of 5.23 per 1000 live births. Seventy percent of the newborns diagnosed with DDH (*n*=183), was diagnosed over 12 weeks of age giving a late diagnosis rate of 12.29 per 1000 live births in the region.

A significant relationship was found between clinical examination of the hips, ultrasound and x-ray in relation to the diagnostic value for screening for DDH. However, sensitivities,

specificities, positive predictive and negative predictive values varied across the 3 screening methods. Seventy percent of referrals to the DDH clinic were diagnosed with DDH. In relation to the role of risk factors in the diagnosis of DDH, bivariate and logistic regression analysis showed that female gender (p=.000) and family history (p=0.019) were statistically significant indicators of DDH. In relation to the late diagnosis of DDH, bivariate analysis showed no significant difference in the effect that key characteristics had on late diagnosis; however logistic regression identified breech presentation (p=0.034) and Rural area 1 (p=0.011) as being significantly associated with receiving a late diagnosis of DDH.

The overall mean (±SD) age at first referral over the 2 year period was 25.92 weeks. Thirty-one percent (n=114) of infants were referred to the clinic by 12 weeks of age, however, the majority of infants were referred between 28 and 52 weeks of age (55%, n=205). The majority of infants who were first referred within 1-12 weeks of age were born in the Regional Centre (41%, n=47). A *Kruskal-Wallis* test revealed a statistically significant difference between places of birth in relation to age at referral χ^2 (n=372) = 26.640, p = 0.000. (GP1, n=95: Regional Centre, GP2, n = 108: Rural 1, GP3, n =115: Rural 2, GP4, n = 51: Rural 3). A Chi-square test indicated a strong significant association between early and late referrals and region of birth χ^2 (4) = 22.741, p = 0.000.

Ninety-two percent of those referred early within 12 weeks of age in 2012 were successfully treated and/or discharged while 8% required referral to a Tertiary Unit. Of those who were referred late, 87% were successfully treated and/or discharged while 13% required referral to a Tertiary Unit. In 2013, 94% of those referred early were successfully treated and/or discharged and 6% required referral to a Tertiary Unit. Of those referred late in 2013, 83% were successfully treated and/or discharged while 17% required referral to a Tertiary Unit.

4.10 Conclusion

This chapter described the key findings from the statistical analysis of the retrospective chart review of all babies born in 2012 and 2013 who were referred to the DDH clinic. Key outcomes measures regarding incidence rates for DDH, late diagnosis rates, screening methods and successful treatment rates in the South East of Ireland were identified.

The findings from the parental questionnaire undertaken in Phase 2 and the semi-structured interviews undertaken by parents and HCP's in Phase 3 are presented in the next chapter whereby the experiences of the parents caring for a child with DDH and their views on

provision of services to DDH are explored in Strand 1 of Phase 3. The views of HCP's who are screening and referring suspected DDH in the community are explored in Strand 2 of Phase 3. It is hoped that the findings from Phases 2 and Strand 1 of Phase 3 will provide important insights into the complexities of a parent receiving a newborn diagnosis of DDH for their child and to gain a detailed understanding of the level of care involved in the management of a child undergoing treatment for the condition. The findings of Strand 2 of Phase 3 will enable us to gain information on the DDH screening and referral practises utilised in the community as part of the Healthy Childhood Programme and to determine any potential barriers to the successful referral and management of infants with potential DDH.

Chapter 5 Presentation of Findings Phases 2 and 3

5.0 Introduction

This mixed-methods study sought to meet the overall research aims and objectives as outlined in Table 3.1 (p. 51). The study incorporated three phases with the intention of exploring the quality of health care outcomes and the provision of DDH services from the perspectives of the parents in receipt of care for their newly diagnosed infants and from the perceptions the HCP's directly involved in the screening and referring of infants with suspected DDH. This chapter presents the findings from two phases of the research project and is reported in two sections. Section 5.1 presents the findings from the second phase of the study, which comprised of a questionnaire representing the second part of the quantitative section of the mixed methods research study. The purpose of Phase 2 was to explore the experiences of parents utilising a dedicated DDH clinic in the south East of Ireland. Section 5.2 presents the findings from the 1st strand of Phase 3 which had the intention of eliciting a deeper understanding of the experiences of parents receiving a diagnosis of DDH and caring for a child at home with DDH. Finally, section 5.3 presents the findings from the 2nd Strand of Phase 3 of the research project representing HCP's (*n*=8) involved with the direct provision of screening and referral services. A summary of the main findings of the study are presented at the end of the chapter. Integration of the findings involving all phases are then discussed in Chapter 6 as is the case with most sequential explanatory designs.

5.1 Findings of Phase 2 – The questionnaire

The purpose of Phase 2 was to determine the satisfaction rates of parents utilising a dedicated DDH clinic. It was also to identify what were the main concerns of parents in relation to their babies being treated for DDH. The data collection period was over 3 months. The results are presented under the following headings:

- Demographic information of the infants referred to the DDH clinic - gender, age at diagnosis, type of delivery and presentation at birth.
- Referral details - type of HCP who referred and reason for referral.
- Type of treatment received by infant in DDH clinic

- Parents' perceptions of the DDH clinic – waiting times for- 1st appointment, waiting times in clinic, HCP seen in clinic, explanations given, opportunity to ask questions, any further treatment required and contact numbers given.
- Parents' worries regarding caring for an infant with DDH - worries related to receiving an early/late diagnosis
- Parents' perceptions of overall quality of the DDH service
- Open ended question in relation to how DDH service could be improved.

5.1.1 Demographic information

Demographic information obtained from the questionnaire provides a profile of the infants attending the DDH clinic. A total of 100 parents/guardians of infants with suspected or diagnosed DDH participated in the survey. Demographic characteristics of the infants attending the DDH clinic are summarized in Table 5.1. Female infants constituted 80% (*n*=80) of the sample, whilst male infants constituted 20% (*n*=20) of the sample. Fifty percent (*n*=50) were diagnosed in the 1-6 week age bracket. It was found that 20% of infants were referred to the clinic after more than 52 weeks.

The largest percentage of participants were born by normal delivery 52% (*n*=52), followed by a lower segment caesarean section rate of 34% (*n*=34) and an instrumental delivery rate of 14% (*n*=14). Twenty-eight percent of infants born were in a breech position while 71% born were in a cephalic presentation.

5.1.2 Referral details.

Participants were asked to specify what type of health professional they had an appointment with and to specify what reason was given to them for their referral. The majority of infants were referred by a paediatrician (74%, *n*=74), a smaller percentage were referred by a Public Health Nurse (12%, *n*=12), a General Practitioner referred 8% (*n*=8) of the infants while a small percentage of infants (4%, *n*=4) were referred by a midwife.

Findings revealed that 26% (*n*=26) were informed that their child's referral was due to dysplasia of the hip. Twenty-two percent (*n*=22) of parents were told the referral was because of a positive family history of DDH while 13% (*n*=13) of parents were told that their referral was due to a dislocation of their child's hips.

Table 5.1 Demographic information

Demographic information (n=100)	**Frequency (*n*)**	**Percentage (%)**
Gender		
Male	20	20%
Female	80	80%
Age of diagnosis (weeks)		
Birth to 6 weeks	50	50%
7-13 weeks	15	15%
14 to 20 weeks	3	3%
More than 21 weeks	10	10%
More than 52 weeks	20	20%
Type of delivery		
Normal	52	52%
Instrumental	14	14%
Caesarean	34	34%
Presentation		
Breech	28	28%
Cephalic	71	71%

5.1.3 Type of treatment received

Participating parents were asked what type of treatment their infant was receiving in the DDH clinic. The findings showed that the Pavlic Harness was used to treat the majority of infants (48%, *n*=48) which indicates that treatment commenced within the first 3 months of life. The Boston Brace which is the treatment of choice for infants over the age of 3 months was used to treat 34% (*n*=34) of infants. Twelve percent of infants were attending the clinic for observation and one infant was referred to a tertiary unit for surgery.

5.1.4 Parents' perceptions of the DDH clinic

Parents were asked a number of questions in relation to different aspects of their experience utilizing the DDH clinic. Findings revealed that the majority of parents were given a first appointment within three weeks of a referral being made (52%, *n*=52), whilst 28% (*n*=28) waited 4-6 weeks for an appointment. Six percent (*n*=6) were waiting 7-10 weeks and 8% (*n*=8) were waiting more than 11 weeks for an initial visit. Respondents were then asked to indicate whether they felt the length of time waiting for the appointment was too long, as expected or better than expected. Eighty-eight percent (*n*=88) of parents felt it was as expected while 11% (*n*=11) of parents thought it was too long. See Table 5.2 below.

Table 5.2 Time waiting for 1st appointment.

Time waiting (weeks)	Frequency (*n*)	Percentage (%)
1-3 weeks	52	52%
4-6 weeks	28	28%
7-10 weeks	6	6%
11 plus weeks	8	8%

The waiting times involved when parents brought their infants to the DDH clinic are summarized in Table 5.3 below. The findings demonstrated that the highest proportion of the sample 37% (*n*= 37) waited between 16-30 minutes to be seen initially at the clinic. Thirty-one percent (*n*=31) waited between 31-60 minutes for their visit and 26% (*n*=26) waited over 60 minutes to be seen. Five percent (*n*=5) of parents were waiting less than 15 minutes.

Table 5.3 Waiting times at DDH clinic.

Waiting times at the DDH clinic	Frequency (*n*)	Percentage (%)
Less than 15 minutes	5	5%
16-30 minutes	37	37%
31-60 minutes	31	31%
Over 60 minutes	26	26%

Respondents were asked to indicate what kind of HCP they saw at each visit. Seventy-nine percent (*n*=79) of parents saw both a doctor and a nurse at each clinic appointment while 14% (*n*=14) saw a doctor only during their visit.

When asked if it was explained to them why their child was being examined, 98% (*n*=98) of parents felt that they were given an adequate explanation in a way that they understood. The participants were asked about whether they were given the opportunity to ask questions about their infant's care, the majority (98%, n=98) of parents felt they were. Ninety-one percent of the participants (*n* = 91) felt that the length of time given during their appointment was appropriate for their needs. When asked if it was explained to them if their infant needed further treatment, 74% (*n*=74) answered yes while 12% (*n*=12) answered no.

Over half of those surveyed (65%, n=65) were given a contact number to use if they had any worries about their infants treatment. Twenty-one percent (*n*=21) answered that they were not

given a contact number while 6% (*n*=6) of parents answered that they felt it was not applicable to them as their child was under observation only.

5.1.5 Parents' worries regarding caring for an infant with DDH

This section of the questionnaire required respondents to rate their worries regarding the diagnosis and care of an infant with DDH using a Likert scale. A high percentage of parents (73%, *n*=69) were very upset when they were first told that their baby had an unstable hip. Fifty-five percent (*n*=49) of parents got upset when they looked at their baby's hips in a harness. A high percentage of parents (73%, *n*=65) worried if their baby was comfortable in the harness provided for treatment. Additionally, a high percentage of parents worried about how the hip instability might affect their baby in the future (69%, *n* = 69) and worried if their baby would be able to walk (56%, *n* =56). When asked if it was difficult to change the baby's nappy under the harness 63% (*n*=57) disagreed with the statement, however 51% (*n*=45) indicated that they found it difficult to wash their baby.

Further statistical tests revealed mean values in relation to parents' worries ranging from 2 which indicated disagreement with the statement, 3 which meant they had no opinion or were uncertain about the statement to 4 which indicated agreement. The statements relating to being upset when told of the baby's unstable hip and worry relating to how the hip instability will affect the baby in the long term scored the highest mean values 3.93 and 3.75 respectively which indicate the highest level of worry scored. The 2 statements relating to cuddling and playing with the baby received the lowest mean values 2.39 and 2.20 respectively. When the standard deviations were examined it appeared that they were similar ranging from 1.05 to 1.42, so levels of variation were similar across the 17 items. See Table 5.4

Table 5.4 Infant hip worries inventory with mean scores for Parents' worries in relation to caring for an infant with DDH

Statement	Disagree	No opinion or uncertain	Agree	Mean (±SD)
I was very upset when I was first told that my baby had DDH	21 (22%)	5 (5%)	69 (73%)	3.93 (1.22)
I get upset when people ask me about my baby's hips	66 (71%)	9 (10%)	18 (19%)	2.37 (1.09)
I worry that I might do something to hurt my baby's hips	50 (54%)	11 (12%)	31 (34%)	2.79 (1.25)
I get upset when I look at my baby in a harness/brace	34 (43%)	6 (7%)	49 (55%)	3.26 (1.33)
I find it difficult to feed my baby	64 (72%)	3 (3%)	22 (25%)	2.38 (1.26)
I find it difficult to wash my baby	38 (43%)	5 (6%)	45 (51%)	3.16 (1.41)
I find it difficult to change my baby's nappy	57 (63%)	6 (7%)	27 (30%)	2.61 (1.17)
I find it difficult to dress my baby	50 (56%)	12 (14%)	27 (30%)	2.67 (1.29)
I find it difficult to cuddle my baby	60 (68%)	6 (7%)	22 (25%)	2.39 (1.29)
I find it difficult to play with my baby	64 (76%)	5 (6%)	15 (18%)	2.20 (1.18)
I find the harness/brace restricts my activity with my baby	39 (45%)	6 (7%)	41 (48%)	3.06 (1.40)
I worry about whether my baby is comfortable	16n (18%)	8 (9%)	65 (73%)	3.75 (1.05)
I find it difficult to manage the harness/brace	50 (60%)	13 (16%)	20 (24%)	2.53 (1.15)
I find it difficult to strap my baby into their car seat	51 (58%)	7 (8%)	30 (34%)	2.75 (1.29)
I worry before each hospital visit related to my baby's hips	36 (40%)	4 (5%)	49 (55%)	3.27 (1.32)
I worry about the effect the hip instability might have on my baby in the future	26 (29%)	2 (2%)	61 (69%)	3.62 (1.33)
I worry about my baby walking in the future	34 (38%)	5 (6%)	49 (56%)	3.33 (1.42)

Percentage agreement (collapsed agreements scored based on the percentage agreeing and strongly agreeing) and frequencies were compared in parents whose child had been diagnosed early(< 3 months of age) or diagnosed late (>3 months of age) with DDH. See Table 5.5. Replies from parents whose child had been diagnosed early or diagnosed late with DDH were compared using a Man-Whitney U Test; this was statistically significant in 4 areas; difficulty in washing baby (p= 0.000), difficulty in dressing baby (p= 0.041), worry before each hospital visit related to baby's hips (p=0.027) and worry relating to baby walking in the future (p= 0.014).. There was no significant difference between the early and late group in relation to how

upset they felt when told that their baby had DDH or in relation to how upset they are when they look at their baby in a harness or brace.

Table 5.5 Worry relating to early or late diagnosis of DDH

Statements	**Early Diagnosis (N=65)** [a] Mean (±SD) ***n*** **(%)**	**Late diagnosis (N= 33)** [a]Mean (±SD) ***n*** **(%)**
I was very upset when I was first told that my baby DDH	3.98 (1.15) **46 (74)**	3.77 (1.38) **22 (69)**
I get upset when people ask me about my Baby's hips	2.44 (1.18) **15 (25)**	2.16 (.86) **3 (9)**
I worry that I might do something to hurt my baby's hips	2.90 (1.25) **23 (37)**	2.59 (1.27) **8 (27)**
I get upset when I look at my baby in a harness/brace	3.43 (1.29) **37 (62)**	2.90 (1.34) **12 (41)**
I find it difficult to feed my baby	2.31 (1.20) **14 (23)**	2.54 (1.37) **8 (29)**
I find it difficult to wash my baby **	3.58 (1.33) **40 (67)**	2.25 (1.14) **5 (18)**
I find it difficult to change my baby's nappy	2.75 (1.26) **23 (38)**	2.31 (.89) **4 (14)**
I find it difficult to dress my baby *	2.85 (1.29) **20 (33)**	2.29 (1.21) **7 (25)**
I find it difficult to cuddle my baby	2.33 (1.25) **14 (23)**	2.52 (1.40) **8 (30)**
I find it difficult to play with my baby	2.28 (1.27) **11 (19)**	2.04 (.96) **4 (15)**
I find the harness/brace restricts my activity with the baby	2.95 (1.43) **26 (43)**	3.31 (1.32) **15 (58)**
I worry about whether my baby is comfortable	3.70 (1.07) **43 (70)**	3.86 (1.00) **22 (79)**
I find it difficult to manage the brace/harness	2.54 (1.15) **14 (25)**	2.50 (1.17) **6 (23)**
I find it difficult to strap my baby into the car seat	2.61 (1.25) **18 (30)**	3.07 (1.33) **12 (44)**
I worry before each hospital visit related to my baby's hips*	3.05 (1.33) **28 (47)**	3.68 (1.19) **21 (72)**
I worry about the effect the hip instability might have on my baby in the future**	3.46 (1.38) **38 (62)**	3.93 (1.14) **23 (82)**
I worry about my baby walking in the future*	3.08 (1.41) **29 (48)**	3.81 (1.30) **20 (71)**

[a]Some percentages calculated using denominator less than stated total due to missing data

*p < .05; ** p < .001

5.1.6 Parents' overall satisfaction levels with quality of the DDH service

Subsequently, findings indicated a high degree of satisfaction with the DDH service. Fifty-four percent (*n*=54) of parents were very satisfied with the service, 43% (*n*=43) of parents were satisfied whilst only 1% (*n*=1) were dissatisfied with the quality of the service provided in the clinic.

5.1.7 Open ended question regarding DDH service

In Phase 2 respondents were also asked to suggest ways the service could be improved in an open ended question. Six broad themes emerged from thematic analysis of the data which could be divided into two areas of satisfaction and dissatisfaction with the DDH clinic.

5.1.7.1 Satisfaction with the clinic:

A variety of positive perspectives were expressed which when taken together resulted in three primary themes being of a positive nature: professional service, caring attitude of the staff and overall satisfaction with the clinic.

Professional service

A common thread through the various answers of the participants was their sense that they were receiving a very professional service in the DDH clinic. Their responses demonstrate respondents' beliefs that they were very happy with quality of the service.

> *'My baby is receiving the best possible care'.*
>
> ***(Parent No 4)***
>
> *'The competency of the staff is great.'*
>
> ***(Parent No 14)***

Caring attitude of the staff

Just over half of those who answered the question reported that they felt very well cared for in the clinic. A significant number of participants felt the staff were very friendly and were found to be most satisfied with how helpful the staff were.

> *'We receive great care and attention in this clinic.'*
>
> **(*Parent No 27)***
>
> *'The staff are very approachable and friendly.'*
>
> ***(Parent No 63)***

Overall satisfaction with the clinic

A recurrent theme in the answers was overall satisfaction with the service and parents felt nothing needed to be improved in the clinic.

'*One of the best hospital clinics. Highly recommend to other parents.'*

(Parent No 45)

'Very impressed with every visit.'

(Parent No 83)

5.7.1.2 Dissatisfaction with the clinic:

Three themes emerged from the negative feedback given by the parents: waiting times for referral to the DDH clinic, the appointment allocation system and waiting times not child friendly.

Waiting times for referral to the clinic

Four participants indicated that they felt the length of time waiting for their child to be referred to the clinic as too long, while three participants felt they did not get enough notice to attend their clinic appointment.

'Should have been referred to the clinic sooner than 6 months.'

(*Parent No 2)*

'2 weeks' notice for appointments would be helpful to organise work schedule.'

(Parent No 93)

Appointment allocation system

Parents were dissatisfied with the allocation of appointment times within the DDH clinic. The majority of complaints classified in this category were general statements on the length of time waiting to be seen once they arrived in the clinic. Some statements blamed the block appointment system used as a cause for the length waiting times.

'Block appointments, too many people waiting at the same time.'

(*Parent No 17)*

)

'More accurate appointment times please, very difficult with young babies'.

(Parent No 66)

Waiting times not child/family friendly

The overwhelming majority of analysed statements highlighted the difficulties of keeping young babies and toddlers settled during the prolonged period of time waiting to be seen.

> *'Long waiting times, especially with young children, hard to keep them entertained.'*
>
> ***(Parent No 40***

> *'These waiting times are very hard on young children.'*
>
> ***(Parent No 76)***

5.1.8 Summary of Phase 2 findings

Overall, findings from Phase 2 of the study revealed that the majority of parents were very satisfied with the quality of service offered by the DDH clinic. Eighty percent (*n* =80) received their first appointment for the DDH clinic within 6 weeks of a referral being made. Ninety-eight percent of parents felt that the examination of their newborn was explained to them in a way that they understood, while the same percentage felt they were given ample opportunity to ask questions. Ninety-one percent of parents felt that the length of time given for their appointment was adequate for their needs.

However, the findings from the questionnaire highlight in particular the psychosocial impact that receiving a diagnosis of DDH and caring for a child with DDH can have on the parents. Seventy-three percent (*n* =73) of parents were very upset when they first received the diagnosis of DDH in the clinic. A further 73% (*n* =73) worried about whether their child was uncomfortable in the harness provided for treatment of DDH, while 69% (*n* =69) of parents worried about whether their child would suffer any long term disability as a result of DDH. When data was compared between parents whose child had been diagnosed early with parents whose child had been diagnosed late, findings revealed that parents in the early group expressed significantly more worries in relation to washing and dressing their baby while the parents in the late group expressed significantly more worries in relation to hospital appointments and relating to whether their baby would walk in the future.

Overall, findings from the open-ended question revealed a variety of positive perspectives in relation to the DDH clinic. Suggestions for improvement in the clinic were predominantly based around the block allocation system for appointment times leading to lengthy waiting

times which were deemed not to be child or family friendly. However, a number of complimentary comments in relation to the staff and service were made. Parents reported that they felt they were receiving a very professional service and felt very well cared for by the staff.

5.2 Findings from Phase 3 Strand 1 - semi-structured interviews with parents

The purpose of Strand 1 of Phase 3 was to elicit a deeper understanding of the experiences of parents caring for a child with DDH and to discover the principal concerns of parents caring for a child who has been diagnosed with DDH and is undergoing treatment for the condition.

5.2.1 Demographic details of parents and infants attending the DDH Clinic

Out of the 11 parents who participated in this part of the study, the primary caregiver was the mother in all cases. These parents were from different parts of the South East region. The demographic details of the parents who participated in the interviews are presented in Table 5.6.

Table 5.6 Demographic characteristics of parents

Demographic characteristics	***n***	**%**
Relationship to the child		
Mother	11	100
Age		
40 years of age and older	3	27
Under 40 years of age	8	73
Relationship status		
Married	9	72
Single	2	18
Employment status		
In full-time employment	4	36
In part-time employment	3	28
Stay at home parent	4	36
Education level		
Second level	2	18
Third level	9	82
Family history of DDH		
Yes	5	45
No	6	55

The demographic details of the children who were treated in the DDH clinic are presented in Table 5.7. A total of 11 children were involved in this part of the study with the greatest number being female.

Table 5.7 Demographic characteristics of infants

Gender	***n***	***%***
Male	2	18
Female	9	82
Age		
Under 3 years of age	4	36
Under 4 years of age	7	64
Firstborn		
Yes	4	36
No	7	64
Type of delivery		
Vaginal birth	5	45
Caesarean birth	6	55
Breech presentation		
Yes	5	45
No	6	55
Normal hip examination at birth		
Yes	5	45
No	6	55
Age at diagnosis		
0-3 months	8	73
4-6 months	2	18
7-9 months	1	1
Type of treatment received		
Pavlic harness	5	46
Boston brace	3	27
Both	3	27

5.2.2 Findings of individual interviews

By using an inductive thematic analyses approach (Thomas 2006), a rigorous and systematic reading and coding of the interviews, 3 major themes emerged from the transcripts including: lack of awareness regarding DDH; difficulties caring for a child in treatment for DDH and finally the role of the DDH clinic. These emerging themes together with the subthemes identified within each theme are presented in Table 5.8, and are described further in the

narrative accounts of the parents' perspectives in sections 5.2.3 – 5.2.5. Quotations are provided to illustrate themes followed by the parent number.

Table 5.8 Emerging themes and subthemes from the parents attending the DDH clinic.

Themes	**Theme 1**	**Theme 2**	**Theme 3**
	'I knew nothing, absolutely nothing.' Lack of awareness regarding DDH.	**'How am I going to manage?' Caring for a child with DDH.**	**'The staff actually cared.' Positive impact of the DDH clinic.**
Subthemes	• Lack of knowledge about DDH • Quality of provision of information by HCP's • Shock at diagnosis • Benefit of hindsight • Wish for an earlier diagnosis	• Manageable after initial shock of diagnosis • Is my child in pain? • Hygiene/skincare issues • Safety concerns • Reaction from public	• High standard of care received in clinic • Supportive role of the nurses in clinic. • Supportive influence of the other parents in clinic • Appointment schedule

5.2.3 Theme 1 – 'I knew nothing, absolutely nothing.'

This theme was characterised by parents discussing their experiences in relation to the lack of DDH and hip health related information that was given to them during the antenatal, postnatal or newborn period (See Figure 5.1). The participants identified five points of relevance within this theme. Parents described their lack of knowledge regarding DDH prior to being pregnant in section 5.2.3.1. That lack of knowledge was compounded by the lack of DDH related information provided by health care professionals during the antenatal, postnatal and newborn

period which is discussed in section 5.2.3.2. The shock experienced by the parents when DDH was diagnosed is discussed in section 5.2.3.3. The benefits of greater awareness following their experience with DDH is discussed in section 5.2.3.4. To conclude this theme, women discussed their wish for earlier diagnosis of DDH as a result of their greater awareness of the condition.

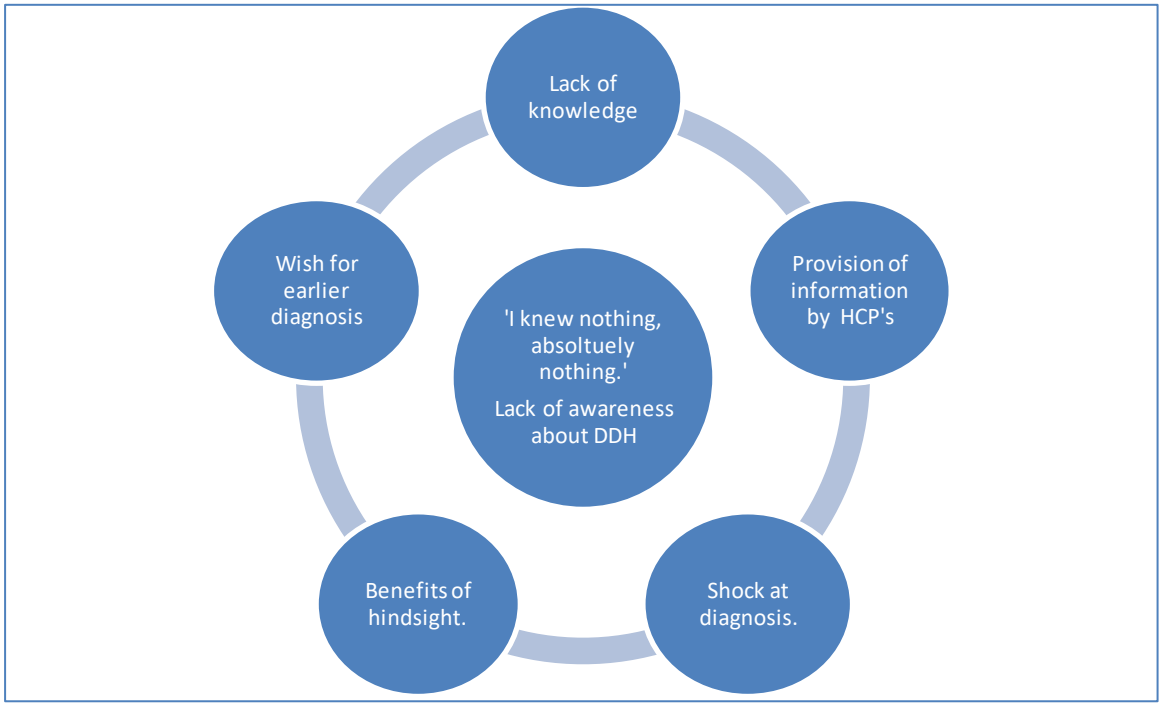

Figure 5.1 Theme 1 'I knew nothing, absolutely nothing.' with subthemes.

5.2.3.1 Lack of prior knowledge about DDH.

This subtheme describes parent's realisation that they had very little, if any knowledge regarding DDH prior to their own first-hand experience with the condition. A number of parents commentated that they were shocked at the number of babies that were affected by the condition and that it was not something they had seen or heard of prior to attending the DDH clinic.

> *'I had heard of children having clicky hips but I never heard any detail of it. I didn't know it was as common as what it was until I was out in the clinic to be honest. My first girl had no problems with her hips at all, she was grand.'*
>
> ***(Parent No 6)***

> *'Bar my nephew, he was the first I ever kind of heard of. I knew nothing, absolutely nothing.'*
>
> ***(Parent No 3)***

'*Em… I knew nothing about it, I had never heard of it to be honest. They might have asked about a family history but do you know there is such a long list of things they ask you that you just say no to everything.*

(Parent No 11)

'*DDH is something that I would think people should look out for, it was something that I knew nothing about. For something that is so common, it's something that has so little known about it out there among other parents. To see all the babies with the same thing in the clinic, I was so shocked.'*

(Parent No 8)

A number of the parents in the study suggested that if they had known more about DDH prior to receiving the diagnosis, they would have coped better with the diagnosis and management of the condition. Lack of prior knowledge led to parents worrying about the long-term consequences of DDH such as their child's ability to walk.

'*It did sound a lot more serious to me… So I really panicked when they told me because I thought she was in pain. So it took me a while to accept it, and look it up myself and see that she wasn't in pain. Because I didn't know any other baby who had this before.'*

(Parent No 2)

'Had I had known beforehand how common it was and known a little bit more about it, I wouldn't have freaked out as much as I did.'

(Parent No 11)

'When it's something you know absolutely nothing about…you are going to worry about whether they are going to walk and will they be able to do this and that. Whereas if I had known it wasn't as serious as what I thought it was in my own head I wouldn't have worried as much.'

(Parent No 9)

5.2.3.2 Provision of information by health care professionals

During the antenatal period, it is routine procedure for the midwife and/or the obstetrician to enquire if there is a first degree family history of DDH, if any risk factors are identified; they are recorded in the antenatal notes and flagged during the newborn examination. Two mothers

described how they were very satisfied with the amount of information provided to them regarding DDH in the pregnancy and in the immediate postnatal period.

> *'When I was with [Consultant] on [child], he had a nurse who asked all the things, so she marked her file then. So straight away like, when I had her then, they were like: oh there was a family history like. And then they were saying she had all the risk factors because she was breech and she was firstborn.'*
>
> ***(Parent No 2)***

> *'It was actually the midwife on the ward who went through it with me. After the doctor had gone I told the midwife what was after happening and she went through the whole thing with me…I was definitely secure going home about it. . She was able to tell me about the brace, what they looked like you know. The importance of wearing it, right from the very beginning.'*
>
> ***(Parent No 3)***

However, this was not the consensus view of the majority of parents in this study. There was a sense of not being given enough information about DDH in their pregnancies or the immediate postnatal period. One participant vaguely remembered being asked about a family history of DDH during the antenatal period while others did not remember being asked anything about DDH or given any information regarding the significance of a positive family history or of their baby being in a breech position prior to birth.

> *'I was told or asked nothing at all. And to be honest I never even knew. I never even knew what clicky hips were and so when it happened to [child] we were devastated. Looking back if I had only knew how easily treated it is, but at the time we knew nothing'.*
>
> ***(Parent No 8)***

> *'A nurse when I was pregnant at the time asked us if there was anything wrong with the hips in any of the family. And then they just checked him after he was born. So yeah, I probably could have done with a bit more information about it really. I didn't really know anything about it, the importance of it, especially with the family history on my husband's side and all that. Very little…There was no DDH on my side of the family so my mother didn't even know what it was really.'*
>
> ***(Parent No 5)***

'So in hindsight maybe knowing what could happen and how common hip dysplasia is might have helped. Especially because I was a breech mother so now I know that the chances of my daughter having it were high you know.'

(Parent No 2)

One parent stated that she was never told anything about DDH by any HCP until a PHN visited her house and picked up on leg length discrepancy during a routine check up.

'I knew nothing about it really until the PHN brought it up. I wasn't looking out for it. And actually, to be honest about it, when the PHN showed it to me, I did think: actually yeah, now that it was explained to me, I could see how one of her legs wasn't sticking out as far as the other one. I don't remember being told to look out for those things when I was pregnant. But it's hard to remember everything they tell you anyway.'

(Parent No 3)

There were suggestions from some parents that they had been given sub-standard information by their GP's regarding both the screening for DDH and the treatment for the condition. For example, one interviewee said:

'We went to our own GP for her 6 week check- up and he thought he could hear a slight click. So he told us there was nothing we could do until she was 6 months old until she could have an x-ray. So at 6 months we went for an x-ray in [Rural 1] and they referred us straight down to [Regional Unit]. That was really disappointing for us…'

(Parent No 8)

I remember bringing [child] for his 6 week check up at the GP and the GP was actually going to take [child] out of the brace! So I don't think he realised the whole idea behind the thing! I said no no you can't take him out of it!

(Parent No 7)

For one parent, it was felt that no adequate information regarding DDH had been given until she attended the DDH clinic with her baby. While another mother explained how, as a vulnerable mother, she felt she should have been given more thorough information regarding DDH and the possible outcomes in the prenatal or postnatal period rather than finding out for the first time in the DDH clinic. Another parent suggested all parents should be given

information on what signs to look out for with DDH. All parents in Phase 3 reported receiving written information as well as verbal information regarding DDH in the DDH clinic.

> *'The only time it was explained to me properly was actually down in the DDH clinic in [Regional Unit], the nurse down there were excellent. Before that we didn't really know what was going on!'.*
>
> ***(Parent No 9)***

> *'When there is something wrong, even something as small as the hip business. Anything that the professionals can do to make it easier. Anything that the nurses can do to make it easier. Just give mommy the information she needs. I wouldn't say I am on my own thinking these things.... So without frightening me, I would have liked some more information maybe when I was pregnant or on the postnatal ward as to what might come out of all this'.*
>
> ***(Parent No 11)***

> *'I was given no information in the pregnancy at all. I think you should get some in pregnancy…. Well I don't know…., and then when maybe it's diagnosed. I think we should be made aware of it regardless. Even so we can watch out for these things. If I had known I might have copped that one of her legs was shorter than the other.'*
>
> ***(Parent No 10)***

5.2.3.2.1 Fear of knowing too much while pregnant.

Whilst parents highlighted the lack of consistent information regarding DDH during the antenatal, postnatal and newborn period a divergent and conflicting discourse emerged. A number of parents communicated their apprehension of knowing too much about DDH while they were pregnant. For example one interviewee said:

> *'For me the post-natal ward was the best time to hear about it. I would be more worried if I had all this information thrown at me while I was pregnant! So if I had known about the hips then I think I would have been more panicky like*.'
>
> ***(Parent No 6)***

Another participant, when asked about the most appropriate time to receive information about DDH, responded that she felt that neither the antenatal or immediate postnatal period was an appropriate time to discuss DDH.

> *'After the birth I just wasn't in the frame of mind to hear about it but… I know if I was pregnant and someone tried to tell me about it I don't think it would sink in either because you don't want to hear about anything like that.'*
>
> ***(Parent No 7)***

One parent admitted that it was difficult to decide when the optimal time for discussing DDH with parents is, however, the respondent also conceded that there is very little awareness of the condition in the community at large. So it was suggested that written information about DDH be included in the antenatal information packs.

> *'It's a hard one! You don't want to… you don't want scare people when they are pregnant about all the things that a baby can have. But then again, I could talk to people now and they wouldn't have a clue what DDH is. Certainly maybe, if there was something in the pack that you get in the hospital, an information booklet or something.'*
>
> ***(Parent No 8)***

5.2.3.2.2 Lack of explanation during newborn examination of the hip

Parents described how distressing they found the newborn examination of their babies on the postnatal ward. Some felt that they were not given enough information prior to or during the examination by the examining doctor. In their accounts of seeing the examination in progress, parents described how upsetting they found watching the examination and how their babies were being handled by the doctor.

> *'I was given no information about DDH in the pregnancy, none whatsoever. So when they come in and start doing all these checks on the baby like, I was actually in tears because it wasn't explained to me, I didn't know what was going on. They were practically turning him upside down and bending his knees this way and that way and it is very upsetting.'*
>
> ***(Parent No 7)***

> *'You have these people coming in and speaking to you about exercises after giving birth and the newborn hearing test and stuff and nobody comes and briefs you as to why they're checking your baby and pulling them up and down and checking their heads*

and stuff. I think because they're doctors? Maybe, I don't know. But I think someone needs to come in and sit down and speak to the mother... If someone had just came down sat beside me for 5 minutes and explained what they were going to do to my child…'

(Parent No 8)

One parent described how she was given no indication as to the importance of the examination, what it meant if there was an abnormal result or what, if any treatment options there were for the condition.

'I just think maybe more explanation in the hospitals when they are doing these checks on the babies. As in if they find a click, what can be done about it! Doctors just come in and take the baby's clothes off and I'm going to do this and there is no why they are doing it. And if there is a problem, what can be done, because it was fixable but no one told me that.'

(Parent No 4)

'Definitely when they check the hips, like you don't really know what they are doing anyway! So a proper explanation about the reasons and possible outcomes is only right I think'.

(Parent No 11)

5.2.3.3 Shock at diagnosis and treatment

The diagnosis of DDH is made by the consultant orthopaedic surgeon in the DDH clinic and treatment is generally commenced immediately. A recurrent theme in the interviews was the sense of shock and upset amongst parents when they received the diagnosis of DDH. The parents went on to describe how it further distressed them to see their child fitted into the abduction harness or brace.

'Because the shock I got when I got down there was just incredible... I felt unknowledgeable about what was going on and I felt helpless by it. It was really frightening, I remember coming out and I was so angry! And I was so cross and so upset. I went back to the car and completely collapsed, crying because of what I had been told inside.'

(Parent No 10)

'I was roaring like. I was choking back tears in there, but when we got to the car I roared the whole way home… we hadn't even bathed the child at that stage. Like, it was just all the things, no one had told us anything.'

(Parent No 5)

'The first appointment when he got diagnosed was such a shock and… it's only when you leave that you start thinking all these questions. Everything goes over your head because you are in shock that this is happening to your child.'

(Parent No 7)

However, one parent explained how the diagnosis of DDH did not upset her as she had been concerned throughout the pregnancy that her baby may be born with a far more serious illness due to her advanced age giving birth. While another parent felt a sense of relief that DDH was her child's only diagnosis as she had been given a far worse prognosis in the initial newborn period.

'To tell you the truth she was our bonus baby, as I call her. I was 45. The way I looked at it if that was all that was wrong with her I was thankful! I could deal with the hips.'

(Parent No 1)

'I was relieved. Because I had been told that he may never walk in his life so I just said actually thanking God. I knew his hips could be fixed. And I knew he was going to be healthy.'

(Parent No 7)

Another mother who attended one of the national children's hospitals with another of her children, spoke of the change in perspective towards DDH the experience had given her.

"To be honest when you go up to [National Children's Hospital] and you see all the other kids who are really sick then it puts it in perspective for you really quickly. But by the end of it [child] came out of it and she was fine".

(Parent No 8)

Some parents elaborated on how distressing it was when treatment was commenced immediately following diagnosis. Witnessing their baby being fitted with an abduction harness or brace for the first time, having never seen this type of device before, was described as being a deeply upsetting experience by the parents.

> *'We just went in thinking like you know, they will just have a look at her and next thing here they were putting her into this big yolk… and she was tiny like. I nearly had a heart attack.'*
>
> ***(Parent No 4)***

> *"I was grand until they put her in the harness and then I was heartbroken looking at her. I was gutted then to be honest. I wasn't expecting her to be put in something like that so young"*
>
> ***(Parent No 8)***

One parent spoke of the grief she felt because she was now no longer going to have the opportunity to have skin to skin contact with her baby because of the harness. This view was echoed by another parent who described the sorrow of not being able to hold her baby close to her anymore.

> *'I was gutted to be honest, because it just looked very scary. And by the time it was on, when I saw her in it I started crying. I was so upset that I wasn't going to be able to get skin to skin contact with her.'*
>
> ***(Parent No 11)***

> *'I think one of the hardest things for us all was not being able to get really close to her, to be hugging her and stuff. Everyone was nervous that they were going to move the harness or hurt her.'*
>
> ***(Parent No 10)***

Another parent suggested that more time be given to parents to digest the information given at diagnosis, prior to treatment being commenced. However she did recognise that time constraints and the high level of work activity may not allow this in a hospital setting.

'See there's lack of time everywhere isn't there? But I think people need more time like, even maybe, right she's diagnosed but go home and come back the next day to start treatment or something? Let you digest first'

(Parent No 2)

5.2.3.3.1 Worse for 1st time mothers.

A number of parents who were interviewed for the study were first time mothers (n = 4). A common emotion among the new mothers was one of sorrow as they described hearing that something was wrong with their child. Other mothers described how receiving a diagnosis for their child made the transition into parenthood appear even more overwhelming.

'Oh sure yea it was upsetting, because obviously you don't want anything to be wrong with your child. You're not used to dealing with your child. She was just 11 days old so we hadn't even got used to having a baby never mind having her in this big contraption like. It's just the initial shock I think.'

(Parent No 2)

'I felt it was very rushed for a first time parent not knowing anything like. New mother and panicking oh my god, how am I going to look at… how am I going to change her nappy how am I going to do this how am I going to do that.'

(Parent No 4)

'It's an emotional time enough like, my first child… Like everyone wants a perfectly healthy child and then when anything little thing goes wrong especially when it is your first you know? Like at that time I was devastated.'

(Parent No 5)

Concerns regarding breastfeeding were expressed by some of the first time mothers. Learning how to hold their harnessed baby in a comfortable and safe position while breastfeeding was described as a worry for them. One parent commented that it was challenging enough to learn the skill of successfully breastfeeding a baby never mind a baby in an abduction harness.

'I was really worried about how I was going to breastfeed her with this harness in the way, I could not hold her in the usual position now. I was so worried she would not feed.'

(Parent No 4)

'I was only just feeling like I was getting the hang of breastfeeding my baby when she was diagnosed with DDH... It was like starting from scratch again, it was very difficult for me and my baby to be honest.'

(Parent No 2)

Several of the respondents who were not first time parents also alluded to the notion that dealing with the diagnosis of DDH would be a far more difficult experience as a first time parent. They were not so overwhelmed by the diagnosis because of their experiences with previous children.

'*See it's difficult because as a new mommy- I would not have liked to hear it all if I was a first time mom, because then I would be thinking bad things all the way.'*

(Parent No 11)

'Now she's my fourth child, and that was grand, but I can say if that had been my first child? I would have found that very daunting, very daunting. I could see how it could be for new mothers ya know?'

(Parent No 1)

'You are anxious when you have a young baby and you would be very worried, especially if it was your first child you know? It was different for me, she was my third.'

(Parent No 3)

5.2.3.4 Benefit of hindsight

Parents expressed the benefits of having greater awareness regarding DDH as a result of their experiences having a child diagnosed with DDH. The condition no longer seemed as serious as treatment progressed for their children as it had done at diagnosis.

'If my new twins had needed treatment I would have been ok. It would have been a pain but there wouldn't be the same fear attached to it. Or panic'

(Parent No 2)

One parent described how she ensured her second child received an early ultrasound due to her first child having required treatment for DDH.

> *'I made sure, with [1st child] after having the kind of DDH she had, I made sure when [2nd child] was born that the doctor was made aware of it. And I made them refer me to the clinic in [Regional Unit] before I even left the hospital. I suppose I had better awareness of the whole thing at that point.'*
>
> ***(Parent No 8)***

It became apparent from the data that when parents had experience of DDH they were able to create further awareness and pass on their knowledge of DDH to family members and friends.

> *'Em I suppose that I have greater awareness of it now. My brother's wife had a baby so she got her kids an ultrasound because of the family history. Now it all came back clear but I suppose if none of this had ever had happened I never would have known to tell her.'*
>
> ***(Parent No 4)***

> *'I remember my friend's child might have had an issue so I was able to say to her: "Make sure you follow up on that." So I had more awareness about it that's for sure and I can pass it on.'*
>
> ***(Parent No 10)***

5.2.3.5 Wish for an earlier diagnosis

Some parents expressed regret that their child's hip condition was not diagnosed earlier. One parent felt anger towards a doctor that delayed screening their infant for DDH, while another parent wondered whether DDH was missed during the newborn period of her child's life.

> *'I was quite angry about it for a long time really. That it was missed. To be told that they couldn't do anything until 6 months because her bones couldn't be x-rayed before then. Looking back now I know she could have had an ultrasound. I will never know now. But if she had the ultrasound maybe it would have been solvable earlier.'*
>
> ***(Parent No 8)***

'Well I always will wonder did they miss on picking up on the hip in those first few weeks in [Rural 3]. If I had known more about it, that because she was breech, I could have been watching her legs.'

(Parent No 10)

'Oh yeah, well at this point it was so late, you know that kind of way? I don't know if it was there in the earlier scans? Was he borderline from the start and could treatment have started earlier, you know that kind of way?'

(Parent No 5)

In summary, the theme called 'lack of awareness about DDH' depicts parents reporting their lack of prior exposure and first-hand knowledge regarding DDH and the general lack of consistent information and education regarding DDH prior to the diagnosis of their children in the DDH clinic. Parents identified that a better awareness of DDH prior to their child's diagnosis, would have made their experience less traumatic. While some parents felt they were given adequate information regarding DDH in the antenatal and postnatal period, the majority perceived an overall lack of information and at times sub-standard level of information given by health care professionals in the hospital and in the community. However, a fear of being given too much information in the antenatal period was also identified by some parents. Parents also raised concerns that having a child diagnosed and treated for DDH was a more difficult experience for first time parents. However, the general consensus amongst the majority of parents regardless of how many children they had, was that hearing about their child's diagnosis and need for subsequent treatment was a deeply upsetting and shocking time for them.

Parents did identify that one of the positive things to emerge from their experience was a greater awareness about DDH which they felt was important to pass on to other family members and friends. Some parents demonstrated regret that the condition had not been picked up sooner in their children and thus treatment could have been started earlier.

5.2.4 Theme 2 – 'How will I manage?' Caring for a child with DDH

This theme "How will I manage?" related to parents experiences coming to terms with caring for a child with DDH. Four emerging subthemes were identified as depicted in the diagram

displayed in Figure 5.2. Findings revealed that care of the infant with DDH was initially very over-whelming and upsetting for the parents. However, parents had no other options other than to accept and learn how to care for their child on a day to day basis. The majority of parents reported that once they had gotten over the initial shock of their child's diagnosis, caring for a child in a Pavlic harness or Boston brace was not as difficult as first imagined. One of the most predominant worries revealed by the parents was whether their child was in pain because of the condition itself or as a result of being in treatment. Finally, worries regarding the prevention of skin irritation/infection and maintaining general hygiene of their babies were also reported widely by the parents.

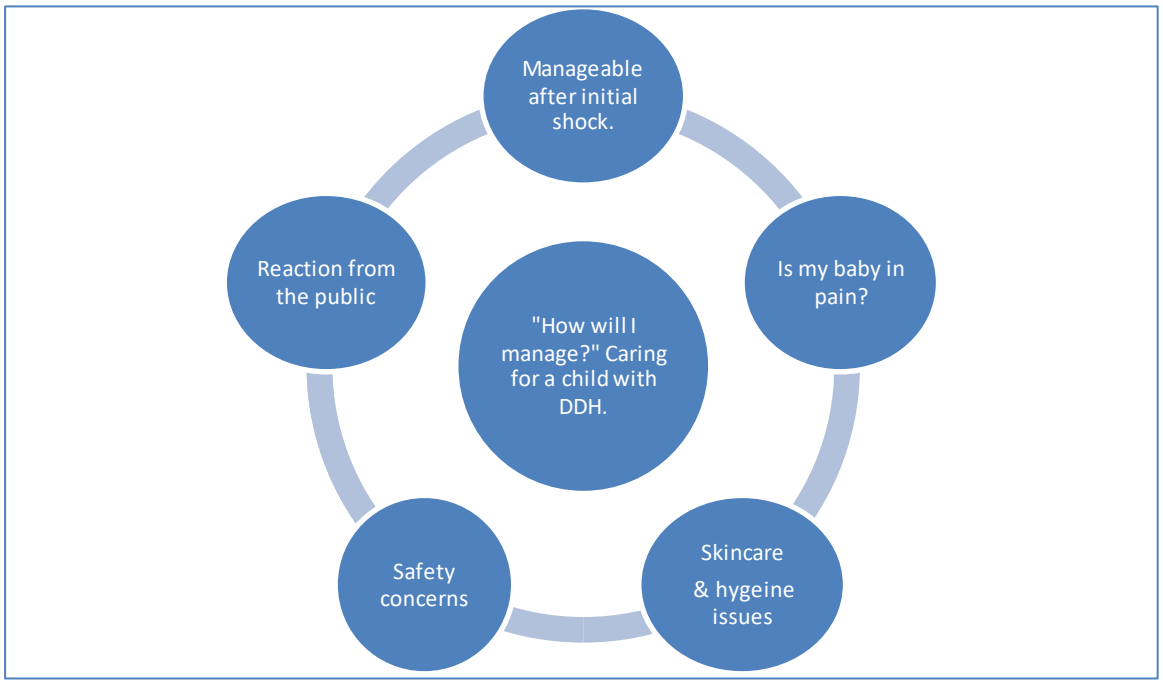

Figure 5.2 Theme 2 'How will I manage?' with subthemes.

5.2.4.1 Manageable after the initial shock

While a number of parents described the very acute shock and upset on receiving the diagnosis of DDH as previously discussed; a similar number of parents' also acknowledged that once they had processed the initial diagnosis, caring for their infant was more manageable than first expected.

'Ah yea sure…like it is not hard to manage really like. Like at the start, you totally think you are never going to manage, how am I going to manage it? But you do. And it is fine.'

(Parent No 2)

'Yea I suppose I had more awareness about it all. I thought at the start that it was all going to be very tedious, driving up and down to [Regional Unit], having this hip brace, dressing and cleaning him but it ended up that it wasn't so bad to be honest.'

(Parent No 7)

'Well it's like anything, at the beginning it seems like a massive daunting task at first. But once you get used to it, it's very easy to manage. You adjust to it very quickly. For the first few weeks it was a bit like Oh my god, I have a baby that can't move in this big monstrosity of a thing. But after a month it was fine.'

(***Parent No 8)***

One parent described how her older infant still managed to meet developmental milestones while wearing a Boston Brace.

'After a couple of weeks of me dealing with it, it got easier, [child] could climb the stairs in the brace, so you know, she got on with it. She didn't know any better and I went back to work and the girls in crèche managed the brace fine. It worked out well in the end. But the first 2 weeks were quite stressful'

(Parent No 3)

Another parent described how the reassuring nature of the nursing staff in the clinic helped to normalise the situation for her.

'Ah I think we got used to it quickly enough. It did help that all the nurses treated it like this was all very normal. I watched the nurses change her nappy and stuff so they showed us how to do all of that. So it became very normal after a while.'

(Parent No 11)

5.2.4.2 Is my baby in pain?

A number of parents in the study expressed that one of the most over-riding concerns they had when DDH was diagnosed was whether their baby was in pain because of the underlying hip condition, or because of the actual treatment itself. For one parent, her lack of prior knowledge regarding DDH led her to believe that her child's dislocated hip was causing her pain.

> *'But I definitely didn't know what it was because I remember thinking when they told me that she had DDH that it must be really painful for her and I got really upset.'*
>
> ***(Parent No 11)***

A number of other parents worried that the harness or brace that was applied to their infants was causing them pain or discomfort.

> *'I was grand until they put her in the harness and then I was heartbroken looking at her. Thinking she was in pain but she was actually perfectly comfortable like, it was just looking at her I got the fright but sure look I got over it, I had to!'*
>
> ***(Parent No 7)***

> *'Well I just found her restricted, because she was a very very active child. Even when I was pregnant with her. So just having her legs restricted I was kind of heartbroken for her you know? It looked such an uncomfortable position for the poor thing.'*
>
> ***(Parent No 6)***

One parent explained how she believed that being in the harness for 12 weeks aggravated her baby's colic.

> *'He screamed for the whole 12 weeks because he couldn't stretch his legs when he got wind. That was tough. Yea… he was very colicky and then he could not go to the toilet due to him not being able to stretch his legs in the brace. So it was tough.'*
>
> ***(Parent No 2)***

In addition, some parents felt that their concerns regarding their baby's discomforts were not listened to by the staff in the clinic.

'A different nurse adjusted the harness, and she adjusted too much and I knew they adjusted it too much on her legs.. she was already getting sore and then you know then with no movement, em…and I kept saying to her: this is not right, and she wouldn't listen. The child cried non-stop for the whole weekend so I had to go back down the following Monday and they had to take it off and readjust it. Like I think they need to listen to the parents more as well. At that stage I knew my baby.'

(Parent No 3)

'But I did think everybody kept saying: "She is not going to know any different, you just treat her same as any other baby." And I don't think that was the case. Like she did know the difference. She was really upset most of the time.. The minute she got the harness off at 3 months, she was a completely different baby. I know in my heart of hearts

(Parent No 11)

5.2.4.3 Skincare and hygiene issues

Many parents expressed how they found the general management of daily hygiene needs and the prevention of skin breakdown problematic during treatment. Parental difficulties with bathing, dressing and inspection of skin creases for signs of irritations or abrasions of the skin were highlighted. The issue of a once weekly clinic and fortnightly visits was also highlighted as a concern when the parents discussed hygiene issues as they worried about how to manage any problems that arose for them between clinic visits.

'Now it was a bit of a pain waiting 2 weeks to give her a bath and stuff but like, we could live with that. It just took that bit longer to clean her up and stuff in the harness. The poos were awkward to clean up'

(Parent No 1)

One mother spoke about how the position of her daughter's hips in harness exacerbated an underlying condition of eczema.

'Making sure she never got any skin infections was also tough because she suffered from eczema as well. Just missing out on bathing her at home for those few months was tough.'

(Parent No 10)

Another parent described how her daughter's treatment was concluded early as the condition of her daughter's skin deteriorated during treatment; while another parent spoke of the discomfort and upset her child was in due to skin breakdown.

> *'She was in the harness for 9 weeks and they were happy then to let her out. See she had very sensitive skin, and it kept getting raw red and em.. he was happy enough to take her out at 9 weeks.'*

(Parent No 2)

> *'The first week or two were very uncomfortable; you know she had ulcers and things on her legs so she was upset at the beginning.'*

(Parent No 3)

5.2.4.4 Safety concerns

For a number of parents, concerns arose surrounding their baby's safety while in treatment for DDH. Due to the wider position of the child's legs in the harness or brace, it became more difficult to sit the infant securely in a car seat or buggy. Worries regarding safely strapping their baby into a car seat while travelling was the most common concern for parents. Participants who travelled long distances with their infants spoke of having to purchase new car seats and buggies in order to ensure their child was safe and comfortable on journeys.

> *'The hardest thing was thinking about her safety. Car seats, stuff like that. We had to take measurements of car seats and things and get a new one to fit her for those few months. For peace of mind.'*

(Parent No 3)

> *'The stroller and buggies and things. Her legs were sticking out over the sides so people would bang off her legs and that would hurt her as they were walking past. So we had to change everything when the brace went on so that she could fit into things more securely.'*

(Parent No 10)

'Our biggest worry was the car seat, the danger of it you know. People not properly having her in the car seat. It was a big deal for me as we lived in the country side so she was in the car with me a lot.'

(Parent No 7)

While parents are advised that it is not necessary to change car seats while their child is in a Pavlic Harness or Boston Brace; they are however, advised not to leave their child in a car seat for any prolonged period of time. This is because the child's position in the car seat can force the hips out of a position of abduction and flexion. One mother described how she stopped going on long journeys for the duration of her child's treatment in order to prevent this from happening.

'Well I stopped going on any long journeys. I was conscious of having her in the car seat for too long because… I was conscious of the position of her legs on long journeys. I didn't want to ruin any chance of the harness working.'

(Parent No 4)

5.2.4.5 Reaction from the public

In their accounts of caring day to day for their child in treatment for DDH, parents described the reaction they would receive from strangers when they would go out in public with their child in a Pavlic Harness or Boston Brace.

'People used to get an awful shock when they saw her I the brace alright. They used to go "Oh my god, what is that!" but it didn't really upset me though.'

(Parent No 4)

'And em, at the end of it, it was more other people's reaction to it, they were more shocked about it than I was in the end. They would be like of my gosh, it's so warm, is she uncomfortable?'

(Parent No 3)

Parents suggested that it was the general lack of awareness regarding DDH that led to the insensitive reactions from the public

'There is not enough awareness about DDH even though so many babies have it! When [child] was younger and in his buggy or whatever people were looking at him as if to say what is wrong with him? What have they done to him!'

(Parent No 7)

'When your child in in a harness, you get some queer looks! What's wrong with her type of thing. So not everyone knows about it, they really don't. When I see it now, I know to be sensitive'

(Parent No 10)

In summary, the theme called 'How will I manage?' explored the personal journey of parents following diagnosis of their child's condition and how they dealt with caring for their child in treatment for DDH. The majority of parents reported that once they had processed the shock of the diagnosis, the day to day task of caring for their child recently placed in a harness or brace was in fact, considerably more manageable than initially expected. A common parental anxiety within the study set was fear of their child being in pain due to the underlying condition or the treatment of the condition. Management of skincare issues and attending to hygiene needs were also identified by the parents as being problematic while their child was in abduction. A number of parents commented on the negative reaction from the general public in relation to their child being seen in a harness or a brace; this was suggested to be as a result of the general lack of awareness in the community regarding DDH.

5.2.5 Theme 3 'The staff actually cared.'

This theme, 'the staff actually cared' related to the typically positive and supportive role the DDH clinic provided for the parents attending the clinic. See Figure 5.3.The theme was further sub-divided into 4 subthemes where parents described that their overall opinion of the service provided by the DDH was of a high standard in section 5.2.5.1. The supportive and at times nurturing role of the clinic nurses is discussed in section 5.2.5.2. The parents discussed the positive influence played by the other parents attending the DDH clinic in section 5.2.5.3. To conclude this category, the parents suggested that the only improvement needed in the clinic was to shorten waiting times (Section 5.2.5.4).

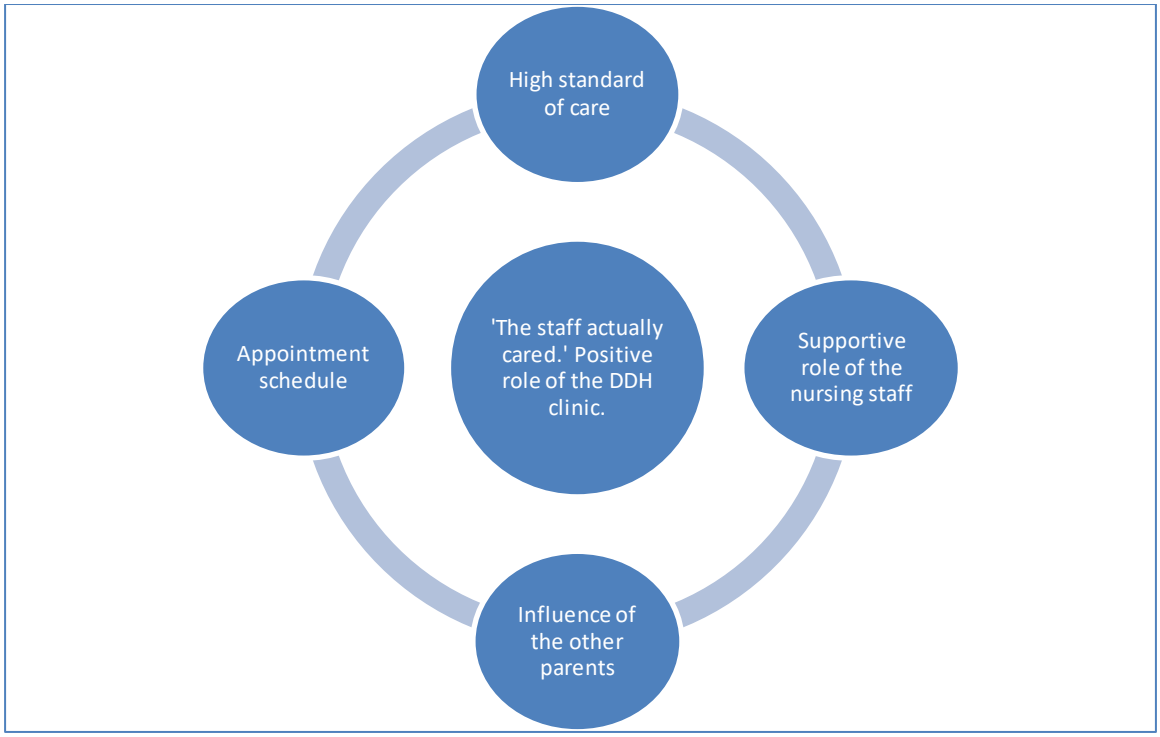

Figure 5.3 Theme 3 'The staff actually cared' with subthemes.

5.2.5.1 High standard of care

The majority of parents in this study revealed that they were very satisfied with the standard of care they received in the DDH clinic. Parents felt supported and cared for by the staff and commented that they never felt any sense of being rushed despite knowing that it was a busy clinic.

> *'But the staff were fantastic, and [Consultant] he was just fantastic. So no look, she got wonderful treatment down there. I honestly don't know how the service could be improved. It is a wonderful service.'*
>
> ***(Parent No 4)***

> '*No matter how busy they were, they were always very accommodating to answer any questions. We both feel, myself and my husband that the care throughout was brilliant.'*
>
> ***(Parent No 11)***

'He was checked very thoroughly. I think it was because more or less the support you got from the clinic. Because you could always phone if you wanted to. And then if there was any questions, they wouldn't let you go unless you were happy enough with everything.'

(Parent No 7)

'They were fantastic. The staff down there, I never had a problem. I asked a hundred questions! So I kind of tormented them a bit! I was a hundred percent confident in everything that they did and they explained everything that's they were doing to her before they did it to her and the whole lot.'

(Parent No 2)

Some parents explained how they had opted to attend the public DDH Clinic despite having private health insurance as they had heard it was consultant led service which offered a high standard of care.

'But actually lots of people said that [Consultant's] clinic was excellent and they had a good service there so that's why I went to be honest.'

(Parent No 9)

'We considered going private in [Capital], but when we asked around, we were told that there was a really efficient service operated publically in the [Regional Centre] by a Consultant Orthopaedic Surgeon so that's where we went..'

(Parent No 10)

The calm demeanour of the staff in the clinic was also noted to have a similar effect on the parents which in turn made the appointment less of a negative experience for the parents.

> *'But I suppose all the staff were so calm and you would know that they do this every day, so you know then it's not as a big a deal as that.'*
>
> ***(Parent No 3)***

It became apparent from the responses from the parents that staff in the clinic engaged with parents, responding with care and empathy which in turn made the experience of receiving a diagnosis of DDH and accepting the need for treatment less traumatic for them.

> *'The staff knew if you were upset and they were there for you. I just found them very good to be honest. There was nothing they could do to improve it because they are there for you. The staff actually cared about us. You can't ask for more than that.'*
>
> ***(Parent No 5)***

> *'I didn't expect to go into that clinic and meet the people I met. Everyone was absolutely so lovely. My first day down there… I was not… I was not in the frame of mind but I actually remember every single member of staff there that day. They did more than just their jobs that day.'*
>
> ***(Parent No 7)***

5.2.5.2 Supportive role of the nursing staff

In particular, the nursing staff was considered to be one of the most positive aspects of the care received in the DDH clinic. The practical advice needed to care for a baby receiving treatment for DDH was given by the nurses in the clinic. Building confidence and time given to ask questions were highlighted by some parents as being a positive aspect to the care they received in the clinic.

> *'I think what helped me the most was the nurses in [Regional Centre]. And the fact that I knew [Consultant] was so thorough. The nurses were the most positive thing about all. I found them absolutely great so I did.*
>
> ***(Parent No 10)***

'I was given great care and I think it was down to the nurses. If I was unsure of anything, the nurses always gave me plenty of time to get my head around things. The nurses understood that this was all new to me.'

(Parent No 3)

'Oh yeah, the nurses were brilliant in there, they showed me how and where to keep the harness clean. How to keep her skin creases clean and particularly how to keep it dry which was important. I was really nervous as a first time mum about having to manage these things at home on my own.'

(Parent No 4)

Continuity of nursing care was identified by one interviewee as an important component to the care she received. Relationships with nursing staff were more easily built when parents saw the same staff on a weekly basis in the clinic.

'It helped that's I got to see a nurse as well, and even better when it was the same nurse at each visit. Because you get to build up a relationship with them then and I wasn't embarrassed asking questions.'

. ***(Parent No 2)***

5.2.5.3 Influence of the other parents

A variety of respondents agreed that time spent talking to other parents in the DDH waiting room resulted in having a reassuring influence. Speaking with other parents who were going through a similar experience appeared to have a therapeutic effect. Observing other children successfully completing treatment also had a reassuring effect on the parents.

'In the waiting area everyone is lovely and chatty about their children and maybe that helps settle people down you know? It's nice like that, to be able to talk about your child and what they are going through.'

(Parent No 1)

'That's another good thing I found, when you're sitting in the waiting room talking to the other parents, when you got chatting to them and asking them about their kids and all and seeing them finish up with everything going so well...'

(Parent No 2)

'I found myself talking too other mothers, you know if I saw them in the clinic and I saw their children in a brace- even now, if I see it. I do always have a chat with them, I always felt better after it, they understood.'

(Parent No 3)

'But the more people I spoke to- and I met so many people down there… and I met a lot of people towards the end of her treatment and they were there like "ah she'll be fine, that helped.'

(Parent No 5)

There were some suggestions that observing other infants in the waiting room who had different severities of DDH or who were of an older age at diagnosis, led parents to feel better about their own child's diagnosis.

'Seeing some parents just arrive to the clinic and their child has already started walking…that must be a nightmare. If your child is not diagnosed until they are 18 months or so that must be a lot more challenging. I had the easy way out in my opinion.'

(Parent No 1)

'I seen other children that were a lot older and they were in the harness for longer or different types of harnesses and stuff like. So I was fairly confident that once the 3 months were up that would be it for us.'

(Parent No 6)

However, one parent commented that watching the other families in the clinic while waiting brought on a sense of panic and dread about what may lay ahead for her own daughter.

'You are waiting so long in there, there are other babies coming in and out and you are looking at them in braces and oh god help that child, oh god help that child. I hope that's not my child. Because you are seeing it all before you.'

(Parent No 10)

5.2.5.4 Appointment schedule

While the general consensus among parents was that the DDH clinic offered a high standard of care, concerns were expressed about the inconvenience of once weekly afternoon appointments and lengthy waiting times. The length of time parents waited in clinic varied from less than an hour to 3 to 4 hours. Parents commented that they found this length of waiting time particularly stressful with young children. When travel time was taken into account, parents did not arrive home with their young babies until late evening.

> *'I know everyone is busy down there and the waiting times are horrific down there but em… we were down there sometimes a good few times waiting 3 or 4 hours before you even get in to see the doctor. And that's tough on families, people get, children get tired. All you want to do is get out of there.'*
>
> ***(Parent No 5)***

> *'Because even though it was crowded, they were very good, very quick getting people in and out and stuff. We were usually finished in an hour, we never felt rushed.'*
>
> ***(Parent No 6)***

> *'Eh… it was just so packed, we had to drive from [Rural 2] and [child] wasn't happy in the brace in the car seat. So the wait around and then the drive home again. So my problem was the actual times, if we had to have a morning appointment it might have been a lot better. Some of our appointments were 2 o clock and we wouldn't get home until 7 o clock.'*
>
> ***(Parent No 7)***

It was noted by one parent that everyone attending the clinic presented at the same time, and the block booking policy was questioned.

> *'So that's the other thing I suppose, I don't know why they don't give everyone different times. Everyone seemed to get the same appointment time. You would be down there for 4 hours. I was often down there until after 5 o clock on a Friday afternoon.'*
>
> ***(Parent No 8)***

Talking about this issue, one participant described how she used to disregard the time on her appointment letter. She reported that she would always arrive at the clinic as soon as it opened and this ensured she was seen more swiftly.

> *'I never really bothered with the time given to me on the appointment letter…I learned very quickly that if you came down first, they pulled your chart first and you were seen fairly quickly!'*
>
> ***(Parent No 9)***

Some parents questioned the practicality of a Friday afternoon clinic as it meant if any concerns arose over the weekend, they had no point of contact in the DDH clinic.

> *'But my problem was if he came out of his harness or destroyed his harness in poo what do I do? Now he did it once but I was actually in the hospital that day so I was able to get a new brace. But other than that, what would I have done?"*
>
> ***(Parent No 7)***

> *'I think another good thing would be if the clinic was not on a Friday because then you don't have to bring home a baby for a weekend if there is anything wrong like. There is no one there to help you at the weekend. I did end up in trouble and I had to wait until the Monday before I could seek advice. There is nowhere to go.'*
>
> ***(Parent No 2)***

One participant commented that she found breastfeeding in the busy waiting room difficult. She felt that the full waiting area could be particularly intimidating for first time mothers who could feel vulnerable feeding their baby in a busy public area

> *'Breastfeeding was a bit of a challenge. The nurses had to find somewhere to put ya. Now she's my fourth child…and that was grand but I can say if that had been my first child? I would have found that very daunting feeding in the waiting area. Very daunting.'*
>
> ***(Parent No 1)***

In summary, the theme called "The staff actually cared" presented the parents perspectives of the impact the DDH clinic and the staff working in the clinic had on their experience navigating the clinic and the diagnosis of DDH. There was an overwhelming sense of feeling supported

in a nurturing environment during a vulnerable time in their lives. The nursing staff in particular, and the continuity of nursing care appeared to play a pivotal role in the parents feeling well informed and prepared for caring for their baby at home in a harness or brace. The impact of being around the other families going through treatment for DDH in the waiting room, on the whole had a positive and reassuring effect on the participants during their own journey through diagnosis and treatment. Finally, the one improvement that the majority of participants suggested was to shorten the length of time waiting in the busy clinic with young babies to be seen by a doctor. In summary, these results indicate that there was an overall high satisfaction rate amongst the participants in relation to the quality of the service provided by the DDH clinic.

5.2.6 Summary of Strand 1 of Phase 3 Findings

To conclude the semi-structured interviews of parents, overall participants were very positive about most aspects of the care that they and their infants received in the DDH Clinic. The specialist consultant-led clinic and the caring and nurturing ethos of the care provided in the clinic appeared to be instrumental in how the parents coped with the transition of going home within an infant in treatment for DDH. One of the most striking results to emerge from the data was the overall lack of awareness amongst parents concerning DDH prior to the diagnosis of their children. This lack of awareness and education of parents during the antenatal and postnatal period, in turn, resulted in the diagnosis and subsequent treatment of their child for DDH, being a traumatic experience for the majority of parents in the study. Some common parental anxieties amongst the participants were in relation to issues such as fear of their child being in pain and the management of skin care issues while their child was in treatment. However, on the whole, parents reported that once they had processed the emotions surrounding the initial shock of diagnosis, the care of their infant was more manageable than initially anticipated.

5.3 Findings of Phase 3 Strand 2– semi-structured interviews with HCPs

The purpose of Strand 2 of Phase 3 was to obtain information on the DDH screening and referring methods of GPs and PHNs who are involved in delivering the Healthy Childhood Programme and to determine any potential barriers to the successful referral and management of infants with potential DDH. The findings have been broken down into four sections: the training received by GPs and the screening and referral pathway utilised by GPs and the training received by PHNs and the screening and referral pathway utilised by PHNs.

5.3.1 Training received by GP's in DDH screening

The 4 GPs who participated in the study reported that GPs generally received their training for clinical examination of the hips during their paediatric rotation of their General Practise training in a general hospital setting. The paediatric rotation typically lasted 6 months. They observed Paediatric Consultants and Registrars perform the Barlow and Ortolani manoeuvres during the full top-to-toe Newborn Examination that is performed on the Postnatal Ward on all babies prior to discharge. It was reported by the GPs that once they had observed several of the Newborn Examinations, they were then instructed to perform the Newborn Examination alone on all babies deemed to be low risk in the postnatal setting. Babies deemed as being high risk were examined by a paediatric consultant or Registrar.

When asked if they felt the training was adequate, all GPs responded that with hindsight, they believed the training they received was not enough. It was suggested by one GP that as GP trainees, there was not enough self-awareness as to what level of training, supervision and practice was really needed to become proficient to identify a dysplastic or dislocated hip.

> *'No probably not. I don't even think we had the awareness to know that we were inadequately trained, we were not taught on model, it was basically see a few then off you go'*
>
> **(GP No 1)**

Another GP spoke about how important it is to have a skilled practitioner performing the examination of the hips.

> *'Screening for DDH is so operator dependant and in terms of applying it as a screening tool I would imagine you need an operator that was doing lots of them and had felt the unusual on a regular basis.'*
>
> **(GP No 2)**

Another GP suggested that it was highly likely that some GPs in training as SHOs were over diagnosing suspected cases of DDH leading to high rates of false positives or missing cases of DDH which lead to higher rates of false negatives.

> *'I would say SHOs sensitivity is really poor. So you would probably have 10 false positives for every true positive or vice versa.'*
>
> **(GP No 4)**

Another GP stated that he felt it was inappropriate for SHOs to be screening infants for DDH given how highly sensitive the HCPs skills are required to be in order to identify DDH accurately.

> *'Frankly I think SHOs screening for DDH is probably useless. 'Junior SHOs and even junior GPs are not identifying DDH all the time. It's not an efficient screening tool.'*
>
> **(GP No 3)**

The majority of the GP's felt that their skill for identifying suspected DDH only came through feeling and examining hips over a sustained period of time once they started working in General Practice.

> *'Back then as an SHO I gave a little wiggle and pull and thought that was a sufficient assessment, It was only when I finally felt some true dislocated hips in my own practise that it started making proper sense to me.'*
>
> **(GP No 2)**

'It certainly took me some time during my own clinical practice as a GP to feel confident with my screening abilities.'

(GP No 1)

One of the GPs argued that having SHOs screening low risk infants was inadequate as the low risk population accounts for the majority of infants being screened in the newborn period.

'The problem is the more lower risk the population is that you need to screen. the more sensitive the tool needs to be. It doesn't make sense to put a blunt instrument out there screening a population that has a low background probability of something happening, but yet have a fair to high likelihood probability of having the condition.'

(GP No 4)

When asked if they received any regular update training with regards to DDH, all GPs responded that they had attended a session on DDH during their Continuous Medical Education (CME) monthly programme at least once over the past 3 years. The session typically was in the form of a short presentation lasting 20 minutes. When asked if they felt they should receive updates on DDH more regularly, all GPs responded by saying yes they should, but given the nature of general practise, that would be challenging

'It's probably not enough but the problem we have as GPs, is that there are hundreds of different things we deal with and if you were to spend even 20 minutes on each one you wouldn't have time to live!'

(GP No 3)

'There are so many issues, updates, new research findings and so on that we need to discuss and familiarise ourselves with at our CME's, DDH is one of many things that should be a priority, unfortunately that's the reality of general practise.'

(GP No 1)

5.3.2 DDH screening and referral pathways used by GPs

All of the GPs who participated in the study reported screening for DDH takes place during the infants scheduled 6 week postnatal check-up and as part of their surveillance of the child's

development during any other engagement with a child and their parents in the first 2 years of life. This was reported as involving: reviewing the postnatal discharge letter; obtaining a verbal history from the parents regarding the pregnancy and birth; assuring themselves that the child has been appropriately screened for DDH in the postnatal period, identifying any new risk factors; identify that the child's gross motor development and gait are normal. All of the GPs reported using the Ortolani and Barlow manoeuvres to screen for DDH at 6 weeks.

All GPs reported that if an abnormality is suspected with the hips, they refer to their local hospital's paediatric clinic. When asked if they felt the referral pathway worked effectively, two GPs responded by saying they felt the pathway did work effectively.

> *'Once I write the referral letter, door to door, I think it is on the [Orthopaedic Surgeon's] desk in two to four weeks. That's pretty efficient in my book.'*
>
> **(GP No 2)**

> *'Yeah, once it's marked as an urgent referral it moves pretty quickly most of the time.'*
>
> **(GP No 3)**

However, two GPs expressed their concern about referrals having to be seen by other HCPs before being given an appointment for the DDH clinic, resulting in occasional lengthy waiting times for 1st appointments.

> *'I can see why we as GPs can't directly refer to the DDH clinic- they would be overloaded… but my referral has to pass through so many hands…from the paediatric clinic and possibly the US department before it gets to the DDH clinic… that all takes time.'*
>
> **(GP No 1)**

> *'You are relying on a lot of HCPs and clerical staff to be efficient at their jobs! But it makes sense that we can't refer every clicky hip or asymmetrical skin fold directly to the clinic.'*
>
> **(GP No 3)**

Another issue that was identified by two of the GPs was the delay caused when a patient has not attended an appointment or changed address and appointment letters for ultrasounds, x-rays or consultations not reaching the patient in a timely manner.

> *'If you knew the amount of letters my practice receives each day… and some of those letters are from the hospital reporting that an infant has not attended for an ultrasound or X-ray. I may not become aware of that issue for a several days or weeks … a Unique Identifier Number would be more efficient- an alert would be issued online across both primary and secondary services that could be flagged by all HCP's immediately.'*
>
> **(GP No 2)**

> *'Again, it's that low risk population, the ones that aren't even aware of DDH, they slip through the gaps because we have so much going on. Then the referral pathway is inadequate. We need a seamless, complete and reliable source of communication and referral.'*
>
> **(GP No 4)**

In summary, all of the GPs felt that the training provided during their general practise training was insufficient to effectively screen infants for DDH, particularly those that they screened as SHOs in the postnatal setting. All of the GPs agreed that in order to correctly identify cases of DDH, the examiner should be a skilled practitioner who routinely examines hips on a continuous basis. It was highlighted that having junior staff screen the majority of infants because they are deemed to be low risk leads to high rates of false positive and false negative diagnosis' of DDH within the low risk population of infants.

While some of GPs felt that their referrals reached the DDH clinic in a timely manner, others expressed their concern with how many points of contact a referral had before it reached the DDH clinic in some cases. It was however conceded that it did not make clinical sense for every suspicion of DDH to be referred directly to a specialist clinic. It was also suggested by some of the GPs that a more up to date communication and referral system was needed between primary and secondary care services in order for clinicians to quickly and accurately make care decisions and identify problems for the optimal wellbeing of infants.

5.3.4 Training received by PHNs in screening for DDH

The four participants in the study reported that PHNs generally receive theoretical training in relation to DDH during the Maternal and Child Health module of their Public Health Nursing postgraduate diploma. They then receive practical training in screening for DDH whilst working with a PHN preceptor in the community. Unlike GPs, PHNs do not perform the Barlow or Ortolani manoeuvres. As part of the surveillance of a child's development, a PHN delivering the Healthy Child Programme needs to obtain a full history regarding the pregnancy and birth of the infant; assure themselves that: a child has been appropriately screened for DDH in the postnatal period; the child's gross motor development and gait are normal; check for asymmetrical skin folds and a positive Galeazzi Sign.

When asked if they felt their training was adequate, the majority of PHNs responded by saying that while the training did appear to be sufficient, the lack of regular updates and refresher study days once qualified was frustrating. However, one newly qualified PHN commented that because she was not a registered midwife, she felt that she was at a disadvantage towards some of the more senior PHNs who were required to have done their midwifery to train as a PHN.

> *'I definitely feel that the PHNs who are also trained midwives have more experience with newborns than I do just being a registered nurse…yes it's covered in our training but I worry it's not enough.'*
>
> **(PHN 1)**

The majority of the PHNs however, felt that more priority needed to be placed on regular training and updates about current screening practises and referral pathways in relation to DDH.

> *'We've often said we would love more updates… DDH is not prioritised; there is no money for travel so as a result no updates.'*
>
> **(PHN 4)**

> *'The whole training and referral pathway needs to be clearer and we badly need updates. DDH never seems to be included in any of our study days.'*
>
> **(PHN 2)**

One PHN went on to say that once qualified, they are not only responsible for screening children and infants for DDH, they are also responsible for teaching student PHNs the skills required to be a proficient screener.

> *'As PHNs we would love more training and support – it's so important! I might add that we are also responsible for training students. We need proficient skills to train the students - train the trainer!'*
>
> **(PHN 3)**

5.3.5 DDH screening and referral pathways used by PHNs

All four of the PHNs who participated in the study reported that they screen infants for signs of DDH during three points of contact in the Healthy Child Programme: following discharge postnatally at approx. 1 week of age; at 3 months and at 7-9 months of age. It was reported by all of the participants that if a child does not meet all of the criteria as described above, the PHN must take appropriate action as per local protocol. All of the PHNs reported that the GP was their first point of referral for an infant that they were concerned may exhibit soft markers for DDH such as asymmetrical skin folds, audible clicks or for more serious concerns such as an abnormal gait.

When asked if they felt the referral pathway worked effectively, one PHN stated that if she wanted to get an urgent referral she would use the GP.

> *'I usually refer to the GP, it's the quickest, or we can go to the Area Medical Officer (AMO). But we tend to have a better working relationship with the GPs… they trust our opinion and will refer onto the Paediatric Clinic immediately.'*
>
> **(PHN No 2)**

However two PHNs reported their frustration regarding the length of time some referrals they had made seemed to take to get to the DDH clinic.

> *'I remember one case where I referred an infant with uneven skin creases to the GP at 3 months of age... the child was promptly referred to the Paediatric Outpatient clinic, but was not seen there for another 3 months.. Eventually got to the DDH clinic at 7 months of age… That's frustrating.'*
>
> **(PHN No 4)**

'I sometimes feel that our referrals are not taken seriously or regarded as urgent by the Paediatric Outpatient department… yes uneven creases are soft markers but they are sometimes an indication of DDH.'

(PHN No 3)

One of the disadvantages of referring to a GP which was highlighted by some of the PHNs was the lack of follow up the PHNs received following referral of an infant for suspected DDH.

'I guess with the AMO's we hear what the outcome is… We don't with the GPs unless we ring up ourselves.'

(PHN No 2)

'We could do with being cc'd on the letters from the DDH clinic or the Paed's clinic… It's only right…It's learning and reflection for us and it helps us keep patients files up to date.'

(PHN No 1)

In summary, findings from the PHN participants revealed that their knowledge and training in relation to DDH was not updated regularly enough. It was felt that this not only may affect the effectiveness of the screening process but also the quality of training the PHNs provided to student PHNs. It was generally acknowledged that DDH was not a priority during any training or study days that the PHNs attended.

In terms of the referral pathways utilised by PHNs, the majority of participants referred suspected cases of DDH to the child's GP. While most felt this was the most efficient referral pathway, it was highlighted that the PHNs received no follow up documentation with regards to the outcome of the referral. This was highlighted as a concern as it meant PHN files could not be kept up to date on infants.

5.4 Conclusion

In conclusion to the chapter, Phase 2 of the study sought to determine what the main concerns of parents were in relation to receiving a diagnosis of DDH and while their infants were in treatment for the condition. There were a number of key findings from the questionnaire. The majority of parents were very satisfied with the quality of service offered by the DDH clinic.

However, the findings from the questionnaire highlight the psychosocial impact that receiving a diagnosis of DDH and caring for a child with DDH can have on parents. In particular, the negative impact of receiving a diagnosis of DDH and concerns regarding any long term sequale of having the condition were recurrent issues for the parents.

In Strand 1 of Phase 3 of the study, parents participated in a semi-structured interview. The purpose of Strand 1 was to elicit a deeper understanding of the experiences of parents caring for a child with DDH and to discover the principal concerns of parents caring for a child who has been diagnosed with DDH and is undergoing treatment for the condition. The key categories that emerged from the interviews were the general lack of awareness regarding DDH; the reality of caring for a child with DDH and the positive impact the DDH clinic had on the parents.

Strand 2 of Phase 3 sought to obtain information on the DDH screening and referring methods of GPs and PHNs who are involved in the screening and referring of infants to the DDH clinic from the community setting. Findings from the semi-structured interviews revealed that the majority of GP's screening and referring for DDH in the community feel their initial training is inadequate to effectively screen for DDH, particularly in the postnatal period. Both the GP's and PHN's suggested that refresher training with regards to DDH should be repeated at more defined intervals in order to ensure a safe and competent workforce. The next chapter will present the discussion and dissemination of these study findings.

Chapter 6 Discussion and integration of findings

Introduction

This study set out to explore the health care outcomes and parental experience in the DDH clinic setting in the South East of Ireland. This chapter presents a discursive interpretation and integration of the data in the context of previous research conducted in the area of DDH. For the purpose of discussion, the results have been grouped into three themes utilising the FCC for infants with DDH conceptual model as a guiding framework, which is discussed in Chapter Three and is displayed in Figure 6.1.This categorisation demonstrates the significance of the findings for clinical practice and for all personnel involved in the provision of and in receipt of care from DDH services whilst also discussing their contribution to the existing literature. This is the first study to explore the possible reasons why there appears to be high incidence rates of DDH in the South East of Ireland, the effectiveness of treatment strategies utilised in the DDH clinic and the care and support offered to parents of infants newly diagnosed with DDH.

The findings are sequenced under the following three main headings:

1. National and community determinants of effective management of DDH
2. Parental determinants of effective management of DDH
3. Quality of care

The implications of the study are also discussed in relation to the development of clinical practice, theory and policy documents.

National & Community determinants of Early Childhood Care

Need for a National Integrated Care Pathway in relation to DDH, Health surveillance and health promotion policies and procedures, Cohesion between Primary and Secondary Care, Quality of training received by HCPs in screening for DDH.

Parental determinants of successful screening and treatment of DDH

Access to care, Expectations of care, Effective relationships with HCPs , Support from family and peers.

FAMILY CENTRED CARE

Quality of Care

Evidenced based care, Functional referral systems, Timely and accurate diagnosis, Use of appropriate technology, Consultant led service, Cultivation of effective communication, Respectful and compassionate care

Figure 6.1 Adapted Family Centred Care conceptual framework for DDH. (Adapted from McCormack and McCance 2010; Tuncalp *et al*. 2015 & Sudhinaraset *et al*.2017).

6.1 National and Community determinants of effective management of DDH

Three of the objectives in the study sought to determine the true incidence rates for DDH, the effectiveness of current screening and treatment methods in the South Eastern region of Ireland and identify scope for the improvement of care in DDH diagnosis and treatment. As identified in the literature, health systems create the structure which enables equitable access to evidenced based quality healthcare (Tuncalp et al. 2015). There is general acknowledgement that the wider determinants of health play a significant role in child and adult health (Healthy Ireland 2013). 'The national and community determinant of effective management of DDH' theme aims to examine some of the interacting factors surrounding the role health service policy planning has on how infants with DDH and their families are treated in Ireland.

6.1.1 Need for a National Integrated Screening Programme in relation to DDH

The first objective of the study sought to determine the overall incidence rate as well as the early and late incidence rates of DDH in the South East of Ireland. One of the major findings of the study was an overall incidence rate of 17.5 per 1000. Prior studies have noted that there is a high incidence rate of DDH in the Irish setting (Gul et al. 2002, Phelan et al. 2014 (Donnelly et al. 2015). This study's findings are however, over three times higher than the findings of a similar study by (Phelan and colleagues (2014) in the same region in 2009 (6.73/1000) and over twice as high as a study (Donnelly et al. 2015) carried out with a similar population in Northern Ireland (8.5/1000). This finding may reflect the increasing rates of suspected DDH referrals to the clinic year on year, resulting in higher treatment rates for mild dysplasia. Donnelly et al. (2015) also came to the same conclusion in their Northern Ireland study which examined reasons for their high rates of DDH. Nonetheless, the high rate of diagnosis and in particular, late diagnosis of DDH which will be discussed further in the chapter, does raise the question as to whether it is due to a high natural incidence in the Irish population, or to poor screening and early management of the condition.

What the high incidence rate does confirm is the need for evidence based, effective planning of care in relation to DDH. Currently, there are no nationally agreed guidelines in relation to

the screening, diagnosis or treatment of DDH in Ireland. There are 19 neonatal units in the country, operating at different levels of complexity (HSE 2013). Only 9 out of the 19 hospital units have access to a hip ultrasound at 6 weeks, the other 10 have to wait for a hip x-ray at 5-6 months. This means that the timing of diagnosis of DDH is dependent on the geographical location of the infant. Consequently, Ireland is currently not providing selective ultrasound screening for DDH equitably.

The Regional Centre and the 3 Rural Centres involved in the study however, had access to a 6 week ultrasound during the duration of data collection of all 3 phases. However, a standardised referral policy was not in place during 2012 and 2013. Having access to early ultrasounds did not appear to have an effect on reducing the late diagnosis of the condition, but it could be argued that not all 'at risk' infants were appropriately referred for an early ultrasound. Findings from Phase 3 revealed an instance where a GP failed to refer a suspected case of DDH at 6 weeks of age for an ultrasound but instead waited until the child was 6 months old to refer her for an x-ray. This scenario highlights the need for a unified approach to diagnosis, treatment and support of families living with DDH. The HSE have produced a number of reports recommending an improvement to the services that are available to children and their families (HSE 2013, HSE 2014, HSE 2017), which will culminate in the development of a new National Healthy Childhood Programme. The Developmental Dysplasia of the Hip Subgroup developed recommendations for an Irish National DDH screening programme to consist of: universal clinical examination at birth and six weeks; universal assessment of risk factors at birth and a selective ultrasound screening programme for babies with eligible risk factors (HSE 2017). The screening programme is not currently underway nationally, but will help to streamline services for families facing a diagnosis of DDH.

Prior to these recommendations in 2017, the DDH clinic in the Regional Centre was one of the first hospitals to undertake this type of screening programme in 2014. Additionally, ultrasound staff in the Regional Centre were sent to Cardiff to undertake specialist infant hip sonography training in late 2014. However, the retrospective chart review for this study focused on infants born in 2012 and 2013. The rationale for choosing these years was in order to follow infants fully through to discharge which is approximately until the age of three to four years of age. Consequently it is important to highlight that the findings from Phase 1 are indicative of practices prior to any type of structured screening or training programme being fully implemented in the South East region, and thus, provide insight into how the lack of a

standardised screening programme and lack of appropriate training can affect incidence rates of DDH.

This problem, however, is not unique to the Irish setting, despite efforts to detect and screen for DDH soon after birth, delay in diagnosis in some infants also remains an issue internationally (Kotlarsky et al. 2015). The USPSTF (2006) concluded in its report on screening strategies for DDH that evidence is insufficient to recommend routine screening for developmental dysplasia of the hip in infants as a means to prevent adverse outcomes and a more recent Cochrane review by Shorter et al. (2011) was also unable to recommend an optimal screening programme for the condition.

The results regardless, are on the whole, not very encouraging as the general consensus within the literature is that DDH should ideally be diagnosed and treated early (Holroyd & Wedge 2009, Sewell et al 2009, Sewell & Eastwood 2011, Clarke et al 2012). Reasons for the high late incidence rates could be multi-factorial. Lack of standardised screening policies and tools, lack of standardised training of staff in the screening for DDH and the lack of experience of HCPs screening for DDH could all contribute to the regions late incidence rates in 2012 and 2013. Without clear national guidelines and referral pathways for the condition at that time, it is possible that referrals from the community were delayed.

The quality of the health system in Ireland has a direct effect on the quality of care received by infants who have been diagnosed with DDH and their families. Robust referral pathways, management, leadership, communication and regular audit are required for hip screening programmes to work efficiently and effectively. This commitment is essential for any screening programme. Action to reduce health inequalities means tackling those factors which impact unequally on the health of the population in a way which is avoidable and can be dealt with through public policy (Commission of the European Communities 2009).

6.1.2 Health surveillance and health promotion policies and procedures

Possibly one of the most important findings of the study was the general lack of awareness regarding the condition DDH and the lack of DDH and hip health related information given to parents during the antenatal, postnatal or newborn period both at primary and secondary care level. The results from Phase 2 and 3 of the study expose issues surrounding parents' general lack of awareness regarding DDH prior to their own personal experience with the condition.

This lack of knowledge regarding DDH was felt by a number of parents to be a catalyst to how they coped with receiving a diagnosis of DDH and further compounded the shock felt by the participants at diagnosis. Parents went on to suggest that had they been given better prior information about DDH they would have coped better with the diagnosis, management of the condition and they may have avoided any unnecessary worry in relation to issues such as the possibility of long term disability for their child. While parental feelings of grief, shock and worry are a normal reaction when receiving a diagnosis for a child (Swallow & Jacoby 2001, Ballantyne et al. 2017); lack of knowledge about DDH, the physical effects of it and the developmental nature of it (Bloomfield et al. 2003) can further compound feelings of anxiety at what is a critical time for parents (Baird et al. 2000, Mooney-Doyle et al. 2017).

Despite general acknowledgment in the literature regarding the association between diagnosis of DDH and levels of stress amongst parents (Swallow & Jacoby 2001, Ballantyne et al. 2017, Mooney-Doyle et al. 2017), there are no standardised policies utilised regarding the support and information that should be offered to parents in the antenatal, postnatal and early childhood period in Ireland. Different regions appear to offer different levels of care. This again, highlights the discrepancy in care and services in relation to DDH (HSE 2017).

The first point of contact that HCP's have with individuals in relation to DDH is in the antenatal period. It is routine procedure for the midwife and/or the obstetrician to enquire if there is any history of a first degree family relative having DDH. Findings in the 1st strand of Phase 3 revealed that the majority of parents had only vague recollections of DDH being discussed, and critically, participants who had known risk factors were not given any additional information regarding DDH or the increased likelihood that their child may develop the condition. No written information regarding DDH was given to any of the participants in Phase 3 of the study either antenatally or postnatally. As a result, the diagnosis of DDH in the DDH clinic was reported as a distressing and shocking experience for the majority of mothers. These findings also echo the findings from Bloomfield et al.'s (2003) study which reported that most parents interviewed reported not knowing the content of the newborn examination or that some abnormalities being screened for might not present till later. It was expressed by the parents in Bloomfield et al.'s (2003) study that examiners should explain what they were doing and what they were looking for and that written information about the examination in the form of a leaflet would be very beneficial. The need for an increased focus on family health promotion is one of the overall reflections included in the Review of Paediatric and Neonatology Services and Framework for Future Development (HSE 2013).

This has also been identified as a concern by the HSE (2013) who advocate for written information about the examination of the hips and information regarding the developmental nature of DDH. The DDH Subgroup of the National Child Health Review Steering Group more recently recommended that culturally-appropriate written and verbal information on the Irish National DDH Screening Programme be given as early in the ante-natal period as part of the antenatal health promotion programme (HSE 2017).

Interestingly, a small number of those interviewed suggested that they would not have welcomed excessive information regarding DDH during the antenatal period as it may have worried them unnecessarily during the pregnancy or the immediate postnatal period. One parent conceded that it was difficult to decide what the most suitable time to speak to parents about DDH is and to what degree but due to the apparent lack of awareness in relation to DDH, written information in the antenatal packs was most likely the best solution.

The second point of contact parents have in relation to the provision of information regarding DDH is during the newborn examination after birth which typically takes place on the postnatal ward. A detailed examination of the newborn in the early perinatal period is recommended as an integral part of Child Health Surveillance. One of the main components is an examination of the hips utilising the Ortolani and Barlow manoeuvres. The examination should include health education and reassurance to parents (Townsend et al.2004).

A number of issues were identified from the 1st strand of Phase 3 in relation to the newborn examination. Concerns were expressed regarding the lack of explanation given about the newborn examination prior to or during the actual examination. The parents felt underprepared for the examination itself and found the way the baby was handled during the examination quite upsetting. The relevance of the examination and of any abnormal results did not seem to be conveyed to some of the parents in the study. This leads to uncertainty as to whether parents are truly giving informed consent for the newborn examination to be performed on their infants. These are areas of concern with relation to DDH. Some parents are being discharged from hospital without adequate explanation of findings and with no clear plan of care for their child. To address this issue from an Irish perspective there is a need for direction at policy level, with agreement on the criteria for competent care delivery and clarity in the responsibility and regulation of training and education of HCPs who are screening infants. The HSE (2017) have recommended that parents be provided with adequate information by a competent trained HCP thus obtaining informed consent. Additionally, if there are abnormal findings, results are to be

given with a clear explanation of what the next steps will be both verbally and in writing. Findings from Strand 2 of Phase 3, documented that GPs reported in hindsight, they were ill equipped to accurately screen infants for DDH as SHOs in the postnatal setting. This confirms the need for improvement within the training practises of HCPs involved in the screening of newborns.

The third point of contact parents have is during their first appointment in the DDH clinic. As already mentioned, parents should be made aware following the newborn examination that there is either a clinical suspicion of DDH or that there are risk factors present that make the likelihood of DDH more apparent. In addition, if the concern has been picked up in the community by a primary level caregiver such as a GP or PHN, parents should be informed about the importance of early intervention and follow up. Once they receive their first appointment, infants are seen by the Consultant Orthopaedic Surgeon who following examination of the hips and review of ultrasound or x-ray findings makes the final diagnosis of DDH.

The findings of the study in Phase 2 and the 1st strand of Phase 3 expose a number of themes surrounding the experience of receiving a diagnosis of DDH in this setting. A number of the parents in Phase 3 suggested that if they had known more about DDH prior to receiving the diagnosis, they would have coped better with the diagnosis and management of the condition. Some parents felt that the DDH clinic was the first place where DDH had been explained to them in a clear way. Parents in Phase 3 also added that as a result of not having adequate information regarding DDH given to them prior to attending the clinic, they felt underprepared for the diagnosis.

These findings are consistent with the findings of a number of authors who all draw attention to the correlation between a new diagnosis of DDH and overwhelming feelings of shock, stress and guilt (Sparks et al. 2004, Sharpe et al. 2006, Hart 2006, Causon 2010 Ballantyne et al. 2017). A study by Jugnoo et al. (2004) which attempted to evaluate the use of a specialist clinic to meet the needs of parents around the time of diagnosis of a disability found that the greatest needs for parents during the critical time of diagnosis of a chronic health condition is for family-professional collaboration in the form of verbal and written information together with emotional support from health care professionals. These findings support the recommendations of the HSE (2017) regarding the importance of incorporating culturally appropriate written and verbal information on DDH, risk factors and the benefits of the

screening programme during the ante-natal period; and during the postnatal period. Subsequently, parents should be given verbal and written instruction on the outcome of the screening and what actions if any are required.

6.1.3 Quality of training received by Health Care Professionals in screening for DDH

The vast majority of care children receive is in primary care. Primary care services should be able to provide for the management of acute and chronic childhood conditions, health surveillance, health promotion and disease prevention (HSE 2013). Currently, GPs screen infants for DDH by clinical examination at the 6 week postnatal check-up. As already discussed, they receive their paediatric training while working as SHOs during their paediatric rotation in the general hospital setting, as SHOs they also perform the first screening contact for DDH - within 72 hours of birth.

On reflection, all 4 GPs in Phase 3 felt that the level of training they received as SHOs was not adequate and that they most likely missed the identification of DDH on some occasions. All GPs agreed that the clinical examination of the hip was very much "operator dependant" and ideally requires a very skilled practitioner to yield the most accurate result. Previous research studies concur with these findings. A study by Bloomfield et al. (2003) exploring junior paediatricians', midwives, GPs' and mothers' experiences and views of the examination of the newborn highlighted poor practice and suggested that SHOs would prefer to have more training in the area of newborn examination.

The overall consensus from the GP's in the study was that more formal training is needed spent working alongside more experienced registrars to facilitate the development of their knowledge and skills in the examination. To further add insight, these findings were also supported by O'Grady et al. (2010), who estimated that neonatal hip examinations were performed by an experienced examiner in less than 30% of newborn examinations.

Similarly, the Review of Paediatric and Neonatology Services and Framework for Future Development report draws attention to criticisms made by medical and non-medical personnel regarding the failure of junior medical staff to detect or identify conditions or anomalies during the newborn examination at a stage when treatment could be more effective (HSE 2013). DDH was identified as one of the conditions of frequent concern. One of their recommendations is the enhancement of training of the Non Consultant Hospital Doctors (NCHDs), paying particular attention to the newborn examination.

Findings from the semi-structured interviews in Strand 1 (parents) of Phase 3 revealed that some parents felt that they had been given sub-standard information by their GPs regarding both the screening for DDH and the treatment for the condition and that no adequate information regarding DDH had been given until they attended the DDH clinic with their infants. It was suggested by GPs in the 2nd strand of Phase 3 that screening for DDH was a skill that needed time and experience to master. One GP concluded by saying increased awareness amongst GPs was warranted and that this could be achieved through monthly Continuous Medical Education (CME) sessions. Focusing on DDH would facilitate better awareness and better practices amongst the profession. One of the recommendations from the DDH Subgroup of the National Child Health Review Steering Group was that the practitioner carrying out the 6 week screening contact has an obligation to maintain competence in screening for DDH, in particular, specifying a minimum number of examinations a year to be performed and annual or biannual updates (HSE 2017). It was highlighted by the GPs however, that facilitating regular updates regarding DDH would be problematic due to the broad range of topics covered during CMEs at general practice level.

Similarly, all of the PHNs stated that their training in the screening of DDH was not sufficient and that the lack of regular updates and refresher study days once qualified was frustrating. Additionally it was highlighted by one PHN that they are also responsible for teaching student PHNs the skills required to be a proficient screener and that this was an added incentive to stay up to date with research in relation to DDH.

One parent spoke about how it was the PHN who picked up on leg length discrepancy during a routine visit which led to a late diagnosis of DDH. Mulcahy et al.'s (2016) study confirms how PHNs often find themselves being the HCP who identifies a missed case of DDH in the community. The authors conclude that's PHNs must as a result, make sure that their knowledge about DDH is up to date and complete; and that they are sensitive to the developmental nature of DDH.

6.1.4 Cohesion between Primary and Secondary Care

It is vital that children access the necessary specialist paediatric and orthopaedic care, in relation to DDH, in a timely manner, as close to home as possible, in an appropriate environment. This requires primary care practitioners, paediatricians and health care managers

working together to ensure a model of care is developed with young people and their families at the centre (HSE 2013). Standardisation of how common conditions are treated in primary care through the roll out of algorithms, referral guidelines and clear documentation methods is essential.

Findings from GPs and PHNs in the 2nd strand of Phase 3 suggest that referrals or vital information sent by post regarding infants with DDH can become lost or may not be opened or flagged in a timely manner due to high volumes of correspondence being sent between primary and secondary caregivers. Enhanced communication between GPs, paediatricians, AMOs, PHNs and public health doctors is needed. The introduction of the Personal Health Record (PHR) or Electronic Health Record (HER) nationally was suggested by GPs in Strand 2 and would certainly help support the delivery of a standardised national core programme but requires national funding. Additionally, PHNs criticised the lack of follow up communication that they receive following a referral to the DDH services. It was suggested that in order to provide a safe and effective service to families, PHNs need to be informed of the outcomes of any referral made in relation to DDH. This would ensure equity; allow evaluation through data collection and analysis and facilitate information sharing with parents and amongst service providers.

The national and community determinants of early childhood care construct addressed the broader issues within the national health care system that affect the quality of care received by infants diagnosed with DDH and their families. While a national selective ultrasound screening programme for DDH has been agreed upon in Ireland in 2018, it has not yet been fully implemented. Additionally, there are currently, no nationally agreed treatment protocols or guidelines in relation to the treatment of DDH. Findings from this study have exposed issues in relation to how the lack of cohesiveness and priority in standardizing care with regards to DDH has affected health outcomes and parental experiences surrounding DDH.

6.2 Parental determinants of successful screening and treatment for DDH

One of the objectives of the study was to explore the experiences of parents in caring for a child with DDH and identify their needs to develop appropriate care packages for service improvements. Within the community setting, it is important to develop and implement a model of care that enables and empowers individuals to have a greater influence over factors that affect their health, which in turn can reduce health inequalities. In order to facilitate this, a

range of integrated strategies and actions are required to encourage, support and enable people to make better choices for themselves and their families (HSE 2013). The theme 'Parental determinants of successful screening and treatment for DDH' seeks to assess the extent to which parental determinants affect the overall outcome of the screening and treatment of DDH.

6.2.1 Access to care

Findings from Phase 2 revealed that the majority of parents (52% n=52), were given a first appointment to the DDH clinic within three weeks of finding out there may be an issue with their baby's hips, whilst 28% (n=28) waited 4-6 weeks for an appointment. Six percent (n=6) were waiting 7-10 weeks and 8% (n=8) were waiting more than 11 weeks for an initial visit. Respondents were then asked to indicate whether they felt the length of time waiting for the appointment was too long, as expected or better than expected. Eighty-eight percent (n=88) of parents felt it was as expected while 11% (n=11) of parents thought it was too long. It is worth noting that the DDH clinic operates a 'same week appointment' policy, where an appointment is made for the DDH clinic as soon as the referral letter arrives with the DDH clinic secretary. This would lead to the assumption that the delay in waiting times for some parents lies at some other point of the referral pathway.

The qualitative data in Phase 3 from the GPs provides information about the referral process in the community. Some GPs expressed concern about their inability to refer directly to the DDH clinic and how this may result in lengthy waiting times for some families. However, it was recognised by GPs that direct referrals of every clinical suspicion picked up in the community would overload a specialist clinic with infants that did not have DDH. , Groarke et al.'s (2017) review as previously discussed, further support this conclusion. These findings raise questions as to whether there is a more effective and prompt way to refer infants with suspected DDH. The utilisation of EHRs, as discussed earlier, would allow clinicians at primary and secondary level to promptly refer cases. GPs and PHNs could directly refer infants to the radiology department, thus cutting out the paediatric outpatient clinic referral and, potentially reduce the waiting times for any infants who go on to have abnormal findings on ultrasound.

6.2.2 Expectations of care

At community level, Mulcahy et al.'s (2015) case study based in Ireland, illustrating the complexities of PHN practice when screening, intervening and managing DDH highlights the importance of PHNs enabling parents to express their concerns in relation to DDH. The

author's earlier study which aimed to explore the experiences of parents who had concerns about their child's growth or development, found that parents may not immediately express concerns to a HCP due to uncertainty or lack of awareness (Mulcahy et al. 2015). The delay in parents expressing concern about their child's hip development or the ineffectiveness of HCPs in listening to and acting on parental worries may lead to missed opportunities to treat DDH sooner rather than later.

Research findings have shown that parents expect support in areas of newborn diagnosis, preparation for practical support needs, emotional support and support and information to assist with the transition to home with their child (Swallow & Jacoby 2001, Chao & Chiang 2003, Kratz et al 2009, Causon 2010). One of the key findings from this study was the level of shock and upset felt by new parents, particularly first-time parents upon hearing their child had been diagnosed with DDH. Parental anxieties regarding pain and risk of long-term disability were some of the factors relating to the trauma of the diagnosis. There was an element of grief spoken about by parents who felt that their relationship with their children was dramatically altered due to the treatment of the condition. These findings provide new insight and accentuate the need for a more family-centred approach to how parents are supported during such a pivotal time in their transition to parenthood.

While there were a small number of parents who felt that their concerns were not listened to in the DDH clinic, an overwhelming finding in Phase 2 and Phase 3 of the study was the very positive impression parents had of the DDH services. In Phase 2 of the study, 98% of parents felt that they were given an opportunity to ask questions about their child's treatment and responded that they were given ample opportunity to ask questions in the specialist clinic. Seventy-four percent responded that any future treatment had been explained to them and 65% of those surveyed knew who to contact if they had any concerns. The findings of the open-ended question in Phase 2 however, revealed that there were areas of deficiency identified. Issues with length of time waiting to be referred to clinic were identified but the majority of complaints were in relation to the block allocation of appointments and highlighted how these block appointments were not very child friendly. Parents found it difficult to keep their babies and toddlers settled during the lengthy waiting times to be seen. These results illuminate the impact that attending a paediatric outpatients department has on the day to day responsibilities of the parents.

In the 1st strand of Phase 3 of the study, parents felt that the staff in the DDH clinic fostered a supportive and nurturing environment which in turn led to high satisfaction rates amongst the parents and gave them a sense of empowerment for the transition into parenting a child receiving treatment for DDH. Similarly, Lee (2005) found in her satisfaction survey of parents attending a nurse led paediatric DDH outpatient clinic that there was a significant level of acceptance for the service with a 100% of participants being either very satisfied (67%) or satisfied (33%) with the specialist service. The majority of parents (80%) were completely satisfied with the service and felt nothing more needed to be added. It was one of the aims of the study to explore parental experience of utilising a dedicated DDH clinic in the South East region; these findings demonstrate that a specialist DDH clinic has the potential to offer parents physical, psychological and social supports during their child's treatment (Kelly 2018).

Research conducted during infancy indicates that when parent needs go unmet, they are more likely to drop out of follow-up services for their infant (Ballantyne et al. 2017). Yet, when parent needs are addressed through engagement with their healthcare team, they embrace more opportunities to communicate, seek information and become familiar with the specialty care their child requires (An & Palisano 2014). In relation to DDH, this view is supported by Causon (2006) who emphasised the importance of appropriate supervision, written and verbal information giving and ample opportunity for parents to express concerns and ask questions. In doing so, parental compliance with the treatment plan is optimised. On the question of the provision of written information, findings from Phase 3 found that all the parents who attended the DDH clinic received written information as well as verbal information regarding DDH.

6.2.3 Support from family and peers

When a child is diagnosed with an illness, parents make sense of their roles through personal, social and cultural influences and previous or current illness experiences. In particular, the provision of meaningful social support (relatives, friends and the health care system) can shape how parents view the illness experience and, subsequently, the outcomes for the patient and family over the illness trajectory (Mooney-Doyle et al. 2017).

One interesting finding from Phase 3 was the beneficial effect parents received from speaking with other parents in the DDH clinic waiting room. Meeting other parents who share the same anxieties and frustrations, can help alleviate the loneliness and isolation that comes with a new diagnosis of DDH (International Hip Dysplasia Institute 2018). Findings also revealed that

observing the progress of other children in the clinic waiting room over time appeared to have a reassuring effect on the parents.

Being a first time parent was suggested by many of the respondents as being a more challenging experience, as first time parents need to deal with the challenging transition to parenthood in general as well as process the diagnosis of DDH (Deave et al. 2008, International Hip Dysplasia Institute 2018). One respondent spoke about how she felt it was important to approach new parents and offer reassurance. This form of reassurance was noted as being very helpful to parents during treatment. Parent to parent support has been closely linked to improvements in the emotional and psychosocial well-being of parents caring for an ill child (Bray et al. 2017).

Parents in Phase 3 described the reaction they would receive from strangers when they would go out in public with their child in a Pavlic Harness or Boston Brace as one of shock. While comments were perceived to be insensitive by the parents, parents suggested that it was the general lack of awareness regarding DDH that led to the insensitive reactions from the public. It became apparent from the data that when parents had experience of DDH they felt it was important to create further awareness and pass on their knowledge of DDH to family members and friends. This in turn, will go towards a better sense of cognisance of DDH in the general population, which will lead to more parents being aware that there can be an issue with their baby's hips, acting on that concern by contacting a HCP which may lead to an earlier diagnosis of the condition (Mulcahy et al. 2016).

By taking cognisance of the broad determinants of child health and the pivotal role of parents in influencing child health outcomes, parental experiences of caring for a child with DDH can be improved as well as improving health outcomes for children diagnosed with DDH (Lee at al. 2005, Hart et al. 2006). These findings further support the benefits of involving parents and giving them a sense of empowerment in relation to their child's care and advances our knowledge in relation to the impact of newborn diagnosis and how we can support parents through this time.

6.3 Quality of care

There is general agreement that the key to effective management of the problem of DDH and the avoidance of long term adverse outcomes is thorough screening, early diagnosis and treatment starting from the initial newborn period (Clarke et al. 2012). While the usual course of the condition (the 'natural history') is not fully understood, despite many years of research,

there is general agreement that if DDH is detected before three months, less complex treatments can give good outcomes for most children compared to children who are detected after three months (HSE 2017).

6.3.1 Evidenced based care

With regard to screening, concern has been raised about the reliability of the newborn examination of the hips which takes place after the birth of the baby (Dezateux & Rosendahl 2007, O'Grady et al. 2010, Donnelly et al. 2015, Pollet et al 2016). O'Grady et al. (2010) highlighted the importance of these manoeuvres being performed by an experienced clinician in order to obtain the most accurate diagnosis. The majority of newborn examinations performed in Ireland and the UK are carried out by SHO's whose training has been highlighted to be insufficient (HSE 2013, Donnelly et al. 2015, HSE 2017). The scope of the study did not allow for the analysis of the effectiveness of the newborn examination in the postnatal period. However, findings from the second strand of Phase 3 which sought to determine the viewpoints of HCP's who screen and refer suspected cases of DDH seem to be consistent with research that suggests further improvements are needed surrounding the formal training that junior doctors and GPs receive in the clinical examination of the hips (Dezateux & Rosendahl 2007, Donnelly et al. 2015, Pollet et al 2016). Paton (2017) suggests that the GP hip check has a very low Positive Predictive Value (PPV) and is of doubtful value in screening and diagnosis.

The findings from the GPs who participated in the study echo this statement when they stated that they believed that their training while working as SHOs on the postnatal ward was not enough. In hindsight, most GPs felt that it was probable that they were over diagnosing or underdiagnosing infants with DDH in the postnatal setting and in the community as GPs. These findings further support the recommendations from HSE (2017) that maternity units must ensure that the clinical examination of the hips is being performed by a skilled examiner who has successfully completed the training requirements, has completed a period of formal supervision, signed as competent and finally that he/she should repeat their training at defined intervals in order to maintain skills. It was beyond the scope of this study to analyse the efficacy of the clinical examination performed during the newborn examination which is carried out by doctors in training. Further research, which takes into account the variables of HCP experience levels and level of training received, will need to be undertaken.

Within the DDH clinic setting, however, statistical analysis indicated a strong significant association between clinical examination of the hips and the detection of DDH $\chi 2$ (1) =

117.044, p = 0.000. Clinical examination of the hips in the DDH clinic had 76% sensitivity that the Consultant Orthopaedic Surgeon would correctly diagnose an infant as having DDH. There was 85% specificity that Consultant Orthopaedic Surgeon would correctly identify normal hips in those who did not have DDH. A clinical examination PPV was calculated to be 92% while the negative predictive value (NPV) was calculated to be 60%. It is worth bearing in mind that the clinical examination is performed by a skilled Consultant Orthopaedic Surgeon in the DDH clinic and that all infants referred to the clinic had already received a differential diagnosis of DDH prior to attending the clinic. These findings further reinforce the recommendation by O'Grady et al. (2010) that the clinical examination should be carried out by a skilled practitioner in order to be a sensitive screening tool. However, the research does highlight the fact that 15% of cases of DDH are not detectable at birth, even by a skilled examiner or sonographer (AAP 2000).

What is striking from the data in Phase 1 of the study is the overall high rate of successful treatment outcomes in the DDH clinic. The majority of infants who were referred to the DDH clinic by the time they were 12 weeks of age were successfully treated and discharged (n=71, 62%) while 36 infants (32%) were ultimately discharged having required no active treatment. Within the 13 -26 week age group, 48% of infants were successfully treated and discharged while 39% of infants were ultimately discharged having required no active treatment. Within the 27-52 week age bracket, 126 (62%) required treatment and were successfully discharged while 50 infants (24%) were ultimately discharged having required no active treatment. The majority of infants (n=11, 69%) who were referred over the age of 1 year were successfully discharged following regular surveillance. When further broken down into early and late referrals in 2012 and 2013, 92% of those referred early within 12 weeks of age in 2012 were successfully treated and/or discharged while 8% required referral to a Tertiary Unit. Of those who were referred late, 87% were successfully treated and/or discharged while 13% required referral to a Tertiary Unit. In 2013, 94% of those referred early were successfully treated and/or discharged and 6% required referral to a Tertiary Unit. Of those referred late in 2013, 83% were successfully treated and/or discharged while 17% required referral to a Tertiary Unit. These findings demonstrate that while early diagnosis and treatment yield the most successful outcomes, the use of non-surgical methods of treatment such as abduction splinting in a specialist consultant led DDH clinic have a high success rate in the management of DDH even when diagnosed later than 12 weeks of age (Atalar et al. 2006, Wada et al. 2013, Cooper et al. 2014).

6.3.2 Functional referral system

Currently all centres in Ireland including all those covered in this study, as well as the UK, adopt a policy of selective screening for DDH, which is an ultrasound scan performed on infants who have been identified as having risk factors or have clinical suspicion on examination (Donnelly et al. 2015, Mulcahy et al. 2016). The utilisation of risk factors to prompt targeted ultrasound screening of infants has been established in the literature as an effective way to identify infants at increased risk of having or developing DDH (Stein-Zamir et al. 2008, Shorter et al.2011, Tafazal and Flowers 2015). In this study, infants who have a first degree family history of DDH or that have been in a breech position after 36 weeks of age are referred for selective ultrasound screening within 4 to 6 weeks of birth. Findings from Phase 1 identified that three quarters (75%, n= 129) of those who had a positive family history of DDH were subsequently diagnosed with DDH; sixty-six percent (n=48) of those infants who were born in a breech position were diagnosed with DDH; confirming that family history and breech position are important indicators of the likelihood of an infant having or developing DDH. Additionally, bivariate analysis also determined those who had a positive family history of DDH in the study were significantly more likely to be diagnosed with DDH. Logistic regression identified female gender (p¬=0.000) and family history (p=0.019) as being significant indicators of a DDH diagnosis.

Interestingly, findings also showed that 77% (n=214) of the referrals who were diagnosed with DDH were female infants and 66% (n=80) of infants who had no identifiable risk factors also received a diagnosis of DDH. Furthermore, bivariate analysis and logistic regression identified female gender (p=0.000) as significantly more likely to be diagnosed with DDH. This finding is in line with the meta-analysis of 31 studies conducted by Ortiz-Neira et al. (2012) which highlighted that female infants were 5 times more likely to develop DDH. However, despite the strong correlation between female infants and DDH, being female is not considered a risk factor in most newborn examination policies (AAP 2000, Sewell et al. 2009). These results are in accordance with other recent studies indicating that most infants with DDH (73-90%) have no identifiable risk factors (AAP 2000, Shipman et al. 2006, Bracken et al. 2012). The findings in this study confirm that while using family history and breech presentation to target and refer infants does successfully identify infants that go on to be diagnosed with DDH; being female or having no identifiable risk factors are significant indicators of a DDH diagnosis. As these

infants are not classified as having a risk factor, they fall under a low risk category, the majority of who are screened by rotating SHOs who, as previously discussed earlier in the section, have been shown to have a low success rate of identifying DDH.

When the incidence rate was further divided into early and late presentation groups in Phase 1, rates remained substantially high (5.23/1000 and 12.29/1000 respectively). The reason for the high late incidence rate is the higher percentage of late referrals to the clinic. The clinical review found that the majority of infants in both years were referred to the clinic at over 12 weeks of age 66%, (n =127) and 72%, (n = 131) respectively. This means that overall, 31% of infants (n=114) were referred early (<12 weeks) to the DDH clinic, while the majority (69%) were referred late (n=258). The overall mean (±SD) age at first referral over the 2 year period was 25.92 weeks (18.29). Referral over 12 weeks of age for DDH is considered a late referral/diagnosis of the condition (Sharpe et al. 2006; Dimeglio et al. 2007). The literature has emphasized the importance of early diagnosis and prompt, appropriate treatment for DDH (Holroyd & Wedge 2009, Sewell et al 2009, Afaq et al. 2011, Clarke et al 2012). There are several possible causes for the high rate of late referrals to the DDH clinic. As already discussed, due to the lack of any definitive national guidelines or algorithms at that time (2012 and 2013), in relation to the screening and diagnosis of the condition, certain high risk infants may not have had a screening ultrasound before 3 months of age. It is also possible, therefore, that due to the lack of clear concise and up to date algorithms in relation to DDH, that the referral pathway for infants who had a clinical suspicion (particularly referrals that require communication between separate institutions) may not have been efficient enough. The lack of specialist Graf ultrasound training during 2012 and 2013 in the regional centre may also have contributed to the late diagnosis of the condition.

Referrals to the DDH clinic came from a varied mix of primary and secondary multi-disciplinary sources. The majority of participants in both 2012 and 2013 were referred from the paediatric clinic 55% (n = 106) and 58% (n = 105) respectively, while the postnatal clinic referred 19% (n = 35) of the participants in 2012 and 14% (n = 26) in 2013. GPs and PHNs referred less than 20% of the participants each; however, it is worth noting that a percentage of the referrals from the paediatric clinic originated from GP or PHN requests. However, this was not always specified in the clinical notes and, therefore, this data was unavailable to the current study. It is very likely that a higher number of the late referrals in Phase 1 originated from a PHN request, but, because of the multiple points of contact an infant requires before being referred to the DDH clinic (GP or AMO, Paediatric OPD and Ultrasound Department), the

primary origin of referral was not always made clear. These findings bring into question the transparency and clarity of the current referral pathway system utilised in the South East Region of Ireland.

Further findings from Phase 1 related to regional differences in age at first referral to the DDH clinic which revealed a statistically significant difference between places of birth in relation to age at referral. The majority of infants referred early to the clinic (1- 12 weeks of age) were born in the Regional Centre (41%, n=47), while the majority of infants born in the later diagnosis age brackets were all born in Rural 1 or Rural 2. A Chi-square test for independence indicated a strong significant association between early and late referrals and region of birth while logistic regression used to determine the effects of key characteristics on the likelihood of a late diagnosis of DDH found that being born in Rural 1 was significantly associated with receiving a late diagnosis of DDH.

Similar findings were evident in a research study by Sharpe et al. (2006) which aimed to identify differences in risks factors between early and late cases of DDH. They concluded that babies born in rural areas were four times more likely to be at risk of late diagnosis. Sharpe et al. (2006) suggested that one explanation for this phenomenon was that professionals in heavily populated areas had more opportunity to examine babies and, therefore, became more experienced. A more recent study by Struder et al. (2016) also found that birth in a rural hospital was a significant perinatal risk factor for late diagnosis of DDH. These findings raise the question as to whether being born in a regional area lends itself to being a protective factor against being diagnosed late with DDH because of the high number of infants being checked by suitably qualified HCPs leading to a higher level of sensitivity in picking up abnormalities during an examination of the hips.

Results from the questionnaire in Phase 2 differed however. Findings showed that the DDH clinic was able to see 80% of infants within 6 weeks. Six percent of infants were seen between 7 to 10 weeks while only 8% had to wait longer than 10 weeks. These waiting times are well below the national average outpatient waiting list times where only 35.7% of patients waited less than 3 months (HSE 2015). The improvement may be because data collection for Phase 2 took place in 2014 and 2015 following the commencement of a more structured screening programme in the South East of Ireland.

6.3.3 Use of appropriate technology

Findings from Phase 1 found that over half, 54% (n=79) of those who had a diagnostic ultrasound were found to have a normal ultrasound screen while, 46% (n=68) had an abnormal ultrasound screen. However, of those who had an initial normal ultrasound, 30% went on to be later diagnosed with DDH at 6 months. Furthermore, when the sensitivity of diagnostic ultrasounds was evaluated, sensitivity was found to be low at 47%, while there was 97% specificity that diagnostic ultrasounds would correctly indicate a negative screen in those who did not have DDH. These findings appear to be contrary to previous observational studies that argue that ultrasound imaging at, or shortly after birth, identifies a high number of immature and abnormal hips, most of which are 'false positives'; and if left untreated would go on to develop normally (Bialik et al. 1999, Woolacott et al. 2005). Reasons for the late diagnosis in these cases could be in relation to the very nature of DDH being a developmental disease (Shipman et al. 2006); or due to the ultrasound screening and diagnostic practises at the time in 2012 and 2013. Again, it should be noted, that it is difficult to ascertain as to whether those hips identified at 6 months would have resolved spontaneously without treatment if kept under close surveillance.

The study did, however, identify a high incidence rate in general for DDH (17.5:1000). The high incidence rate in the DDH clinic could be argued to be a consequence of the employment of ultrasound screening and consequently, over diagnosis of the condition (McCarthy et al. 2005). USPSTF (2006) acknowledged that while there is evidence that screening leads to early identification, it also said that a high percentage of those identified as abnormal or suspicious of DDH by ultrasound in the newborn period may have resolved spontaneously without any intervention. Eleven years later, this view is still supported by Paton (2017) who states that sonographic diagnosis of DDH has a higher prevalence of abnormality than clinical diagnosis, raising the possibility of an over diagnosis of the condition which leads to over treatment. This viewpoint begs the question as to whether the high incidence rates points to over treatment as a consequence of variable screening methods. Lehmann et al.'s (2000) meta- analysis suggests that the incidence of DDH revealed from examination by a paediatrician to be 8.6/1000, the examination by an orthopaedic surgeon to be 11.5/1000 while the incidence diagnosed by ultrasound examination to be 25/1000. Paton (2017) goes on further to suggest that hip screening internationally, does not meet most of the World Health Organisation's criteria for an effective screening programme and, therefore, should only be considered as a form of surveillance rather than a strict screening programme. While it does seem evident that there is,

as of yet, no gold standard method of accurately screening for DDH, and that there is a high likelihood that DDH is over diagnosed and treated; future negative consequences for infants left untreated when treatment was in fact warranted needs to be considered (Raposch and Wright 2007).

A possible solution was put forward by Rosendahl et al. (2010) who conducted a 5 year single centre blinded randomised control trial in Norway where 128 newborns with mild hip dysplasia identified by ultrasound were randomly assigned to receive either 6 weeks of abduction treatment or active sonographic surveillance at 6 weeks of age and then again at 3 months. Results showed active sonographic surveillance halved the number of children requiring treatment, did not increase the duration of treatment, and yielded similar results at 1 year follow up. The authors suggest that active sonographic surveillance of infants with stable but mildly dysplastic hips can reduce use of abduction splinting treatment without increasing the risk of persistent or more severe dysplasia. As mentioned earlier in the section, it must be taken into consideration that this study focused on infants born in 2012 and 2013. Formal ultrasound training and the adoption of a standardised screening programme incorporating the Graf technique was not commenced until 2014. Graf recommended that hips with a α-angle of more than 50 degrees when an infant is less than 3 months of age (Type IIa), should be considered as immature rather than abnormal. These infants did not require treatment according to Graf, but should, however, be kept under close observation radiologically. This rationale is in line with Rosendahl et al.'s (2010) earlier proposal of actively monitoring mildly dysplastic hips for a period of time prior to starting treatment. Further research, which compares incidence rates and screening protocols between the practises evaluated in this study and what is practised currently, would provide the DDH clinic with information as to whether close surveillance of mildly dysplastic hips rather than immediate treatment has reduced overall incidence rates in the region.

6.3.4 Timely and accurate diagnosis

When data was compared between parents whose child had been diagnosed early with parents whose child had been diagnosed late, data revealed that parents of those diagnosed early expressed significantly more worries in relation to washing and dressing their baby while the parents in the group diagnosed late expressed significantly more worries in relation to hospital appointments and relating to whether their baby would walk in the future. The early group findings are in line with Bergo & Rosendahl's (2013) study which found that parents whose

baby was treated from birth found treatment more distressing than those treated at 9 weeks or beyond. They concluded that new parents placed high value on the initial few weeks with their newborn. This finding was also reported in Phase 3 of the study where new parents spoke of the grief they felt when their newborn went into an abduction harness. Feelings of sorrow at not having skin to skin contact were described. The results are also consistent with Gardner et al.'s (2005) findings which highlighted that early intervention with a splinting device was related to increased maternal distress. A possible explanation for the results from the group diagnosed late might be the association between late diagnosis of DDH, failed treatment rates and possible long term disability for their child.

Further findings from Phase 3 highlighted the regret expressed by some parents that their child's hip condition was not diagnosed earlier, with some parents questioning if there was a missed opportunity to diagnose DDH at an earlier stage. Other parents commented that if they had received better information about DDH during the pregnancy, they may have noticed that there was an issue with their child's hips and sought help sooner. These concerns led parents to wonder if there may have been a better outcome for their children if DDH had been treated at a younger age. These findings reveal how upsetting a diagnosis of DDH can be for parents, particularly the late diagnosis of the condition and highlights how it can often leave parents with many unanswered questions.

6.3.5 Specialist DDH service and staff

Overall, there was a very high satisfaction rate with the DDH clinic across Phases 2 and 3. As already discussed, the majority of parents in Phase 2 and 3 were either very satisfied or satisfied with the DDH clinic and when asked in an open-ended question if there was any way the service could be improved, 56% felt nothing needed improvement. Findings from the open-ended question revealed a variety of positive perspectives in relation to the DDH clinic and a number of complimentary comments in relation to the staff and service were made. Parents reported that they felt they were receiving a very professional service and felt very well cared for by the staff. Seventy-nine percent of parents in Phase 2 reported seeing both a doctor and a nurse at each clinic appointment.

Findings from Phase three's qualitative data showed that parents felt they could trust the service and standard of care in the DDH clinic as it was a consultant led service with specialist staff offering continuity of care. These findings were echoed by Lee's (2005) study previously discussed in the chapter. Lee (2005) argued that children's orthopaedic health services have

historically been provided in adult centred environments with an adult focused provision of care and thus the principal needs of the child and their families may not be clearly identified and, therefore, not always met. These results further support the idea that a specialist clinic empowers parents and enables parents to feel involved in their child's care.

The provision of a child focused health service has been widely acknowledged as a more effective way of delivering family centred care to children and their families while in hospital (Department of Children and Youth Affairs 2013). This research illuminates the many benefits of providing a specialist DDH service to infants and their families in terms of the overall health outcome of the child and the parents' transition to parenthood caring for a child with DDH. By taking into consideration the psychosocial needs of the parent regarding the screening and treatment policies of DDH (Gardner et al. 2005), a holistic family centred approach to the care of children with DDH and their families can be implemented, which can help with some of the stress, anxiety and altered parenting roles that accompany their baby's condition (Kelly 2018).

6.3.6 Cultivation of effective communication

Research into the experiences of parents surrounding the time of diagnosis of a chronic or serious condition, highlight how the manner in which a diagnosis is disclosed is very important and should reflect sympathy, honesty and openness (Mooney-Doyle et al. 2017). Equally, it is recommended that HCPs talk with clarity and give parents as much time as they wish to ask questions (Baird et al. 2000). Issues surrounding the lack of communication, both written and verbal, from HCPs during the antenatal and postnatal period were discussed in length in Section 6.1.2 which focused on health surveillance and health promotion policies and procedures. However, it is worth emphasising again how the resulting lack of knowledge regarding DDH was felt by a number of parents to be a catalyst to how they coped with receiving a diagnosis of DDH and further compounded the shock felt at diagnosis.

Within the DDH setting, however, 98% of parents in Phase 2 felt that the examination of their newborn was explained to them in a way that they understood, while the same percentage felt they were given ample opportunity to ask questions. Ninety-one percent of parents also felt that the length of time given for their appointment was adequate for their needs. In Phase 3, all parents reported receiving written information regarding DDH. While a small number of parents felt their concerns regarding their baby's discomforts during treatment were not listened to by the staff in the clinic, the majority felt that the nursing care was one of the most positive aspects to their experience in the DDH clinic.

6.3.7 Respectful and compassionate care

One of the main objectives of the study was to explore the experience of parents receiving a diagnosis of DDH and caring for a child in receipt of treatment for the condition. The qualitative data from Phases 2 and 3 reveal an overwhelming sense of the parents in the study being very satisfied with the standard of care they received in the DDH clinic. A number of the parents commented that they felt supported and cared for by the specialist staff in the clinic. According to a majority of the parents, the staff acted with empathy and understanding, particularly at the time of diagnosis and commencement of treatment, which in turn made the experience of receiving a diagnosis of DDH and accepting the need for treatment less traumatic for them.

In particular, the nursing staff in the DDH clinic, were found to have a very positive effect on the majority of parents in Strand 1 of Phase 3. Parents commented that the nurses played a crucial role in their transition to being a caregiver for their child now in treatment for DDH by providing practical and emotional support and allowing parents plenty of time to process the situation and ask questions. The calm demeanour of the staff in the clinic was noted to have a reassuring effect on the parents, decreasing levels of anxiety and building the capacity of parents to self-manage the care of their infants in treatment at home.

The provision of supportive and nurturing care at time of diagnosis, in the form of verbal and written practical information, emotional and social support were identified in Jugnoo et al.'s (2004) qualitative study and were found to increase parents early transition experiences, psychosocial wellbeing and overall parent satisfaction with healthcare services. Witting et al.'s (2012) study which explored parental satisfaction with ultrasound hip screening also found that satisfaction was significantly influenced by the time offered to parents to ask questions and the competence, friendliness and carefulness of the ultrasound screener also befitted the parents.

In relation to parental experiences of caring for a child in treatment for DDH, data from the Likert scale in Phase 2 revealed that several of the questions scored highly in terms of worry/distress in relation to their baby's hips. A high percentage of parents expressed worries relating to being told about the DDH diagnosis (73%), when looking at their baby's hips in harness (55%), worry relating to the comfort of their baby in harness (73%), the effect the hip instability would have in the future (69%) and if their baby was going to be able to walk (56%). These results confirm the association between the diagnosis and treatment of DDH and negative psychosocial consequences for parents (Chao & Chiang 2003, Gardner et al. 2005).

Findings from Phase 3 (parents) further confirm the association between a child starting treatment for DDH and parental anxiety and distress. A number of parents expressed that one of the most over-riding concerns they had when DDH was diagnosed was whether their baby was in pain because of the underlying hip condition, or because of the actual treatment itself. Many parents expressed how they found the general management of daily hygiene needs and the prevention of skin breakdown problematic during treatment. Parental difficulties with bathing, dressing and inspection of skin creases for signs of irritations or abrasions of the skin were highlighted.

These results match those observed in Chao & Chiang's (2003) case study which focused on the impact and coping behaviours of a Chinese mother whose child was diagnosed with DDH at 17 months. The study revealed that the mother felt shock of diagnosis, fear of potential risk of surgery, feelings of loss and anger for the unexpected, uncertainties and anxiety about the future and excessive and incontrollable emotions. Coping behaviours were also identified from the case study such as seeking out of family support, additional knowledge relating to DDH and the day to day care of an infant with DDH and meeting the child's special needs. The authors concluded that health care professionals need to provide greater opportunities for mothers to express their concerns regarding the condition and any negative feelings they may be harbouring following the diagnosis. It was also suggested by the authors that by acknowledging and recognising when parents are managing the care of their infant in treatment for DDH, that this would increase self-confidence and possible acceptance of the condition. A number of mothers in Phase 3 described how the calm, reassuring nature of the nurses in the clinic reduced their anxiety and helped them transition to parenthood caring for a child in treatment for DDH. These findings further support the idea that respectful, compassionate dialogue between HCPs and families not only benefits the health outcome of the infant in treatment but also helps reduce the amount of parental stress and anxiety surrounding the diagnosis of DDH.

6.4 Application of Conceptual Framework

The Adapted Family Centred Care Framework adapted from (McCormack and McCance 2010; Tuncalp et al. 2015 & Sudhinaraset et al.2017) emphasises the circumstances surrounding the child and family and how they have a direct influence on a family's ability to cope with the diagnosis and treatment of DDH. The fundamental approach of FCC is to provide care that puts the multi-dimensional needs of the child and their family first, which provides the potential

to improve health outcomes and offer parents physical, psychological and social supports during their child's treatment (Kelly 2018).

One of the main aims of the current study was to assess the effectiveness of current screening and treatment methods in the South East region of Ireland. Findings from Phase 1 revealed that while the dedicated DDH clinic does achieve high success rates in terms of treatment, there does appear to be high incidence rates of DDH in the region, particularly a high late incidence rate. These findings suggest that screening and diagnostic practises in 2012 and 2013 may have contributed to the high incidence rates at the time.

One of the core concepts of FCC developed by the IPFCC in 2012 encourages health care leaders to collaborate with patients and families in policy and programme development, implementation, and evaluation and in the delivery of equitable care (Johnson & Abraham 2012). It is hoped that the findings from this study will shine a light on the health outcomes of infants with DDH and the experiences of parents in the South East of Ireland who have navigated the screening and treatment practises at primary and secondary health service level. To ensure that children's voices and experiences of health care are heard, the Review of Paediatric and Neonatology Services proposed a number of principles which mirror the philosophy of FCC (HSE 2013):

6.4.1 Development of a national model of care for newborns

The findings in Phase 1 have identified a number of practical implications that provide scope for the promotion of FCC in relation to the screening, diagnosis and management of DDH at national level. The high incidence rates in 2012 and 2013 reflect the need for national screening and treatment polices to be implemented as soon as possible. This will ensure that HCPs nationwide will receive up to date training in evidence based screening methods and as a result babies in Ireland will receive equitable, early and effective health care in relation to DDH.

6.4.2 Focus on health promotion, prevention and screening.

Health promotion campaigns and supports that ensure the best possible outcome from pregnancy are vitally important. Screening and early detection of existing conditions such as DDH with timely intervention can make a significant difference to the health and wellbeing of children (HSE 2013). Findings from Phase 3 revealed that there was an overwhelming lack of awareness regarding DDH during the antenatal and postnatal period. The general consensus view of the majority of parents in the study was that they were not being given enough

information about DDH in their pregnancies or the immediate postnatal period. As a result many parents felt overwhelmed and underprepared when they received a diagnosis of DDH.

6.4.3 A consultant delivered service.

The provision of a consultant delivered DDH service has been suggested to be a key element for delivering better infant care in Ireland (HSE 2013). Findings from Phase 1 reveal that the majority of infants in receipt of treatment from the specialist dedicated DDH clinic had a successful outcome and were discharged from DDH services. Others had to be referred to specialised tertiary care for possible closed or open surgery and this decision was made by the consultant.

6.4.4 Involving and empowering parents

This study also set out to explore the experiences of parents caring for a child with DDH and utilising a dedicated DDH clinic in the South East region of Ireland. Parents have identified many elements within their care environments which impact upon the care their children received and their overall experience. Findings from Phase 3 establishes the positive effect that timely, accurate and mindful communication with HCPs, while receiving clear and accurate information about their child's condition and how to manage the care of their child in treatment had on parents. A number of positive outcomes were identified in the findings which suggest that by using a FCC approach in how HCPs communicate with families in the DDH setting, parents accepted the diagnosis more easily, felt more confident and able to care for their baby at home and this in turn reduced the amount of stress and anxiety surrounding the diagnosis and management of DDH.

6.5 Conclusion

This chapter considered the key findings of the study and critically compared these findings with the literature. The study provides valuable information needed when working with families who have had a diagnosis of DDH. Findings from Phase 1 have revealed that despite a high late referral and diagnosis rate of DDH in the region, treatment in a specialist consultant led DDH clinic has shown to provide successful outcomes in the management of DDH. It is evident from the findings in Phase 1 that that there is a need for the newly formulated national screening guidelines for DDH to be implemented as soon as possible nationally. Study findings

from Phases 2 and 3 of the study provide new insight and accentuate the need for a family centred approach to how HCPs practically and psychologically support families through the diagnosis and treatment of DDH. While there was an overwhelming sense of parental satisfaction with the dedicated DDH clinic in the South East of Ireland, the lack of provision of this specialist care nationally means that health services are currently failing to provide equitable family centred care to infants with DDH and their families nationally. Chapter 7 will now discuss the findings in light of the contribution of the study to the literature, the implications of the study for clinical practice and future research studies.

Chapter 7 Conclusions and Recommendations

Introduction

This chapter considers the relevance of the study findings. The contribution of the research study is discussed in Section 7.1 in accordance to the following areas; the existing body of research literature, contributions for professional practice and theoretical contribution of the study. A number of strengths were associated with the study and these are discussed in Section 7.2 in addition to the identification and portrayal of the limitations of this study. Suggestions for further research which have evolved from this research study are outlined and justified in Section 7.3. Finally, recommendations are made and their significance discussed in relation to anticipated improvements for care provision in Section 7.4.

7.1 Contribution of the research study

The overall findings, the conclusions drawn from the research findings combined with the review of the literature have provided a new contribution to knowledge to the provision of DDH services in Ireland. Research relating specifically to the quality of health care outcomes and parents caring for an infant with DDH represents an area which has not been previously researched in Ireland. Subsequently, there are many implications and contributions for the general body of research literature, professional practice, nursing theoretical knowledge, and policy implementation.

7.1.1 Contribution to research literature

The use of a mixed methods approach is a strength of this study relative to other published research in this area. Previous quantitative studies have attempted to determine the incidence of DDH, including the incidence of late diagnosis, in Ireland; while also examining the treatment outcomes of patients diagnosed with the condition (Gul et al. 2002, O'Grady et al. 2010, Phelen et al. 2014). This, however, does not provide evidence of the reality of receiving a diagnosis of DDH as a parent or caring for a child in treatment from an Irish perspective. A recent qualitative case study which sought to capture the experience from one Irish mother's perspective (Mulcahy et al. 2016), while informative, cannot be generalised to the wider population (Zainal 2007). Consequently, a particular strength of this study is that it is representative of parents from a wide geographical spread across the South East region of

Ireland. This means that the findings from each of the phases offer a unique perspective on the process of infants being screened for DDH postnatally, referred to the DDH clinic, diagnosed, and finally the subsequent transition home with a child in treatment in one of 4 centres in the South East region of Ireland thus adding to the body of knowledge that already exists. Exploring the multi-dimensional impact that DDH has on families with a family-centred approach, not only gives a voice to families but provides significant benefit to infant medical outcomes and it can also be used to develop, implement, and evaluate services (Jugnoo et al. 2004)

7.1.2 Contributions to professional practice

GPs and PHNs interviewed in Strand 2 of Phase 3 repeatedly expressed their concerns regarding the short fallings of their professional training with regards to DDH. All of the GPs interviewed conceded that it was highly likely that they were not accurately screening infants for DDH during their time as SHOs or as newly qualified GPs. The reason given for this was the ad hoc nature of their supervision during their paediatric rotations as SHOs. It was suggested by one GP that there was also the likelihood that they were over diagnosing suspected cases of DDH. These findings echo the results of Bloomfield et al.'s (2003) study that highlighted poor practice and suggested that SHOs would prefer to have more training in the area of newborn examination. The following conclusions can be drawn from these findings: the high rates of false positives and the possibility of missed cases of DDH which lead to higher rates of false negatives could be a determining factor that contributed to the high incidence rate and high late diagnosis rate of DDH in the region in 2012 and 2013. The findings highlight the importance of introducing more structured formal training in the area of newborn examination as suggested by the Review of Paediatric and Neonatology Services in 2013 (HSE 2013) and the DDH Subgroup of the National Child Health Review Steering Group in 2017 (HSE 2017).

In relation to the PHNs, findings also revealed that PHNs agreed that while their training did appear to be sufficient, the lack of regular updates once qualified was frustrating. Other research has suggested that PHNs are often the HCP who identifies a missed case of DDH in the community (Mulcahy *et al.* 2016). It is imperative that PHNs must, as a result, make sure that their knowledge about DDH is up to date and complete. Taken together, the findings from GPs and PHNs contribute in several ways to an understanding of the experiences of HCPs in the community screening for DDH and provides the basis for a re-evaluation of the training practices currently provided to them in Ireland.

Findings from both the GPs and PHNs provided insight into how some referring HCPs were frustrated at the lack of cohesive communication between primary and secondary caregivers. There was a lack of follow up reported by PHNs in terms of referrals they had made with suspected DDH and GPs complained that correspondence regarding patients may not be identified in time due to the high levels of correspondence being posted via health institutions and departments. The insights gained from this data expands an understanding of how enhanced communication between GPs, paediatricians, AMOs, PHNs and public health doctors would ensure equity; allow evaluation through data collection and analysis and facilitate information sharing with parents and amongst service providers. The introduction of the PHR or EHR nationally was suggested by GPs and would certainly help support the delivery of a standardised national care programme but requires national funding.

The findings of this study extend the evidence base concerning the benefits of a specialist DDH clinic in relation to the diagnosing and treatment of infants with DDH. While the high incidence rates, particularly the high incidence of late presentation of DDH in the region is worrying, it is worth noting that Phase 1 focused on infants born in 2012 and 2013, and formal ultrasound training and the adoption of a standardised screening programme did not commence until 2014. Consequently, the findings confirm the possible association between lack of standardised care for DDH and high incidence and late diagnosis of the condition. It is evident, however, that despite the high incidence of late presentation of DDH, there is a high rate of overall successful treatment outcomes in the DDH clinic. These findings demonstrate the benefits of attending a specialist consultant led DDH clinic in terms of overall health outcomes for infants with DDH. A strength, therefore, of the study, is that a number of the findings from Phase 1 can be used as key performance indicators for national and local monitoring of the national treatment programme.

The evidence from the study suggests that receiving a diagnosis of DDH is a deeply upsetting time for parents. Findings revealed that due to the lack of adequate information given to parents during the antenatal and postnatal period, parents felt overwhelmed and underprepared for the diagnosis and what it meant for their child. First time parents in particular, found the diagnosis extremely stressful, not only were they making the new and difficult transition into parenthood but also they have to experience the feelings that are associated with a newborn diagnosis such as loss of idealised dreams, insecurity of an uncertain future, grief, loneliness and isolation (Stube & Stumm 2017, International Hip Dysplasia Institute 2018). A factor that appeared to compound these negative feelings even further was the lack of awareness amongst the general

population regarding DDH. The qualitative data highlights how very little, if any knowledge regarding DDH parents had prior to their own first-hand experience with the condition. This finding suggests that more needs to be done at national level to create better awareness regarding DDH through health promotion and health surveillance policies and procedures at community and hospital level during the antenatal and postnatal period.

This study has identified that the transition to home with a child in treatment for DDH in a Pavlik Harness or Boston Brace is a challenging time for parents. Parents reported how distressing it was when treatment was commenced immediately following diagnosis, and how upsetting the abduction brace looked being applied to their newborns, particularly having never seen that type of device before. Worries and fears regarding pain caused by the harness, lack of close contact with their infants because of the harness, breastfeeding challenges, skincare and safety concerns while travelling in a car seat were all common sources of anxiety for parents. However, it was also acknowledged that once they had processed the initial diagnosis, caring for their infant was more manageable than first expected, the reassuring and supportive environment in the DDH clinic highlighted as a contributing factor that helped to normalise the situation for parents.

Parents interviewed repeatedly expressed how crucial the role of the nursing staff in the DDH clinic was in helping parents transition to parenthood caring for a child in treatment for DDH. The supportive nature of their care was considered to be one of the most positive aspects of their experience in the clinic. Building confidence, the written and verbal practical advice and time given to ask questions were highlighted by a number of parents as being a positive aspect to the care they received in the clinic and helped with the transition into their new roles as caregivers as well as parents. These findings build on evidence that suggests that greater priority needs to be placed on the psychosocial support needs of parents during the time of diagnosis and treatment (Chao & Chiang 2003,Gardner et al. 2004, Kratz et al. 2009).

The findings confirm the possible association between lack of standardised care for DDH and high incidence and late diagnosis of the condition. As previously discussed, lack of formal training in screening and regular updates for HCPs who screen infants for signs of DDH, may lead to an over diagnosis of DDH or conversely, missed cases of DDH in the newborn period resulting in a late diagnosis instead. The findings from the study has helped identify scope for the improvement of care in DDH diagnosis and treatment and supports the recommendations from the Review of Paediatric and Neonatology Services in 2013 (HSE 2013) and the DDH

Subgroup of the National Child Health Review Steering Group in 2017 (HSE 2017) for the introduction of more structured formal training in the area of newborn examination. The findings of this study further contribute to an Irish healthcare health policy called 'National Standards for Safer Better Healthcare' which refers to taking into account the needs and preferences of service users and providing equitable access based on assessed need (HIQA 2013).

This study provided a baseline for the preferences of parents, including increased information about DDH, continuity of care and compassionate care, particularly around the time of newborn diagnosis. These findings provide evidence for an area which has not been previously researched within an Irish context and builds on previous European and International research (Chao & Chiang 2003, Gardner et al. 2004, Hart et al. 2006, Kratz et al. 2009), that advocate for a more family centred approach to how HCPs support parents who are caring for a sick child.

7.1.3 Theoretical contribution of the study

A possible theoretical contribution emerged from the findings of this research study which may provide a baseline framework for a future model of care. As described in Chapter 3, this study employed the integration of 3 conceptual frameworks into one comprehensive model suitable for this population of children with DDH and their parents (Adapted from McCormack and McCance 2010; Tuncalp et al. 2015 & Sudhinaraset et al. 2017). The conceptual framework was devised from this combination with 3 constructs encircling the main concept of family-centred care to provide a guiding framework for the study. Needs were identified from the findings representing all perspectives involved in the care of infants with DDH. Such a model highlights possible suggestions for future research/ models of care in relation to the screening, treatment and care of infants with DDH and their families.

The national and community determinants construct can help guide and address some of the broader issues within the national health care system that effect how DDH is perceived and managed in Ireland. The parental determinants of successful screening and treatment of DDH construct helps demonstrate the many factors that can influence how parents utilise health services for their children while the quality of care construct provides a deeper insight into how the provision of care that HCPs deliver effect the experience of care for families which can ultimately lead to outcomes of family centred care.

7.2 Strengths and Limitations of the study

A strength of this study is that it employed a mixed methods approach using a sequential exploratory design. This approach permits the researcher to approach the study from different vantage points using different methods. By utilising a mixed methods approach and integrating quantitative and qualitative tools, it is then possible to foster a greater understanding of the experiences of parents attending a DDH clinic with their infants. The findings from each phase highlighted the need to further explore the experiences of parents caring for a child with DDH and to explore the provision of DDH services from the perspectives of the parents of the infants in receipt of care from the clinic and from the perspective of HCPs who screen and refer for suspected DDH in the community. Overall, by using a sequential exploratory approach, the study captured the complexities of screening and treating a still largely misunderstood condition, as well as the experiences of families who have received a diagnosis of DDH and have received treatment for it in a specialist DDH clinic.

It is important in quantitative research to determine how many people are required to survey in order to get results that reflect the target population as precisely as required in a study. A further strength is the sample size calculation which showed that when using a confidence level of 95%, and a confidence interval of 10, the recommended sample size for this study is 65 participants. Therefore, the sample size of 100 used for this study was considered appropriate and adequate.

The results and conclusions of this study should be considered in the light of limitations. It is not possible for a single study to capture all that could be discovered or known about a given topic and certainly a study undertaken by a single researcher, within a limited timeframe. This

study is no exception. A number of limitations have been identified with this study and include the following: Phase one's chart review represented data gathered from just one Regional Centre in the South East. The use of a single location could be considered to have limited the study generalisability as this data might not be representative of the entire population of families with DDH in Ireland. In Phases 2 and 3 the questionnaire and interviews with the parents also took place in one centre. The numbers of GPs and PHNs interviewed for the study was very restricted and may not represent all GPs and PHNs in the region. Given that there are very few dedicated DDH clinics in Ireland, it would be difficult to carry out a multi-centre review of this nature at this present time.

The use of telephone interviews as opposed to face-to-face interviews could be viewed as a limitation of this study. Some qualitative methodologists argue that telephone interviews may impede the researcher's ability to build a rapport with participants and therefore affect the quality of the data collected. The decision to interview parents by phone was based on the needs and time constraints of the participants. Both options of face to face or telephone interviews were offered to all participants. . The parents involved in this study were spread over a large area and those who opted to be interviewed welcomed the choice of participating in the study via telephone. By taking a family centred approach to data collection, the researcher was mindful of not imposing on family time, particularly keeping in mind the time parents had given to attending regular and sometimes lengthy appointments in the DDH clinic. Telephone interviews with HCPs transpired to be the only realistic option for HCPs to allocate time for an interview into their busy working schedules.

Another possible limitation of the study was the time period that had lapsed since participants had received a diagnosis and treatment for their child and when they participated in the study. In some cases, up to two years had passed, so there is the possibility that memories may not be as accurate and feelings had changed with the passing of time. The rationale for this length of time was due to the possible developing nature of DDH and the typical 3 year time frame of being monitored by the clinic prior to discharge.

A final limitation was identified as a potential ethical concern in relation to issues of objectivity and independence as a result of the researcher working in the DDH clinic as a staff nurse towards the end of the lifetime of the project. It should be noted however that the researcher did not commence working in the clinic until after data collection was completed.

7.3 Recommendations for future research

The following recommendations are suggested:

1. Internationally, there are no agreed guidelines or standards in relation to screening for DDH. There is a need for enhanced international research in relation to best practice in the area of screening and detection of DDH.
2. To develop a full picture, further research comparing screening and referral practises in the South East region of Ireland post the introduction of the new national screening programme with these study findings are recommended.
3. Given the high incidence rates identified in the South East region of Ireland, the need for better research in the early diagnosis and treatment of DDH needs to be commissioned to establish the incidence, management and outcomes of treatment of DDH in the Republic of Ireland.
4. Further research into the experience of parents caring for a child with DDH, focusing on supporting parents through information provision is recommended. The use of different types of media to inform parents could be explored such as text alerts for appointments; resource links sent via email or text; videos to provide information in relation to DDH to parents and improved information leaflets provided during the antenatal and postnatal period.
5. A natural progression of this work would be to determine how we could better support HCPs screening and referring for suspected DDH in the community. The findings of this study suggests that HCPs feel under supported and inadequately trained to effectively screen for DDH in the hospital postnatal setting and in the community setting. Further research could usefully explore what further training is required for HCPs in order for them to safely work within their scope of practice as a screener for DDH.

7.4 Recommendations for future practice

The following recommendations can be drawn from completion of this study:

1. Parents should be given written and verbal information on the reasons for DDH screening during the ante-natal period. This should be incorporated into the antenatal health promotion programme more effectively than it is at present.

2. Improved screening training for HCPs involved in neonatal DDH screening, with a more structured period of supervised practice before being signed off as competent. The training should be repeated at appropriate defined intervals to maintain competency.

3. The training of more midwives in the postnatal setting to carry out the newborn examination of the hips under the examination of the consultant. This would allow for the development of a small skilled cohort of staff to carry out the examination on a regular basis.

4. The implementation of a screening and referral algorithm that would clearly direct staff on the correct pathways to follow for the timely diagnosis of DDH.

5. The parents should be told verbally and given written instruction on the outcome of the screening and what actions are required, if any.

6. The results of the neonatal screening should be recorded using an electronic Personal PHR and online referral system so that GPs and PHNs are made aware in a timely manner of screening results

7. People undertaking ultrasound screening should be trained and have competency signed off for ultrasound examination of hips. A standardized programme needs to be developed using a competency framework.

8. GPs and PHNs who screen for DDH in the community should have their competency maintained by performing a specified number of examinations per year and the provision of regular annual or biannual updates in training.

9. HCPs in contact with families in the community should create better awareness regarding the developmental nature of DDH and encourage parents to speak to their PHN or GP or other HCP if they have any concerns about their baby's hips.

7.5 Conclusion

In summary, this study contributes to the body of knowledge by enhancing the understanding of DDH and caring for children with this condition. The findings of this study provide insight into the value of early referral, diagnosis and treatment of the children. As no studies were found looking at a FCC approach to the care of children with DDH, this study has contributed to nursing knowledge in Ireland and abroad. This study explored the care of children with DDH and provides a strong basis for the development of national guidelines for the detection, treatment and care of infants with DDH.

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Appendix I Parent Satisfaction Survey

EXPLORING THE DETECTION AND CARE OF INFANTS WITH DEVELOPMENTAL DYSPLASIA OF THE HIP

Information provided will remain strictly confidential.

Participants may withdraw from the study at any time.

Code **I____I**

Today's Date (D/M/Y) **I____I____I____I**

ALL INFORMATION IS ANONYMOUS AND CONFIDENTIAL

Please complete all questions and return it to the clinic secretary's desk or in the stamped addressed envelope provided.
Answer the following questions as they apply to you. Where indicated please tick the appropriate box.

DEMOGRAPHIC DETAILS

Q1.

What age is your child? ☐

Q2.

What gender is your child?

Female ☐

Male ☐

Q3.

What type of treatment is your child undergoing in relation to DDH?

Harness ☐

Brace ☐

Surgery ☐

Q4.

What age was your child at diagnosis of his/her condition? ☐

Q5.

What type of delivery did you have?

Normal ☐

Instrumental ☐

Caesarean section ☐

Q6.

Was your baby born breech?

Yes ☐

No ☐

Q7.

Has your child undergone a **hip ultrasound** for his/her condition?

Yes ☐

No ☐

Q8.

Has your child undergone a **hip x-ray** for his/her condition?

Yes ☐

No ☐

Q9.

Who referred your child to this clinic?

Consultant ☐

Midwife ☐

GP ☐

PHN ☐

Other ☐
(please identify)
_____

Q10.

How long has your child been attending this clinic?
(*Years/Months*) _____

Q11.

Do you know why your child was referred to this clinic? Please explain.

_____

Waiting Times

Q12.

How many weeks/months did you wait from being told your child needed to be seen at the hospital to your first appointment?

_____

Q13.

Did you think this waiting time was?

Too long ☐

As expected ☐

Better than expected ☐

Appointments

Q14.

How long did you wait in the clinic before you were seen?

Less than 15 minutes ☐

16-30 minutes ☐

31-60 minutes ☐

Over 60 minutes ☐

Q15.

Can you remember what health professional you saw?

Doctor ☐

Nurse ☐

Both ☐

Q16.

Was it explained to you why your child was being examined in a way that you understood?

Yes ☐

No ☐

Q17.

Were you given the opportunity to ask questions about your child's care?

Yes ☐

No ☐

Q18.

Did you think the appointment time was appropriate?

Yes ☐

No ☐

Q19.

If your child needed further treatment for DDH, was this explained to you?

Yes ☐

No ☐

Q20.

If your child is undergoing treatment for DDH and you had worries, were you made aware of anyone you could contact?

Yes ☐

No ☐

INFANT HIP WORRIES INVENTORY

The following are a list of statements that other parents/caregivers have said are important.
Please respond by giving a score ranging from 1 (strongly agree) 2 (agree) 3 (no opinion or uncertain) 4 (disagree) 5 (strongly disagree).

Q21.

	Question	Strongly agree	Agree	No opinion or uncertain	Disagree	Strongly disagree

1	I was very upset when I was first told that my baby had an unstable hip					
2	I get upset when people ask me about my baby's hips					
3	I worry that I might do something to hurt my baby's hips					
4	I get upset when I look at my baby in a harness / brace					
5	I find it difficult to feed my baby					
6	I find it difficult to wash my baby					
7	I find it difficult to change my baby's nappy					
8	I find it difficult to dress my baby					
9	I find it difficult to cuddle my baby					
10	I find it difficult to play with my baby					
11	I find the harness/brace restricts my activity with my baby					
12	I worry about whether my baby is comfortable					
13	I find it difficult to manage harness/brace					
14	I find it difficult to strap my baby into their car seat					
15	I worry before each hospital visit related to my baby's hips					
16	I worry about the effect the hip instability might have on my baby in the future					
17	I worry about my baby walking in the future					

Overall quality of service

Q22.

Overall, what was your impression of the quality of service?

Very satisfied ☐

Satisfied ☐

Dissatisfied ☐

Don't know ☐

Q23.

Is there anyway the service could be improved?

Would you be willing to participate in an interview in relation to this research project?
The interview could possibly take 1/2 an hour to 1 hour with myself Heather Jennings, held at your convenience in the clinic before/after your clinic appointment or in your own home if that is more suitable for you and your family needs.
An explanatory form regarding the interview format will be sent to you if you do wish to participate. Participation is voluntary and participation may be withdrawn at any stage with no reason needed.
I would be grateful if you would consider taking part in this research study and I thank you in anticipation of your participation.

Heather Jennings
Email: hjessjenn@gmail.com Tel: (Office) 051 845593

I would like to participate in an interview ☐

Name and telephone number_____

No thanks, I would not like to participate in an interview ☐

Appendix II Gardner et al (2005) email

Heather Jennings <hjessjenn@gmail.com> 4 Apr

to frances.gardner

Dear Frances

My name is Heather Jennings. I am a registered nurse and midwife in the Republic of Ireland. I am currently working on a research masters project in relation to a DDH clinic that is running in the South east of Ireland, in particular, the parents experiences of utilising the clinic and caring for infants receiving treatment at home.I am respectfully requesting if I can use a modified version of your Infant Hip Worries Inventory in my project? My contact number is +353 87 7799269 (Mobile) if you would like to speak with me in relation to this request.

Kindest regards,

Frances Gardner <frances.gardner@wolfson.ox.ac.uk> 4 Apr

to me

Yes of course, delighted for you to use this. Would of course appreciate the paper being acknowledged in any theses, publications, talks reports etc.
Let me know if there's anything I can help with

Frances

Heather Jennings <hjessjenn@gmail.com> 5 Apr

to Frances

Dear Frances,

Thank you so much for the speedy reply and for the go ahead to use your Inventory.
Absolutely, you will of course be cited in any future publications and in my thesis. Thank you again.

Kindest regards

Appendix III Lee et al (2005) email

Lee Angela <Angela.Lee@royalberkshire.nhs.uk> 6 Apr

to me

Dear Heather

Not a problem. We are happy for you to do this. If we can be of any help do let me know.

Kind regards

Angie

==========

Royal Berkshire NHS Foundation Trust
London Road
Reading
Berkshire
RG1 5AN

Angie Lee Paediatric Nurse
ConsultantTrauma, Orthopaedics & Injury Prevention
☎ Tel: 0118 322 8747 ☎ Fax: 0118 322 8908
✉ Email: Angela.Lee@royalberkshire.nhs.uk

From: CAT5 (ROYAL BERKSHIRE NHS FOUNDATION TRUST) [rbb-tr.CAT5@nhs.net]
Sent: 04 April 2016 17:44
To: Lee Angela
Subject: FW: For the attention of Angela Lee

Hi Angie
Please see request below
KR
M

From: Heather Jennings [hjessjenn@gmail.com]
Sent: 04 April 2016 16:30
To: CAT5 (ROYAL BERKSHIRE NHS FOUNDATION TRUST)
Subject: For the attention of Angela Lee

Dear Angela

My name is Heather Jennings. I am a registered nurse and midwife in the Republic of Ireland. I am currently working on a research masters project in relation to a DDH clinic that is running in the South east of Ireland, in particular, the parents experiences of utilising the clinic and caring for infants receiving treatment at home.I am respectfully requesting if I can use a modified version of your questionnaire cited in "A satisfaction survey of a nurse led paediatric clinic for hip dysplasia in infants" in my project? My contact number is +353 87 7799269 (Mobile) if you would like to speak with me in relation to this request.

Kindest regards,
Heather Jennings

Appendix IV Topic Guide for Semi structured interviews with parents

Demographic Details of Parent

- **What is your relationship to the child?**
- **Age**
- **Married**
- **Educational level what is the highest degree or level of education that you have received?**

Demographic Details of infant

- What age is your child?
- What gender is your child?
- Was she/he your firstborn?
- What type of delivery did your child have?
- Was your baby breech?
- Is there a family history of DDH in your or your partners close family?
- Did your child have a normal hip examination at birth?
- Did your child have a normal hip examination at the 6 week routine check?
- Were you given any information on hip health in pregnancy/in the postnatal period/ from GP at 6 week check?
- Who referred your child to this clinic? Consultant / GP / Midwife / Public Health Nurse / Other (please identify).
- Was it explained to you why your child was referred to the DDH clinic?
- How long were you waiting for your child's first appointment?
- Were you happy with this length of time?
- What age was your child at diagnosis of his/her condition?
- How long has your child been attending this clinic?
- What type of treatment did your child undergo? Harness/Brace/Surgery
- Did your child undergo a hip ultrasound for his/her condition?
- Did your child undergo a hip x-ray for his/her condition?
- How is your child doing now?

Questions:

- What did you know about DDH prior to your child's diagnosis?
- Did you feel you were given enough information about hip health and DDH when the condition was suspected?
- When do you feel is the most appropriate time to be given information about hip health and DDH
- How did you feel when DDH was diagnosed and treatment began?
- What information verbal/written were you given when treatment started?
- Did you feel you were given enough practical information about caring for a child with DDH when the condition was diagnosed?
- What can you tell me about caring for an infant with DDH?
- Were there any challenging aspects for you or your family while caring for your child?
- Were there any challenging aspects to your experience utilising the DDH clinic?
- Did you feel any differently about DDH by the time treatment had finished?
- What do you feel helped you the most during diagnosis and treatment if anything?
- Is there anything that you would suggest that would be helpful for parents who have just had a child diagnosed with DDH.
- Were there any positive aspects to your experience?
- Is there anything else you would like to mention?

Appendix V Semi structured interviews with GPs

Demographic Information

Age

Male/female

No of years in profession

Place of work

Academic qualifications

- How many years' experience do you have screening for DDH?
- Where and when were you given training in the NIPE examination programme? (Newborn and Infant Physical Examination)
- Do you receive regular update training in the NIPE examination?
- Do you feel that it is enough?
- What is the purpose and value of screening for DDH in your opinion?
- Are you given any discharge data in relation to DDH on infants in your GP practise?
- When and where are infants screened for DDH in your practise?
- How do you screen for DDH in your practise?
- What verbal/written information do you give parents if you suspect a diagnosis of DDH?
- What is your procedure for referring suspected cases of DDH in the community?
- Do you know the average timeline of these referrals?
- Does the referral pathway work effectively in your opinion?
- What are the relative advantages and disadvantages of the examination being performed by a GP?
- What are the weaknesses of the screening process?
- Have you any suggestions for its improvement?

Adapted from Bloomfield *et al* 2002

Appendix VI Semi structured interviews with PHNs

Demographic Information

Age

Male/female

No of years in profession

Place of work

Academic qualification

- How many years' experience do you have screening for DDH?
- What training have you been given in relation to the screening of DDH?
- Is your training updated at any point?
- How and when do you assess an infant for issues in relation to DDH in your practise?
- Do you feel that this assessment is adequate?
- What is the purpose and value of screening for DDH in your opinion?
- Are you given any discharge data in relation to DDH on infants in your PHN practise?
- What is your procedure for referring suspected cases of DDH in the community?
- What verbal/written information do you give parents if you suspect a diagnosis of DDH?
- Do you know the average timeline of these referrals?
- Does the referral pathway for DDH work effectively in your opinion?
- What verbal/written information do you give parents if you suspect a diagnosis of DDH?
- What are the relative advantages and disadvantages of screening for DDH being performed by a PHN?
- What are the weaknesses of the screening process?
- Have you any suggestions for its improvement?

Adapted from Bloomfield *et al* 2002

Appendix VII Information Sheet

Participant information sheet

The purpose of this study **'Exploring the detection and care of infants with developmental dysplasia of the hip**' is to identify the true incidence of DDH and late diagnosis in the South Eastern region of Ireland and assess the effectiveness of treatment and screening methods in the region. It also aims to explore the experiences of parents/care givers of infants with DDH and HCPs involved in the screening and referral of infants with suspected DDH. As this is the first study of its kind to be conducted in the Irish context, your individual participation in this timely study is greatly appreciated.

Why as a participant have I been asked to take part in this study?

You have been asked to participate in this study as this is a study gathering data from parents/caregivers of infants with DDH and HCPs involved in the screening and referral of infants suspected to have DDH.

Voluntary Participation

You are free to withdraw from the research at any time without giving reason.

What does it involve?

The questionnaire has been distributed by the secretary in the DDH clinic. Please read the information provided here and think about whether you wish to take part by completing a short questionnaire which should take about 15-20 minutes to complete. At your earliest convenience, drop it in the box provided at the clinic desk or place it in the enclosed stamped addressed envelope and place in the return post.

Potential Benefits

It is anticipated that findings of this study will:

- Provide valuable data regarding incidence rates of DDH, late diagnosis rates, successful treatment rates and ultrasound reliability rates in DDH detection in the South Eastern region of Ireland.
- Provide a basis for an evaluation of current treatment and service provision in Ireland.
- Enable HCP's to provide patients with appropriate education so that patient specific information requirements are addressed.
- Allow service users and service providers an opportunity to articulate their views on service provision within the DDH setting in the South East of Ireland.

- Provide valuable data to draw wider inferences for the development of care packages for health care professionals and parent/caregivers.

Potential Harms/Risks

There are none anticipated. All questionnaires are completely anonymous. The information will be stored in a locked cabinet or a password protected computer and I will be the only person to have access to this computer. Participation in this research will not be communicated to the consultant or to any participant's direct line manager.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher- myself or the Orthopaedic Consultant (name and details listed below), we will do our best to answer any questions that you may have. Any complaints or concerns regarding any aspect of taking part in the research will be considered carefully by the academic supervisor and the steering group overseeing this research project at WIT.

Who is organising and funding this study?

The study is being carried out by Heather Jennings a midwife in WRH. . Funding to carry out this research has been granted by the Nursing and Midwifery Planning and Development Unit.

Who has reviewed the study?

This research has been reviewed and approved by the Regional Research Ethics Committees- Health Service Executive (HSE) South-East and the Research Ethics Committee at WIT. A steering group of HSE and WIT staff as well as direct project supervisors have also reviewed the project.

Contact details

Heather Jennings. Researcher. Email: hjessjenn@gmail.com Tel (Office):051 845593

Linda Sheahan. Academic Supervisor LSHEAHAN@wit.ie Tel (Office):051 845543

Mr Joe O'Beirne. Orthopaedic Consultant Surgeon nuala.maher@hse.ie Tel (Office) 051 842633

Thank you for taking the time to read this information and considering taking part in the survey.

Yours sincerely,

_____

Heather Jennings.

Appendix VIII Consent Form

Title of study: Exploring the detection and care of infants with developmental dysplasia of the hip.

Principal researcher: Heather Jennings RGN RM

☐ I give my consent to be included in the above study

☐ I understand that my participation in the study is voluntary and that I may withdraw at any stage.

☐ I give my permission to be interviewed and for the interview to be tape recorded. The contents of the tapes will be transcribed.

☐ I understand that my identity will not be made known to anyone and that the principal researcher will be the only person with knowledge of my identity.

☐ I understand that this research study has the UHW Research Ethics Committee approval.

☐ I understand that in the event of any issues revealed during observation, or the interviews disclose unethical or malpractice behaviours, such events will be reported. I understand that a consultant orthopaedic surgeon and a senior nurse manager have been identified within the research site to report such issues.

☐ I have received the information leaflet and any concerns or questions regarding the study have been addressed

Signature of participant: _____

Signature of researcher: _____

Date: _____

Appendix IX WIT Ethical Approval

Institiúid Teicneolaíochta Phort Láirge Waterford Institute *of* Technology

Port Láirge, Éire.
T: +353-51-302000
info@wit.ie

Waterford, Ireland.
T: +353-51-302000
www.wit.ie

Ref: 14/NUR/02

5th June, 2014.

Ms. Heather Jennings,
28, Christendom Square,
Abbeylands,
Ferrybank,
Waterford.

Dear Heather,

Thank you for submitting your amended documentation in relation to your project *'Exploring the detection and care of infants with developmental dysplasia of the hip'* to the WIT Research Ethics Committee.

I am pleased to inform you that we now fully approve WIT's participation in this project and we will convey this to Academic Council.

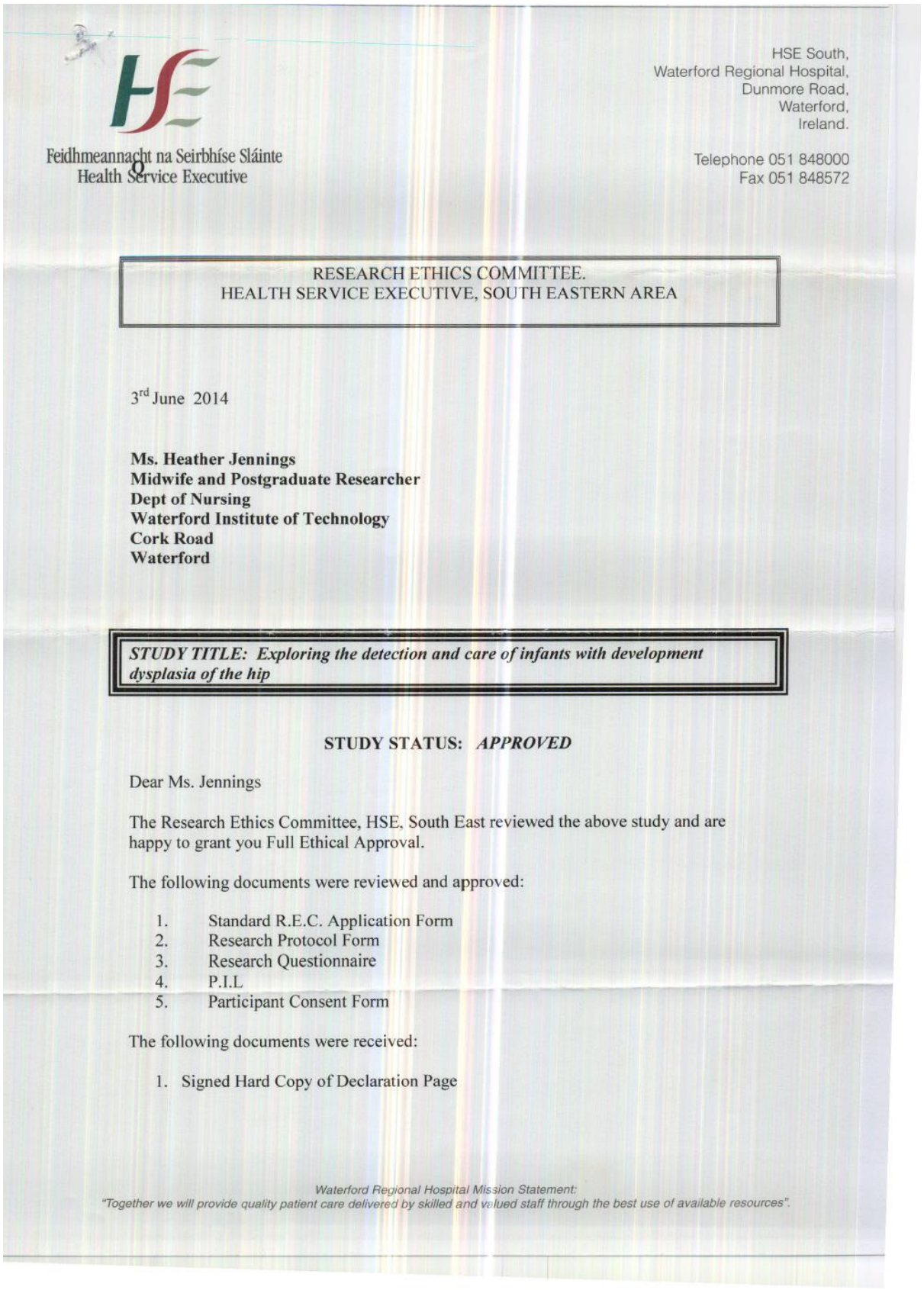
We wish you well in the work ahead.

Yours sincerely,

Prof. John S. Wells,
Chairperson,
Research Ethics Committee

cc: Dr. Linda Sheahan
Dr. Martina Gooney

Appendix X HSE Ethical Approval



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

HSE South,
Waterford Regional Hospital,
Dunmore Road,
Waterford,
Ireland.

Telephone 051 848000
Fax 051 848572

RESEARCH ETHICS COMMITTEE.
HEALTH SERVICE EXECUTIVE, SOUTH EASTERN AREA

3rd June 2014

Ms. Heather Jennings
Midwife and Postgraduate Researcher
Dept of Nursing
Waterford Institute of Technology
Cork Road
Waterford

STUDY TITLE: Exploring the detection and care of infants with development dysplasia of the hip

STUDY STATUS: *APPROVED*

Dear Ms. Jennings

The Research Ethics Committee, HSE. South East reviewed the above study and are happy to grant you Full Ethical Approval.

The following documents were reviewed and approved:

1. Standard R.E.C. Application Form
2. Research Protocol Form
3. Research Questionnaire
4. P.I.L
5. Participant Consent Form

The following documents were received:

1. Signed Hard Copy of Declaration Page

Waterford Regional Hospital Mission Statement:
"Together we will provide quality patient care delivered by skilled and valued staff through the best use of available resources".

Appendix XI Letter seeking approval from Director of Nursing

Dear Ms Tully,

My name is Heather Jennings. I am a Registered Staff Midwife in the Maternity Unit in [Regional Centre]. I am currently undertaking a Master's of Science in Nursing in Waterford Institute of Technology and as part of this I am required to undertake a research study.

I am writing this letter to request your permission to carry out a research study regarding the exploration of the detection and care of infants with developmental dysplasia of the hip (DDH). The research will involve me the researcher, in Phase One, analysing the results of a clinical audit of the DDH clinic in [Regional Centre]. Phase Two involves giving a questionnaire to 150 parents of infants with DDH and also interviewing twenty of this group regarding their experiences caring for infants with DDH. Phase Three involves interviewing 8 members of nursing staff in the DDH clinic regarding their experiences caring for infants with DDH and their families.

The confidentiality and anonymity of all participants will be protected at all times. An information leaflet with more details on the research study is enclosed. I appreciate you giving your time to read this letter and would gratefully appreciate your consideration of this request.

Yours sincerely,

Heather Jennings.

Appendix XII Study outputs

Oral Presentations

Jennings H, Gooney M, Sheahan L. Exploring the detection and care of infants with Developmental Dysplasia of the hip. 16th Healthcare Interdisciplinary Research Conference, Trinity College, Dublin, Ireland. Oral Presentation.

Jennings H, Gooney M, Sheahan L. Exploring the experiences of parents caring for an infant with Developmental Dysplasia of the hip attending a dedicated clinic. Annual International Nursing & Midwifery Research & Education Conference, Royal College of Surgeons, Dublin, Ireland. Oral Presentation.

Jennings H, Gooney M, Sheahan L. Developmental Dysplasia of the hip DDH) Nursing care & support for parents. National Orthopaedic Nurses Conference 2016 Cappagh Hospital, Dublin, Ireland. Guest speaker.

Jennings H, , Gooney M, Sheahan L. Developmental Dysplasia of the hip (DDH) Parent satisfaction survey of using a dedicated DDH Clinic. WIT Research Day 2016, Waterford, Ireland. Oral Presentation.

Jennings H, Gooney M, Sheahan L. Exploring the screening and incidence rates of infants with Developmental Dysplasia of the hip. 17th Healthcare Interdisciplinary Research Conference, Trinity College, Dublin, Ireland. Oral Presentation.

Jennings H, Gooney M, Sheahan L. Clinical review of patients seen in UHW DDH Clinic born in 2012 & 2013. Royal College of Physicians. Dublin. Oral Presentation

Jennings H, Gooney M, Sheahan L Exploring the screening and incidence rates of infantswith Developmental Dysplasia of the hip. PHN & practice Nurses Maternity & Newborn Education Day. UHW Waterford

Poster Presentations

Jennings H, Gooney M, Sheahan L. Exploring the detection and care of infants with Developmental Dysplasia of the hip. WIT Research day 2015, Waterford, Ireland. Poster Presentation.

Jennings H, Gooney M, Sheahan L. Exploring the experiences of parents caring for an infant with Developmental Dysplasia of the hip. University Hospital Waterford Research Day, Waterford, Ireland. Poster Presentation.

Jennings H, Gooney M, Sheahan L. Exploring the experiences of parents caring for an infant with Developmental Dysplasia of the hip. Waterford Institute of Technology O'Connell Bianconi Building- Nursing Conference, Waterford Ireland. Poster presentation.

Publications

Jennings H, O'Beirne J, Gooney M, Sheahan L

Exploring the experiences of parents caring for an infant with Developmental Dysplasia of the hip attending a dedicated clinic. International Journal of Orthopaedic and Trauma Nursing. Journal Article

Future publications

2 Manuscripts in progress at present.

International Journal of Orthopaedic and Trauma Nursing 25 (2017) 48–53

Contents lists available at ScienceDirect

International Journal of Orthopaedic and Trauma Nursing

journal homepage: http://www.journals.elsevier.com/international-journal-of-orthopaedic-and-trauma-nursing

Review article

Exploring the experiences of parents caring for infants with developmental dysplasia of the hip attending a dedicated clinic

Heather J. Jennings [a, *], Martina Gooney [a], Joseph O'Beirne [b], Linda Sheahan [a]

[a] Department of Nursing, Waterford Institute of Technology, Ireland
[b] HSE South, Ireland

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Parents' experiences
Pavlic harness

ABSTRACT

Specialised DDH (developmental dysplasion of the hip) clinics are developing around Ireland but are, however, variable in how they are operated. A DDH clinic was set up in the South-east of Ireland in 2002 with the goal of achieving an integrated care pathway between the orthopaedic surgical team and nursing team, working to an explicit protocol while also fostering a strong collaboration with the ultrasound department. This paper aims to explore the effectiveness of this dedicated clinic in the Southeast of Ireland.

Introduction

A DDH (developmental dysplasia of the hip) clinic was established in the Southeast of Ireland in 2002 aimed at examining and treating infants referred with suspected DDH. The clinic sees more infants each year with suspected issues, with new referrals reaching approximately 300 both in 2014 and 2015. In addition to recalls, this gives a total number seen in clinic of approximately 2000 per year.

Literature review

DDH, formerly termed congenital dislocation of the hip (CDH), describes a range of anatomic abnormalities in which the femoral head and the acetabulum are aligned improperly or mature abnormally (USPSTF, 2006). DDH is a poorly understood disorder as evidenced by the abundance of literature, both recent and historical, on the topic (Klisic, 1989; Mahan et al., 2009; Bracken et al., 2012; Shorter et al., 2013).

DDH is one of the most common congenital defects in the newborn and is a leading cause of childhood and adult disability (Gelfer and Kennedy, 2008). It accounts for 9% of all hip replacements; a quarter or more being performed on patients under the age of 60 (Engesaeter et al., 2011). What is largely agreed across the literature is that, if DDH is diagnosed and treated early, the risk of significant morbidity is reduced (Stein-Zamir et al., 2008). However, despite best practise, young adults still present with hip dysplasia that was not detected at birth or in the newborn period (Schwend et al., 2014).

Late diagnosis is considered to be DDH which has not been detected in the first 3 months of life (Sharpe et al., 2006; Woodacre et al., 2013); however, interpretation of rates of late diagnosis can often be difficult in relation to the strict definition and age of diagnosis (Sharpe et al., 2006). Late diagnosed or persistent DDH is increasingly recognised as a leading cause of significant long term morbidity including: impaired walking, chronic pain and premature degenerative joint disease, (Holroyd and Wedge, 2009; Sewell et al., 2009; Sewell and Eastwood, 2011; Clarke et al., 2012) and can affect patients socially, functionally and psychologically (Flynn, 2016).

The reported incidence of DDH worldwide varies widely from 1.4 to 35.0 cases per 1000 live births (Mahan et al.,2009). The epidemiologic literature regarding DDH is vast and confusing due to various definitions of hip dysplasia, different methods of diagnosis, ages of the population studied, clinical experience of the examiner, ethnicity of the population being examined and different geographic locations within similar ethnic populations (Bracken et al.,2012). The situation in Ireland is even more uncertain and the literature contains only a small number of papers from the Irish

* Corresponding author. Department of Nursing, Room G03, O'Connell Bianconi Building, Waterford Institute of Technology, Waterford, Ireland.
E-mail address: hjessjenn@gmail.com (H.J. Jennings).

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1878-1241/

setting. While it is believed that there is a high incidence of late diagnosis of DDH in Ireland (Gul et al., 2002), evidence is lacking as to whether this is due to a high natural incidence in the Irish population, or to poor screening and poor early management of the condition.

The overall incidence of DDH in the Republic of Ireland is unknown. However, Phelan et al. (2014) carried out a retrospective study of all cases of DDH in children born between 1st January and the 31st December 2009 in the south-eastern region of Ireland. Of the 8317 live births in the southeast region in 2009, 56 cases of DDH were diagnosed; giving an incidence rate 6.73 per 1000 live births. Donnelly et al. (2015) recently reported an overall incidence rate of 8.5 per 1000 births in a similar population in Northern Ireland.

No international or Irish guidelines or algorithm currently exist for the screening and treatment of DDH (Feeley et al., 2014). The National Clinical Programme for Paediatrics and Neonatology (Paediatric/Neonatal Programme), which is a joint collaboration between the Health Service Executive (HSE) Clinical Programmes and Strategy Directorate and the Royal College of Physicians of Ireland (RCPI), recommended that national guidelines be developed as soon as possible.

The Paediatric/Neonatal Programme has highlighted the concerns of a number of medical and non-medical sources regarding the failure of newborn screening programmes to detect or identify conditions and anomalies at a stage when treatment could be more effective (HSE, 2013). The discrepancy in the management and detection of DDH has been of particular concern. Only 9 out of the 19 hospital units in the Republic of Ireland have access to hip ultrasounds at 6 weeks of age, while the other 10 units have to wait for a hip x-ray at 5 months of age (HSE, 2013), thus losing vital time to treat infants for DDH.

The American Academy of Pediatrics (AAP, 2000) also suggests that early intervention resources be utilised and that key disciplines are brought together to provide a high quality skilled service for children who are at risk both developmentally and medically. The successful use of integrated care pathways (ICPs) has been shown to have a positive influence on the quality of service that is enabled by the enhanced communication between all members of the multidisciplinary team which in turn can lead to improved patient satisfaction (Beazley and Brady, 2006).

The literature lacks information on parental issues and attitudes regarding DDH services and caring for a child being treated for DDH (Hassan, 2009). Parents play a pivotal role in the doctor-parent-child relationship, where parents are relied upon as the source or voice of information about their child's health status (Tates et al., 2002). Satisfaction with health services is known to be associated with positive patient behaviour, including the use of preventative health services (Halfon et al., 2004). Satisfaction is, in turn, considered to be an important predictor of health related behaviour by, for example, influencing parents' commitment to, and effectiveness of, recommended treatment for DDH (Witting et al.,2012). It has also become an important factor in the evaluation of health services (Bergenmar et al., 2006).

The psychosocial consequences for parents regarding the screening and treatment policies of DDH are potentially important in the management of DDH. Parents will often feel overwhelmed when a new diagnosis of DDH is made or when a treatment is initiated. A lot of information is given to them regarding diagnosis, treatment, possible failure of treatment and possible surgery if early treatment fails which can be a lot for parents to absorb (Causon, 2010). Coming to terms with the diagnosis of DDH and the need for treatment may invoke feelings of guilt and stress that their child has been affected (Causon, 2010). The role of the nurse as a support person is often critical for a successful outcome to be achieved (Hart et al., 2006).

The condition poses tremendous challenges for caregivers and impacts on nearly every aspect of parent and family lives such as work, transportation, skin care and feeding (Gardner et al., 2005; Hart et al., 2006). Continuity of nursing care in a specialist nurse led paediatric clinic for hip dysplasia, from the first consultation and throughout treatment to on-going follow-up visits has been shown, in a previous study, to yield high levels of satisfaction among the parents of the infants (Lee, 2005).

It can be concluded that DDH remains a poorly understood disorder despite a great deal of research being carried out on the subject. To date, there is very little literature pertaining to the parents' perspective in relation to caring for a child in a Pavlic harness or Boston brace. Furthermore, much less is known about the impact of caring for a child with DDH within the Irish healthcare setting. Consequently, the aim of this study was to investigate the experience of parents of infants with DDH attending a dedicated clinic in the south-east of Ireland.

Method

Following a review of the literature and with consideration of the aim of the study, it was deemed that a mixed methods framework was most suitable, integrating quantitative and qualitative tools to foster a greater understanding of the experiences of parents attending a DDH clinic with their infants.

A twenty-three question parent satisfaction survey including a Likert scale was constructed. The questionnaire was modelled on Lee's (2005) satisfaction survey and Gardner et al.'s (2005) Hip Worries Inventory. With permission, both instruments were modified to suit the study. It was hoped that the questionnaire would elucidate the experiences of parents of children revieving treatment in the dedicated DDH clinic.

Ethical approval was granted from the local Regional and College Ethics Committees in May 2014. A pilot study was undertaken in the clinic in October 2014 involving ten parents of infants with DDH to assess the acceptability of the questionnaire, to check for ambiguities in relation to the understanding of the questions and to investigate the length of time for completion of the questionnaire. Following evaluation of the pilot questionnaire, minor editing changes and revision of the overall layout were made prior to the main study. Nonprobability convenience sampling was used to select study participants. A three-month data collection phase between November 2014 and January 2015 was agreed upon. Mothers and fathers who attended the clinic for the first time during this period were invited to complete the questionnaire. Due to the high volume of weekly and fortnightly repeat visits, an average of 10 new families attended the clinic per week during this time frame. After three months, one hundred questionnaires had been administered. A response rate of 100% was achieved as one hundred questionnaires were returned to the researcher.

To establish internal consistency and reliability of the research questionnaire in this study, the Cronbach's alpha was calculated. The result (0.80) indicated the questionnaire as an accurate measuring tool. Statistical analysis included the Mann-Whitney *U* test which was carried out using a two-tailed significance of 5% using the statistical packages SPSS 21.

Findings

Demographic details of infants attending DDH clinic

Eighty percent of the infants attending the clinic were female. Table 1 illustrates the age of diagnosis of infants who attended the clinic. The majority of infants were diagnosed within 13 weeks of

Table 1
Age at diagnosis of DDH.

Age at diagnosis	Number	%
Birth to 6 weeks	50	50%
7 to 13 weeks	15	15%
14 to 20 weeks	3	3%
More than 21 weeks	30	30%

birth (65%) while thirty infants (30%) were diagnosed with DDH at 21 weeks of age or later which is considered a late diagnosis.

Referral to the clinic

Table 2 illustrates the type of health professional who referred the respondents to the DDH clinic. The majority of infants were referred by a paediatrician (74%), a smaller percentage were referred by a Public Health Nurse (12%), a General Practitioner referred 8% of the infants while 4% were referred by a midwife.

Reason for referral to DDH clinic

Table 3 displays the various reasons for referral to the DDH clinic. The majority of referrals were for hip dysplasia (26%) followed by 22% for positive family history.

Type of treatment

Table 4 displays the type of treatment received by infants attending the DDH clinic. The Pavlic Harness was used to treat the majority of infants (48%), indicating that treatment commenced within the first 3 months of life. The Boston Brace, which is the treatment of choice for infants over the age of 3 months, was used to treat 34% of infants. Twelve percent of infants were neither treated with a harness or brace but were attending for observation suggesting that immaturity of the hip joint was suspected rather than an abnormality of the hip. One infant was referred to a tertiary unit for surgery.

Time to first appointment to DDH clinic

Table 5 represents the length of time parents were waiting for their first appointment in the DDH clinic. Seventy-six percent of parents were seen for the first time in the DDH within the first 10 weeks while 4% were waiting 21 weeks or more for an appointment.

Appointment time

The majority of parents (42%) were waiting less than 30 min in the waiting area, 31% waited up to 1 h, and 26% waited over an hour. The majority of parents saw both a doctor and nurse at each visit (79%), while a small percentage (14%) saw a doctor only and 7% saw only a nurse. Eighty-nine percent of parents felt the amount of time given at each appointment was appropriate. Ninety-eight percent of parents felt their questions were answered appropriately and details of their infant's condition were explained suitably (Table 6).

Infant hip worries

Table 7 provides a list of statements relating to the practical difficulties of caring for a baby in abduction splinting and the

Table 2
Types of Health Professionals who refer to DDH clinic.

Person who referred to clinic	Frequency	Percent
Paediatrician	74	74%
Midwife	4	4%
General Practitioner	8	8%
Public Health Nurse	12	12%
Radiologist	2	2%

Table 3
Reasons for referral to DDH clinic.

Reason for referral	Frequency	Percent
Dysplasia	26	26%
Family history	22	22%
Dislocation	13	13%
Breech	10	10%
Click hip	10	10%
Creases	3	3%
Limb abduction	3	3%
Immaturity	1	1%
Unstable hip	1	1%
Paediatric referral	1	1%
Not recorded	10	10%

Table 4
Type of treatment received.

Type of treatment	Percent
Harness	48
Brace	34
Harness and brace	5
Observation	12
Surgery	1

Table 5
Time till first appointment.

Time to first appointment	Frequency	Percent
1–5 weeks	66	66%
6–10 weeks	20	20%
11–15 weeks	2	2%
16–20 weeks	2	2%
21 weeks plus	4	4%
Not recorded	4	4%

Table 6
Appointment times.

Length of appointment time	Frequency	Percent
Less than 15 min	5	5%
16–30 min	37	37%
31–60 min	31	31%
Over 60 min	27	27%
Person seen at appointments		
Doctor only	14	14%
Nurse only	7	7%
Doctor and nurse	79	79%
Appropriate appointment time		
Yes	89	89%
No	11	11%
Questions answered appropriately		
Yes	98	98%
No	2	2%
Explanation provided		
Yes	98	98%
No	2	2%

Table 7
Infant hip worries inventory with mean scores for Parents' worries in relation to caring for an infant with DDH.

Statement	Disagree	No opinion or uncertain	Agree	Mean (±SD)
I was very upset when I was first told that my baby had an unstable hip	21 (22%)	5 (5%)	69 (73%)	3.93 (1.22)
I get upset when people ask me about my baby's hips	66 (71%)	9 (10%)	18 (19%)	2.37 (1.09)
I worry that I might do something to hurt my baby's hips	50 (54%)	11 (12%)	31 (34%)	2.79 (1.25)
I get upset when I look at my baby in a harness/brace	34 (43%)	6 (7%)	49 (55%)	3.26 (1.33)
I find it difficult to feed my baby	64 (72%)	3 (3%)	22 (25%)	2.38 (1.26)
I find it difficult to wash my baby	38 (43%)	5 (6%)	45 (51%)	3.16 (1.41)
I find it difficult to change my baby's nappy	57 (63%)	6 (7%)	27 (30%)	2.61 (1.17)
I find it difficult to dress my baby	50 (56%)	12 (14%)	27 (30%)	2.67 (1.29)
I find it difficult to cuddle my baby	60 (68%)	6 (7%)	22 (25%)	2.39 (1.29)
I find it difficult to play with my baby	64 (76%)	5 (6%)	15 (18%)	2.20 (1.18)
I find the harness/brace restricts my activity with my baby	39 (45%)	6 (7%)	41 (48%)	3.06 (1.40)
I worry about whether my baby is comfortable	16 (18%)	8 (9%)	65 (73%)	3.75 (1.05)
I find it difficult to manage the harness/brace	50 (60%)	13 (16%)	20 (24%)	2.53 (1.15)
I find it difficult to strap my baby into their car seat	51 (58%)	7 (8%)	30 (34%)	2.75 (1.29)
I worry before each hospital visit related to my baby's hips	36 (40%)	4 (5%)	49 (55%)	3.27 (1.32)
I worry about the effect the hip instability might have on my baby in the future	26 (29%)	2 (2%)	61 (69%)	3.62 (1.33)
I worry about my baby walking in the future	34 (38%)	5 (6%)	49 (56%)	3.33 (1.42)

potential psychosocial consequences of receiving a diagnosis of DDH. Seventy-three percent of parents were very upset when they were first told that their baby had an unstable hip. Fifty-five percent of parents became upset when they looked at their baby's hips in a harness. Many parents (73%) worried whether their baby was comfortable. Additionally, a high percentage of parents worried about how the hip instability might affect their baby in the future (69%) and if their baby would be able to walk (56%).

Further statistical analysis revealed mean values in relation to parents' worries; ranging from 2 which indicated disagreement with the statement, 3 which meant they had no opinion or were uncertain about the statement to 4 which indicated agreement. The statements relating to being upset when told of the baby's unstable hip and worry relating to how the hip instability will affect the baby in the future scored the highest mean values, 3.93 and 3.75 respectively, which indicated the highest level of worry scored. The 2 statements relating to cuddling and playing with the baby received the lowest mean values 2.39 and 2.20 respectively. When the standard deviations were examined it appeared that they were similar; ranging from 1.05 to 1.42, so levels of variation were similar across the 17 items. See Table 7.

Early/late diagnosis and hip worries

Percentage agreement (collapsed agreements scored based on the percentage agreeing and strongly agreeing) and frequencies were compared for parents whose child had been diagnosed early (<3 months of age) or diagnosed late (>3 months of age) with DDH (Table 8). Replies from parents whose child had been diagnosed early or diagnosed late with DDH were compared using a Man-Whitney *U* Test; this was statistically significant in 4 areas; difficulty in washing baby ($p = 0.000$), difficulty in dressing baby ($p = 0.041$), worry before each hospital visit related to baby's hips ($p = 0.027$) and worry relating to baby walking in the future ($p = 0.014$). There was no significant difference between the early and late group in relation to how upset they felt when told that their baby had an unstable hip or in relation to how upset they were when they looked at their baby in a harness or brace.

Open ended question

Respondents were also asked to suggest ways the service could be improved in an open ended question. Six broad themes emerged from thematic analysis of the data. Overall parents were satisfied with the level of care they received in the clinic. A variety of positive perspectives were expressed which when taken together resulted in three primary themes being of a positive nature: professional service, caring attitude of the staff and overall satisfaction with the clinic.

Professional service

A common thread through the various answers of the participants was their sense that they were receiving a very professional service in the DDH clinic. Their responses demonstrate respondents' beliefs that they were very happy with quality of the service. One participant commented: *"My baby is receiving the best possible care"*. Similarly, one respondent wrote: *"the competency of the staff is great"*.

Caring attitude of the staff

Just over half of those who answered the question reported that they felt very well cared for in the clinic. A significant number of participants felt the staff were very friendly and were found to be most satisfied with how helpful the staff were. One respondent said: *"We receive great care and attention in this clinic"*. Likewise, another informant responded: *"the staff are very approachable and friendly"*.

Overall satisfaction with the clinic

A recurrent theme in the answers was overall satisfaction with the service and parents felt nothing needed to be improved.

Three categories of reasons for dissatisfaction with the DDH clinic were generated from the responses: appointment allocation system, length of time waiting to be seen and waiting times for referral to the clinic.

Appointment allocation system

Parents were dissatisfied with the allocation of appointment times within the DDH clinic. The majority of complaints in this category were general statements on the length of time waiting to be seen once they arrived in the clinic. Some statements blamed the block appointment system used as a cause for the length of waiting times. One participant commented: *"Block appointments, too many people waiting at the same time"*. Similarly, one respondent wrote: *"More accurate appointment times please"*.

Table 8
Worry relating to early or late diagnosis of DDH.

Statements	Early diagnosis (**n = 65**)[a] Mean (±SD) **n (%)**	Late diagnosis (**n = 33**)[a] Mean (±SD) **n (%)**
I was very upset when I was first told that my baby had an unstable hip	3.98 (1.15) **46 (74)**	3.77 (1.38) **22 (69)**
I get upset when people ask me about my Baby's hips	2.44 (1.18) **15 (25)**	2.16 (0.86) **3 (9)**
I worry that I might do something to hurt my baby's hips	2.90 (1.25) **23 (37)**	2.59 (1.27) **8 (27)**
I get upset when I look at my baby in a harness/brace	3.43 (1.29) **37 (62)**	2.90 (1.34) **12 (41)**
I find it difficult to feed my baby	2.31 (1.20) **14 (23)**	2.54 (1.37) **8 (29)**
I find it difficult to wash my baby **	3.58 (1.33) **40 (67)**	2.25 (1.14) **5 (18)**
I find it difficult to change my baby's nappy	2.75 (1.26) **23 (38)**	2.31 (0.89) **4 (14)**
I find it difficult to dress my baby *	2.85 (1.29) **20 (33)**	2.29 (1.21) **7 (25)**
I find it difficult to cuddle my baby	2.33 (1.25) **14 (23)**	2.52 (1.40) **8 (30)**
I find it difficult to play with my baby	2.28 (1.27) **11 (19)**	2.04 (0.96) **4 (15)**
I find the harness/brace restricts my activity with the baby	2.95 (1.43) **26 (43)**	3.31 (1.32) **15 (58)**
I worry about whether my baby is comfortable	3.70 (1.07) **43 (70)**	3.86 (1.00) **22 (79)**
I find it difficult to manage the brace/harness	2.54 (1.15) **14 (25)**	2.50 (1.17) **6 (23)**
I find it difficult to strap my baby into the car seat	2.61 (1.25) **18 (30)**	3.07 (1.33) **12 (44)**
I worry before each hospital visit related to my baby's hips*	3.05 (1.33) **28 (47)**	3.68 (1.19) **21 (72)**
I worry about the effect the hip instability might have on my baby in the future**	3.46 (1.38) **38 (62)**	3.93 (1.14) **23 (82)**
I worry about my baby walking in the future*	3.08 (1.41) **29 (48)**	3.81 (1.30) **20 (71)**

*$p < 0.05$; **$p < 0.001$.
[a] Some percentages calculated using denominator less than stated total due to missing data.

Length of time waiting to be seen

The majority of analysed statements expressed dissatisfaction with the prolonged period of time waiting to be seen by a doctor. Respondents felt they were kept a long time in the waiting area with their young infants, which they found to be problematic.

As one respondent said: *"Long waiting times, especially with young children, hard to keep them entertained"*. In the same way, one participant commentated: *"always a packed waiting room, I was waiting two and a half hours to be seen"*.

Waiting times for referral to the clinic

Four participants indicated that they felt the length of time waiting for their child to be referred to the clinic as too long. Three participants felt they did not get enough notice to attend their clinic appointment. As one respondent said: *"Should have been referred to the clinic sooner than 6 months"* Another participant wrote: *"2 weeks' notice for appointments would be helpful to organise work schedule"*.

Discussion

The results indicated that the majority of parents were waiting less than 5 weeks for their first appointment. Having a specialist clinic where direct prompt referrals can be made from postnatal/paediatric clinics, the community or from the ultrasound department means that at-risk infants are being seen earlier. Utilising a small cohort of skilled examiners and specialist nursing staff working in the clinic could also improve the effectiveness of the clinic (Lee, 2005). An implication of this is the likelihood that DDH can be treated early, therefore reducing the risk of significant morbidity. The results from the study appear to further support the idea that streamlined dedicated clinics enhance patient care and the provision of services (Heaney and Hahessey, 2011).

The majority of parents (97%) were either very satisfied or satisfied with the DDH clinic and when asked in an open-ended question if there was any way the service could be improved; 56% felt nothing needed improvement. Overall, findings from the open-ended question revealed a variety of positive perspectives in relation to the DDH clinic and a number of complimentary comments in relation to the staff and service were made. Parents reported that they felt they were receiving a very professional service and felt very well cared for by the staff.

Data from the Likert scale questions revealed that several of the questions scored highly in terms of parents' worry/distress in relation to their baby's hips. Many parents expressed worries about being told about the DDH diagnosis (73%), when looking at their baby's hips in harness (55%), worry relating to the comfort of their baby in harness (73%), the effect the hip instability would have in the future (69%) and if their baby was going to be able to walk (56%). These results confirm the association between the diagnosis and treatment of DDH and negative psychosocial consequences for parents (Chao and Chiang, 2003; Gardner et al., 2005).

When data were compared between parents whose child had been diagnosed early with parents whose child had been diagnosed

late, data revealed that parents in the early group expressed significantly more worries in relation to washing and dressing their baby while the parents in the late group expressed significantly more worries in relation to hospital appointments and relating to whether their baby would walk in the future. These findings are in line with Bergo and Rosendahl's (2013) study which found that parents whose baby was treated from birth found treatment more distressing than those treated at 9 weeks or beyond. They concluded that new parents placed high value on the initial few weeks with their newborn. The results are also consistent with Gardner et al.'s (2005) findings which highlighted that early intervention with a splinting device was related to increased maternal distress. A possible explanation for the results from the late group might be the association between late diagnosis of DDH and failed treatment rates.

Conclusion

This study has provided a deeper understanding of the psychosocial impact that receiving a diagnosis of DDH and caring for a child with DDH can have on the parents. The results of the questionnaire also help elucidate parents' observations about using a dedicated DDH service. The study has identified good practices which seem to have enhanced the parents' overall satisfaction with the dedicated clinic; in particular, the caring and professional attitude of the staff. By listening to parents' views in relation to their children's care, there is an opportunity to implement child and family centred care. Going forward, further qualitative research results from future semi-structured interviews taken together with the empirical findings already highlighted in this study may help with the development of appropriate care packages, the implementation of national guidelines and the streamlining of services to further enhance DDH services.

Limitations

The scope of the study was limited in terms of generalizability as it was conducted in a single-centre review. Secondly, the participants comprised of a non-probability convenience sample so the findings may underestimate parental worries about the diagnosis or treatment of an infant with DDH as some of the infants may have successfully completed treatment and may be attending routine follow up appointments at the time of study participation. This may be a potential bias and threat to the internal validity of this study. The relatively low number of participants may also limit generalisability. However, this study gives an insight into caring for an infant following a diagnosis of DDH and also reports the unique observations of parents using a dedicated clinic for the treatment of DDH.

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Appendix XIII Studies included in Literature Review

Date, author and country	Aim of research	Research design and instrument	Sample	Key findings	Implications
Barlow . (1962) United Kingdom	To determine the incidence of instability of the hip in the first year of life To determine if dislocation occurs after birth To clarify the indications of early treatment	Clinical testing of Barlow manoeuvre	n=9,289	Incidence of hip instability at birth was 1 in 60. 1 in 60 incidence reduced by 60% at one week. 1 in 60 incidence reduced to 88% at two months.	A high percentage of hips found to be dysplastic at birth spontaneously resolve at two months.
Bergo . & Rosendahl (2013) Norway	To determine parental satisfaction with early or delayed treatment for mild DDH	Cross-sectional study Questionnaire designed specifically for the study	Parents; n=91	No significant difference in parental satisfaction between early and late intervention groups.	Early or delayed intervention for DDH does not have an effect on parental psychosocial consequences.
Bloomfield et al. (2003) England	To explore the experiences and attitudes of midwives, junior paediatricians, (SHOs),GPs, and mothers to the examination of the newborn baby.	Qualitative using semi-structured interviews, which were exploratory and interactive.	Midwives; n=10. SHOs; n=10. GPs; n=10. Mothers; n=10	All groups perceived the examination to be a useful screening tool providing reassurance to parents Both midwives and SHOs considered to be appropriate professionals to carry out the examination. Midwives considered to have a better rapport with mothers. Few SHOs reported receiving any formal training in the examination of the newborn baby.	The extension of the practice of midwives examining the newborn baby following relevant training would be acceptable to all stakeholders.
Burnett et al (2018) Australia	To audit referral time frames for ultrasound screening of developmental hip dysplasia in neonates with a normal antenatal clinical examination	Literature review and retrospective clinical audit	Patients; n=187	41% of babies in the cohort scanned at or before 4 weeks of age demonstrated a Graf 2A classification, compared with 20.5% of babies scanned after 5 weeks. Early screening ultrasounds may result in over diagnosis of DDH during the maturation process of the neonatal acetabulum, potentially causing anxiety and unnecessary follow-up.	There was a twofold increase in the number of babies diagnosed with abnormal hips when scanned before 5 weeks of age. Early screening ultrasounds may result in over diagnosis of DDH during the maturation process of the neonatal acetabulum, potentially causing anxiety and unnecessary follow-up

Date, author and country	Aim of research	Research design and instrument	Sample	Key findings	Implications
Chao & Chang (2003) China	To investigate the impact on a mother with a child suffering from developmental dysplasia of the hip.	Qualitative. Case Study. Participant observation. Telephone interviews	Mother; n=1	Impact of diagnosis fell into 5 categories: Shock of the diagnosis; Fear of potential risk of surgery; Feelings of loss and anger; Uncertainty and anxiety about the future and Excessive and uncontrollable emotions. Several coping behaviours of the mother were identified: Seeking out for family support; Active learning about medical knowledge and nursing skills; Actively interacting with the child and meeting the child's special needs; Enlisting spouse participation and maintaining a positive outlook	The role of the nurse plays an important role in helping parents to feel supported, enabling them to deal with practical issues and providing psychosocial support for the unexpected shock of caring for an infant with DDH
De Hunt et al. (2012) The Netherlands	Evaluate the evidence in relation to the risk factors for developmental dysplasia of the hip:	Systematic review. A meta-analysis. Odds ratios used to quantify factors that indicate a risk for DDH.	Studies: n=30	Key finding: infants born in breech presentation, female infants, infants with a positive family history and clicking hips at clinical examination have an increased risk for DDH.	Provides a clear overview of all the evidence on risk factors in DDH. These results can be used in improving existing and developing new screening programs for DDH,
Donnelly et al. (2015) Northern Ireland	Evaluate reasons there is delayed diagnosis of DDH in Northern Ireland.	Retrospective chart, ultrasound and x-ray review	75,856 live births between 2008 and 2010	645 children were treated for DDH (8.5 per 1000). The minimum follow-up of our cohort from birth, to detect late presentation, was four years and six months. 32 children (33 hips) were diagnosed after their first birthday (0.42 per 1000).	By utilizing a small cohort of skilled practitioners, implementing further training and specialisation and maintaining the four month health visitor check, late incidence rates could be improved.
Gardner et al. (2005) UK	To assess clinical effectiveness, economic and psychosocial costs, of ultrasound imaging compared with conventional clinical assessment alone to guide the management of infants with neonatal hip instability.	Multicentre randomised controlled trial.	Infants with instability; n=629. Mothers; n= 561 at 8 weeks. Mothers; n=494 at 1 year	At 8 weeks, there were no differences between US and non-US groups of the trial in maternal anxiety The same pattern was evident at 1 year. Early splinting was associated with increased anxiety and levels of hip worries at 8 weeks	No difference between US and non-US groups in terms of anxiety. Early splinting was linked with increased anxiety.

Date, author and country	Aim of research	Research design and instrument	Sample	Key findings	Implications
Groarke et al. (2017) Ireland	To evaluate diagnostic value of the clinical findings as per a GP when referring for DDH.	Multicentre retrospective review of all referrals by GPs to local orthopaedic OPDs for DDH over a 12-month period.	Infants; n-174 referred. Infants; n=26 diagnosed with DDH	26 (14.9%) patients had a radiologic diagnosis of DDH (20 female and 6 male). There was a total of 212 positive signs among the 174 patients.The most common indication was skin folds (45.8%). Hip click accounted for 19.8% limb shortening (16%) and reduced abduction for 8% None of the clinical findings by the GP showed an acceptable level of sensitivity.	Certain clinical signs have poor diagnostic reliability for DDH Asymmetric skin creases and clicky hips are not reliable clinical signs,but reduced leg abduction and limb shortening are specific but not very sensitive. The findings suggest that clinical examination by GPs does not reliably detect radiographically-defined DDH
Gul et al . (2002) Ireland	Identify the reasons for the late presentation of DDH in the presence of a screening programme in the South of Ireland	Retrospective study of all cases of late DDH presenting from 1988 to 2000, identified using inpatient database.	Infants diagnosed with DDH; n=49	94% of infants diagnosed with DDH were female Female:male ratio of 46:3 Mean age of diagnosis was 14.8 months There was a reduction in the incidence of late presentation from 1988 to 2000. The majority of patients in this study had no risk factors highlighting the difficulty in ensuring earlypresentation.	Screening using clinical methods and screening of at risk neonates will never eradicate late presenting DDH. Ultrasound screening may help in detecting those at risk hips but this tends to over diagnose, resulting in overtreatment.
Hassan (2009) Jordan	Assessment of compliance of parents with regard to Pavlik harness treatment in DDH	A prospective study analysis using compliance assessment, interviews, diary, physical examinations and chart review	Parents; n=160	154 (96.25%) parents claimed that they had received adequate information regarding the instructions, method of application and care for theharness at the first visit after application of the harness. At the completion of treatment, 96.25% of the parents declared that the harness was easy to use There was a statistically significant progressive decrease in the difficulty index from the initial application of the harness to the end of treatment	Active maternal participation, under direct supervision of an orthopaedic surgeon, with written instructions can ensure parental compliance with Pavlic Harness treatment. Mothers found management of harness easier by the end of treatment.

Date, author and country	Aim of research	Research design and instrument	Sample	Key findings	Implications
Holen et al. (2002) Norway	To evaluate whether universal (all neonates) or selective (neonates belonging to risk groups) ultrasound screening of the hips should be recommended at birth.	Randomized Control Trial	15829 included in study. Universal screening group n=7840. Selective screening group n=7989	Number of late detected cases of DDH was: Universal screening group = 1 diagnosed at age 3 months (rate 0.13 per 1000) Selective screening group = 5 diagnosed between 5 and 11 months (rate 0.65 per 1000) RR = 0.21 (95% CI: 0.03, 1.45), p=0.22 (Fisher's Exact test)	No statistical difference found when comparing universal US to clinical screening, They do recommend an US for infants with hip instability or with risk factors, and that clinical screening needs to be of high quality to reduce the rate of late diagnosed DDH.
Jugnoo et al. (2004) UK	Evaluation of a Key Worker Programme for families of infants with disabilities.	Qualitative 2 stage comparative study Questionnaire. In depth Interviews	Pre CLT group: n=79 Post CLT group; n=68 participated in questionnaire Pre CLT group: n=29 Post CLT group; n=19 participated in interview	In both groups, the highest score was for respectful and supportive care and the lowest was for provision of general information. Parents and HCPs agreed that the CLT provided both emotional and social support, while providing information and helping facilitate access to specific services	The greatest needs for parents during the critical time of diagnosis of a chronic health condition is for family-professional collaboration in the form of verbal and written information together with emotional support from HCPs
Kokavec & Bialik (2007) Slovakia	To identify those neonatal hips which if left untreated would develop DDH	Clinical study. Single site study. Serial Ultrasound examination of hips which were identified with any type of sonographic pathology at 2 and 6 weeks	Cohort sample n= 4356 hips screened for DDH Deviation from norm identified in n=301 Requiring treatment n=21	2 categories of neonatal hip pathologies identified: Sonographic DDH which eventually develops in to a normal hip and True DDH which remains abnormal and requires treatment Of 301 initial abnormal ultrasound findings, 21 hips remained abnormal and required treatment Sonographic DDH incidence rate of 69.5/1000 True DDH incidence rate of 4.8/1000	Results indicate that the true incidence rate of DDH is relatively low (5:1000) resembling rates pre ultrasonographic screening era. Establishing a valid definition of DDH would allow fro the development of more accurate screening and management programmes.

Date, author and country	Aim of research	Research design and instrument	Sample	Key findings	Implications
Lee (2005) UK	To identify whether the specialist orthopaedic service was providing an acceptable alternative for children/infants and to ascertain whether parents were happy with a nurse led clinic	Qualitative study Purposive sample A self-administered tick box questionnaire	100 questionnaires sent out with 66% return rate; n=66	Nurse led clinic was able to see 80% of infants referred within 2 months, 6% waiting longer than 3 months. There was a significant level of acceptance for the service with 100% of participants being either very satisfied (67%) or satisfied (33%). Majority of parents (80%) were completely satisfied with the service and felt nothing more needed to be added.	Study provides evidence to support the use of specialist nurse led clinics for the detection of infants with hip dysplasia Appears to be wide acceptance by parents for these clinics. These clinics appear to add a continuity of care that is absent from the general orthopaedic structure
Lehmann et al. (2000) USA	To create a recommendation for pediatricians and other primary care providers about their role as screeners for detecting developmental dysplasia of the hip (DDH) in children.	Bayesian hierarchical meta-analysis	298 evidence tables from 118 studies Reduced from a larger set of 624 articles.	The incidence of DDH revealed by physical examination performed by paediatricians is 8.6 per 1000; for orthopaedic screening, 11.5; for ultrasonography, 25. The odds ratio for DDH, given breech delivery, is 5.5; for female sex, 4.1; for positive family history, 1.7	The decision model suggests that orthopaedic screening is optimal. However, Difference between orthopaedists and paediatricians is statistically insignificant, so conclusions drawn that paediatric screening is to be recommended. Not enough data available about diagnosis by ultrasonographic screening to permit definitive recommendations
Loder & Skopelja (2011) USA	To review the etiology of developmental dysplasia of the hip	Systematic medical literature review	2277 manuscripts related to DDH. Reduced to 422 manuscripts included in review.	Incidence of DDH is high in Native Americans, likely due to a combination of genetics and swaddling. DDH is extremely rare in Africans Carrying the infant in an abducted position straddling the iliac crest is postulated as protective against DDH in the African peoples Predictors of DDH are breech presentation, positive family history, and gender (female).	The etiology of developmental dysplasia of the hip (DDH) remains unknown There is significant variability in incidence within each racial group by geographic location Swaddling is strongly associated with DDH

Date, author and country	Aim of research	Research design and instrument	Sample	Key findings	Implications
Maxwell et al. 2002 Northern Ireland	To determine the late incidence of developmental dysplasia of the hip in Northern Ireland.	Two site study. Comparative retrospective study	Children born from 1991 to 1997 who had operative treatment for DDH by December 2000. (n=196) hips in 179 children required operative treatment	Increased emphasis on staff training, introduction of a centralized nurse led clinic to improve faster access to orthopaedic surgeons and an increased use of ultrasound, the incidence of DDH diagnosed after 6 requiring surgery months fell to 0.59/ 1000 from previous study findings of 1.75/1000.	Screening may never eliminate the need for surgical treatment, as shown by the fact that (n=42) children in the study required operative intervention despite being diagnosed within the first 3 months of life. Nevertheless, competent screening practices should reduce the late presenting operative rate.
Mulcahy et al. (2016) Ireland	To illustrate the complexities of public health nursing practice with parents to screen, intervene and manage DDH.	Qualitative study Case study approach Interview	Mother; n=1	There was a delay of 6 months between parental concerns regarding DDH and a PHN being informed of the concern. Subsequent child not referred for screening for DDH despite family history. Both issues identified and referrals made by PHN	Captures the experience of concern about DDH from a parent's perspective. Parents may be slow to verbalize concerns. Findings particularly useful for HCPs who strive to adopt a person-centred approach. Screening by PHNs can detect previously unknown or missed cases of DDH in children. PHNs must ensure that their knowledge about DDH is up to date and complete with a good understanding of the natural course of history of the condition.
O'Grady et al. (2010) Ireland	To ascertain the current approach to screen for developmental dysplasia of the hip in the Republic of Ireland.	Two-pronged prospective and retrospective study. Postal questionnaire to consultant paediatricians responsible for the routine neonatal care of infants in the Irish Republic. Retrospective database review	Maternity Units; n=19. Response rate among consultants was 61%.	Eight (42%) units had a formal DDH screening protocol or algorithm. 16 (84%) units used radiographs as their primary method of imaging hips, 2 used ultrasound and 1 unit used both modalities in equal proportions. Seven (37%) centres in total had access to hip ultrasound. Neonatal hip examination was carried out by a senior house officer (SHO) alone in 13 (68%) centres. One department had an orthopaedically trained registrar A consultant paediatrician examined all hips in 6 (32%) centres, data therefore estimates that 17,850 (29.1%) infants had a hip examination in the newborn period by an experienced examiner	The most effective interventions (selective ultrasound and examination by an experienced Clinician) are not widely practiced. excessive reliance on radiographs for the diagnosis of DDH in infants with risk factors or abnormal newborn examination. Significance of these findings is that delay could be of clinical importance with regard to treatment.

Date, author and country	Aim of research	Research design and instrument	Sample	Key findings	Implications
Ortiz-Neira et al. (2012) Canada	A meta-analysis of common risk factors associated with the diagnosis of developmental dysplasia of the hip in newborns	Quantitative study. A meta-analysis Effect sizes for each study were computed using random relative risk (RR) ratio calculations along with the 95% confidence limits.	Studies: n=31	Relative Risk ratio (RR) for each factor in newborns was: breech presentation 3.75 (95% CI: 2.25–6.24), females 2.54 (95% CI: 2.11–3.05), left hip side 1.54 (95% CI: 1.25–1.90), first born 1.44 (95% CI: 1.12–1.86), and family history 1.39 (95% CI: 1.23–1.57). A nonsignificant RR value of 1.22 (95% CI: 0.46–3.23) was found for mode of delivery	Results suggest that ultrasound and radiology screening methods be used to confirm DDH in newborns that present with one or a combination of the following common risk factors: breech presentation, female, left hip affected, first born and family history of DDH Based on the current findings future research should focus on the development of clinical guidelines related to the screening and diagnosis of DDH in association with the common risk factors identified
Phelen et al. (2014) Ireland	To determine the incidence of DDH in children born from the 1st January 2009 to 31st December 2009 in the South East if Ireland	Quantitative study Retrospective clinical analysis. Data of all referrals that were diagnosed with DDH extracted from clinic database	8317 live births in the Southeast Region in 2009 n=56 confirmed to have DDH	56 cases of DDH in 2009, 14 required referral to tertiary centre. When patients divided into early and late presentation groups, 58.9% (n=33) were referred to the clinic and began treatment early while 41.1% (n=23) presented late. Giving an incidence of early diagnosis of 3.97 per 1000 and late diagnosis of 2.77 per 1000.	Ireland has a high incidence of late diagnosis. The introduction of a national screening programme which incorporates greater use of ultrasound and examination by those experienced in DDH assessment advocated by authors
Roovers et al. (2005) The Netherlands	To determine the effectiveness of ultrasound screening for developmental dysplasia of the hip	Prospective cohort study. Intervention group screened by US at 1,2 and 3 months. Control group screened by routine physical examination. All participants had US at 6 months for evaluation.	Control group; n=2066 Intervention group; n=5170	The sensitivity of the ultrasound screening was 88.5%, and the referral rate 7.6%. 4.6% of the children were treated. The sensitivity of the CHC screening was 76.4%, with a referral rate of 19.2%. The treatment rate was 2.7%. Of the treated children in the ultrasound screening group, 67% were referred before the age of 13 weeks, whereas in the CHC screening group 29% were referred before this age.	This study shows that ultrasound screening detects more children with DDH than CHC screening and that more of them are detected at an earlier age. general ultrasound screening seems not to eradicate late cases of DDH. The higher treatment rate in the population screened by ultrasound may be a result of overtreatment.
Rosendahl et al. (2010) Norway	To examine whether mildly dysplastic both stable or instable hips would benefit from early treatment, as compared with surveillance	Blinded, randomized, controlled trial Group 1 immediate treatment, Group 2 sonographic surveillance	Newborns with mild DDH n=128	Active sonographic surveillance halved the number of children requiring treatment, did not increase the duration of treatment, and yielded similar results at 1 year follow up.	A strategy of active surveillance would reduce the overall treatment rate by 0.6%. These results may have important implications for families as well as for health care costs.

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Shorter et al. (2011) Australia	To determine the effect of different screening programmes for DDH on the incidence of late presentation of congenital hip dislocation.	Cochrane systematic review. Programmes that were compared were no screening, clinical screening and ultrasound screening (universal or targeted) aloneor in combination.	Five studies met the eligibility criteria n=5	No study examined the effect of screening and early treatment versus not screening and later treatment. One study reported universal ultrasound compared to clinical examination alone did not result in a significant reduction in late diagnosed DDH or surgery but was associated with a significant increase in treatment. One study reported targeted ultrasound compared to clinical examination alone did not result in a significant reduction in late diagnosed. DDH or surgery, with no significant difference in rate of treatment. Meta-analysis of two studies found universal ultrasound compared to targeted ultrasound did not result in a significant reduction in late diagnosed DDH or surgery.	Overall, there is insufficient evidence to give clear recommendations for practice due to no significant decrease in late presentation of DDH with any screening method.
Sink et al. (2014) USA	To identify the prevalence of risk factors for DDH that would have warranted selective ultrasound screening in patients with symptomatic acetabular dysplasia after skeletal maturity	Quantitative study, analysis of prospective single-centre hip registry and questionnaire regarding birth history and risk factors for DDH.	Skeletally mature patients undergoing corrective hip surgery for symptomatic hip dysplasia after skeletal maturity; n=68	Average age was 26.4 years. 67 (98.5 %) females and 1 (1.5 %) male. Left hip presented as the symptomatic hip in 21 (30.9 %) cases, and the right hip in 47 (69.1 %) cases. Results from questionnaire identified 8 patients (11.8 %) were confirmed breech. A family history of DDH was present in 2 additional patients (2.9 %). Therefore, current guidelines would recommend selective ultrasound screening in 10/68 patients (14.7 %) of this cohort	Only 14.7 % of skeletally mature patients presenting with symptomatic acetabular dysplasia would meet current criteria for selective ultrasound screening for a stable hip. Current screening may improve the incidence of early diagnosis and treatment of hip dysplasia in the high-risk group (breech and family history of DDH), but it may not have a significant impact on the incidence of skeletally mature acetabular dysplasia
Von Kries et al. (2012) Germany	To assess the effectiveness of universal ultrasound screening to prevent first operative procedures of the hip.	Population-based case-control study Cases of children who had developmental dysplasia of the hip requiring an operative procedure and children who did not (control subjects)	Cases of first operative procedures for developmental dysplasia of the hip (n = 446) compared with 1173 control subjects (who had not requires an operative procedure)for ultrasound screening.	Results showed that effectiveness of ultrasound screening to prevent first operative procedures for DDH was estimated as 52% (95% CI, 32-67). However, the introduction of universal screening was associated with a 5% to 7% early treatment rate, compared to 2% of newborns treated with clinical screening alone	Provides evidence for effectiveness of a general ultrasound screening program to prevent operative procedures in developmental dysplasia of the hip However, also suggests a connection between universal ultrasound screening and overtreatment.

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Wirth et al. (2004) Germany	To determine the long term effects that universal neonatal sonographic hip screening had on the evolution of late presenting DDH,	Quantitative study, analysis of prospective single-centre universal neonatal ultrasound hip screening programme	12 331 patients were included in the general neonatal ultrasound hip screening programme for DDH Patients who needed treatment (n=604) were compared with a second group of (n=73) unscreened children	In the hip screening group, the splintage rate was 49 per 1000 live births Only 4 patients in this group required surgical treatment. In the non US screened group, 25 closed and eight open reductions were carried out.	Universal ultrasound screening programme led to a reduction in late presentations, inpatient treatment and surgical treatment. Results of study underline the considerable potential of universal sonographic screening to reduce the need for inpatient treatment and surgical procedures. However cost effectiveness of such a programme is controversial
Witting et al. (2012) The Netherlands	To measure parental satisfaction with US hip screening in preventative child health care	Qualitative study Parental satisfaction was measured using a questionnaire	1,140 questionnaires sent to parents. Return rate of 61.7%; n=703	Parents reported positive scores on all factors. Competence, friendliness and carefulness of the ultrasound screener influenced satisfaction significantly. Unpleasantness of the crying of an infant during screening proved to be a significant predictor of satisfaction	Conclusions drawn were that good information provision before US screening and communication during the screening are means by which parental satisfaction can be influenced positively