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A qualitative study on parental experiences of children with developmental dysplasia of the hip

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Abstract

Objective: The aim of this qualitative study was to explore the experiences of Dutch parents of children with Developmental Dysplasia of the Hip (DDH), treated with a Pavlik harness, during the diagnostic and treatment process in the first year of life.

Design: A qualitative study by means of semi-structured interviews was conducted between September and December 2020. Qualitative content analysis was applied to code, categorise and thematise data.

Setting: A large, tertiary referral centre for paediatric orthopaedics in The Netherlands.

Participants: A purposive sample of parents of children aged younger than 1 year, who were treated for DDH with a Pavlik harness, were interviewed until data saturation was achieved. A total of 20 interviews with 22 parents (20 mothers and 2 fathers) were conducted.

Results: Five main themes emerged: (1) positive experiences with professionals and peers, (2) insufficient information, (3) treatment concerns, (4) difficulties parenting and (5) emotional burden. Most prominent features that resonated across the interviews which led to insecurity by parents were: insufficient pre-hospital information, unfiltered online information and lack of patient journey overview.

Conclusion: This study offers novel insights into parental experiences in DDH care. Parents were generally satisfied with DDH care. Biggest challenges were to cope with the insufficient and unfiltered information provision and lack of patient journey overview, which led to concerns during treatment. Future research and interventions should focus on optimising information provision for parents of children with DDH.

Strengths and limitations of this study

- A holistic view on parental experiences of DDH care was attained by a qualitative research approach. Parents were able to provide insights beyond the scope of the medical professionals.
- A unique feature of this study is the focus on patient perspectives of the healthcare process, rather than the healthcare professionals perspectives. As such, knowledge gaps have been identified that allow to further shape the DDH research agenda from a patient-oriented perspective.
- A representative cross-section of the DDH population was realised by purposive sampling.
- This qualitative research reflects the specific situation at a large, tertiary referral centre for paediatric orthopaedics in The Netherlands. Although the study findings seem universal, additional research is needed to verify the generalisability of our study results.
- Fathers were underrepresented in the interviews. Potentially different experiences may have been identified if more fathers were involved in the interview process.

Keywords

Developmental Dysplasia of the Hip, hip dysplasia, DDH, experiences, paediatric orthopaedics

Word count

4.063

Introduction

Developmental Dysplasia of the Hip (DDH) is one of the most common diagnosed conditions that parents of newborns face.[1,2] The term DDH refers to a broad spectrum of anatomical abnormalities to the paediatric hip joint, ranging from a dysplastic to a dislocated hip.[3] In the Netherlands, 3-4% of the infants up to 6 months of age develops DDH.[4] Every newborn is screened for DDH at the age of 1 month and 3 months at the children's healthcare centre as part of regular developmental check-ups.[5] The screening program consists of physical examination and risk factor assessment.[5] Once positively screened, a diagnostic ultrasound of the hip joint is conducted. Infants with abnormalities on hip ultrasound are directly referred to an orthopaedic surgeon for additional examination and treatment (figure 1).[5] Abduction bracing with a Pavlik harness is the first-line treatment in children aged younger than 6 months. Surgery is only indicated in children in whom non-operative treatment has failed and in late diagnosed DDH.[6] Therefore, early diagnosis and treatment are crucial, as untreated DDH might cause hip osteoarthritis in early adulthood and lifelong gait problems.[7]

In paediatric orthopaedic care, parents play a pivotal role as they are relied upon as main source of information regarding their child's health status.[8] Parental involvement and compliance to treatment are even more prominent in infants with DDH, as Pavlik harness treatment takes place in the home setting.[9] In recent years, the scope of parental participation in paediatric health care services has gained attention, as experiences and satisfaction of parents are considered as vital components of quality of care.[10,11] Parental satisfaction with health care services is associated with positive patient behaviour[12] and an important positive predictor of parents' commitment to and effectiveness of treatment.[13,14] Greater satisfaction leads to better treatment adherence and better health outcomes.[10]

Worldwide, DDH is the most common orthopaedic disorder in newborns.[15] Diagnosis and treatment of DDH can be a stressful event for parents causing anxiety, psychosocial problems and practical difficulties in daily life with a Pavlik harness.[2] Worries regarding the diagnosis, ability to walk and future perspectives have been expressed in previous research.[16] Parents often feel overwhelmed by the vast amount of information that is given on diagnosis and treatment.[17] Drawback of these studies on parental experiences of DDH care is the usage of closed-ended questionnaires. This may lead to missing data and bias introduced by leading questions and suggesting responses.[18] To adequately address the experiences of parents of children with DDH, a qualitative research approach with a holistic view would be more suitable.

Despite the crucial role of parents in the treatment of DDH, little is known regarding the experiences of parents caring for a child with DDH. Better understanding of parental experiences throughout care for children with DDH will improve healthcare professionals' ability to align their

support with the parents' perspectives and needs. The aim of this qualitative study is to explore the experiences of parents caring for a child with DDH, treated with a Pavlik harness, during the diagnostic and treatment process in the first year of life.

Patients and Methods

Study design

A qualitative study was conducted to gain in-depth information on parental experiences of care for children with DDH. Semi-structured interviews were used as source of information. The study was reported according to the Consolidated Criteria for Reporting Qualitative Research guideline (COREQ).

Study population

We selected parents of children (maximum 1 year of age) who were treated for DDH with a Pavlik harness. Age limit was chosen to minimise recall bias and no new information was expected after this period as treatment with a Pavlik harness is usually discontinued after 6 to 9 months of age.[19] Parents were selected based on the purposive sampling principle to ensure diversity of parents, representing a cross-section of the DDH population. Selection criteria were infant-based (DDH grade, Pavlik harness treatment duration and gender) and parent-based (age and education level).

Setting

Recruitment for the interviews took place in the *** *(blinded for review process)*, which is a large, tertiary referral centre for paediatric orthopaedics with approximately 425 new DDH patients a year. At the *** *(blinded for review process)*, DDH patients are treated in a clinical care pathway by a team of two paediatric orthopaedic surgeons, one fellow paediatric orthopaedic surgery and two orthopaedic clinical nurse specialists (figure 1).

Procedure

An interview guide was set up by several stakeholders in the DDH healthcare trajectory. A group composed of two paediatric orthopaedic surgeons, one fellow paediatric orthopaedic surgery, one paediatric orthopaedic PhD student, one orthopaedic researcher and one representative of the board of the Dutch patient association for DDH (*** *(blinded for review process)*)set up the interview guide for the interviews. Subsequently, semi-structured interviews were conducted to gain in depth information on parental experiences of care for children with DDH. The estimated sample size for the individual interviews was 15-20 parents. Data saturation was used as main criteria for discontinuing parent interviews.[20] Eligible parents were contacted by phone to assess their willingness to participate. Next, parents received written information about the study and were asked to participate. Participants gave their written informed consent. Individual interviews were conducted via a secured online webcam system, Webcamconsult BV (Bergen op Zoom, The Netherlands). Anonymity of participants and infants was secured in the interview transcripts.

Data collection

All interviews took place between September and December 2020. The semi-structured interviews with the parents were conducted by a paediatric orthopaedic PhD student, who was specifically trained in conducting qualitative interviews. The interviewer had no prior encounter or relationship with the patients or parents, but briefly introduced himself at the start of the interviews. The interview guide was used to facilitate the discussion and was iteratively modified in response to evolving study findings. All interviews were digitally audio recorded and transcribed verbatim in the native language (Dutch) by an independent transcription agency.

Data analysis

All transcripts were independently reviewed and coded using ATLAS.ti version 9.0 (Berlin, Germany) by a paediatric orthopaedic PhD student and an orthopaedic researcher to increase intercoder reliability. After each five transcripts, discrepancies in codes were discussed and iteratively refined until consensus was reached. After the coding process, categorical and thematic analysis was conducted by these two researchers. Consensus over final categories and themes was reached after discussion with a third researcher and approved by the rest of the study group. During the coding process, representative quotes were listed to illustrate the themes. Quotes were translated into English by a third researcher. The research team validated the English translations by translating them back to Dutch, to check whether the quotes had the same tenor as the original Dutch quotes.

Patient and Public Involvement

Parents of children with DDH were the main information resource for this study. The Dutch patient association for DDH was actively involved in building the interview guide, cross-checking and reviewing the results.

Results

After 20 interviews with parents of children with DDH, data saturation was achieved. In all interviews, the mother of the child participated and in two interviews the father attended as second participant. Average duration of the interviews was 30 minutes (12 to 52 minutes). Participant characteristics are listed in table 1.

Table 1. Characteristics of interviewed parents and their child

Interview	Parent				Child		
	Gender	Age	Home situation	Education level*	Gender	DDH grade	Treatment duration
1	♀	30	Two parent household	HVT	♀	2b	6 weeks
2	♀+ ♂	29+31	Two parent household	HVT	♀	3	12 weeks
3	♀	29	Two parent household	HVT	♀	D	6 weeks
4	♀	34	Two parent household	IVT	♂	2b	6 weeks
5	♀	33	Two parent household	IVT	♂	2b	6 weeks
6	♀	33	Two parent household	University	♂	2b	6 weeks
7	♀	29	Single parent household	IVT	♂	2c	6 weeks
8	♀	29	Two parent household	IVT	♂	D	6 weeks
9	♀	29	Two parent household	HVT	♀	2b	6 weeks
10	♀	31	Two parent household	HVT	♀	2b	6 weeks
11	♀	28	Two parent household	HVT	♀	3	12 weeks
12	♀	41	Two parent household	IVT	♂	2c	6 weeks
13	♀	35	Two parent household	IVT	♀	2b	12 weeks
14	♀	28	Two parent household	University	♀	D	6 weeks
15	♀+ ♂	29+31	Two parent household	IVT	♂	2b	6 weeks
16	♀	28	Two parent household	IVT	♀	2c	6 weeks
17	♀	31	Two parent household	University	♂	D	12 weeks
18	♀	30	Two parent household	University	♀	2c	6 weeks
19	♀	29	Two parent household	HVT	♂	2b	6 weeks
20	♀	31	Two parent household	HVT	♀	2b	6 weeks

* IVT: intermediate vocational education; HVT: higher vocational education

Themes

Thematic analysis identified 5 themes among parents throughout care for children with DDH during the first year of life: (1) positive experiences with professionals and peers, (2) insufficient information, (3) treatment concerns, (4) difficulties parenting, (5) emotional burden (figure 2). Within the 5 themes, multiple categories emerged, which are further explained with representative quotations to illustrate the parental experiences throughout care for children with DDH (table 2-3).

Table 2. Overview of themes, categories, and corresponding quotes (part 1)

Theme	Category	Quote [quote number; interview number]
Theme 1: Positive experiences with professionals and peers	1.1 Interplay orthopaedic surgeon and nurse	*He (=the orthopedic surgeon) more or less dropped the bomb and then the clinical nurse specialist came to calmly explain everything and I had the feeling all questions could be asked. Those two together was an excellent collaboration. [q1;i17]* *First the orthopedic surgeon briefly joins and next you see the nurse specialist extensively. I think it's the more the practical things you encounter as parents that you want information about and that is exactly what the nurse specialist provides. [q2;i14]*
	1.2 Accessibility for questions	*Because the first night you have to deal with a crying baby. The tips and commitment from the nurse are especially welcome. So, that they call you on the first day is very pleasant. [q3;i2]* *I found it especially pleasant that this [first day follow-up appointment] was over the telephone. You don't really want back to go back to the hospital after 1 day and now my husband could join. [q4: i2]* *Every time I called I was helped very pleasantly by the department. Once, the Velcro didn't work anymore and I was allowed to come by right the next day to get a new brace fitted. So there is a lot of thinking along with the parents to solve problems as quickly as possible.[q5; i20]*
	1.3 Support community	*There is this Facebook group you know? So as a parent you can get quite a lot of tips from there. There were very helpful things on there for my child. I was a member at the time. I didn't post or chat about anything, but there are quite active people there, so that was nice. [q6: i14]* *Our neighbors' first needed an abduction brace as well. She explained some practical things, on how she experienced things. That was very helpful. [q7;i5]*
Theme	**Category**	**Quote**
Theme 2: Insufficient information	2.1 Pre-hospital information	*I know we were briefly informed [at the diagnostic centre] that the hip dysplasia was severe and we needed to come to the hospital within one week, but we did not get any further information. That was the moment I started looking for information on the internet myself and came across the worst things, making me even more worried. Is she going to get a cast or even an operation? [q8;i2]*

2.2 Online information	*When I got home, me and my boyfriend immediately searched on the internet to find out what it all meant and then you immediately encounter the worst things. I think it's a logical step for parents when they hear that there's something wrong with their child, to quickly start looking for information. [q9;i2]* *On the internet you see plaster casts, devices where kids are hung vertically from their legs up and even images of surgery. It was a huge shock seeing those images, especially in combination with the announcement from the health clinic that the hip dysplasia was severe. I must say I had a few sleepless nights because of that. [q10;i2]*
2.3 Patient journey	*It was not entirely clear to me what the relationship was between the children's healthcare center, the diagnostic centre and the hospital. Why we had to go to all these places was unclear to me. [q11;i12]* *No, that [= the follow-up protocol during treatment] was not clear to me. I assumed they were going to do another ultrasound. Actually, I didn't know if they were going to. That was not explained to me at the beginning. [q12:i3]*
2.4 Practical issues	*Of course, you want to know; do we have to buy something, what do we have to consider? Will he still fit in his bed? Can we still sit him in his chair? Can we still use his car seat? [q13;i7]* *Practical issues, like how will I do the breastfeeding? [q14;i9]* *I also asked, when my child was hoisted into that apparatus, am I going to break his legs or is this going to go smoothly? [q15;i9]*

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Table 3. Overview of themes, categories, and corresponding quotes (part 2)

Theme	Category	Quote
Theme 3: Treatment concerns	3.1 Acceptance of treatment	*I did have some concerns on how we were going to get through that period, because she has quite a temperament. I thought, well this is surely going to be a rough 5 weeks. [q16;i9]*
		Eventually he slept extremely well. Obviously, that's not something you can be certain of beforehand. [q17;i6]
		He wasn't really that bothered by it [=Pavlik harnas]. So it ended up being not that bad for us.[q18;i5]
		I expected 5 tough days and nights, but it ended up to be the full 9 weeks with just hardly any sleep, and a lot, from her side al lot of either panicking or apathy. She was really hysterical. [q19;i9]
		The first days she cried a lot. Not so much the first day, but the day after she cried a lot because it was uncomfortable. After a few days it got less and after a week it was OK, she didn't know any better [q20;i20].
	3.2 Effect of treatment	*Yes, that [the 12-week clinic visit] worried me more than the 6 weeks check-up. Would it now have sorted any effect in those second 6 weeks? [q21;i13]*
	3.3 Future perspectives	*Especially concerning growth development. Will she grow crooked? Will she have a leg length difference? Will she be able to walk? Can she do sports? Those things are a lot on your mind. [q22;i11]*
Theme	**Category**	**Quote**
Theme 4: Difficulties parenting	4.1 Mother child relationship	*Especially the holding and cuddling. That felt less personal. It wasn't really a baby anymore, it was more like a parcel. [q23;i5]*
		I couldn't hold him like a baby and lay him in my arms anymore. When the brace came of I thought, wow what has he grown a lot. [q24;i5]
	4.2 Interference with work	*Normally, when you are at home with your baby and she is in good spirits, well than she is just lying there playing and babbling, and in the meantime, you could get some work done, you would be able to*

		squeeze that in. But with her, that was just not going to work, she continuously kept me occupied. [q25;i9]
	4.3 COVID-19 isolation	*It might have been due the hormones, but it is very difficult to memorize al that info. Being there with the two of you, would have made it all easier to process. [q26;i12]*
		We were in that lockdown, so what was very tough on us, was that my child was inconsolable and nobody was allowed to come and help us. [q27;i9]
Theme	**Category**	**Quote**
Theme 5: Emotional burden	5.1 Overwhelmed by diagnosis	*When we saw the paediatric orthopaedic surgeon in the hospital, to be honest, I was quite blown away. For him it was all cut and dry. Of course, he is a specialist and the conversation went quite quickly. Don't get me wrong, I can switch pretty quickly, but it was all a bit overwhelming. [q28;i3]*
	5.2 Wearing a Pavlik harness	*Actually, it [= child in a Pavlik harness] was more difficult for us parents to witness than it was on my child herself. My child accepted it quite rapidly. [q29;i1]*
	5.3 Reactions surrounding	*Where you first just have a baby, people react to the baby. Then [=child with a Pavlik harness], the surrounding suddenly react to the handicap. [q30;i20]*
	5.4 Expectation management	*The message from the children's healthcare center that it was severe hip dysplasia. I had a sleepless first night after that. I assumed that severe dysplasia would automatically mean she would have to undergo some sort of operation. [q31;i2]*
	5.5 COVID-19 delay in diagnosis	*And I was also concerned that we ended up at the children's healthcare center later because of corona. I was really wondering what the effect would be of ending up there 1 month later than we normally would have, because of corona. [q32;i2]*

Theme 1: Positive experiences with professionals and peers

1.1 Interplay orthopaedic surgeon and nurse

The interplay of healthcare professionals within the multidisciplinary team of the hospital (figure 1) was highly valuated by all parents. Especially the supportive role of the clinical nurse specialists was highly appreciated by parents. Paediatric orthopaedic surgeons were seen as the authority regarding the medical part, while the clinical nurse specialists were seen as first contact person with a very low threshold to ask practical questions and as guidance on day-to-day problems. [quote 1-2]

1.2 Accessibility for questions

Accessibility of health care professionals was one of the main positive points parents highlighted during the interviews. As pointed out by several parents, most questions regarding DDH care arose at home, often shortly after the visit to the hospital. The phone call parents received from the clinical nurse specialist one day after initiation of treatment was therefore highly valued. [quote 3-5]

1.3 Support community

A recurring topic among parents was the highly valuated support from peers. Peer support mainly came from friends, neighbours and fellow parents on the Facebook page of the VAH. Both practical help and emotional support from people who went through the same ups and downs was very useful. [quote 6-7] A strong feeling of 'we are in this together' arose among parents once they heard other parents dealt with the same issues.

Theme 2: Insufficient information

2.1 Pre-hospital information

The infrastructure for children with DDH at the **** (blinded for review process)* (figure 1) partially underlies the common criticism of parents towards the insufficient information provision. More than half of the interviewed parents reported no or insufficient information about DDH at time of referral form the community diagnostic centre to the **** (blinded for review process)*. Although parents were aware of abnormalities in the screening process or abnormal ultrasound findings, the subsequent hospital referral was accompanied by limited additional information regarding diagnosis and the further diagnostic and treatment process. As a result, there was an unfulfilled information need, this caused parents to search for online information themselves. [quote 8]

2.2 Online information

The majority of parents of children with DDH used internet as primary source of information. Various reasons were mentioned: insufficient or no pre-hospital information, wish to prepare for the first

hospital visit and the ease with which online information was accessible. A shortage of well-organised and patient specific information was the main remark of parents regarding online information on DDH. Although it was easily accessible, main concern was the staggering amount of unfiltered online information on treatment options, varying from an abduction device to traction treatment and surgery, which led to insecurity and anxiety. [quote 9-10]

2.3 Patient journey

Some parents were unaware of the different organizations and healthcare professionals that function within the DDH patient journey (figure 1). The role of the children's healthcare centre as screening institution and the community diagnostic centre as ultrasound imaging institution was not clearly defined for the parents, which led to confusion. [quote 11] Furthermore, a few parents were not aware of the follow up schedule after initiation of treatment. [quote 12]

2.4 *Practical issues*

The majority of the parents reported a lack of practical information and guidance on the application of the Pavlik harness in daily life. Especially in the early days of treatment, a lot of practical questions on a child in a Pavlik harness were encountered: which clothes to wear, how to transport, where to find a car-seat suitable in combination with a Pavlik harness, how to eat and how to breastfeed? [quote 13-15]

Theme 3: Treatment concerns

3.1 Acceptance of treatment

Once abduction treatment with a Pavlik harness was initiated, many parents were concerned whether the treatment would be accepted by their child. [quote 16] Doubts were raised by parents on how their child would react to a period of restricted mobility. Overall the parents report that, in hindsight, the acceptance of treatment turned out better than expected and that their worries in this regard had been unnecessary. [quote 17-18] On the other hand, one mother did mention a difficult treatment period with a child in a Pavlik harness. She reported problems during the entire treatment period, with a hysterical child and sleepless nights. [quote 19] Primary concern of most parents was the fear of sleepless nights once treatment had started. In retrospect, most parents described that only the first couple of nights were troublesome and overall the treatment period was less demanding than expected. [quote 17,20]

3.2 Effect of treatment

Parents reported their main worry was whether abduction splinting had the desired effect. Especially parents of children who needed an extended treatment period compared to what was initially discussed at the first hospital appointment, were in doubt whether the treatment would have the desired effect in the extended treatment period. [quote 21]

3.3 Future perspectives

A high number of parents were worried about how DDH might affect their child in the future, especially regarding the ability to walk, leg length difference and hip instability. These worries on future perspectives arose both in the pre-treatment and post-treatment phase with a Pavlik harness. [quote 22]

Theme 4: Difficulties parenting

4.1 Mother child relationship

A recurring theme among the interviews was the disturbed relationship between mother and child. Mothers reported a change in perception of the relationship with their child, once Pavlik harness treatment was initiated. They felt that the Pavlik harness functioned as a physical barrier between them and their child. [quote 23-24] The sudden onset of treatment combined with an abduction device that was worn 23-24 hours a day interfered with the normal upbringing they had in mind once they became parents.

4.2 Interference with work

A child in a Pavlik harness in the home situation led to need for additional care. For parents working at home (due to COVID-19), more than usual attention and care for their child was needed. This interfered with the daily work the parents had. [quote 25]

4.3 COVID-19 isolation

As in all healthcare services, the COVID-19 pandemic affected DDH care. In contrast to the normal situation, only one parent was allowed to accompany the infant during the outpatient clinic visits. Some mothers wished for the presence of their partner and were afraid to miss crucial information which the orthopaedic paediatric surgeon shared with them. [quote 26] In the home situation, the majority of the parents felt isolated and had the feeling of being left alone in the treatment phase due to the COVID-19 isolation. [quote 27]

Theme 5: Emotional burden

5.1 Overwhelmed by diagnosis

Some parents reported that paediatric orthopaedic surgeons should acknowledge that the official diagnosis of DDH had a big impact on the parents' and child's life. They felt that this was not fully appreciated by the paediatric orthopedic surgeon during their clinic visit. Parents felt overwhelmed once diagnosis was made and often required more time being adequately informed on diagnosis and treatment by the orthopaedic surgeon. [quote 28]

5.2 Wearing a Pavlik harness

In the early days of treatment, many parents found it a distressing sight to see their three-month-old child restricted in a Pavlik harness. They were worried whether their child was comfortable and reported that it was unpleasant to see their child's movements restricted. This feeling was reported to resolve during treatment at least partially by most parents, as the majority saw their child quite rapidly accepted the Pavlik harness. [quote 29]

5.3 Reactions surrounding

Parents emphasised that they continuously had to deal with reactions from the surrounding on their child in a Pavlik harness. Parents sometimes had the feeling of having a child with a handicap instead of a healthy child. [quote 30] A lot of attention of the surrounding was paid to the aberrant looking position of the child's legs in a Pavlik harness.

5.4 Expectation management

Expectation management was a recurrent subject among the interviews. In particular expectations that were created in the pre-hospital phase, which had to be disproved at the hospital. This discrepancy between expectations and reality often led to confusion for parents. Parents often went to the hospital with wrong expectations on treatment type and duration, partially caused by the suboptimal information. It is noteworthy that parents link words like 'severe grade DDH' - that was mentioned several times in the pre-hospital phase - to heavy treatment options like 'surgery, cast immobilization or traction treatment'. [quote 31]

5.5 COVID-19 delay in diagnosis

As for many healthcare services, DDH screening had to be temporarily halted and postponed in The Netherlands during the first wave of the COVID-19 pandemic. Many parents raised concerns about the consequences of the delay in screening and diagnosis of DDH regarding their child's hip. [quote 32]

Discussion

This qualitative study offers an up-to-date view on parental experiences on care for children with DDH treated with a Pavlik harness in the Netherlands during the first year of life. On the whole, the majority of the parents was satisfied with DDH care. However, some remarks in different phases of the diagnostic and treatment process have been made, which offer novel leads to optimise care for children with DDH.

Parents were generally satisfied with the DDH care provided by the hospital. Especially the collaboration between the paediatric orthopaedic surgeon, who provided the medical information, and the orthopaedic clinical nurse specialist, who provided the practical information and emotional support, was highly valued by all parents at the **** (blinded for review process)*. In addition, the accessibility of the clinical nurse specialist during the treatment phase on medical and practical issues was appreciated by parents. Although this response might partially be socially desirable in the current setting, these positive points on DDH care are in line with variables reported by Peng et al.[21] They showed that predictive aspects to recommend a paediatric orthopaedic hospital to others were collaboration between paediatric orthopaedic healthcare professionals, friendliness of healthcare providers, patient-healthcare provider relationship and provided medical information.[21] Besides the information by healthcare professionals, parents valued support from peers on both practical and emotional support.[22] On the basis of the positive hospital experience, we recommend awareness for both medical, practical and emotional support for parents of children with DDH during the treatment phase.

The most apparent issues in the pre-hospital phase of DDH care were the insufficient information provision, unfiltered online information and a lack of the patient journey overview. Provision of adequate patient information is an integral part of the medical profession. The importance of information prior to the first outpatient appointment was previously shown in parents of children with a craniofacial condition. Parents were most curious about what would happen during and after their appointment and wanted to be able to prepare questions to ask.[23] Furthermore, parents had particular interest in the identity of the healthcare professionals involved.[24] In our study parents reported an inadequate information provision prior to their first hospital appointment. As a result, several parents pointed out they felt unprepared and surprised by the sudden onset of treatment, which led to insecurity. Partially due to the insufficient information supply on DDH prior to the first hospital appointment, parents felt forced to use internet as primary source of information.
Over the past few years, the use of internet and social media as primary source of medical information has become increasingly popular among patients.[25] An unprecedented access to an

immense amount of information is available online.[26] However, the quality and reliability of the online information varies substantially, as a result patients may be misinformed about their medical condition and treatment options.[27] Our findings suggest that due to the broad amount of unfiltered and non-patient specific information on DDH treatment, parents may become unnecessarily anxious. Previous studies showed that in general the online information on DDH is written on a level above the recommended level for medical patient information.[28] This may lead to misunderstanding and misinterpretation of the information, which is associated with poorer health care outcomes.[28] Orthopaedic healthcare professionals must be aware of the variability of the level of quality, reliability and understandability of the online information. Parents should preferably be referred to prescreened and trustworthy online sources by the youth health care physician and orthopaedic surgeon.

Patient perspectives on the healthcare process are increasingly used to optimise the patient journey. Data provided by the patient experiences can help to improve the quality or efficacy of the clinical management towards the activities most valued by patients.[29] In our qualitative study unawareness of the different organizations involved in the diagnostic and treatment process, a global overview of the treatment process and future perspectives were recurrent features that resonated across most of the interviews. By incorporating these aspects in the patient information in a timely fashion, parental experiences might be improved.[30]

DDH is one of the most common diagnosed conditions that parents of newborns face.[31] Diagnosis and treatment of DDH can be a stressful event for parents during an already major life event. Previous studies suggest that infant disorders lead to anxiety, psychosocial problems and practical difficulties in daily life for mothers.[2] Drawback of the study by Gardner and colleagues, is the usage of close-ended questionnaires. Therefore, this study was not able to grasp the detailed nature of the psychosocial problems parents had. We performed one of the first qualitative studies on the experiences of parents on DDH care and showed that underlying reasons of anxiety were: concerns on acceptance of Pavlik harness by child, effect of Pavlik harness treatment, distressing to see child in Pavlik harness, reactions surroundings and future perspectives regarding ability to walk, leg length difference and hip stability. Mothers were specifically concerned on their mother child relationship as the Pavlik harness functioned as a physical barrier between them and their child, which interfered with the maternal attachment they had in mind. These parental concerns are at least partly supported by recent research on maternal attachment in infants, showing that deprivation of mother's tactile and proximity related signals leads to biobehavioural dysregulation.[32] Practical difficulties of caring for a child in abduction splinting due to little guidance is a known phenomenon.[33] Especially a lack of practical information on clothing, transport, breastfeeding and

furniture is a recognised problem.[22] To the best of our knowledge, this is the first study that reported parental anxiety on future perspectives of a child treatment for DDH. Parents were afraid of leg length differences, gait problems and hip instability. Optimisation of information on future perspectives of children successfully treated for DDH could partially resolve these concerns.

Despite the strengths of this study, our study has some limitations. The local infrastructure and involvement of multiple healthcare organizations for children with DDH at the *** *(blinded for review process)* (figure 1) potentially influences parental experiences during the patient journey. Yet, the experiences on Pavlik harness treatment are presumably universal, as the principles of abduction splinting with a Pavlik harness are generally similar worldwide.[15] Despite, additional research is needed to verify the generalisability of our study results to other DDH care settings. Second, fathers were underrepresented in the interviews. Low levels of father participitation in paediatric research is a known phenomenon[34] and is contributed to lack of time[35], lack of interest[35], lack of accesibility[35] and not being asked to participate.[34] Potentially different experiences may have been identified if more fathers were involved in the interview process. Finally, recall bias is a factor that potentially affected the results, as parents need to look back on their experiences from the past. Impact of recall bias was minimised by setting an age limit of 1 year, as no new information was expected after this period.

The current findings suggest that future interventions should focus primarily on optimising (online) information provision, patient journey overview, future perspectives and practical information for parents of children with DDH. Specific attention should be given to understandable information for parents in all layers of the society to minimise misunderstanding or misinterpretation of information.[28] Communication with pictures, videos, diagrams [36,37] and electronic patient specific information [38,39] can be used as these initiatives may improve parents' preparedness, reliability of patient care and enhance the value of healthcare.

The novelty of the current study lies within its qualitative aspect. This allowed parents of children with DDH to share their detailed experiences from a personal point of view and facilitated the expression of beliefs that may be left undiscussed in previously performed studies with close-ended questionnaires.[2] Unique feature of this qualitative study is the focus on patient perspectives of the healthcare process, rather than the healthcare professional perspectives.[40] As such, this study improves our understanding of parental experiences on care for children with DDH and serves as first step to improve the patient journey. In conclusion despite general positive experiences, the results of this qualitative research document numerous opportunities for improvements in current DDH care.

Especially, pre-hospital information, trustworthy online information, patient specific information and overview of the patient journey are important points of improvement.

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Authors Contributions

WT: prepared study protocol, conducted interviews, coded data, analysed data and wrote the manuscript. MS: prepared study protocol, coded data, analysed data and wrote the manuscript. MVV: analysed data and wrote the manuscript. FVD: critical reviewer of study protocol and manuscript. MW: critical reviewer of study protocol and manuscript. JT: initiator study design, prepared study protocol, analysed data and wrote the manuscript.

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Competing Interests

None declared.

Data Sharing Statement

No additional data are available.

Ethics Approval

The Medical Ethics Committee of the *** *(blinded for review process)* assessed the study and judged that ethics approval was not required under Dutch National Law, METC number N20.077.

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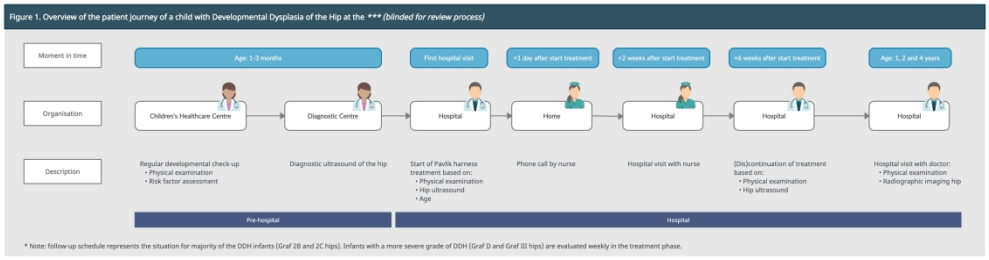

Figure1

1460x395mm (72 x 72 DPI)

Figure 2. Schematic overview of 5 themes and categories

1 - Positive experiences with professionals and peers	2 - Insufficient information	3 - Treatment concerns	4 - Difficulties parenting	5 - Emotional burden
1.1 Interplay orthopaedic surgeon and nurse	2.1 Pre-hospital information	3.1 Acceptance of treatment	4.1 Mother child relationship	5.1 Overwhelmed by diagnosis
1.2 Accessibility for questions	2.2 Online information	3.2 Effect of treatment	4.2 Interference with work	5.2 Child in Pavlik harness
1.3 Support community	2.3 Patient journey	3.3 Future perspectives	4.3 COVID-19 isolation	5.3 Reactions surrounding
	2.4 Practical issues			5.4 Expectation management
				5.5 COVID-19 delay in diagnosis

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	8
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1,8 (PhD)
Occupation	3	What was their occupation at the time of the study?	8 (PhD)
Gender	4	Was the researcher male or female?	8 (male)
Experience and training	5	What experience or training did the researcher have?	8
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	8
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	8
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	8
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	7,8
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	2,7
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	7
Sample size	12	How many participants were in the study?	2,9
Non-participation	13	How many people refused to participate or dropped out? Reasons?	8
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	7,8
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	8
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	9 + table 1
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	7
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	7-9
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were field notes made during and/or after the inter view or focus group?	7,8
Duration	21	What was the duration of the inter views or focus group?	9
Data saturation	22	Was data saturation discussed?	9
Transcripts returned	23	Were transcripts returned to participants for comment and/or	9

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	8
Description of the coding tree	25	Did authors provide a description of the coding tree?	9 + fig 2
Derivation of themes	26	Were themes identified in advance or derived from the data?	9
Software	27	What software, if applicable, was used to manage the data?	8
Participant checking	28	Did participants provide feedback on the findings?	9
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	table 2
Data and findings consistent	30	Was there consistency between the data presented and the findings?	9-13
Clarity of major themes	31	Were major themes clearly presented in the findings?	9-13 + table 2
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	9-13

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Parental experiences of children with developmental dysplasia of the hip: a qualitative study

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Parental experiences of children with developmental dysplasia of the hip: a qualitative study

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Abstract

Objective: The aim of this qualitative study was to explore the experiences of Dutch parents of children with Developmental Dysplasia of the Hip (DDH), treated with a Pavlik harness, during the diagnostic and treatment process in the first year of life.

Design: A qualitative study by means of semi-structured interviews was conducted between September and December 2020. Qualitative content analysis was applied to code, categorise and thematise data.

Setting: A large, tertiary referral centre for paediatric orthopaedics in The Netherlands.

Participants: A purposive sample of parents of children aged younger than 1 year, who were treated for DDH with a Pavlik harness, were interviewed until data saturation was achieved. A total of 20 interviews with 22 parents (20 mothers and 2 fathers) were conducted.

Results: Five main themes emerged: (1) positive experiences with professionals and peers, (2) insufficient information, (3) treatment concerns, (4) difficulties parenting and (5) emotional burden. Most prominent features that resonated across the interviews which led to insecurity by parents were: insufficient pre-hospital information, unfiltered online information and lack of patient journey overview.

Conclusion: This study offers novel insights into parental experiences in DDH care. Parents were generally satisfied with DDH care provided by the hospital. Biggest challenges were to cope with: (1) insufficient and unfiltered information, (2) lack of patient journey overview and (3) practical problems and emotional doubts, which led to concerns during treatment. Future research and interventions should focus on optimising information provision and guidance with practical and emotional support for parents of children with DDH.

Strengths and limitations of this study

- The qualitative research approach enabled parents of children with DDH to share their personal experiences and beliefs, with the aim of detecting knowledge gaps and optimising DDH care from a patient-oriented perspective.
- The Dutch patient association for DDH was actively involved in the development of the interview guide.
- A representative cross-section of the DDH population was realised by purposive sampling.
- This study reflects the situation at a large, tertiary referral centre for paediatric orthopaedics in The Netherlands. Generalisability of our study results needs to be verified.
- Fathers were underrepresented in the interviews, which might underexpose the information on their experiences and perspectives.

Keywords

Developmental Dysplasia of the Hip, hip dysplasia, DDH, experiences, paediatric orthopaedics

Word count

3.930

Introduction

Developmental Dysplasia of the Hip (DDH) is one of the most common diagnosed conditions that parents of newborns face.[1,2] The term DDH refers to a broad spectrum of anatomical abnormalities to the paediatric hip joint, ranging from a dysplastic to a dislocated hip.[3] In the Netherlands, 3-4% of the infants up to 6 months of age develops DDH.[4] Every newborn is screened for DDH at the age of 1 month and 3 months at the children's healthcare centre as part of regular developmental check-ups.[5] The screening program consists of physical examination and risk factor assessment.[5] Once positively screened, a diagnostic ultrasound of the hip joint is conducted. Infants with abnormalities on hip ultrasound are directly referred to an orthopaedic surgeon for additional examination and treatment (figure 1).[5] Abduction bracing with a Pavlik harness is the first-line treatment in children aged younger than 6 months. Surgery is only indicated in children in whom non-operative treatment has failed and in late diagnosed DDH.[6] Therefore, early diagnosis and treatment are crucial, as untreated DDH might cause hip osteoarthritis in early adulthood and lifelong gait problems.[7]

In paediatric orthopaedic care, parents play a pivotal role as they are relied upon as main source of information regarding their child's health status.[8] Parental involvement and compliance to treatment are even more prominent in infants with DDH, as Pavlik harness treatment takes place in the home setting.[9] Parental satisfaction with health care services is associated with positive patient behaviour[10] and an important positive predictor of commitment to and effectiveness of treatment.[11,12] Greater satisfaction leads to better treatment adherence and better health outcomes.[13] In recent years, the scope of parental participation in paediatric health care services has gained attention, as experiences and satisfaction of parents are considered as vital components of quality of care.[13,14]

Diagnosis and treatment of DDH can be a stressful event for parents.[2] Psychosocial consequences of receiving the diagnosis of DDH, practical difficulties with a Pavlik harness (washing, dressing, feeding and cuddling), worries regarding future perspectives and ability to walk have previously been reported by parents of children with DDH.[15] Difficulties adjusting life to a child in a Pavlik harness with little guidance is a known phenomenon.[16] Parents often feel overwhelmed by the vast amount of information on DDH that is given on diagnosis and treatment.[17] Drawback of these studies on parental experiences of DDH care is the usage of closed-ended questionnaires. This may lead to missing data and bias introduced by leading questions and suggesting responses.[18] To adequately address the experiences of parents of children with DDH, a qualitative research approach with a holistic view would be more suitable.

Despite the crucial role of parents in the treatment of DDH, little is known regarding the experiences of parents caring for a child with DDH. Better understanding of parental experiences throughout care for children with DDH will improve healthcare professionals' ability to align their support with the parents' perspectives and needs. The aim of this qualitative study is to explore the experiences of parents caring for a child with DDH, treated with a Pavlik harness, during the diagnostic and treatment process in the first year of life.

Patients and Methods

Study design

A qualitative study was conducted to gain in-depth information on parental experiences of care for children with DDH. Semi-structured interviews were used as source of information. The study was reported according to the Consolidated Criteria for Reporting Qualitative Research guideline (COREQ).

Study population

We selected parents of children (maximum 1 year of age) who were treated for DDH with a Pavlik harness. Age limit was chosen to minimise recall bias and no new information was expected after this period as treatment with a Pavlik harness is usually discontinued after 6 to 9 months of age.[19] Parents were selected based on the purposive sampling principle to ensure diversity of parents, representing a cross-section of the DDH population. Selection criteria were infant-based (DDH grade, Pavlik harness treatment duration and gender) and parent-based (age and education level).

Setting

Recruitment for the interviews took place in the Máxima Medical Centre, which is a large, tertiary referral centre for paediatric orthopaedics with approximately 425 new DDH patients a year. At the Máxima Medical Centre, DDH patients are treated in a clinical care pathway by a team of two paediatric orthopaedic surgeons, one fellow paediatric orthopaedic surgery and two orthopaedic clinical nurse specialists (figure 1).

Procedure

An interview guide was set up by several stakeholders in the DDH healthcare trajectory. A group composed of two paediatric orthopaedic surgeons, one fellow paediatric orthopaedic surgery, one paediatric orthopaedic PhD student, one orthopaedic researcher and one representative of the board of the Dutch patient association for DDH (Vereniging Afwijkende Heupontwikkeling [VAH]) set up the interview guide for the interviews. Input from representatives from the Dutch patient association for DDH was used to revise the initial draft of the interview guide to a final version. Subsequently, semi-structured interviews were conducted to gain in depth information on parental experiences of care for children with DDH. The estimated sample size for the individual interviews was 15-20 parents. Data saturation was used as main criterion for discontinuing interviews.[20] Data was considered as saturated, when no new codes and themes were identified and repeatedly the same themes were scored. Eligible parents were contacted by phone to assess their willingness to participate. Next, parents received written information about the study and were asked to

participate. Participants gave their written informed consent. Individual interviews were conducted via a secured online webcam system, Webcamconsult BV (Bergen op Zoom, The Netherlands). Anonymity of participants and infants was secured in the interview transcripts.

Data collection

All interviews took place between September and December 2020. The semi-structured interviews with the parents were conducted by a paediatric orthopaedic PhD student, who was specifically trained in conducting qualitative interviews. The interviewer had no prior encounter or relationship with the patients or parents, but briefly introduced himself at the start of the interviews. The interview guide was used to facilitate the discussion and was iteratively modified in response to evolving study findings. All interviews were digitally audio recorded and transcribed verbatim in the native language (Dutch) by an independent transcription agency.

Data analysis

All transcripts were independently reviewed and coded using ATLAS.ti version 9.0 (Berlin, Germany) by a paediatric orthopaedic PhD student and an orthopaedic researcher to increase intercoder reliability. After each five transcripts, discrepancies in codes were discussed and iteratively refined until consensus was reached. After the coding process, categorical and thematic analysis was conducted by these two researchers. Consensus over final categories and themes was reached after discussion with a third researcher and approved by the rest of the study group. During the coding process, representative quotes were listed to illustrate the themes. Quotes were translated into English by a third researcher. The research team validated the English translations by translating them back to Dutch, to check whether the quotes had the same tenor as the original Dutch quotes.

Patient and Public Involvement

Parents of children with DDH were the main information resource for this study. The VAH was actively involved in building the interview guide, cross-checking and reviewing the results.

Results

After 20 interviews with parents of children with DDH, data saturation was achieved. In all interviews, the mother of the child participated and in two interviews the father attended as second participant. Average duration of the interviews was 30 minutes (12 to 52 minutes). Participant characteristics are listed in table 1.

Table 1. Characteristics of interviewed parents and their child

Interview	Parent				Child		
	Gender	Age range	Home situation	Education level*	Gender	DDH grade	Treatment duration
1	♀	30-34	Two parent household	HVT	♀	2b	6 weeks
2	♀+ ♂	25-34	Two parent household	HVT	♀	3	12 weeks
3	♀	25-29	Two parent household	HVT	♀	D	6 weeks
4	♀	30-34	Two parent household	IVT	♂	2b	6 weeks
5	♀	30-34	Two parent household	IVT	♂	2b	6 weeks
6	♀	30-34	Two parent household	University	♂	2b	6 weeks
7	♀	25-29	Single parent household	IVT	♂	2c	6 weeks
8	♀	25-29	Two parent household	IVT	♂	D	6 weeks
9	♀	25-29	Two parent household	HVT	♀	2b	6 weeks
10	♀	30-34	Two parent household	HVT	♀	2b	6 weeks
11	♀	25-29	Two parent household	HVT	♀	3	12 weeks
12	♀	40-44	Two parent household	IVT	♂	2c	6 weeks
13	♀	35-39	Two parent household	IVT	♀	2b	12 weeks
14	♀	25-29	Two parent household	University	♀	D	6 weeks
15	♀+ ♂	25-34	Two parent household	IVT	♂	2b	6 weeks
16	♀	25-29	Two parent household	IVT	♀	2c	6 weeks
17	♀	30-34	Two parent household	University	♂	D	12 weeks
18	♀	30-34	Two parent household	University	♀	2c	6 weeks
19	♀	25-29	Two parent household	HVT	♂	2b	6 weeks
20	♀	30-34	Two parent household	HVT	♀	2b	6 weeks

* IVT: intermediate vocational education; HVT: higher vocational education

Themes

Thematic analysis identified 5 themes among parents throughout care for children with DDH during the first year of life: (1) positive experiences with professionals and peers, (2) insufficient information, (3) treatment concerns, (4) difficulties parenting, (5) emotional burden (figure 2). Within the 5 themes, multiple categories emerged, which are further explained with representative quotations to illustrate the parental experiences throughout care for children with DDH (table 2-3).

183 **Table 2.** Overview of themes, categories, and corresponding quotes (part 1)

Theme	Category	Quote [quote number; interview number]
Theme 1: Positive experiences with professionals and peers	1.1 Interplay orthopaedic surgeon and nurse	*He (=the orthopedic surgeon) more or less dropped the bomb and then the clinical nurse specialist came to calmly explain everything and I had the feeling all questions could be asked. Those two together was an excellent collaboration. [q1;i17]* *First the orthopedic surgeon briefly joins and next you see the nurse specialist extensively. I think it's the more the practical things you encounter as parents that you want information about and that is exactly what the nurse specialist provides. [q2;i14]*
	1.2 Accessibility for questions	*Because the first night you have to deal with a crying baby. The tips and commitment from the nurse are especially welcome. So, that they call you on the first day is very pleasant. [q3;i2]* *I found it especially pleasant that this [first day follow-up appointment] was over the telephone. You don't really want back to go back to the hospital after 1 day and now my husband could join. [q4: i2]* *Every time I called I was helped very pleasantly by the department. Once, the Velcro didn't work anymore and I was allowed to come by right the next day to get a new brace fitted. So there is a lot of thinking along with the parents to solve problems as quickly as possible.[q5; i20]*
	1.3 Support community	*There is this Facebook group you know? So as a parent you can get quite a lot of tips from there. There were very helpful things on there for my child. I was a member at the time. I didn't post or chat about anything, but there are quite active people there, so that was nice. [q6: i14]* *Our neighbors' first needed an abduction brace as well. She explained some practical things, on how she experienced things. That was very helpful. [q7;i5]*
Theme	**Category**	**Quote**
Theme 2: Insufficient information	2.1 Pre-hospital information	*I know we were briefly informed [at the diagnostic centre] that the hip dysplasia was severe and we needed to come to the hospital within one week, but we did not get any further information. That was the moment I started looking for information on the internet myself and came across the worst things, making me even more worried. Is she going to get a cast or even an operation? [q8;i2]*

2.2 Online information	*When I got home, me and my boyfriend immediately searched on the internet to find out what it all meant and then you immediately encounter the worst things. I think it's a logical step for parents when they hear that there's something wrong with their child, to quickly start looking for information. [q9;i2]* *On the internet you see plaster casts, devices where kids are hung vertically from their legs up and even images of surgery. It was a huge shock seeing those images, especially in combination with the announcement from the health clinic that the hip dysplasia was severe. I must say I had a few sleepless nights because of that. [q10;i2]*
2.3 Patient journey	*It was not entirely clear to me what the relationship was between the children's healthcare center, the diagnostic centre and the hospital. Why we had to go to all these places was unclear to me. [q11;i12]* *No, that [= the follow-up protocol during treatment] was not clear to me. I assumed they were going to do another ultrasound. Actually, I didn't know if they were going to. That was not explained to me at the beginning. [q12:i3]*
2.4 Practical issues	*Of course, you want to know; do we have to buy something, what do we have to consider? Will he still fit in his bed? Can we still sit him in his chair? Can we still use his car seat? [q13;i7]* *Practical issues, like how will I do the breastfeeding? [q14;i9]* *I also asked, when my child was hoisted into that apparatus, am I going to break his legs or is this going to go smoothly? [q15;i9]*

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Table 3. Overview of themes, categories, and corresponding quotes (part 2)

Theme	Category	Quote
Theme 3: Treatment concerns	3.1 Acceptance of treatment	*I did have some concerns on how we were going to get through that period, because she has quite a temperament. I thought, well this is surely going to be a rough 5 weeks. [q16;i9]*
		Eventually he slept extremely well. Obviously, that's not something you can be certain of beforehand. [q17;i6]
		He wasn't really that bothered by it [=Pavlik harnas]. So it ended up being not that bad for us.[q18;i5]
		I expected 5 tough days and nights, but it ended up to be the full 9 weeks with just hardly any sleep, and a lot, from her side al lot of either panicking or apathy. She was really hysterical. [q19;i9]
		The first days she cried a lot. Not so much the first day, but the day after she cried a lot because it was uncomfortable. After a few days it got less and after a week it was OK, she didn't know any better [q20;i20].
	3.2 Effect of treatment	*Yes, that [the 12-week clinic visit] worried me more than the 6 weeks check-up. Would it now have sorted any effect in those second 6 weeks? [q21;i13]*
	3.3 Future perspectives	*Especially concerning growth development. Will she grow crooked? Will she have a leg length difference? Will she be able to walk? Can she do sports? Those things are a lot on your mind. [q22;i11]*
Theme	**Category**	**Quote**
Theme 4: Difficulties parenting	4.1 Mother child relationship	*Especially the holding and cuddling. That felt less personal. It wasn't really a baby anymore, it was more like a parcel. [q23;i5]*
		I couldn't hold him like a baby and lay him in my arms anymore. When the brace came of I thought, wow what has he grown a lot. [q24;i5]
	4.2 Interference with work	*Normally, when you are at home with your baby and she is in good spirits, well than she is just lying there playing and babbling, and in the meantime, you could get some work done, you would be able to*

		squeeze that in. But with her, that was just not going to work, she continuously kept me occupied. [q25;i9]
	4.3 COVID-19 isolation	*It might have been due the hormones, but it is very difficult to memorize al that info. Being there with the two of you, would have made it all easier to process. [q26;i12]*
		We were in that lockdown, so what was very tough on us, was that my child was inconsolable and nobody was allowed to come and help us. [q27;i9]
Theme	**Category**	**Quote**
Theme 5: Emotional burden	5.1 Overwhelmed by diagnosis	*When we saw the paediatric orthopaedic surgeon in the hospital, to be honest, I was quite blown away. For him it was all cut and dry. Of course, he is a specialist and the conversation went quite quickly. Don't get me wrong, I can switch pretty quickly, but it was all a bit overwhelming. [q28;i3]*
	5.2 Wearing a Pavlik harness	*Actually, it [= child in a Pavlik harness] was more difficult for us parents to witness than it was on my child herself. My child accepted it quite rapidly. [q29;i1]*
	5.3 Reactions from others	*Where you first just have a baby, people react to the baby. Then [=child with a Pavlik harness], the surrounding suddenly react to the handicap. [q30;i20]*
	5.4 Expectation management	*The message from the children's healthcare center that it was severe hip dysplasia. I had a sleepless first night after that. I assumed that severe dysplasia would automatically mean she would have to undergo some sort of operation. [q31;i2]*
	5.5 COVID-19 delay in diagnosis	*And I was also concerned that we ended up at the children's healthcare center later because of corona. I was really wondering what the effect would be of ending up there 1 month later than we normally would have, because of corona. [q32;i2]*

Theme 1: Positive experiences with professionals and peers

1.1 Interplay orthopaedic surgeon and nurse

The interplay of healthcare professionals within the multidisciplinary team of the hospital (figure 1) was highly valued by all parents. The supportive role of the clinical nurse specialists was particularly appreciated by parents. Paediatric orthopaedic surgeons were seen as the authority regarding the medical part, while clinical nurse specialists were seen as point of contact as they were easily accessible to ask practical questions and as guidance on day-to-day problems. [quote 1-2]

1.2 Accessibility for questions

Accessibility of health care professionals was one of the main positive points parents highlighted during the interviews. As pointed out by several parents, most questions regarding DDH care arose at home, often shortly after the visit to the hospital. The phone call parents received from the clinical nurse specialist one day after initiation of treatment was therefore highly valued. [quote 3-5]

1.3 Support community

A recurring topic among parents was the highly valued support from peers. Peer support mainly came from friends, neighbours and fellow parents on the Facebook page of the VAH. Both practical help and emotional support from people who went through the same ups and downs was very useful. [quote 6-7] A strong feeling of 'we are in this together' arose among parents once they heard other parents dealt with the same issues.

Theme 2: Insufficient information

2.1 Pre-hospital information

The infrastructure for children with DDH at the Máxima Medical Centre (figure 1) partially underlies the common criticism of parents towards the insufficient information provision. More than half of the interviewed parents reported no or insufficient information about DDH at time of referral from the community diagnostic centre to the Máxima Medical Centre. Although parents were aware of abnormalities in the screening process or abnormal ultrasound findings, the subsequent hospital referral was accompanied by limited additional information regarding diagnosis and the further diagnostic and treatment process. As a result, there was an unfulfilled information need, which caused parents to search for online information themselves. [quote 8]

2.2 Online information

The majority of parents of children with DDH used internet as primary source of information. Various reasons were mentioned: insufficient or no pre-hospital information, wish to prepare for the first

hospital visit and the ease with which online information was accessible. A shortage of well-organised, patient-friendly language and information specific to their child's situation were the main remarks of parents regarding online information on DDH. Although it was easily accessible, main concern was the staggering amount of unfiltered online information on treatment options, varying from an abduction device to traction treatment and surgery, which led to insecurity and anxiety. [quote 9-10]

2.3 Patient journey

Some parents were unaware of the different organizations and healthcare professionals that function within the DDH patient journey (figure 1). The role of the children's healthcare centre as screening institution and the community diagnostic centre as ultrasound imaging institution was not clearly defined for the parents, which led to confusion. [quote 11] Furthermore, a few parents were not aware of the follow up schedule after initiation of treatment. [quote 12]

2.4 *Practical issues*

The majority of the parents reported a lack of practical information and guidance on the application of the Pavlik harness in daily life. In particular in the early days of treatment, a lot of practical questions on a child in a Pavlik harness were encountered: which clothes to wear, how to transport, where to find a car-seat suitable in combination with a Pavlik harness, how to eat and how to breastfeed? [quote 13-15]

Theme 3: Treatment concerns

3.1 Acceptance of treatment

Once abduction treatment with a Pavlik harness was initiated, many parents were concerned whether the treatment would be accepted by their child. [quote 16] Doubts were raised by parents on how their child would react to a period of restricted mobility. Overall the parents report that, in hindsight, the acceptance of treatment turned out better than expected and that their worries in this regard had been unnecessary. [quote 17-18] On the other hand, one mother did mention a difficult treatment period with a child in a Pavlik harness. She reported problems during the entire treatment period, with a hysterical child and sleepless nights. [quote 19] Primary concern of most parents was the fear of sleepless nights once treatment had started. In retrospect, most parents described that only the first couple of nights were troublesome and overall the treatment period was less demanding than expected. [quote 17,20]

3.2 Effect of treatment

Parents reported their main worry was whether abduction splinting had the desired effect. In particular, parents of children who needed an extended treatment period compared to what was initially discussed at the first hospital appointment, were in doubt whether the treatment would have the desired effect in the extended treatment period. [quote 21]

3.3 Future perspectives

A high number of parents were worried about how DDH might affect their child in the future, especially regarding the ability to walk, leg length difference and hip instability. These worries on future perspectives arose both in the pre-treatment and post-treatment phase with a Pavlik harness. [quote 22]

Theme 4: Difficulties parenting

4.1 Mother child relationship

A recurring theme among the interviews was the disturbed relationship between mother and child. Mothers reported a change in perception of the relationship with their child, once Pavlik harness treatment was initiated. They felt that the Pavlik harness functioned as a physical barrier between them and their child. [quote 23-24] The sudden onset of treatment combined with an abduction device that was worn 23-24 hours a day interfered with the normal upbringing they had in mind once they became parents.

4.2 Interference with work

A child in a Pavlik harness in the home situation led to need for additional care. For parents working at home (due to COVID-19), more than usual attention and care for their child was needed. This interfered with the daily work the parents had. [quote 25]

4.3 COVID-19 isolation

As in all healthcare services, the COVID-19 pandemic affected DDH care. In contrast to the normal situation, only one parent was allowed to accompany the infant during the outpatient clinic visits. Some mothers wished for the presence of their partner and were afraid to miss crucial information which the orthopaedic paediatric surgeon shared with them. [quote 26] In the home situation, the majority of the parents felt isolated and had the feeling of being left alone in the treatment phase due to the COVID-19 isolation. [quote 27]

Theme 5: Emotional burden

5.1 Overwhelmed by diagnosis

Some parents reported that paediatric orthopaedic surgeons should acknowledge that the official diagnosis of DDH had a big impact on the parents' and child's life. They felt that this was not fully appreciated by the paediatric orthopaedic surgeon during their clinic visit. Parents felt overwhelmed once diagnosis was made and often required more time being adequately informed on diagnosis and treatment by the orthopaedic surgeon. [quote 28]

5.2 Wearing a Pavlik harness

In the early days of treatment, many parents found it a distressing sight to see their three-month-old child restricted in a Pavlik harness. They were worried whether their child was comfortable and reported that it was unpleasant to see their child's movements restricted. This feeling was reported to resolve during treatment at least partially by most parents, as the majority saw their child quite rapidly accepted the Pavlik harness. [quote 29]

5.3 Reactions from others

Parents emphasised that they continuously had to deal with reactions from other people in their environment (e.g. family, friends, neighbours and strangers) on their child in a Pavlik harness. Parents sometimes got the feeling of having a child with a handicap instead of a healthy child. [quote 30] A lot of attention was paid to the aberrant looking position of the child's legs in a Pavlik harness.

5.4 Expectation management

Expectation management was a recurrent subject among the interviews. In particular expectations that were created in the pre-hospital phase, which had to be disproved at the hospital. This discrepancy between expectations and reality often led to confusion for parents. Parents often went to the hospital with wrong expectations on treatment type and duration, partially caused by the suboptimal information. It is noteworthy that parents link words like 'severe grade DDH' - that was mentioned several times in the pre-hospital phase - to heavy treatment options like 'surgery, cast immobilization or traction treatment'. [quote 31]

5.5 COVID-19 delay in diagnosis

As for many healthcare services, DDH screening had to be temporarily halted and postponed in The Netherlands during the first wave of the COVID-19 pandemic. Many parents raised concerns about the consequences of the delay in screening and diagnosis of DDH regarding their child's hip. [quote 32]

Discussion

This study offers a novel view on parental experiences on care for children with DDH treated with a Pavlik harness in the Netherlands during the first year of life. The qualitative research approach identified new insights and leads from the patients' perspective, which can be used to further optimise care for children with DDH. The present study outlined the complexity of DDH care. We highly recommend awareness for medical, practical and emotional support for parents of children with DDH.

Parents were generally satisfied with the DDH care provided by the hospital. The collaboration between the paediatric orthopaedic surgeon, who provided medical information, and the clinical nurse specialist, who provided practical information and emotional support, was particularly valued by the parents. On top of that, accessibility of the clinical nurse specialist during the treatment phase on medical and practical issues was appreciated by parents. These responses are in line with previously identified predictors for recommending a paediatric orthopaedic hospital to other parents[21]: collaboration between paediatric orthopaedic healthcare professionals, friendliness of healthcare providers, patient-healthcare provider relationship and provided medical information.[21] Furthermore, parents highly appreciated the practical help and emotional support by peers.[16] Based on these results, collaboration between paediatric orthopaedic healthcare professionals and involvement of peers is crucial.

In the pre-hospital phase, most concerns by parents of children with DDH were expressed on insufficient information provision prior to the first hospital appointment and unfiltered online information. Due to the insufficient information provision, parents felt unprepared and surprised by the sudden onset of treatment which led to insecurity. The importance of information prior to the first outpatient appointment was previously shown in parents of children with a craniofacial condition. These parents were curious about what would happen during and after their appointment and wanted to be able to prepare questions to ask.[22] Because parents felt that the information they received on DDH prior to the first hospital appointment was insufficient, they felt forced to use internet as primary source of information. The quality and reliability of the online information varies substantially and as a result patients may be misinformed about their medical condition and treatment options.[23] Our findings suggest that due to the broad amount of unfiltered and non-patient specific information on DDH treatment, parents may become unnecessarily anxious. Previous studies showed that in general the online information on DDH is written on a level above the recommended level for medical patient information.[24] This may lead to misunderstanding and misinterpretation of the information, which is associated with poorer health care outcomes.[24]

Orthopaedic healthcare professionals must be aware of the variability of the level of quality, reliability and understandability of the online information. Parents should preferably be referred to pre-screened and trustworthy online sources by the youth health care physician and orthopaedic surgeon. Besides general information on DDH, parents experienced a lack of overview on the DDH patient journey. Patient perspectives on the healthcare process are increasingly used to optimise the patient journey. Data provided by the patient experiences can help to improve the quality or efficacy of the clinical management towards the activities most valued by patients.[25] In our qualitative study unawareness of the different organizations involved in the diagnostic and treatment process, a global overview of the treatment process and future perspectives were recurrent features that resonated across most of the interviews. By incorporating these aspects in the patient information in a timely fashion, parental experiences might be improved.[26]

Although anxiety and psychosocial problems on diagnosis of DDH has been reported by parents in previous research, these studies were not able to grasp the detailed nature of these problems.[2,15] A better understanding of the underlying causes of parental anxiety and psychosocial problems on diagnosis and treatment of DDH is essential to optimise DDH care and support during this process. Our qualitative research was able to identify a spectrum of these underlying reasons: concerns on acceptance of Pavlik harness by child, effect of Pavlik harness treatment, distressing to see child in Pavlik harness, reactions from others on a child in a Pavlik harness and future perspectives regarding ability to walk, leg length difference and hip stability. Mothers were specifically concerned on their mother child relationship as the Pavlik harness functioned as a physical barrier between them and their child, which interfered with the maternal attachment they had in mind. These parental concerns are at least partly supported by recent research on maternal attachment in infants, showing that deprivation of mother's tactile and proximity related signals leads to biobehavioural dysregulation.[27] Practical difficulties is a recurring theme among parents of children with DDH.[28] Lack of practical information on clothing, transportation, breastfeeding and furniture is a recognised problem.[16] Parents require information on future perspectives and additional practical information and guidance on the application of a Pavlik harness in daily life.

Despite the strengths of this study, our study has some limitations. The local infrastructure and involvement of multiple healthcare organizations for children with DDH at the Máxima Medical Centre potentially influences parental experiences during the patient journey. Yet, the experiences on Pavlik harness treatment are presumably universal, as the principles of abduction splinting with a Pavlik harness are generally similar worldwide.[29] Despite, additional research is needed to verify the generalisability of our study results to other DDH care settings. Second, fathers were

underrepresented in the interviews. Low levels of father participation in paediatric research is a known phenomenon[30] and is attributed to lack of time[31], lack of interest[31], lack of accessibility[31] and not being asked to participate.[30] Finally, recall bias is a factor that potentially affected the results, as parents need to look back on their experiences from the past. Impact of recall bias was minimised by setting an age limit of 1 year, as no new information was expected after this period.

The current findings suggest that future interventions should focus on optimisation of (online) information, optimisation of the patient journey overview, better understanding of future perspectives and guidance with practical and emotional support for parents of children with DDH. Specific attention should be given to understandable information for parents in all layers of the society to minimise misunderstanding or misinterpretation of information.[24] Communication with pictures, videos, diagrams [32,33] and electronic patient specific information [34,35] can be used as these initiatives may improve parents' preparedness, reliability of patient care and enhance the value of healthcare.

The novelty of this qualitative study is the focus on parental perspectives of the healthcare process, rather than the healthcare professional perspectives.[36] This allowed parents of children with DDH to share their detailed experiences from a personal point of view and facilitated the expression of beliefs that may be left undiscussed in previously performed studies with close-ended questionnaires.[2] As such, this study improves our understanding of parental experiences on care for children with DDH and serves as first step to improve the patient journey. The results of this qualitative research document numerous opportunities for improvements in current DDH care. Pre-hospital information, trustworthy online information, overview of the patient journey and guidance with practical and emotional support are the main points of improvement.

Figures legend

Figure 1

Overview of the patient journey of a child with Developmental Dysplasia of the Hip at the Máxima Medical Centre.

Figure 2

Schematic overview of 5 themes and categories.

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Authors Contributions

WT: prepared study protocol, conducted interviews, coded data, analysed data and wrote the manuscript. MS: prepared study protocol, coded data, analysed data and wrote the manuscript. MVV: analysed data and wrote the manuscript. FVD: critical reviewer of study protocol and manuscript. MW: critical reviewer of study protocol and manuscript. JT: initiator study design, prepared study protocol, analysed data and wrote the manuscript.

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Competing Interests

None declared.

Data Sharing Statement

No additional data are available.

Ethics Approval

The Medical Ethics Committee of the Máxima Medical Centre assessed the study and judged that ethics approval was not required under Dutch National Law, METC number N20.077.

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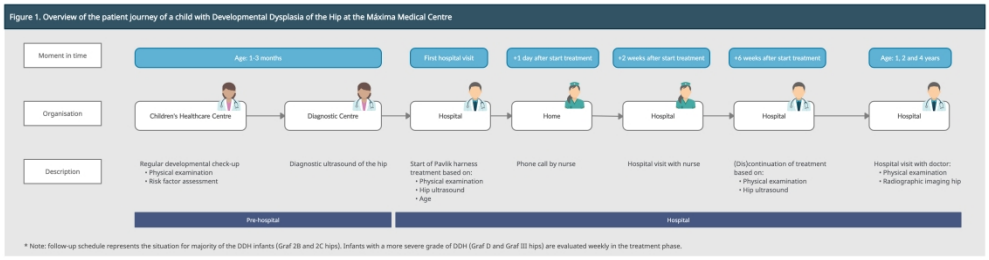

Figure1
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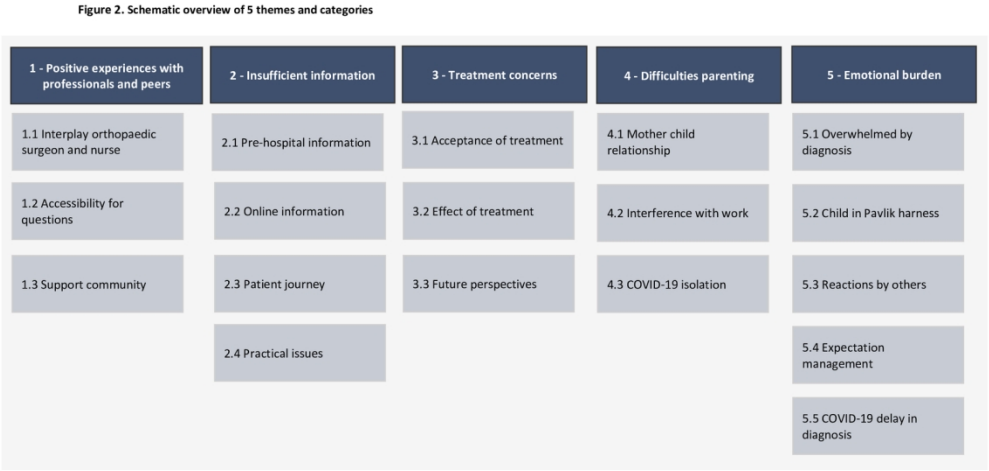

Figure2

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	7
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1,7 (PhD)
Occupation	3	What was their occupation at the time of the study?	1,7 (PhD)
Gender	4	Was the researcher male or female?	~~7 (male/female~~
Experience and training	5	What experience or training did the researcher have?	7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	7
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6-7
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	6-7
Sample size	12	How many participants were in the study?	8
Non-participation	13	How many people refused to participate or dropped out? Reasons?	7-8
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	6-7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	7
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	9 + table 1
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	6-7
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were field notes made during and/or after the inter view or focus group?	7
Duration	21	What was the duration of the inter views or focus group?	8
Data saturation	22	Was data saturation discussed?	6,8
Transcripts returned	23	Were transcripts returned to participants for comment and/or	7

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	7
Description of the coding tree	25	Did authors provide a description of the coding tree?	10 + fig 2
Derivation of themes	26	Were themes identified in advance or derived from the data?	10
Software	27	What software, if applicable, was used to manage the data?	7
Participant checking	28	Did participants provide feedback on the findings?	7
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	table 2-3
Data and findings consistent	30	Was there consistency between the data presented and the findings?	11-18
Clarity of major themes	31	Were major themes clearly presented in the findings?	11-18 + table 2
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	11-18

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

Parental experiences of children with developmental dysplasia of the hip: a qualitative study

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Parental experiences of children with developmental dysplasia of the hip: a qualitative study

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Abstract

Objective: The aim of this qualitative study was to explore the experiences of Dutch parents of children with Developmental Dysplasia of the Hip (DDH), treated with a Pavlik harness, during the diagnostic and treatment process in the first year of life.

Design: A qualitative study by means of semi-structured interviews was conducted between September and December 2020. Qualitative content analysis was applied to code, categorise and thematise data.

Setting: A large, tertiary referral centre for paediatric orthopaedics in The Netherlands.

Participants: A purposive sample of parents of children aged younger than 1 year, who were treated for DDH with a Pavlik harness, were interviewed until data saturation was achieved. A total of 20 interviews with 22 parents (20 mothers and 2 fathers) were conducted.

Results: Five main themes emerged: (1) positive experiences with professionals and peers, (2) insufficient information, (3) treatment concerns, (4) difficulties parenting and (5) emotional burden. Most prominent features that resonated across the interviews which led to insecurity by parents were: insufficient pre-hospital information, unfiltered online information and the lack of patient journey overview.

Conclusion: This study offers novel insights into parental experiences in DDH care. Parents were generally satisfied with DDH care provided by the hospital. The biggest challenges were to cope with: (1) insufficient and unfiltered information, (2) the lack of patient journey overview and (3) practical problems and emotional doubts, which led to concerns during treatment. Future research and interventions should focus on optimising information provision and guidance with practical and emotional support for parents of children with DDH.

Strengths and limitations of this study

- The qualitative research approach enabled parents of children with DDH to share their personal experiences and beliefs, with the aim of detecting knowledge gaps and optimising DDH care from a patient-oriented perspective.
- The Dutch patient association for DDH was actively involved in the development of the interview guide.
- A representative cross-section of the DDH population was realised by purposive sampling.
- This study reflects the situation at a large, tertiary referral centre for paediatric orthopaedics in The Netherlands. Generalisability of our study results needs to be verified.
- Fathers were underrepresented in the interviews, which might underexpose the information on their experiences and perspectives.

Keywords

Developmental Dysplasia of the Hip, hip dysplasia, DDH, experiences, paediatric orthopaedics

Word count

3.928

Introduction

Developmental Dysplasia of the Hip (DDH) is one of the most common diagnosed conditions that parents of newborns face.[1,2] The term DDH refers to a broad spectrum of anatomical abnormalities to the paediatric hip joint, ranging from a dysplastic to a dislocated hip.[3] In the Netherlands, 3-4% of the infants up to 6 months of age develops DDH.[4] Every newborn is screened for DDH at the age of 1 month and 3 months at the children's healthcare centre as part of regular developmental check-ups.[5] The screening program consists of physical examination and risk factor assessment.[5] Once positively screened, a diagnostic ultrasound of the hip joint is conducted. Infants with abnormalities on the hip ultrasound are directly referred to an orthopaedic surgeon for additional examination and treatment (figure 1).[5] Abduction bracing with a Pavlik harness is the first-line treatment in children aged younger than 6 months. Surgery is only indicated in children in whom non-operative treatment has failed and in late diagnosed DDH.[6] Therefore, early diagnosis and treatment are crucial, as untreated DDH might cause hip osteoarthritis in early adulthood and lifelong gait problems.[7]

In paediatric orthopaedic care, parents play a pivotal role as they are relied upon as main source of information regarding their child's health status.[8] Parental involvement and compliance to treatment are even more prominent in infants with DDH, as Pavlik harness treatment takes place in the home setting.[9] Parental satisfaction with healthcare services is associated with positive patient behaviour[10] and an important positive predictor of commitment to and effectiveness of treatment.[11,12] Greater satisfaction leads to better treatment adherence and better health outcomes.[13] In recent years, the scope of parental participation in paediatric healthcare services has gained attention, as experiences and satisfaction of parents are considered as vital components of quality of care.[13,14]

Diagnosis and treatment of DDH can be a stressful event for parents.[2] Psychosocial consequences of receiving the diagnosis of DDH, practical difficulties with a Pavlik harness (washing, dressing, feeding and cuddling), worries regarding future perspectives and the ability to walk have previously been reported by parents of children with DDH.[15] Difficulties adjusting life to a child in a Pavlik harness with little guidance is a known phenomenon.[16] Parents often feel overwhelmed by the vast amount of information on DDH that is given on diagnosis and treatment.[17] A drawback of these studies on parental experiences of DDH care is the usage of closed-ended questionnaires. This may lead to missing data and bias introduced by leading questions and suggesting responses.[18] To adequately address the experiences of parents of children with DDH, a qualitative research approach with a holistic view would be more suitable.

Despite the crucial role of parents in the treatment of DDH, little is known regarding the experiences of parents caring for a child with DDH. Better understanding of parental experiences throughout care for children with DDH will improve healthcare professionals' ability to align their support with the parents' perspectives and needs. The aim of this qualitative study is to explore the experiences of parents caring for a child with DDH, treated with a Pavlik harness, during the diagnostic and treatment process in the first year of life.

Patients and Methods

Study design

A qualitative study was conducted to gain in-depth information on parental experiences of care for children with DDH. Semi-structured interviews were used as source of information. The study was reported according to the Consolidated Criteria for Reporting Qualitative Research guideline (COREQ).[19]

Study population

We selected parents of children (maximum 1 year of age) who were treated for DDH with a Pavlik harness. Age limit was chosen as this study was interested in the experiences of parents of children with DDH in the diagnostic and treatment phase with a Pavlik harness, which ends before the age of 1 year. Parents were selected based on the purposive sampling principle to ensure diversity of parents, representing a cross-section of the DDH population. Selection criteria were infant-based (DDH grade, Pavlik harness treatment duration and gender) and parent-based (age and education level).

Setting

Recruitment for the interviews took place in the Máxima Medical Centre, which is a large, tertiary referral centre for paediatric orthopaedics with approximately 425 new DDH patients a year. At the Máxima Medical Centre, DDH patients are treated in a clinical care pathway by a team of two paediatric orthopaedic surgeons, one fellow paediatric orthopaedic surgery and two orthopaedic clinical nurse specialists (figure 1).

Procedure

An interview guide was set up by several stakeholders in the DDH healthcare trajectory. A group composed of two paediatric orthopaedic surgeons, one fellow paediatric orthopaedic surgery, one paediatric orthopaedic PhD student, one orthopaedic researcher and one representative of the board of the Dutch patient association for DDH (Vereniging Afwijkende Heupontwikkeling [VAH]) set up the interview guide for the interviews. Input from representatives from the Dutch patient association for DDH was used to revise the initial draft of the interview guide to a final version [supplementary file 1]. Subsequently, semi-structured interviews were conducted to gain in depth information on parental experiences of care for children with DDH. The estimated sample size for the individual interviews was 15-20 parents. Data saturation was used as main criterion for discontinuing interviews.[20] Data was considered as saturated, when no new codes and themes were identified and repeatedly the same themes were scored. Eligible parents were contacted by phone to assess

their willingness to participate. Next, parents received written information about the study and were asked to participate. Participants gave their written informed consent. Individual interviews were conducted via a secured online webcam system, Webcamconsult BV (Bergen op Zoom, The Netherlands). Anonymity of participants and infants was secured in the interview transcripts.

Data collection

All interviews took place between September and December 2020. The semi-structured interviews with the parents were conducted by a paediatric orthopaedic PhD student, who was specifically trained in conducting qualitative interviews. The interviewer had no prior encounter or relationship with the patients or parents, but briefly introduced himself at the start of the interviews. The interview guide was used to facilitate the discussion and was iteratively modified in response to evolving study findings. All interviews were digitally audio recorded and transcribed verbatim in the native language (Dutch) by an independent transcription agency.

Data analysis

All transcripts were independently reviewed and coded using ATLAS.ti version 9.0 (Berlin, Germany). The coding process was carried out by two researchers – a paediatric orthopaedic PhD student and an orthopaedic researcher – to increase intercoder reliability[21], which reflects the agreement between these two coders for coding the same content with the most representative code. After each of the five transcripts, discrepancies in codes were discussed and iteratively refined until consensus was reached. After the coding process, categorical and thematic analysis was conducted by these two researchers. Consensus over the final categories and themes was reached after discussion with a third researcher and approved by the rest of the study group. During the coding process, representative quotations were listed to illustrate the themes. Quotations were translated into English by a third researcher. The research team validated the English translations by translating them back to Dutch, to check whether the quotations had the same tenor as the original Dutch quotations.

Patient and Public Involvement

Parents of children with DDH were the main information resource for this study. The VAH was actively involved in building the interview guide, cross-checking and reviewing the results.

Results

After 20 interviews with parents of children with DDH, data saturation was achieved. In all interviews, the mother of the child participated and in two interviews the father attended as second participant. Average duration of the interviews was 30 minutes (12 to 52 minutes). Participant characteristics are listed in table 1.

Table 1. Characteristics of interviewed parents and their child

Interview	Parent				Child		
	Gender	Age range	Home situation	Education level*	Gender	DDH grade	Treatment duration
1	♀	30-34	Two parent household	HVT	♀	2b	6 weeks
2	♀+ ♂	25-34	Two parent household	HVT	♀	3	12 weeks
3	♀	25-29	Two parent household	HVT	♀	D	6 weeks
4	♀	30-34	Two parent household	IVT	♂	2b	6 weeks
5	♀	30-34	Two parent household	IVT	♂	2b	6 weeks
6	♀	30-34	Two parent household	University	♂	2b	6 weeks
7	♀	25-29	Single parent household	IVT	♂	2c	6 weeks
8	♀	25-29	Two parent household	IVT	♂	D	6 weeks
9	♀	25-29	Two parent household	HVT	♀	2b	6 weeks
10	♀	30-34	Two parent household	HVT	♀	2b	6 weeks
11	♀	25-29	Two parent household	HVT	♀	3	12 weeks
12	♀	40-44	Two parent household	IVT	♂	2c	6 weeks
13	♀	35-39	Two parent household	IVT	♀	2b	12 weeks
14	♀	25-29	Two parent household	University	♀	D	6 weeks
15	♀+ ♂	25-34	Two parent household	IVT	♂	2b	6 weeks
16	♀	25-29	Two parent household	IVT	♀	2c	6 weeks
17	♀	30-34	Two parent household	University	♂	D	12 weeks
18	♀	30-34	Two parent household	University	♀	2c	6 weeks
19	♀	25-29	Two parent household	HVT	♂	2b	6 weeks
20	♀	30-34	Two parent household	HVT	♀	2b	6 weeks

* IVT: intermediate vocational education; HVT: higher vocational education

Themes

Thematic analysis identified 5 themes among parents throughout care for children with DDH during the first year of life: (1) positive experiences with professionals and peers, (2) insufficient information, (3) treatment concerns, (4) difficulties parenting, (5) emotional burden (figure 2). Within the 5 themes, multiple categories emerged, which are further explained with representative quotations to illustrate the parental experiences throughout care for children with DDH (table 2-3).

Table 2. Overview of themes, categories, and corresponding quotations (part 1)

Theme	Category	Quotation [quotation number; interview number]
Theme 1: Positive experiences with professionals and peers	1.1 Interplay orthopaedic surgeon and nurse	*He (=the orthopedic surgeon) more or less dropped the bomb and then the clinical nurse specialist came to calmly explain everything and I had the feeling all questions could be asked. Those two together was an excellent collaboration. [q1;i17]* *First the orthopedic surgeon briefly joins and next you see the nurse specialist extensively. I think it's the more the practical things you encounter as parents that you want information about and that is exactly what the nurse specialist provides. [q2;i14]*
	1.2 Accessibility for questions	*Because the first night you have to deal with a crying baby. The tips and commitment from the nurse are especially welcome. So, that they call you on the first day is very pleasant. [q3;i2]* *I found it especially pleasant that this [first day follow-up appointment] was over the telephone. You don't really want back to go back to the hospital after 1 day and now my husband could join. [q4: i2]* *Every time I called I was helped very pleasantly by the department. Once, the Velcro didn't work anymore and I was allowed to come by right the next day to get a new brace fitted. So there is a lot of thinking along with the parents to solve problems as quickly as possible.[q5; i20]*
	1.3 Support community	*There is this Facebook group you know? So as a parent you can get quite a lot of tips from there. There were very helpful things on there for my child. I was a member at the time. I didn't post or chat about anything, but there are quite active people there, so that was nice. [q6: i14]* *Our neighbors' first needed an abduction brace as well. She explained some practical things, on how she experienced things. That was very helpful. [q7;i5]*
Theme	**Category**	**Quotation**
Theme 2: Insufficient information	2.1 Pre-hospital information	*I know we were briefly informed [at the diagnostic centre] that the hip dysplasia was severe and we needed to come to the hospital within one week, but we did not get any further information. That was the moment I started looking for information on the internet myself and came across the worst things, making me even more worried. Is she going to get a cast or even an operation? [q8;i2]*

2.2 Online information	*When I got home, me and my boyfriend immediately searched on the internet to find out what it all meant and then you immediately encounter the worst things. I think it's a logical step for parents when they hear that there's something wrong with their child, to quickly start looking for information. [q9;i2]* *On the internet you see plaster casts, devices where kids are hung vertically from their legs up and even images of surgery. It was a huge shock seeing those images, especially in combination with the announcement from the health clinic that the hip dysplasia was severe. I must say I had a few sleepless nights because of that. [q10;i2]*
2.3 Patient journey	*It was not entirely clear to me what the relationship was between the children's healthcare center, the diagnostic centre and the hospital. Why we had to go to all these places was unclear to me. [q11;i12]* *No, that [= the follow-up protocol during treatment] was not clear to me. I assumed they were going to do another ultrasound. Actually, I didn't know if they were going to. That was not explained to me at the beginning. [q12:i3]*
2.4 Practical issues	*Of course, you want to know; do we have to buy something, what do we have to consider? Will he still fit in his bed? Can we still sit him in his chair? Can we still use his car seat? [q13;i7]* *Practical issues, like how will I do the breastfeeding? [q14;i9]* *I also asked, when my child was hoisted into that apparatus, am I going to break his legs or is this going to go smoothly? [q15;i9]*

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Table 3. Overview of themes, categories, and corresponding quotations (part 2)

Theme	Category	Quotation
Theme 3: Treatment concerns	3.1 Acceptance of treatment	*I did have some concerns on how we were going to get through that period, because she has quite a temperament. I thought, well this is surely going to be a rough 8 weeks. [q16;i9]*
		Eventually he slept extremely well. Obviously, that's not something you can be certain of beforehand. [q17;i6]
		He wasn't really that bothered by it [=Pavlik harnas]. So it ended up being not that bad for us.[q18;i5]
		I expected 5 tough days and nights, but it ended up to be the full 9 weeks with just hardly any sleep, and a lot, from her side al lot of either panicking or apathy. She was really hysterical. [q19;i9]
		The first days she cried a lot. Not so much the first day, but the day after she cried a lot because it was uncomfortable. After a few days it got less and after a week it was OK, she didn't know any better [q20;i20].
	3.2 Effect of treatment	*Yes, that [the 12-week clinic visit] worried me more than the 6 weeks check-up. Would it now have sorted any effect in those second 6 weeks? [q21;i13]*
	3.3 Future perspectives	*Especially concerning growth development. Will she grow crooked? Will she have a leg length difference? Will she be able to walk? Can she do sports? Those things are a lot on your mind. [q22;i11]*
Theme	**Category**	**Quotation**
Theme 4: Difficulties parenting	4.1 Mother child relationship	*Especially the holding and cuddling. That felt less personal. It wasn't really a baby anymore, it was more like a parcel. [q23;i5]*
		I couldn't hold him like a baby and lay him in my arms anymore. When the brace came of I thought, wow what has he grown a lot. [q24;i5]
	4.2 Interference with work	*Normally, when you are at home with your baby and she is in good spirits, well than she is just lying there playing and babbling, and in the meantime, you could get some work done, you would be able to*

		squeeze that in. But with her, that was just not going to work, she continuously kept me occupied. [q25;i9]
	4.3 COVID-19 isolation	*It might have been due the hormones, but it is very difficult to memorize al that info. Being there with the two of you, would have made it all easier to process. [q26;i12]*
		We were in that lockdown, so what was very tough on us, was that my child was inconsolable and nobody was allowed to come and help us. [q27;i9]
Theme	**Category**	**Quotation**
Theme 5: Emotional burden	5.1 Overwhelmed by diagnosis	*When we saw the paediatric orthopaedic surgeon in the hospital, to be honest, I was quite blown away. For him it was all cut and dry. Of course, he is a specialist and the conversation went quite quickly. Don't get me wrong, I can switch pretty quickly, but it was all a bit overwhelming. [q28;i3]*
	5.2 Wearing a Pavlik harness	*Actually, it [= child in a Pavlik harness] was more difficult for us parents to witness than it was on my child herself. My child accepted it quite rapidly. [q29;i1]*
	5.3 Reactions from others	*Where you first just have a baby, people react to the baby. Then [=child with a Pavlik harness], the surrounding suddenly react to the handicap. [q30;i20]*
	5.4 Expectation management	*The message from the children's healthcare center that it was severe hip dysplasia. I had a sleepless first night after that. I assumed that severe dysplasia would automatically mean she would have to undergo some sort of operation. [q31;i2]*
	5.5 COVID-19 delay in diagnosis	*And I was also concerned that we ended up at the children's healthcare center later because of corona. I was really wondering what the effect would be of ending up there 1 month later than we normally would have, because of corona. [q32;i2]*

Theme 1: Positive experiences with professionals and peers

1.1 Interplay orthopaedic surgeon and nurse

The interplay of healthcare professionals within the multidisciplinary team of the hospital (figure 1) was highly valued by all parents. The supportive role of the clinical nurse specialists was particularly appreciated by parents. Paediatric orthopaedic surgeons were seen as the authority regarding the medical part, while clinical nurse specialists were seen as point of contact as they were easily accessible to ask practical questions and as a guidance on day-to-day problems. [quotation 1-2]

1.2 Accessibility for questions

Accessibility of healthcare professionals was one of the main positive points parents highlighted during the interviews. As pointed out by several parents, most questions regarding DDH care arose at home, often shortly after the visit to the hospital. The phone call parents received from the clinical nurse specialist one day after initiation of treatment was therefore highly valued. [quotation 3-5]

1.3 Support community

A recurring topic among parents was the highly valued support from peers. Peer support mainly came from friends, neighbours and fellow parents on the Facebook page of the VAH. Both practical help and emotional support from people who went through the same ups and downs was very useful. [quotation 6-7] A strong feeling of 'we are in this together' arose among parents once they heard other parents dealt with the same issues.

Theme 2: Insufficient information

2.1 Pre-hospital information

The infrastructure for children with DDH at the Máxima Medical Centre (figure 1) partially underlies the common criticism of parents towards the insufficient information provision. More than half of the interviewed parents reported no or insufficient information about DDH at time of referral from the community diagnostic centre to the hospital. Although parents were aware of abnormalities in the screening process or abnormal ultrasound findings, the subsequent hospital referral was accompanied by limited additional information regarding diagnosis and the further diagnostic and treatment process. As a result, there was an unfulfilled information need, which caused parents to search for online information themselves. [quotation 8]

2.2 Online information

The majority of parents of children with DDH used internet as primary source of information. Various reasons were mentioned: insufficient or no pre-hospital information, wish to prepare for the first

hospital visit and the ease with which online information was accessible. A shortage of well-organised information specific to their child's situation that is written in a manner easily understood by caregivers was the main remark of parents regarding online information on DDH. Although it was easily accessible, main concern was the staggering amount of unfiltered online information on treatment options, varying from an abduction device to traction treatment and surgery, which led to insecurity and anxiety. [quotation 9-10]

2.3 Patient journey

Some parents were unaware of the different organisations and healthcare professionals that function within the DDH patient journey (figure 1). The role of the children's healthcare centre as screening institution and the community diagnostic centre as ultrasound imaging institution was not clearly defined for the parents, which led to confusion. [quotation 11] Furthermore, a few parents were not aware of the follow-up schedule after initiation of treatment. [quotation 12]

2.4 *Practical issues*

The majority of the parents reported a lack of practical information and guidance on the application of the Pavlik harness in daily life. In particular in the early days of treatment, a lot of practical questions on a child in a Pavlik harness were encountered: which clothes to wear, how to transport, where to find a car-seat suitable in combination with a Pavlik harness and how to eat and how to breastfeed? [quotation 13-15]

Theme 3: Treatment concerns

3.1 Acceptance of treatment

Once the abduction treatment with a Pavlik harness was initiated, many parents were concerned whether the treatment would be accepted by their child. [quotation 16] Doubts were raised by parents on how their child would react to a period of restricted mobility. Overall the parents report that, in hindsight, the acceptance of treatment turned out better than expected and that their worries in this regard had been unnecessary. [quotation 17-18] On the other hand, one mother did mention a difficult treatment period with a child in a Pavlik harness. She reported problems during the entire treatment period, with a hysterical child and sleepless nights. [quotation 19] Primary concern of most parents was the fear of sleepless nights once treatment had started. In retrospect, most parents described that only the first couple of nights were troublesome and overall the treatment period was less demanding than expected. [quotation 17,20]

3.2 Effect of treatment

Parents reported their main worry was whether abduction splinting had the desired effect. In particular, parents of children who needed an extended treatment period compared to what was initially discussed at the first hospital appointment, were in doubt whether the treatment would have the desired effect in the extended treatment period. [quotation 21]

3.3 Future perspectives

A high number of parents were worried about how DDH might affect their child in the future, especially regarding the ability to walk, leg length difference and hip instability. These worries on future perspectives arose both in the pre-treatment and post-treatment phase with a Pavlik harness. [quotation 22]

Theme 4: Difficulties parenting

4.1 Mother child relationship

A recurring theme among the interviews was the disturbed relationship between mother and child. Mothers reported a change in perception of the relationship with their child, once Pavlik harness treatment was initiated. They felt that the Pavlik harness functioned as a physical barrier between them and their child. [quotation 23-24] The sudden onset of treatment combined with an abduction device that was worn 23-24 hours a day interfered with the normal upbringing they had in mind once they became parents.

4.2 Interference with work

A child in a Pavlik harness in the home situation led to a need for additional care. For parents working at home (due to COVID-19), more than usual attention and care for their child was needed. This interfered with the daily work the parents had. [quotation 25]

4.3 COVID-19 isolation

As in all healthcare services, the COVID-19 pandemic affected DDH care. In contrast to the normal situation, only one parent was allowed to accompany the infant during the outpatient clinic visits. Some mothers wished for the presence of their partner and were afraid to miss crucial information which the paediatric orthopaedic surgeon shared with them. [quotation 26] In the home situation, the majority of the parents felt isolated and had the feeling of being left alone in the treatment phase due to the COVID-19 isolation. [quotation 27]

Theme 5: Emotional burden

5.1 Overwhelmed by diagnosis

Some parents reported that paediatric orthopaedic surgeons should acknowledge that the official diagnosis of DDH had a big impact on the parents' and child's life. They felt that this was not fully appreciated by the paediatric orthopaedic surgeon during their clinic visit. Parents felt overwhelmed once diagnosis was made and often required more time being adequately informed on diagnosis and treatment by the paediatric orthopaedic surgeon. [quotation 28]

5.2 Wearing a Pavlik harness

In the early days of treatment, many parents found it a distressing sight to see their three-month-old child restricted in a Pavlik harness. They were worried whether their child was comfortable and reported that it was unpleasant to see their child's movements restricted. This feeling was reported to resolve during treatment at least partially by most parents, as the majority saw their child quite rapidly accepted the Pavlik harness. [quotation 29]

5.3 Reactions from others

Parents emphasised that they continuously had to deal with reactions from other people in their environment (e.g. family, friends, neighbours and strangers) on their child in a Pavlik harness. Parents sometimes got the feeling of having a child with a handicap instead of a healthy child. [quotation 30] A lot of attention was paid to the aberrant looking position of the child's legs in a Pavlik harness.

5.4 Expectation management

Expectation management was a recurrent subject among the interviews. In particular expectations that were created in the pre-hospital phase, which had to be disproved at the hospital. This discrepancy between expectations and reality led to confusion for parents. Parents often went to the hospital with wrong expectations on treatment type and duration, partially caused by the suboptimal information. It is noteworthy that parents link words like 'severe grade DDH' - that was mentioned several times in the pre-hospital phase - to heavy treatment options like 'surgery, cast immobilization or traction treatment'. [quotation 31]

5.5 COVID-19 delay in diagnosis

As for many healthcare services, DDH screening had to be temporarily halted and postponed in The Netherlands during the first wave of the COVID-19 pandemic. Many parents raised concerns about the consequences of the delay in screening and diagnosis of DDH regarding their child's hip. [quotation 32]

Discussion

This study offers a novel view on parental experiences on care for children with DDH treated with a Pavlik harness in the Netherlands during the first year of life. The qualitative research approach identified new insights and leads from the patients' perspective, which can be used to further optimise care for children with DDH. The present study highlights the complexity of DDH care and the need for increasing awareness for medical, practical, and emotional support for parents of children with DDH.

Parents were generally satisfied with the DDH care provided by the hospital. The collaboration between the paediatric orthopaedic surgeon, who provided medical information, and the clinical nurse specialist, who provided practical information and emotional support, was particularly valued by the parents. On top of that, accessibility of the clinical nurse specialist during the treatment phase on medical and practical issues was appreciated by parents. These responses are in line with previously identified predictors for recommending a paediatric orthopaedic hospital to other parents[22]: collaboration between paediatric orthopaedic healthcare professionals, friendliness of healthcare providers, patient-healthcare provider relationship and provided medical information.[22] Furthermore, parents highly appreciated the practical help and emotional support by peers.[16] Based on these results, collaboration between paediatric orthopaedic healthcare professionals and involvement of peers is crucial.

In the pre-hospital phase, most concerns by parents of children with DDH were expressed on insufficient information provision prior to the first hospital appointment and unfiltered online information. Due to the insufficient information provision, parents felt unprepared and surprised by the sudden onset of treatment which led to insecurity. The importance of information prior to the first outpatient appointment was previously shown in parents of children with a craniofacial condition. These parents were curious about what would happen during and after their appointment and wanted to be able to prepare questions to ask.[23] Because parents felt that the information they received on DDH prior to the first hospital appointment was insufficient, they felt forced to use internet as primary source of information. The quality and reliability of the online information varies substantially and as a result patients may be misinformed about their medical condition and treatment options.[24] Our findings suggest that due to the broad amount of unfiltered and non-patient specific information on DDH treatment, parents may become unnecessarily anxious. Previous studies showed that in general the online information on DDH is written on a level above the recommended level for medical patient information.[25] This may lead to misunderstanding and misinterpretation of the information, which is associated with worse healthcare outcomes.[25]

Orthopaedic healthcare professionals must be aware of the variability of the level of quality, reliability and understandability of the online information. Parents should preferably be referred to pre-screened and trustworthy online sources by the youth healthcare physician and orthopaedic surgeon. Besides general information on DDH, parents experienced a lack of overview on the DDH patient journey. Patient perspectives on the healthcare process are increasingly used to optimise the patient journey. Data provided by the patient experiences can help to improve the quality or efficacy of the clinical management towards the activities most valued by patients.[26] In our qualitative study unawareness of the different organisations involved in the diagnostic and treatment process, a global overview of the treatment process and future perspectives were recurrent features that resonated across most of the interviews. By incorporating these aspects in the patient information in a timely fashion, parental experiences might be improved.[27]

Although anxiety and psychosocial problems on diagnosis of DDH have been reported by parents in previous research, these studies were not able to grasp the detailed nature of these problems.[2,15] A better understanding of the underlying causes of parental anxiety and psychosocial problems on diagnosis and treatment of DDH is essential to optimise DDH care and support during this process. Our qualitative research was able to identify a spectrum of these underlying reasons: concerns on acceptance of Pavlik harness by child, effect of Pavlik harness treatment, distressing to see child in Pavlik harness, reactions from others on a child in a Pavlik harness and future perspectives regarding ability to walk, leg length difference and hip stability. Mothers were specifically concerned on their mother child relationship as the Pavlik harness functioned as a physical barrier between them and their child, which interfered with the maternal attachment they had in mind. These parental concerns are at least partly supported by recent research on maternal attachment in infants, showing that deprivation of mother's tactile and proximity related signals leads to biobehavioural dysregulation.[28] Practical difficulties is a recurring theme among parents of children with DDH.[29] A lack of practical information on clothing, transportation, breastfeeding and furniture is a recognised problem.[16] Parents require information on future perspectives and additional practical information and guidance on the application of a Pavlik harness in daily life.

Despite the strengths of this study, our study has some limitations. The local infrastructure and involvement of multiple healthcare organizations for children with DDH at the Máxima Medical Centre potentially influences parental experiences during the patient journey. Yet, the experiences on Pavlik harness treatment are presumably universal, as the principles of abduction splinting with a Pavlik harness are generally similar worldwide.[30] Despite this, additional research is needed to verify the generalisability of our study results to other DDH care settings. Secondly, fathers were

underrepresented in the interviews. Low levels of father participation in paediatric research is a known phenomenon[31] and is attributed to a lack of time[32], a lack of interest[32], a lack of accessibility[32] and not being asked to participate.[31]

The current findings suggest that future interventions should focus on optimisation of (online) information, optimisation of the patient journey overview, better understanding of future perspectives and guidance with practical and emotional support for parents of children with DDH. Specific attention should be given to understandable information for parents in all layers of the society to minimise misunderstanding or misinterpretation of information.[25] Communication with pictures, videos, diagrams [33,34] and electronic patient specific information [35,36] can be used as these initiatives may improve parents' preparedness, reliability of patient care and enhance the value of healthcare.

The novelty of this qualitative study is the focus on parental perspectives of the healthcare process, rather than the healthcare professional perspectives.[37] This allowed parents of children with DDH to share their detailed experiences from a personal point of view and facilitated the expression of beliefs that may be left undiscussed in previously performed studies with close-ended questionnaires.[2] As such, this study improves our understanding of parental experiences on care for children with DDH and serves as first step to improve the patient journey. The results of this qualitative research document numerous opportunities for improvements in current DDH care. Pre-hospital information, trustworthy online information, overview of the patient journey and guidance with practical and emotional support are the main points of improvement.

Figures legend

Figure 1

Overview of the patient journey of a child with Developmental Dysplasia of the Hip at the Máxima Medical Centre.

Figure 2

Schematic overview of 5 themes and categories.

Supplementary file

File 1: Topic guide

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Authors Contributions

WT: prepared study protocol, conducted interviews, coded data, analysed data and wrote the manuscript. MS: prepared study protocol, coded data, analysed data and wrote the manuscript. MVV: analysed data and wrote the manuscript. FVD: critical reviewer of study protocol and manuscript. MW: critical reviewer of study protocol and manuscript. JT: initiator study design, prepared study protocol, analysed data and wrote the manuscript.

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Competing Interests

None declared.

Data Sharing Statement

No additional data are available.

Ethics Approval

The Medical Ethics Committee of the Máxima Medical Centre assessed the study and judged that ethics approval was not required under Dutch National Law, METC number N20.077.

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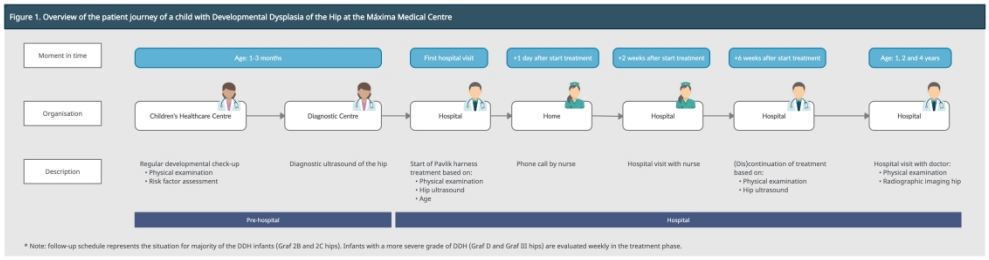

Figure1
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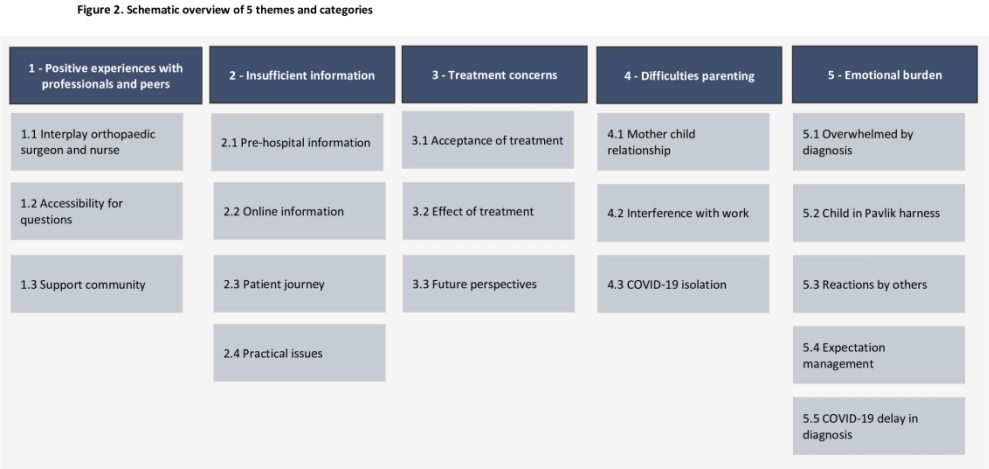

Figure2

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SUPPLEMENTARY FILE

Manuscript: Parental experiences of children with developmental dysplasia of the hip: a qualitative study

Topic guide

General information

1. Name parent: _____
2. Gender parent: _____
3. Age parent: _____
4. Home situation: _____
5. Level of education: _____
5. Gender child: _____
6. DDH grade: _____
7. Treatment duration: _____

Interview framework

General introduction to the aim of this qualitative study. A large number of children with DDH (n=425 / year) are treated at the Máxima MC. We want to learn from parental experiences in DDH care as this is not studied before. Ultimate goal is to increase the quality of DDH care and we do think parental experiences add valuable information to achieve this goal.

Phase 1: Pre-diagnosis

1. Was this the first child with DDH or did you have had experiences with a previous child with DDH?
2. What were the experiences at the children's healthcare center?
3. What were the experiences at the diagnostic center?
4. What were the experiences in the referral process between children's healthcare center, diagnostic center, and hospital?

Phase 2: Diagnosis

1. What were the experiences at the first hospital visit, when diagnosis was made?
2. What were the experiences with the healthcare professionals (orthopaedic surgeon and nurse) at the first hospital visit?
3. What was the experience with the explanation of the diagnosis?
4. What was the experience with the explanation of the follow-up schedule?
5. What was the experience with practical cases with the Pavlik harness?
6. Did you miss anything during the first hospital visit? If so, explain.
7. Did you have had positive experiences during the first hospital visit? If so, explain.
8. Did you have had negative experiences during the first hospital visit? If so, explain.

Phase 3: Follow up

1. What were the experiences at the follow-up appointments in the hospital?
2. What were the experiences once Pavlik harness treatment ended?
3. Did you miss anything once treatment ended? If so, explain.
4. Did you have had positive experiences once you heard treatment ended? If so, explain.
5. Did you have had negative experiences once you heard treatment ended? If so, explain.
6. What were the experiences with the frequency of the follow-up appointments?
7. What were the experiences of having a child in a Pavlik harness at home?
8. What were the experiences with support from peers, family, or friends?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	7
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1,7 (PhD)
Occupation	3	What was their occupation at the time of the study?	1,7 (PhD)
Gender	4	Was the researcher male or female?	~~7 (male/female~~
Experience and training	5	What experience or training did the researcher have?	7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	7
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6-7
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	6-7
Sample size	12	How many participants were in the study?	8
Non-participation	13	How many people refused to participate or dropped out? Reasons?	7-8
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	6-7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	7
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	9 + table 1
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	6-7
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were field notes made during and/or after the inter view or focus group?	7
Duration	21	What was the duration of the inter views or focus group?	8
Data saturation	22	Was data saturation discussed?	6,8
Transcripts returned	23	Were transcripts returned to participants for comment and/or	7

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	7
Description of the coding tree	25	Did authors provide a description of the coding tree?	10 + fig 2
Derivation of themes	26	Were themes identified in advance or derived from the data?	10
Software	27	What software, if applicable, was used to manage the data?	7
Participant checking	28	Did participants provide feedback on the findings?	7
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	table 2-3
Data and findings consistent	30	Was there consistency between the data presented and the findings?	11-18
Clarity of major themes	31	Were major themes clearly presented in the findings?	11-18 + table 2
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	11-18

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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