



BMJ Open 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 semistructured 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 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 overview of the patient journey.

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.

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

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The qualitative research approach enabled parents of children with developmental dysplasia of the hip (DDH) to share their personal experiences and beliefs, with the aim of detecting knowledge gaps and optimising DDH care from a parent-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.

children's healthcare centre as part of regular developmental check-ups.⁵ The screening programme consists of physical examination and risk factor assessment.⁵ Once positively screened, a diagnostic ultrasound of the hip joint is conducted at the community diagnostic centre. Infants with abnormalities on the hip ultrasound are directly referred to a paediatric 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 on 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

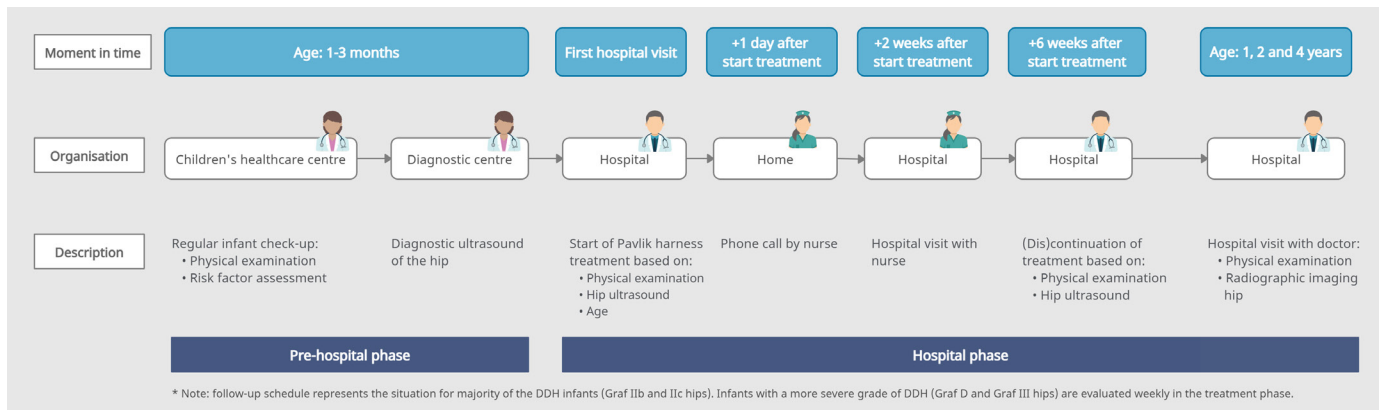


Figure 1 Overview of the patient journey of a child with developmental dysplasia of the hip at the Máxima Medical Centre.

harness treatment takes place in the home setting.⁹ Parental satisfaction with healthcare services is associated with positive patient behaviour¹⁰ 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. Semistructured 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, patients with DDH are treated in a clinical care pathway by a team of two paediatric orthopaedic surgeons, one fellow paediatric orthopaedic surgery and two paediatric 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 (online supplemental file 1). Subsequently, semistructured 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 were 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 semistructured 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 V.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.

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 min (12 min to 52 min). Participant characteristics are listed in [table 1](#).

Themes

Thematic analysis identified five 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 and (5) emotional burden ([figure 2](#)). Within the five themes, multiple categories emerged, which are further explained with representative quotations to illustrate the parental experiences throughout care for children with DDH ([tables 2–3](#)).

Theme 1: Positive experiences with professionals and peers *Interplay orthopaedic surgeon and nurse*

The interplay of healthcare professionals within the multidisciplinary team of the hospital 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. (quotations 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 1 day after initiation of treatment was therefore highly valued. (quotations 3–5)

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 were very useful. (quotations 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 *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,

Table 1 Characteristics of interviewed parents and their child

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

DDH, developmental dysplasia of the hip; HVT, higher vocational education; IVT, intermediate vocational education.

which caused parents to search for online information themselves. (quotation 8)

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

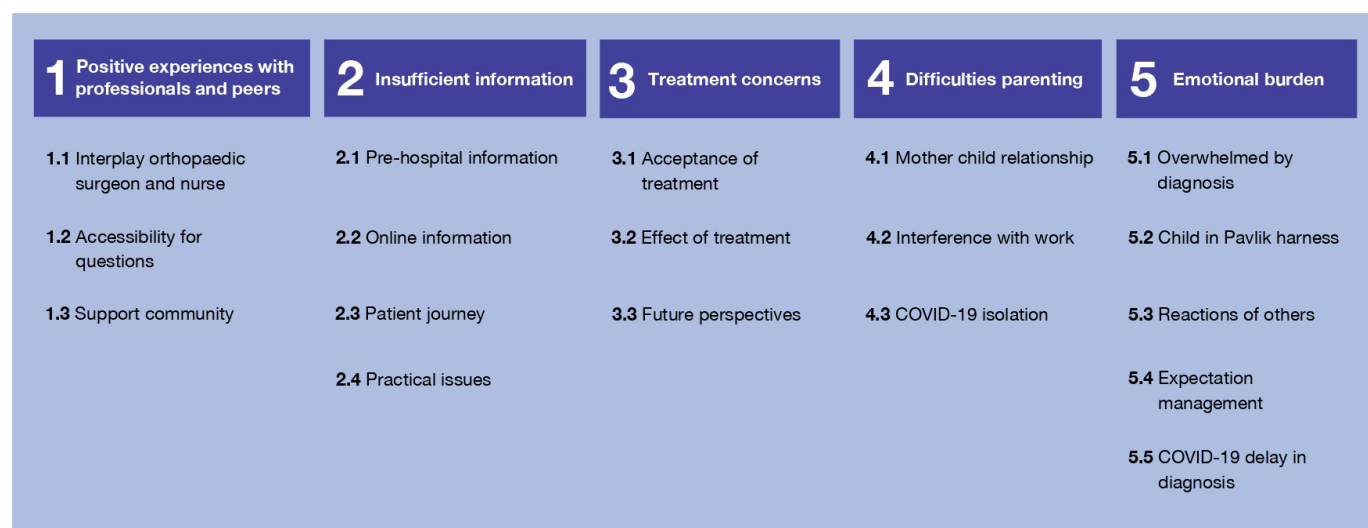
**Figure 2** Schematic overview of 5 themes and categories.

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	<i>He (= the paediatric 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 paediatric orthopedic surgeon briefly joins and next you see the clinical 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 clinical nurse specialist provides. (q2;i14)</i>
	1.2 Accessibility for questions	<i>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)</i>
		<i>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)</i>
	1.3 Support community	<i>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)</i>
		<i>Our neighbours' first needed an abduction brace as well. She explained some practical things, on how she experienced things. That was very helpful. (q7;i5)</i>
Theme 2: Insufficient information	2.1 Pre-hospital information	<i>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)</i>
	2.2 Online information	<i>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)</i>
		<i>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)</i>
	2.3 Patient journey	<i>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)</i>
		<i>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)</i>
	2.4 Practical issues	<i>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)</i>
	<i>Practical issues, like how will I do the breastfeeding? (q14;i9)</i>	
	<i>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)</i>	

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

Theme	Category	Quotation
Theme 3: Treatment concerns	3.1 Acceptance of treatment	<i>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 6 weeks. (q16;i9) Eventually he slept extremely well. Obviously, that's not something you can be certain of beforehand. (q17;i6)</i>
		<i>He wasn't really that bothered by it (= Pavlik harness). 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 a 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)</i>
	3.2 Effect of treatment	<i>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)</i>
	3.3 Future perspectives	<i>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)</i>
Theme 4: Difficulties parenting	4.1 Mother child relationship	<i>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 off I thought, wow what has he grown a lot. (q24;i5)</i>
	4.2 Interference with work	<i>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)</i>
	4.3 COVID-19 isolation	<i>It might have been due the hormones, but it is very difficult to memorize all 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)</i>

Continued

Table 3 Continued

Theme	Category	Quotation
Theme 5: Emotional burden	5.1 Overwhelmed by diagnosis	<i>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)</i>
	5.2 Child in Pavlik harness	<i>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)</i>
	5.3 Reactions of others	<i>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)</i>
	5.4 Expectation management	<i>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)</i>
	5.5 COVID-19 delay in diagnosis	<i>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)</i>

online information on treatment options, varying from an abduction device to traction treatment and surgery, which led to insecurity and anxiety. (quotations 9–10)

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)

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? (quotations 13–15)

Theme 3: Treatment concerns

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. (quotations 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. (quotations 17,20)

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 with 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)

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

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. (quotations 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.

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)

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

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)

Child in Pavlik harness

In the early days of treatment, many parents found it a distressing sight to see their 3-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)

Reactions of others

Parents emphasised that they continuously had to deal with reactions from other people in their environment (eg, 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.

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)

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 parents' 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 parents²²: 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 of 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, breast feeding 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. First, the local infrastructure and involvement of multiple healthcare organisations 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. Second, fathers were underrepresented in the interviews. Low levels of father participation in paediatric research is a known phenomenon³¹ and is attributed to a lack of time,³² a lack of interest,³² a lack of accessibility³² 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 and 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.

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