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# BMJ Open

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

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4 1 **A qualitative study on parental experiences of children with**  
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6 2 **developmental dysplasia of the hip**  
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3 27 Abstract

4 28 Objective: The aim of this qualitative study was to explore the experiences of Dutch parents of  
5 29 children with Developmental Dysplasia of the Hip (DDH), treated with a Pavlik harness, during the  
6 30 diagnostic and treatment process in the first year of life.

7 31 Design: A qualitative study by means of semi-structured interviews was conducted between  
8 32 September and December 2020. Qualitative content analysis was applied to code, categorise and  
9 33 thematise data.

10 34 Setting: A large, tertiary referral centre for paediatric orthopaedics in The Netherlands.

11 35 Participants: A purposive sample of parents of children aged younger than 1 year, who were treated  
12 36 for DDH with a Pavlik harness, were interviewed until data saturation was achieved. A total of 20  
13 37 interviews with 22 parents (20 mothers and 2 fathers) were conducted.

14 38 Results: Five main themes emerged: (1) positive experiences with professionals and peers, (2)  
15 39 insufficient information, (3) treatment concerns, (4) difficulties parenting and (5) emotional burden.  
16 40 Most prominent features that resonated across the interviews which led to insecurity by parents  
17 41 were: insufficient pre-hospital information, unfiltered online information and lack of patient journey  
18 42 overview.

19 43 Conclusion: This study offers novel insights into parental experiences in DDH care. Parents were  
20 44 generally satisfied with DDH care. Biggest challenges were to cope with the insufficient and  
21 45 unfiltered information provision and lack of patient journey overview, which led to concerns during  
22 46 treatment. Future research and interventions should focus on optimising information provision for  
23 47 parents of children with DDH.

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3 48 Strengths and limitations of this study

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5 49 • A holistic view on parental experiences of DDH care was attained by a qualitative research  
6 50 approach. Parents were able to provide insights beyond the scope of the medical  
7  
8 51 professionals.  
9  
10 52 • A unique feature of this study is the focus on patient perspectives of the healthcare process,  
11 53 rather than the healthcare professionals perspectives. As such, knowledge gaps have been  
12 54 identified that allow to further shape the DDH research agenda from a patient-oriented  
13 55 perspective.  
14  
15 56 • A representative cross-section of the DDH population was realised by purposive sampling.  
16  
17 57 • This qualitative research reflects the specific situation at a large, tertiary referral centre for  
18 58 paediatric orthopaedics in The Netherlands. Although the study findings seem universal,  
19 59 additional research is needed to verify the generalisability of our study results.  
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21 60 • Fathers were underrepresented in the interviews. Potentially different experiences may have  
22 61 been identified if more fathers were involved in the interview process.  
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30 62  
31 63 Keywords

32 64 Developmental Dysplasia of the Hip, hip dysplasia, DDH, experiences, paediatric orthopaedics  
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## 68 Introduction

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

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

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

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

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3 103 support with the parents' perspectives and needs. The aim of this qualitative study is to explore the  
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5 104 experiences of parents caring for a child with DDH, treated with a Pavlik harness, during the  
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7 105 diagnostic and treatment process in the first year of life.  
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## 106 Patients and Methods

### 107 *Study design*

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

112

### 113 *Study population*

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

120

### 121 *Setting*

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

127

### 128 *Procedure*

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

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5 142 *Data collection*

6 143 All interviews took place between September and December 2020. The semi-structured interviews  
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8 144 with the parents were conducted by a paediatric orthopaedic PhD student, who was specifically  
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10 145 trained in conducting qualitative interviews. The interviewer had no prior encounter or relationship  
11  
12 146 with the patients or parents, but briefly introduced himself at the start of the interviews. The  
13  
14 147 interview guide was used to facilitate the discussion and was iteratively modified in response to  
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16 148 evolving study findings. All interviews were digitally audio recorded and transcribed verbatim in the  
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18 149 native language (Dutch) by an independent transcription agency.  
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21 151 *Data analysis*

22 152 All transcripts were independently reviewed and coded using ATLAS.ti version 9.0 (Berlin, Germany)  
23  
24 153 by a paediatric orthopaedic PhD student and an orthopaedic researcher to increase intercoder  
25  
26 154 reliability. After each five transcripts, discrepancies in codes were discussed and iteratively refined  
27  
28 155 until consensus was reached. After the coding process, categorical and thematic analysis was  
29  
30 156 conducted by these two researchers. Consensus over final categories and themes was reached after  
31  
32 157 discussion with a third researcher and approved by the rest of the study group. During the coding  
33  
34 158 process, representative quotes were listed to illustrate the themes. Quotes were translated into  
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36 159 English by a third researcher. The research team validated the English translations by translating  
37  
38 160 them back to Dutch, to check whether the quotes had the same tenor as the original Dutch quotes.  
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41 162 *Patient and Public Involvement*

42 163 Parents of children with DDH were the main information resource for this study. The Dutch patient  
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44 164 association for DDH was actively involved in building the interview guide, cross-checking and  
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46 165 reviewing the results.  
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166 Results

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

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171 **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

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

173 *Themes*

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

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

Theme	Category	Quote [quote number; interview number]
<b>Theme 1: Positive experiences with professionals and peers</b>	1.1 Interplay orthopaedic surgeon and nurse	<i>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]</i>
		<i>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]</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>
		<i>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 neighbors' 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	Category	Quote
<b>Theme 2: Insufficient information</b>	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

*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]*

180

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

Theme	Category	Quote
<b>Theme 3: Treatment concerns</b>	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 9 weeks. [q16;i9]</i>
		<i>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>
		<i>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]</i>
		<i>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	Category	Quote
<b>Theme 4: Difficulties parenting</b>	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>
		<i>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]</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</i>



		<i>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;i1]</i>
		<i>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>
Theme	Category	Quote
<b>Theme 5: Emotional burden</b>	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 Wearing a 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 surrounding	<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>

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3 183 Theme 1: Positive experiences with professionals and peers

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5 184 *1.1 Interplay orthopaedic surgeon and nurse*

6 185 The interplay of healthcare professionals within the multidisciplinary team of the hospital (figure 1)  
7  
8 186 was highly valued by all parents. Especially the supportive role of the clinical nurse specialists was  
9  
10 187 highly appreciated by parents. Paediatric orthopaedic surgeons were seen as the authority regarding  
11  
12 188 the medical part, while the clinical nurse specialists were seen as first contact person with a very low  
13  
14 189 threshold to ask practical questions and as guidance on day-to-day problems. [quote 1-2]  
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17 191 *1.2 Accessibility for questions*

18 192 Accessibility of health care professionals was one of the main positive points parents highlighted  
19  
20 193 during the interviews. As pointed out by several parents, most questions regarding DDH care arose at  
21  
22 194 home, often shortly after the visit to the hospital. The phone call parents received from the clinical  
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24 195 nurse specialist one day after initiation of treatment was therefore highly valued. [quote 3-5]  
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27 197 *1.3 Support community*

28 198 A recurring topic among parents was the highly valued support from peers. Peer support mainly  
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30 199 came from friends, neighbours and fellow parents on the Facebook page of the VAH. Both practical  
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32 200 help and emotional support from people who went through the same ups and downs was very  
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34 201 useful. [quote 6-7] A strong feeling of 'we are in this together' arose among parents once they heard  
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36 202 other parents dealt with the same issues.  
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39 204 Theme 2: Insufficient information

40 205 *2.1 Pre-hospital information*

41 206 The infrastructure for children with DDH at the \*\*\* (blinded for review process) (figure 1) partially  
42  
43 207 underlies the common criticism of parents towards the insufficient information provision. More than  
44  
45 208 half of the interviewed parents reported no or insufficient information about DDH at time of referral  
46  
47 209 from the community diagnostic centre to the \*\*\* (blinded for review process). Although parents  
48  
49 210 were aware of abnormalities in the screening process or abnormal ultrasound findings, the  
50  
51 211 subsequent hospital referral was accompanied by limited additional information regarding diagnosis  
52  
53 212 and the further diagnostic and treatment process. As a result, there was an unfulfilled information  
54  
55 213 need, this caused parents to search for online information themselves. [quote 8]  
56

57 214

58 215 *2.2 Online information*

59 216 The majority of parents of children with DDH used internet as primary source of information. Various  
60  
217 reasons were mentioned: insufficient or no pre-hospital information, wish to prepare for the first

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3 218 hospital visit and the ease with which online information was accessible. A shortage of well-  
4  
5 219 organised and patient specific information was the main remark of parents regarding online  
6  
7 220 information on DDH. Although it was easily accessible, main concern was the staggering amount of  
8  
9 221 unfiltered online information on treatment options, varying from an abduction device to traction  
10  
11 222 treatment and surgery, which led to insecurity and anxiety. [quote 9-10]  
12

223

### 13 224 *2.3 Patient journey*

14  
15 225 Some parents were unaware of the different organizations and healthcare professionals that  
16  
17 226 function within the DDH patient journey (figure 1). The role of the children's healthcare centre as  
18  
19 227 screening institution and the community diagnostic centre as ultrasound imaging institution was not  
20  
21 228 clearly defined for the parents, which led to confusion. [quote 11] Furthermore, a few parents were  
22  
23 229 not aware of the follow up schedule after initiation of treatment. [quote 12]  
24

230

### 25 231 *2.4 Practical issues*

26  
27 232 The majority of the parents reported a lack of practical information and guidance on the application  
28  
29 233 of the Pavlik harness in daily life. Especially in the early days of treatment, a lot of practical questions  
30  
31 234 on a child in a Pavlik harness were encountered: which clothes to wear, how to transport, where to  
32  
33 235 find a car-seat suitable in combination with a Pavlik harness, how to eat and how to breastfeed?  
34  
35 236 [quote 13-15]

237

## 36 238 Theme 3: Treatment concerns

### 37 239 *3.1 Acceptance of treatment*

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40 240 Once abduction treatment with a Pavlik harness was initiated, many parents were concerned  
41  
42 241 whether the treatment would be accepted by their child. [quote 16] Doubts were raised by parents  
43  
44 242 on how their child would react to a period of restricted mobility. Overall the parents report that, in  
45  
46 243 hindsight, the acceptance of treatment turned out better than expected and that their worries in this  
47  
48 244 regard had been unnecessary. [quote 17-18] On the other hand, one mother did mention a difficult  
49  
50 245 treatment period with a child in a Pavlik harness. She reported problems during the entire treatment  
51  
52 246 period, with a hysterical child and sleepless nights. [quote 19] Primary concern of most parents was  
53  
54 247 the fear of sleepless nights once treatment had started. In retrospect, most parents described that  
55  
56 248 only the first couple of nights were troublesome and overall the treatment period was less  
57  
58 249 demanding than expected. [quote 17,20]

250

### 59 251 *3.2 Effect of treatment*

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3 252 Parents reported their main worry was whether abduction splinting had the desired effect. Especially  
4 253 parents of children who needed an extended treatment period compared to what was initially  
5 254 discussed at the first hospital appointment, were in doubt whether the treatment would have the  
6 255 desired effect in the extended treatment period. [quote 21]  
7  
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10 256

### 11 257 *3.3 Future perspectives*

12  
13 258 A high number of parents were worried about how DDH might affect their child in the future,  
14 259 especially regarding the ability to walk, leg length difference and hip instability. These worries on  
15 260 future perspectives arose both in the pre-treatment and post-treatment phase with a Pavlik harness.  
16  
17 261 [quote 22]  
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19

20 262

## 21 263 Theme 4: Difficulties parenting

### 22 264 *4.1 Mother child relationship*

23 265 A recurring theme among the interviews was the disturbed relationship between mother and child.  
24 266 Mothers reported a change in perception of the relationship with their child, once Pavlik harness  
25 267 treatment was initiated. They felt that the Pavlik harness functioned as a physical barrier between  
26 268 them and their child. [quote 23-24] The sudden onset of treatment combined with an abduction  
27 269 device that was worn 23-24 hours a day interfered with the normal upbringing they had in mind once  
28 270 they became parents.  
29  
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33 271

### 34 272 *4.2 Interference with work*

35 273 A child in a Pavlik harness in the home situation led to need for additional care. For parents working  
36 274 at home (due to COVID-19), more than usual attention and care for their child was needed. This  
37 275 interfered with the daily work the parents had. [quote 25]  
38  
39  
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43 276

### 44 277 *4.3 COVID-19 isolation*

45 278 As in all healthcare services, the COVID-19 pandemic affected DDH care. In contrast to the normal  
46 279 situation, only one parent was allowed to accompany the infant during the outpatient clinic visits.  
47 280 Some mothers wished for the presence of their partner and were afraid to miss crucial information  
48 281 which the orthopaedic paediatric surgeon shared with them. [quote 26] In the home situation, the  
49 282 majority of the parents felt isolated and had the feeling of being left alone in the treatment phase  
50 283 due to the COVID-19 isolation. [quote 27]  
51  
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## 57 285 Theme 5: Emotional burden

### 58 286 *5.1 Overwhelmed by diagnosis*

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3 287 Some parents reported that paediatric orthopaedic surgeons should acknowledge that the official  
4 288 diagnosis of DDH had a big impact on the parents' and child's life. They felt that this was not fully  
5 289 appreciated by the paediatric orthopedic surgeon during their clinic visit. Parents felt overwhelmed  
6 290 once diagnosis was made and often required more time being adequately informed on diagnosis and  
7 291 treatment by the orthopaedic surgeon. [quote 28]

292

### 293 *5.2 Wearing a Pavlik harness*

15 294 In the early days of treatment, many parents found it a distressing sight to see their three-month-old  
16 295 child restricted in a Pavlik harness. They were worried whether their child was comfortable and  
17 296 reported that it was unpleasant to see their child's movements restricted. This feeling was reported  
18 297 to resolve during treatment at least partially by most parents, as the majority saw their child quite  
19 298 rapidly accepted the Pavlik harness. [quote 29]

299

### 300 *5.3 Reactions surrounding*

26 301 Parents emphasised that they continuously had to deal with reactions from the surrounding on their  
27 302 child in a Pavlik harness. Parents sometimes had the feeling of having a child with a handicap instead  
28 303 of a healthy child. [quote 30] A lot of attention of the surrounding was paid to the aberrant looking  
29 304 position of the child's legs in a Pavlik harness.

305

### 306 *5.4 Expectation management*

36 307 Expectation management was a recurrent subject among the interviews. In particular expectations  
37 308 that were created in the pre-hospital phase, which had to be disproved at the hospital. This  
38 309 discrepancy between expectations and reality often led to confusion for parents. Parents often went  
39 310 to the hospital with wrong expectations on treatment type and duration, partially caused by the  
40 311 suboptimal information. It is noteworthy that parents link words like 'severe grade DDH' - that was  
41 312 mentioned several times in the pre-hospital phase - to heavy treatment options like 'surgery, cast  
42 313 immobilization or traction treatment'. [quote 31]

314

### 315 *5.5 COVID-19 delay in diagnosis*

51 316 As for many healthcare services, DDH screening had to be temporarily halted and postponed in The  
52 317 Netherlands during the first wave of the COVID-19 pandemic. Many parents raised concerns about  
53 318 the consequences of the delay in screening and diagnosis of DDH regarding their child's hip. [quote  
54 319 32]

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3 320 Discussion

4  
5 321 This qualitative study offers an up-to-date view on parental experiences on care for children with  
6 322 DDH treated with a Pavlik harness in the Netherlands during the first year of life. On the whole, the  
7  
8 323 majority of the parents was satisfied with DDH care. However, some remarks in different phases of  
9  
10 324 the diagnostic and treatment process have been made, which offer novel leads to optimise care for  
11 325 children with DDH.

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13 326  
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15 327 Parents were generally satisfied with the DDH care provided by the hospital. Especially the  
16 328 collaboration between the paediatric orthopaedic surgeon, who provided the medical information,  
17 329 and the orthopaedic clinical nurse specialist, who provided the practical information and emotional  
18 329 support, was highly valued by all parents at the \*\*\* (*blinded for review process*). In addition, the  
19 330 accessibility of the clinical nurse specialist during the treatment phase on medical and practical issues  
20 331 was appreciated by parents. Although this response might partially be socially desirable in the  
21 332 current setting, these positive points on DDH care are in line with variables reported by Peng et  
22 333 al.[21] They showed that predictive aspects to recommend a paediatric orthopaedic hospital to  
23 334 others were collaboration between paediatric orthopaedic healthcare professionals, friendliness of  
24 335 healthcare providers, patient-healthcare provider relationship and provided medical information.[21]  
25 336 Besides the information by healthcare professionals, parents valued support from peers on both  
26 337 practical and emotional support.[22] On the basis of the positive hospital experience, we recommend  
27 338 awareness for both medical, practical and emotional support for parents of children with DDH during  
28 339 the treatment phase.

29 340  
30 341  
31 342 The most apparent issues in the pre-hospital phase of DDH care were the insufficient information  
32 343 provision, unfiltered online information and a lack of the patient journey overview. Provision of  
33 344 adequate patient information is an integral part of the medical profession. The importance of  
34 345 information prior to the first outpatient appointment was previously shown in parents of children  
35 346 with a craniofacial condition. Parents were most curious about what would happen during and after  
36 347 their appointment and wanted to be able to prepare questions to ask.[23] Furthermore, parents had  
37 348 particular interest in the identity of the healthcare professionals involved.[24] In our study parents  
38 349 reported an inadequate information provision prior to their first hospital appointment. As a result,  
39 350 several parents pointed out they felt unprepared and surprised by the sudden onset of treatment,  
40 351 which led to insecurity. Partially due to the insufficient information supply on DDH prior to the first  
41 352 hospital appointment, parents felt forced to use internet as primary source of information.  
42 353 Over the past few years, the use of internet and social media as primary source of medical  
43 354 information has become increasingly popular among patients.[25] An unprecedented access to an

1  
2  
3 355 immense amount of information is available online.[26] However, the quality and reliability of the  
4  
5 356 online information varies substantially, as a result patients may be misinformed about their medical  
6  
7 357 condition and treatment options.[27] Our findings suggest that due to the broad amount of  
8  
9 358 unfiltered and non-patient specific information on DDH treatment, parents may become  
10  
11 359 unnecessarily anxious. Previous studies showed that in general the online information on DDH is  
12  
13 360 written on a level above the recommended level for medical patient information.[28] This may lead  
14  
15 361 to misunderstanding and misinterpretation of the information, which is associated with poorer  
16  
17 362 health care outcomes.[28] Orthopaedic healthcare professionals must be aware of the variability of  
18  
19 363 the level of quality, reliability and understandability of the online information. Parents should  
20  
21 364 preferably be referred to prescreened and trustworthy online sources by the youth health care  
22  
23 365 physician and orthopaedic surgeon.  
24  
25 366 Patient perspectives on the healthcare process are increasingly used to optimise the patient journey.  
26  
27 367 Data provided by the patient experiences can help to improve the quality or efficacy of the clinical  
28  
29 368 management towards the activities most valued by patients.[29] In our qualitative study  
30  
31 369 unawareness of the different organizations involved in the diagnostic and treatment process, a global  
32  
33 370 overview of the treatment process and future perspectives were recurrent features that resonated  
34  
35 371 across most of the interviews. By incorporating these aspects in the patient information in a timely  
36  
37 372 fashion, parental experiences might be improved.[30]  
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39 373  
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41 374 DDH is one of the most common diagnosed conditions that parents of newborns face.[31] Diagnosis  
42  
43 375 and treatment of DDH can be a stressful event for parents during an already major life event.  
44  
45 376 Previous studies suggest that infant disorders lead to anxiety, psychosocial problems and practical  
46  
47 377 difficulties in daily life for mothers.[2] Drawback of the study by Gardner and colleagues, is the usage  
48  
49 378 of close-ended questionnaires. Therefore, this study was not able to grasp the detailed nature of the  
50  
51 379 psychosocial problems parents had. We performed one of the first qualitative studies on the  
52  
53 380 experiences of parents on DDH care and showed that underlying reasons of anxiety were: concerns  
54  
55 381 on acceptance of Pavlik harness by child, effect of Pavlik harness treatment, distressing to see child in  
56  
57 382 Pavlik harness, reactions surroundings and future perspectives regarding ability to walk, leg length  
58  
59 383 difference and hip stability. Mothers were specifically concerned on their mother child relationship  
60  
384 as the Pavlik harness functioned as a physical barrier between them and their child, which interfered  
385 with the maternal attachment they had in mind. These parental concerns are at least partly  
386 supported by recent research on maternal attachment in infants, showing that deprivation of  
387 mother's tactile and proximity related signals leads to biobehavioural dysregulation.[32] Practical  
388 difficulties of caring for a child in abduction splinting due to little guidance is a known  
389 phenomenon.[33] Especially a lack of practical information on clothing, transport, breastfeeding and



1  
2  
3 390 furniture is a recognised problem.[22] To the best of our knowledge, this is the first study that  
4 391 reported parental anxiety on future perspectives of a child treatment for DDH. Parents were afraid of  
5 392 leg length differences, gait problems and hip instability. Optimisation of information on future  
6 393 perspectives of children successfully treated for DDH could partially resolve these concerns.  
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10 394  
11 395 Despite the strengths of this study, our study has some limitations. The local infrastructure and  
12 396 involvement of multiple healthcare organizations for children with DDH at the \*\*\* (*blinded for review*  
13 397 *process*) (figure 1) potentially influences parental experiences during the patient journey. Yet, the  
14 398 experiences on Pavlik harness treatment are presumably universal, as the principles of abduction  
15 399 splinting with a Pavlik harness are generally similar worldwide.[15] Despite, additional research is  
16 400 needed to verify the generalisability of our study results to other DDH care settings. Second, fathers  
17 401 were underrepresented in the interviews. Low levels of father participation in paediatric research is  
18 402 a known phenomenon[34] and is contributed to lack of time[35], lack of interest[35], lack of  
19 403 accesibility[35] and not being asked to participate.[34] Potentially different experiences may have  
20 404 been identified if more fathers were involved in the interview process. Finally, recall bias is a factor  
21 405 that potentially affected the results, as parents need to look back on their experiences from the past.  
22 406 Impact of recall bias was minimised by setting an age limit of 1 year, as no new information was  
23 407 expected after this period.  
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32  
33 409 The current findings suggest that future interventions should focus primarily on optimising (online)  
34 410 information provision, patient journey overview, future perspectives and practical information for  
35 411 parents of children with DDH. Specific attention should be given to understandable information for  
36 412 parents in all layers of the society to minimise misunderstanding or misinterpretation of  
37 413 information.[28] Communication with pictures, videos, diagrams [36,37] and electronic patient  
38 414 specific information [38,39] can be used as these initiatives may improve parents' preparedness,  
39 415 reliability of patient care and enhance the value of healthcare.  
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48 416  
49 417 The novelty of the current study lies within its qualitative aspect. This allowed parents of children  
50 418 with DDH to share their detailed experiences from a personal point of view and facilitated the  
51 419 expression of beliefs that may be left undiscussed in previously performed studies with close-ended  
52 420 questionnaires.[2] Unique feature of this qualitative study is the focus on patient perspectives of the  
53 421 healthcare process, rather than the healthcare professional perspectives.[40] As such, this study  
54 422 improves our understanding of parental experiences on care for children with DDH and serves as first  
55 423 step to improve the patient journey. In conclusion despite general positive experiences, the results of  
56 424 this qualitative research document numerous opportunities for improvements in current DDH care.  
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425 Especially, pre-hospital information, trustworthy online information, patient specific information and  
426 overview of the patient journey are important points of improvement.

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2  
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6 430 their long-standing and extremely valuable work in the DDH trajectory at the \*\*\* (*blinded for review*  
7 431 *process*).

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11 432  
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13 433 Authors Contributions

14 434 WT: prepared study protocol, conducted interviews, coded data, analysed data and wrote the  
15 435 manuscript. MS: prepared study protocol, coded data, analysed data and wrote the manuscript.  
16 436 MVV: analysed data and wrote the manuscript. FVD: critical reviewer of study protocol and  
17 437 manuscript. MW: critical reviewer of study protocol and manuscript. JT: initiator study design,  
18 438 prepared study protocol, analysed data and wrote the manuscript.

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20  
21  
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26 443 interpretation or reporting.

27 444  
28 445 Competing Interests

29 446 None declared.

30 447  
31 448 Data Sharing Statement

32 449 No additional data are available.

33 450  
34 451 Ethics Approval

35 452 The Medical Ethics Committee of the \*\*\* (*blinded for review process*) assessed the study and judged  
36 453 that ethics approval was not required under Dutch National Law, METC number N20.077.

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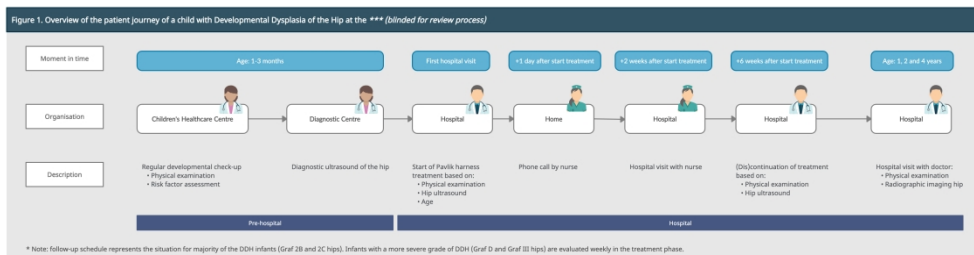


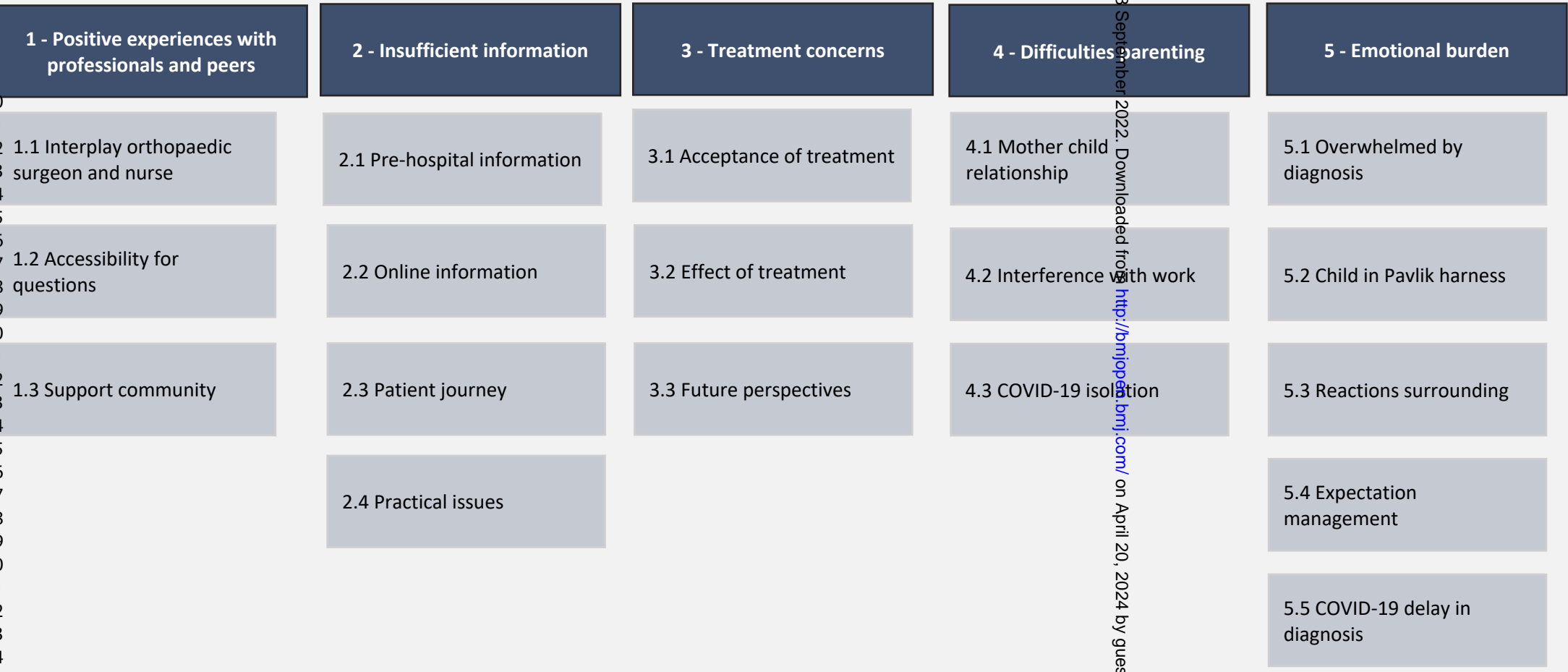
Figure1

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Figure 2. Schematic overview of 5 themes and categories

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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.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	



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

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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# 1 Parental experiences of children with developmental dysplasia of 2 the hip: a qualitative study

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1  
2  
3 27 Abstract

4 28 Objective: The aim of this qualitative study was to explore the experiences of Dutch parents of  
5 29 children with Developmental Dysplasia of the Hip (DDH), treated with a Pavlik harness, during the  
6 30 diagnostic and treatment process in the first year of life.

7 31 Design: A qualitative study by means of semi-structured interviews was conducted between  
8 32 September and December 2020. Qualitative content analysis was applied to code, categorise and  
9 33 thematise data.

10 34 Setting: A large, tertiary referral centre for paediatric orthopaedics in The Netherlands.

11 35 Participants: A purposive sample of parents of children aged younger than 1 year, who were treated  
12 36 for DDH with a Pavlik harness, were interviewed until data saturation was achieved. A total of 20  
13 37 interviews with 22 parents (20 mothers and 2 fathers) were conducted.

14 38 Results: Five main themes emerged: (1) positive experiences with professionals and peers, (2)  
15 39 insufficient information, (3) treatment concerns, (4) difficulties parenting and (5) emotional burden.  
16 40 Most prominent features that resonated across the interviews which led to insecurity by parents  
17 41 were: insufficient pre-hospital information, unfiltered online information and lack of patient journey  
18 42 overview.

19 43 Conclusion: This study offers novel insights into parental experiences in DDH care. Parents were  
20 44 generally satisfied with DDH care provided by the hospital. Biggest challenges were to cope with: (1)  
21 45 insufficient and unfiltered information, (2) lack of patient journey overview and (3) practical  
22 46 problems and emotional doubts, which led to concerns during treatment. Future research and  
23 47 interventions should focus on optimising information provision and guidance with practical and  
24 48 emotional support for parents of children with DDH.

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3 49 Strengths and limitations of this study

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5 50 • The qualitative research approach enabled parents of children with DDH to share their  
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7 51 personal experiences and beliefs, with the aim of detecting knowledge gaps and optimising  
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9 52 DDH care from a patient-oriented perspective.  
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11 53 • The Dutch patient association for DDH was actively involved in the development of the  
12  
13 54 interview guide.  
14  
15 55 • A representative cross-section of the DDH population was realised by purposive sampling.  
16  
17 56 • This study reflects the situation at a large, tertiary referral centre for paediatric orthopaedics  
18  
19 57 in The Netherlands. Generalisability of our study results needs to be verified.  
20  
21 58 • Fathers were underrepresented in the interviews, which might underexpose the information  
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23 59 on their experiences and perspectives.  
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26  
27 61 Keywords

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29 62 Developmental Dysplasia of the Hip, hip dysplasia, DDH, experiences, paediatric orthopaedics  
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## 66 Introduction

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

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

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

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5 102 Despite the crucial role of parents in the treatment of DDH, little is known regarding the experiences  
6 103 of parents caring for a child with DDH. Better understanding of parental experiences throughout care  
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8 104 for children with DDH will improve healthcare professionals' ability to align their support with the  
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10 105 parents' perspectives and needs. The aim of this qualitative study is to explore the experiences of  
11 106 parents caring for a child with DDH, treated with a Pavlik harness, during the diagnostic and  
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13 107 treatment process in the first year of life.  
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## 108 Patients and Methods

### 109 *Study design*

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

114

### 115 *Study population*

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

122

### 123 *Setting*

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

129

### 130 *Procedure*

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

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3 143 participate. Participants gave their written informed consent. Individual interviews were conducted  
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5 144 via a secured online webcam system, Webcamconsult BV (Bergen op Zoom, The Netherlands).  
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7 145 Anonymity of participants and infants was secured in the interview transcripts.  
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#### 10 147 *Data collection*

11 148 All interviews took place between September and December 2020. The semi-structured interviews  
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13 149 with the parents were conducted by a paediatric orthopaedic PhD student, who was specifically  
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15 150 trained in conducting qualitative interviews. The interviewer had no prior encounter or relationship  
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17 151 with the patients or parents, but briefly introduced himself at the start of the interviews. The  
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19 152 interview guide was used to facilitate the discussion and was iteratively modified in response to  
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21 153 evolving study findings. All interviews were digitally audio recorded and transcribed verbatim in the  
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23 154 native language (Dutch) by an independent transcription agency.  
24

#### 25 156 *Data analysis*

26 157 All transcripts were independently reviewed and coded using ATLAS.ti version 9.0 (Berlin, Germany)  
27  
28 158 by a paediatric orthopaedic PhD student and an orthopaedic researcher to increase intercoder  
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30 159 reliability. After each five transcripts, discrepancies in codes were discussed and iteratively refined  
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32 160 until consensus was reached. After the coding process, categorical and thematic analysis was  
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34 161 conducted by these two researchers. Consensus over final categories and themes was reached after  
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36 162 discussion with a third researcher and approved by the rest of the study group. During the coding  
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38 163 process, representative quotes were listed to illustrate the themes. Quotes were translated into  
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40 164 English by a third researcher. The research team validated the English translations by translating  
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42 165 them back to Dutch, to check whether the quotes had the same tenor as the original Dutch quotes.  
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#### 44 167 *Patient and Public Involvement*

45 168 Parents of children with DDH were the main information resource for this study. The VAH was  
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47 169 actively involved in building the interview guide, cross-checking and reviewing the results.  
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170 Results

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

For peer review only

175 **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

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

177 *Themes*

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

For peer review only

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

Theme	Category	Quote [quote number; interview number]
<b>Theme 1: Positive experiences with professionals and peers</b>	1.1 Interplay orthopaedic surgeon and nurse	<i>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]</i>
		<i>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]</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>
		<i>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 neighbors' 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	Category	Quote
<b>Theme 2: Insufficient information</b>	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

*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]*

184

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

Theme	Category	Quote
<b>Theme 3: Treatment concerns</b>	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 9 weeks. [q16;i9]</i>
		<i>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>
		<i>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]</i>
		<i>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	Category	Quote
<b>Theme 4: Difficulties parenting</b>	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>
		<i>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]</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</i>



		<i>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;i1]</i>
		<i>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>
Theme	Category	Quote
<b>Theme 5: Emotional burden</b>	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 Wearing a 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 from 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>

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3 187 Theme 1: Positive experiences with professionals and peers

4  
5 188 *1.1 Interplay orthopaedic surgeon and nurse*

6 189 The interplay of healthcare professionals within the multidisciplinary team of the hospital (figure 1)  
7  
8 190 was highly valued by all parents. The supportive role of the clinical nurse specialists was particularly  
9  
10 191 appreciated by parents. Paediatric orthopaedic surgeons were seen as the authority regarding the  
11  
12 192 medical part, while clinical nurse specialists were seen as point of contact as they were easily  
13  
14 193 accessible to ask practical questions and as guidance on day-to-day problems. [quote 1-2]

15 194

16 195 *1.2 Accessibility for questions*

17  
18 196 Accessibility of health care professionals was one of the main positive points parents highlighted  
19  
20 197 during the interviews. As pointed out by several parents, most questions regarding DDH care arose at  
21  
22 198 home, often shortly after the visit to the hospital. The phone call parents received from the clinical  
23  
24 199 nurse specialist one day after initiation of treatment was therefore highly valued. [quote 3-5]

25 200

26 201 *1.3 Support community*

27  
28 202 A recurring topic among parents was the highly valued support from peers. Peer support mainly  
29  
30 203 came from friends, neighbours and fellow parents on the Facebook page of the VAH. Both practical  
31  
32 204 help and emotional support from people who went through the same ups and downs was very  
33  
34 205 useful. [quote 6-7] A strong feeling of 'we are in this together' arose among parents once they heard  
35  
36 206 other parents dealt with the same issues.

37 207

38 208 Theme 2: Insufficient information

39 209 *2.1 Pre-hospital information*

40  
41 210 The infrastructure for children with DDH at the Máxima Medical Centre (figure 1) partially underlies  
42  
43 211 the common criticism of parents towards the insufficient information provision. More than half of  
44  
45 212 the interviewed parents reported no or insufficient information about DDH at time of referral from  
46  
47 213 the community diagnostic centre to the Máxima Medical Centre. Although parents were aware of  
48  
49 214 abnormalities in the screening process or abnormal ultrasound findings, the subsequent hospital  
50  
51 215 referral was accompanied by limited additional information regarding diagnosis and the further  
52  
53 216 diagnostic and treatment process. As a result, there was an unfulfilled information need, which  
54  
55 217 caused parents to search for online information themselves. [quote 8]

56 218

57 219 *2.2 Online information*

58 220 The majority of parents of children with DDH used internet as primary source of information. Various  
59  
60 221 reasons were mentioned: insufficient or no pre-hospital information, wish to prepare for the first

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

228

### 229 *2.3 Patient journey*

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

235

### 236 *2.4 Practical issues*

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

242

## 243 Theme 3: Treatment concerns

### 244 *3.1 Acceptance of treatment*

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

255

### 256 *3.2 Effect of treatment*

1  
2  
3 257 Parents reported their main worry was whether abduction splinting had the desired effect. In  
4  
5 258 particular, parents of children who needed an extended treatment period compared to what was  
6  
7 259 initially discussed at the first hospital appointment, were in doubt whether the treatment would  
8  
9 260 have the desired effect in the extended treatment period. [quote 21]  
10

261

### 11 262 *3.3 Future perspectives*

12  
13 263 A high number of parents were worried about how DDH might affect their child in the future,  
14  
15 264 especially regarding the ability to walk, leg length difference and hip instability. These worries on  
16  
17 265 future perspectives arose both in the pre-treatment and post-treatment phase with a Pavlik harness.  
18  
19 266 [quote 22]  
20

267

## 21 268 Theme 4: Difficulties parenting

### 22 269 *4.1 Mother child relationship*

23  
24  
25 270 A recurring theme among the interviews was the disturbed relationship between mother and child.  
26  
27 271 Mothers reported a change in perception of the relationship with their child, once Pavlik harness  
28  
29 272 treatment was initiated. They felt that the Pavlik harness functioned as a physical barrier between  
30  
31 273 them and their child. [quote 23-24] The sudden onset of treatment combined with an abduction  
32  
33 274 device that was worn 23-24 hours a day interfered with the normal upbringing they had in mind once  
34  
35 275 they became parents.  
36

276

### 37 277 *4.2 Interference with work*

38  
39 278 A child in a Pavlik harness in the home situation led to need for additional care. For parents working  
40  
41 279 at home (due to COVID-19), more than usual attention and care for their child was needed. This  
42  
43 280 interfered with the daily work the parents had. [quote 25]  
44

281

### 45 282 *4.3 COVID-19 isolation*

46  
47 283 As in all healthcare services, the COVID-19 pandemic affected DDH care. In contrast to the normal  
48  
49 284 situation, only one parent was allowed to accompany the infant during the outpatient clinic visits.  
50  
51 285 Some mothers wished for the presence of their partner and were afraid to miss crucial information  
52  
53 286 which the orthopaedic paediatric surgeon shared with them. [quote 26] In the home situation, the  
54  
55 287 majority of the parents felt isolated and had the feeling of being left alone in the treatment phase  
56  
57 288 due to the COVID-19 isolation. [quote 27]  
58

289

## 58 290 Theme 5: Emotional burden

### 59 291 *5.1 Overwhelmed by diagnosis*

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2  
3 292 Some parents reported that paediatric orthopaedic surgeons should acknowledge that the official  
4 293 diagnosis of DDH had a big impact on the parents' and child's life. They felt that this was not fully  
5 294 appreciated by the paediatric orthopaedic surgeon during their clinic visit. Parents felt overwhelmed  
6 295 once diagnosis was made and often required more time being adequately informed on diagnosis and  
7 296 treatment by the orthopaedic surgeon. [quote 28]  
8  
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12 297

### 13 298 *5.2 Wearing a Pavlik harness*

14 299 In the early days of treatment, many parents found it a distressing sight to see their three-month-old  
15 300 child restricted in a Pavlik harness. They were worried whether their child was comfortable and  
16 301 reported that it was unpleasant to see their child's movements restricted. This feeling was reported  
17 302 to resolve during treatment at least partially by most parents, as the majority saw their child quite  
18 303 rapidly accepted the Pavlik harness. [quote 29]  
19  
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21  
22

23 304

### 24 305 *5.3 Reactions from others*

25 306 Parents emphasised that they continuously had to deal with reactions from other people in their  
26 307 environment (e.g. family, friends, neighbours and strangers) on their child in a Pavlik harness.  
27 308 Parents sometimes got the feeling of having a child with a handicap instead of a healthy child. [quote  
28 309 30] A lot of attention was paid to the aberrant looking position of the child's legs in a Pavlik harness.  
29  
30  
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33 310

### 34 311 *5.4 Expectation management*

35 312 Expectation management was a recurrent subject among the interviews. In particular expectations  
36 313 that were created in the pre-hospital phase, which had to be disproved at the hospital. This  
37 314 discrepancy between expectations and reality often led to confusion for parents. Parents often went  
38 315 to the hospital with wrong expectations on treatment type and duration, partially caused by the  
39 316 suboptimal information. It is noteworthy that parents link words like 'severe grade DDH' - that was  
40 317 mentioned several times in the pre-hospital phase - to heavy treatment options like 'surgery, cast  
41 318 immobilization or traction treatment'. [quote 31]  
42  
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50 319

### 51 320 *5.5 COVID-19 delay in diagnosis*

52 321 As for many healthcare services, DDH screening had to be temporarily halted and postponed in The  
53 322 Netherlands during the first wave of the COVID-19 pandemic. Many parents raised concerns about  
54 323 the consequences of the delay in screening and diagnosis of DDH regarding their child's hip. [quote  
55 324 32]  
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3 325 Discussion

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5 326 This study offers a novel view on parental experiences on care for children with DDH treated with a  
6  
7 327 Pavlik harness in the Netherlands during the first year of life. The qualitative research approach  
8  
9 328 identified new insights and leads from the patients' perspective, which can be used to further  
10  
11 329 optimise care for children with DDH. The present study outlined the complexity of DDH care. We  
12  
13 330 highly recommend awareness for medical, practical and emotional support for parents of children  
14  
15 331 with DDH.

16  
17 332  
18 333 Parents were generally satisfied with the DDH care provided by the hospital. The collaboration  
19  
20 334 between the paediatric orthopaedic surgeon, who provided medical information, and the clinical  
21  
22 335 nurse specialist, who provided practical information and emotional support, was particularly valued  
23  
24 336 by the parents. On top of that, accessibility of the clinical nurse specialist during the treatment phase  
25  
26 337 on medical and practical issues was appreciated by parents. These responses are in line with  
27  
28 338 previously identified predictors for recommending a paediatric orthopaedic hospital to other  
29  
30 339 parents[21]: collaboration between paediatric orthopaedic healthcare professionals, friendliness of  
31  
32 340 healthcare providers, patient-healthcare provider relationship and provided medical information.[21]  
33  
34 341 Furthermore, parents highly appreciated the practical help and emotional support by peers.[16]  
35  
36 342 Based on these results, collaboration between paediatric orthopaedic healthcare professionals and  
37  
38 343 involvement of peers is crucial.

39  
40 344  
41 345 In the pre-hospital phase, most concerns by parents of children with DDH were expressed on  
42  
43 346 insufficient information provision prior to the first hospital appointment and unfiltered online  
44  
45 347 information. Due to the insufficient information provision, parents felt unprepared and surprised by  
46  
47 348 the sudden onset of treatment which led to insecurity. The importance of information prior to the  
48  
49 349 first outpatient appointment was previously shown in parents of children with a craniofacial  
50  
51 350 condition. These parents were curious about what would happen during and after their appointment  
52  
53 351 and wanted to be able to prepare questions to ask.[22] Because parents felt that the information  
54  
55 352 they received on DDH prior to the first hospital appointment was insufficient, they felt forced to use  
56  
57 353 internet as primary source of information. The quality and reliability of the online information varies  
58  
59 354 substantially and as a result patients may be misinformed about their medical condition and  
60  
355 treatment options.[23] Our findings suggest that due to the broad amount of unfiltered and non-  
356  
357 patient specific information on DDH treatment, parents may become unnecessarily anxious. Previous  
358  
359 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]

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2  
3 360 Orthopaedic healthcare professionals must be aware of the variability of the level of quality,  
4 361 reliability and understandability of the online information. Parents should preferably be referred to  
5 362 pre-screened and trustworthy online sources by the youth health care physician and orthopaedic  
6 363 surgeon. Besides general information on DDH, parents experienced a lack of overview on the DDH  
7 364 patient journey. Patient perspectives on the healthcare process are increasingly used to optimise the  
8 365 patient journey. Data provided by the patient experiences can help to improve the quality or efficacy  
9 366 of the clinical management towards the activities most valued by patients.[25] In our qualitative  
10 367 study unawareness of the different organizations involved in the diagnostic and treatment process, a  
11 368 global overview of the treatment process and future perspectives were recurrent features that  
12 369 resonated across most of the interviews. By incorporating these aspects in the patient information in  
13 370 a timely fashion, parental experiences might be improved.[26]

14 371  
15 372 Although anxiety and psychosocial problems on diagnosis of DDH has been reported by parents in  
16 373 previous research, these studies were not able to grasp the detailed nature of these problems.[2,15]  
17 374 A better understanding of the underlying causes of parental anxiety and psychosocial problems on  
18 375 diagnosis and treatment of DDH is essential to optimise DDH care and support during this process.  
19 376 Our qualitative research was able to identify a spectrum of these underlying reasons: concerns on  
20 377 acceptance of Pavlik harness by child, effect of Pavlik harness treatment, distressing to see child in  
21 378 Pavlik harness, reactions from others on a child in a Pavlik harness and future perspectives regarding  
22 379 ability to walk, leg length difference and hip stability. Mothers were specifically concerned on their  
23 380 mother child relationship as the Pavlik harness functioned as a physical barrier between them and  
24 381 their child, which interfered with the maternal attachment they had in mind. These parental  
25 382 concerns are at least partly supported by recent research on maternal attachment in infants,  
26 383 showing that deprivation of mother's tactile and proximity related signals leads to biobehavioural  
27 384 dysregulation.[27] Practical difficulties is a recurring theme among parents of children with DDH.[28]  
28 385 Lack of practical information on clothing, transportation, breastfeeding and furniture is a recognised  
29 386 problem.[16] Parents require information on future perspectives and additional practical information  
30 387 and guidance on the application of a Pavlik harness in daily life.

31 388  
32 389 Despite the strengths of this study, our study has some limitations. The local infrastructure and  
33 390 involvement of multiple healthcare organizations for children with DDH at the Máxima Medical  
34 391 Centre potentially influences parental experiences during the patient journey. Yet, the experiences  
35 392 on Pavlik harness treatment are presumably universal, as the principles of abduction splinting with a  
36 393 Pavlik harness are generally similar worldwide.[29] Despite, additional research is needed to verify  
37 394 the generalisability of our study results to other DDH care settings. Second, fathers were



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2  
3 395 underrepresented in the interviews. Low levels of father participation in paediatric research is a  
4 396 known phenomenon[30] and is attributed to lack of time[31], lack of interest[31], lack of  
5 397 accessibility[31] and not being asked to participate.[30] Finally, recall bias is a factor that potentially  
6 398 affected the results, as parents need to look back on their experiences from the past. Impact of recall  
7 399 bias was minimised by setting an age limit of 1 year, as no new information was expected after this  
8 400 period.  
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13 401  
14  
15 402 The current findings suggest that future interventions should focus on optimisation of (online)  
16 403 information, optimisation of the patient journey overview, better understanding of future  
17 404 perspectives and guidance with practical and emotional support for parents of children with DDH.  
18 405 Specific attention should be given to understandable information for parents in all layers of the  
19 406 society to minimise misunderstanding or misinterpretation of information.[24] Communication with  
20 407 pictures, videos, diagrams [32,33] and electronic patient specific information [34,35] can be used as  
21 408 these initiatives may improve parents' preparedness, reliability of patient care and enhance the  
22 409 value of healthcare.  
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30 410  
31 411 The novelty of this qualitative study is the focus on parental perspectives of the healthcare process,  
32 412 rather than the healthcare professional perspectives.[36] This allowed parents of children with DDH  
33 413 to share their detailed experiences from a personal point of view and facilitated the expression of  
34 414 beliefs that may be left undiscussed in previously performed studies with close-ended  
35 415 questionnaires.[2] As such, this study improves our understanding of parental experiences on care  
36 416 for children with DDH and serves as first step to improve the patient journey. The results of this  
37 417 qualitative research document numerous opportunities for improvements in current DDH care. Pre-  
38 418 hospital information, trustworthy online information, overview of the patient journey and guidance  
39 419 with practical and emotional support are the main points of improvement.  
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3 420 Figures legend

4  
5 421 Figure 1

6 422 Overview of the patient journey of a child with Developmental Dysplasia of the Hip at the Máxima  
7  
8 423 Medical Centre.

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10 424

11 425 Figure 2

12 426 Schematic overview of 5 themes and categories.

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14  
15 427

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19  
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21  
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23 432

24  
25 433 Authors Contributions

26 434 WT: prepared study protocol, conducted interviews, coded data, analysed data and wrote the  
27  
28 435 manuscript. MS: prepared study protocol, coded data, analysed data and wrote the manuscript.  
29  
30 436 MVV: analysed data and wrote the manuscript. FVD: critical reviewer of study protocol and  
31  
32 437 manuscript. MW: critical reviewer of study protocol and manuscript. JT: initiator study design,  
33  
34 438 prepared study protocol, analysed data and wrote the manuscript.

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41  
42 443 reporting.

43 444

44  
45 445 Competing Interests

46 446 None declared.

47  
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49  
50 448 Data Sharing Statement

51 449 No additional data are available.

52  
53 450

54  
55 451 Ethics Approval

56 452 The Medical Ethics Committee of the Máxima Medical Centre assessed the study and judged that  
57  
58 453 ethics approval was not required under Dutch National Law, METC number N20.077.

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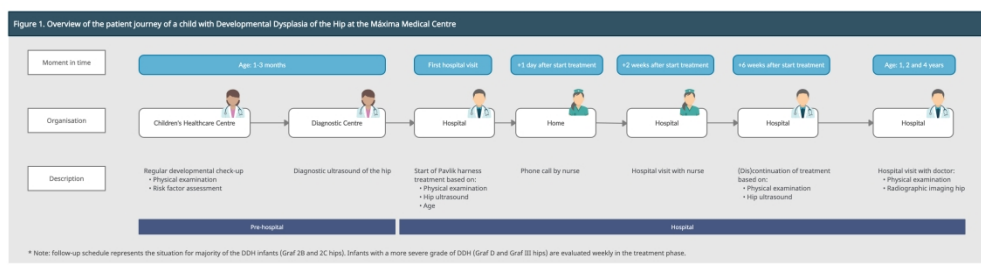


Figure1  
Is illustrated by 1st author Theunissen

669x181mm (157 x 157 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 by others
	2.4 Practical issues			5.4 Expectation management
				5.5 COVID-19 delay in diagnosis

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.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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

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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3 27 Abstract

4  
5 28 Objective: The aim of this qualitative study was to explore the experiences of Dutch parents of  
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7 29 children with Developmental Dysplasia of the Hip (DDH), treated with a Pavlik harness, during the  
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9 30 diagnostic and treatment process in the first year of life.

10 31 Design: A qualitative study by means of semi-structured interviews was conducted between  
11  
12 32 September and December 2020. Qualitative content analysis was applied to code, categorise and  
13  
14 33 thematise data.

15 34 Setting: A large, tertiary referral centre for paediatric orthopaedics in The Netherlands.

16 35 Participants: A purposive sample of parents of children aged younger than 1 year, who were treated  
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18 36 for DDH with a Pavlik harness, were interviewed until data saturation was achieved. A total of 20  
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20 37 interviews with 22 parents (20 mothers and 2 fathers) were conducted.

21 38 Results: Five main themes emerged: (1) positive experiences with professionals and peers, (2)  
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23 39 insufficient information, (3) treatment concerns, (4) difficulties parenting and (5) emotional burden.

24  
25 40 Most prominent features that resonated across the interviews which led to insecurity by parents  
26  
27 41 were: insufficient pre-hospital information, unfiltered online information and the lack of patient  
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29 42 journey overview.

30 43 Conclusion: This study offers novel insights into parental experiences in DDH care. Parents were  
31  
32 44 generally satisfied with DDH care provided by the hospital. The biggest challenges were to cope with:  
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34 45 (1) insufficient and unfiltered information, (2) the lack of patient journey overview and (3) practical  
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36 46 problems and emotional doubts, which led to concerns during treatment. Future research and  
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38 47 interventions should focus on optimising information provision and guidance with practical and  
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40 48 emotional support for parents of children with DDH.

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3 49 Strengths and limitations of this study

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5 50 • The qualitative research approach enabled parents of children with DDH to share their  
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7 51 personal experiences and beliefs, with the aim of detecting knowledge gaps and optimising  
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9 52 DDH care from a patient-oriented perspective.  
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11 53 • The Dutch patient association for DDH was actively involved in the development of the  
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13 54 interview guide.  
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15 55 • A representative cross-section of the DDH population was realised by purposive sampling.  
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17 56 • This study reflects the situation at a large, tertiary referral centre for paediatric orthopaedics  
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19 57 in The Netherlands. Generalisability of our study results needs to be verified.  
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21 58 • Fathers were underrepresented in the interviews, which might underexpose the information  
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23 59 on their experiences and perspectives.  
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26  
27 61 Keywords

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29 62 Developmental Dysplasia of the Hip, hip dysplasia, DDH, experiences, paediatric orthopaedics  
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## 66 Introduction

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

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

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

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5 102 Despite the crucial role of parents in the treatment of DDH, little is known regarding the experiences  
6 103 of parents caring for a child with DDH. Better understanding of parental experiences throughout care  
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8 104 for children with DDH will improve healthcare professionals' ability to align their support with the  
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10 105 parents' perspectives and needs. The aim of this qualitative study is to explore the experiences of  
11 106 parents caring for a child with DDH, treated with a Pavlik harness, during the diagnostic and  
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13 107 treatment process in the first year of life.  
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For peer review only

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3 108 Patients and Methods

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5 109 *Study design*

6 110 A qualitative study was conducted to gain in-depth information on parental experiences of care for  
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8 111 children with DDH. Semi-structured interviews were used as source of information. The study was  
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10 112 reported according to the Consolidated Criteria for Reporting Qualitative Research guideline  
11 113 (COREQ).[19]

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15 115 *Study population*

16 116 We selected parents of children (maximum 1 year of age) who were treated for DDH with a Pavlik  
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18 117 harness. Age limit was chosen as this study was interested in the experiences of parents of children  
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20 118 with DDH in the diagnostic and treatment phase with a Pavlik harness, which ends before the age of  
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22 119 1 year. Parents were selected based on the purposive sampling principle to ensure diversity of  
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24 120 parents, representing a cross-section of the DDH population. Selection criteria were infant-based  
25 121 (DDH grade, Pavlik harness treatment duration and gender) and parent-based (age and education  
26 122 level).

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30 124 *Setting*

31 125 Recruitment for the interviews took place in the Máxima Medical Centre, which is a large, tertiary  
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33 126 referral centre for paediatric orthopaedics with approximately 425 new DDH patients a year. At the  
34  
35 127 Máxima Medical Centre, DDH patients are treated in a clinical care pathway by a team of two  
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37 128 paediatric orthopaedic surgeons, one fellow paediatric orthopaedic surgery and two orthopaedic  
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39 129 clinical nurse specialists (figure 1).

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42 131 *Procedure*

43 132 An interview guide was set up by several stakeholders in the DDH healthcare trajectory. A group  
44  
45 133 composed of two paediatric orthopaedic surgeons, one fellow paediatric orthopaedic surgery, one  
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47 134 paediatric orthopaedic PhD student, one orthopaedic researcher and one representative of the  
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49 135 board of the Dutch patient association for DDH (Vereniging Afwijkende Heupontwikkeling [VAH]) set  
50 136 up the interview guide for the interviews. Input from representatives from the Dutch patient  
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52 137 association for DDH was used to revise the initial draft of the interview guide to a final version  
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54 138 [supplementary file 1]. Subsequently, semi-structured interviews were conducted to gain in depth  
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56 139 information on parental experiences of care for children with DDH. The estimated sample size for the  
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58 140 individual interviews was 15-20 parents. Data saturation was used as main criterion for discontinuing  
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60 141 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



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3 143 their willingness to participate. Next, parents received written information about the study and were  
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5 144 asked to participate. Participants gave their written informed consent. Individual interviews were  
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7 145 conducted via a secured online webcam system, Webcamconsult BV (Bergen op Zoom, The  
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9 146 Netherlands). Anonymity of participants and infants was secured in the interview transcripts.

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#### 11 148 *Data collection*

12  
13 149 All interviews took place between September and December 2020. The semi-structured interviews  
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15 150 with the parents were conducted by a paediatric orthopaedic PhD student, who was specifically  
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17 151 trained in conducting qualitative interviews. The interviewer had no prior encounter or relationship  
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19 152 with the patients or parents, but briefly introduced himself at the start of the interviews. The  
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21 153 interview guide was used to facilitate the discussion and was iteratively modified in response to  
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23 154 evolving study findings. All interviews were digitally audio recorded and transcribed verbatim in the  
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25 155 native language (Dutch) by an independent transcription agency.

26 156

#### 27 157 *Data analysis*

28 158 All transcripts were independently reviewed and coded using ATLAS.ti version 9.0 (Berlin, Germany).  
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30 159 The coding process was carried out by two researchers – a paediatric orthopaedic PhD student and  
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32 160 an orthopaedic researcher – to increase intercoder reliability[21], which reflects the agreement  
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34 161 between these two coders for coding the same content with the most representative code. After  
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36 162 each of the five transcripts, discrepancies in codes were discussed and iteratively refined until  
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38 163 consensus was reached. After the coding process, categorical and thematic analysis was conducted  
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40 164 by these two researchers. Consensus over the final categories and themes was reached after  
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42 165 discussion with a third researcher and approved by the rest of the study group. During the coding  
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44 166 process, representative quotations were listed to illustrate the themes. Quotations were translated  
45  
46 167 into English by a third researcher. The research team validated the English translations by translating  
47  
48 168 them back to Dutch, to check whether the quotations had the same tenor as the original Dutch  
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50 169 quotations.

51 170

#### 52 171 *Patient and Public Involvement*

53 172 Parents of children with DDH were the main information resource for this study. The VAH was  
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55 173 actively involved in building the interview guide, cross-checking and reviewing the results.

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174 Results

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

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179 **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

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

181 *Themes*

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

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

Theme	Category	Quotation [quotation number; interview number]
<b>Theme 1: Positive experiences with professionals and peers</b>	1.1 Interplay orthopaedic surgeon and nurse	<i>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]</i>
		<i>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]</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>
		<i>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 neighbors' 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	Category	Quotation
<b>Theme 2: Insufficient information</b>	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

*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]*

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

Theme	Category	Quotation
<b>Theme 3: Treatment concerns</b>	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 12 weeks. [q16;i9]</i>
		<i>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>
		<i>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]</i>
		<i>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	Category	Quotation
<b>Theme 4: Difficulties parenting</b>	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>
		<i>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]</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</i>

		<i>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;i1]</i>
		<i>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>
Theme	Category	Quotation
<b>Theme 5: Emotional burden</b>	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 Wearing a 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 from 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>



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3 191 Theme 1: Positive experiences with professionals and peers

4  
5 192 *1.1 Interplay orthopaedic surgeon and nurse*

6 193 The interplay of healthcare professionals within the multidisciplinary team of the hospital (figure 1)  
7  
8 194 was highly valued by all parents. The supportive role of the clinical nurse specialists was particularly  
9  
10 195 appreciated by parents. Paediatric orthopaedic surgeons were seen as the authority regarding the  
11  
12 196 medical part, while clinical nurse specialists were seen as point of contact as they were easily  
13  
14 197 accessible to ask practical questions and as a guidance on day-to-day problems. [quotation 1-2]

15 198

16 199 *1.2 Accessibility for questions*

17  
18 200 Accessibility of healthcare professionals was one of the main positive points parents highlighted  
19  
20 201 during the interviews. As pointed out by several parents, most questions regarding DDH care arose at  
21  
22 202 home, often shortly after the visit to the hospital. The phone call parents received from the clinical  
23  
24 203 nurse specialist one day after initiation of treatment was therefore highly valued. [quotation 3-5]

25 204

26 205 *1.3 Support community*

27  
28 206 A recurring topic among parents was the highly valued support from peers. Peer support mainly  
29  
30 207 came from friends, neighbours and fellow parents on the Facebook page of the VAH. Both practical  
31  
32 208 help and emotional support from people who went through the same ups and downs was very  
33  
34 209 useful. [quotation 6-7] A strong feeling of 'we are in this together' arose among parents once they  
35  
36 210 heard other parents dealt with the same issues.

37 211

38 212 Theme 2: Insufficient information

39 213 *2.1 Pre-hospital information*

40  
41 214 The infrastructure for children with DDH at the Máxima Medical Centre (figure 1) partially underlies  
42  
43 215 the common criticism of parents towards the insufficient information provision. More than half of  
44  
45 216 the interviewed parents reported no or insufficient information about DDH at time of referral from  
46  
47 217 the community diagnostic centre to the hospital. Although parents were aware of abnormalities in  
48  
49 218 the screening process or abnormal ultrasound findings, the subsequent hospital referral was  
50  
51 219 accompanied by limited additional information regarding diagnosis and the further diagnostic and  
52  
53 220 treatment process. As a result, there was an unfulfilled information need, which caused parents to  
54  
55 221 search for online information themselves. [quotation 8]

56 222

57 223 *2.2 Online information*

58 224 The majority of parents of children with DDH used internet as primary source of information. Various  
59  
60 225 reasons were mentioned: insufficient or no pre-hospital information, wish to prepare for the first

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2  
3 226 hospital visit and the ease with which online information was accessible. A shortage of well-  
4  
5 227 organised information specific to their child's situation that is written in a manner easily understood  
6  
7 228 by caregivers was the main remark of parents regarding online information on DDH. Although it was  
8  
9 229 easily accessible, main concern was the staggering amount of unfiltered online information on  
10  
11 230 treatment options, varying from an abduction device to traction treatment and surgery, which led to  
12  
13 231 insecurity and anxiety. [quotation 9-10]  
14

232

### 233 *2.3 Patient journey*

16 234 Some parents were unaware of the different organisations and healthcare professionals that  
17  
18 235 function within the DDH patient journey (figure 1). The role of the children's healthcare centre as  
19  
20 236 screening institution and the community diagnostic centre as ultrasound imaging institution was not  
21  
22 237 clearly defined for the parents, which led to confusion. [quotation 11] Furthermore, a few parents  
23  
24 238 were not aware of the follow-up schedule after initiation of treatment. [quotation 12]  
25

239

### 240 *2.4 Practical issues*

28 241 The majority of the parents reported a lack of practical information and guidance on the application  
29  
30 242 of the Pavlik harness in daily life. In particular in the early days of treatment, a lot of practical  
31  
32 243 questions on a child in a Pavlik harness were encountered: which clothes to wear, how to transport,  
33  
34 244 where to find a car-seat suitable in combination with a Pavlik harness and how to eat and how to  
35  
36 245 breastfeed? [quotation 13-15]  
37

246

## 247 Theme 3: Treatment concerns

### 248 *3.1 Acceptance of treatment*

41 249 Once the abduction treatment with a Pavlik harness was initiated, many parents were concerned  
42  
43 250 whether the treatment would be accepted by their child. [quotation 16] Doubts were raised by  
44  
45 251 parents on how their child would react to a period of restricted mobility. Overall the parents report  
46  
47 252 that, in hindsight, the acceptance of treatment turned out better than expected and that their  
48  
49 253 worries in this regard had been unnecessary. [quotation 17-18] On the other hand, one mother did  
50  
51 254 mention a difficult treatment period with a child in a Pavlik harness. She reported problems during  
52  
53 255 the entire treatment period, with a hysterical child and sleepless nights. [quotation 19] Primary  
54  
55 256 concern of most parents was the fear of sleepless nights once treatment had started. In retrospect,  
56  
57 257 most parents described that only the first couple of nights were troublesome and overall the  
58  
59 258 treatment period was less demanding than expected. [quotation 17,20]  
60

259

### 260 *3.2 Effect of treatment*

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2  
3 261 Parents reported their main worry was whether abduction splinting had the desired effect. In  
4  
5 262 particular, parents of children who needed an extended treatment period compared to what was  
6  
7 263 initially discussed at the first hospital appointment, were in doubt whether the treatment would  
8  
9 264 have the desired effect in the extended treatment period. [quotation 21]  
10

265

### 11 266 *3.3 Future perspectives*

12  
13 267 A high number of parents were worried about how DDH might affect their child in the future,  
14  
15 268 especially regarding the ability to walk, leg length difference and hip instability. These worries on  
16  
17 269 future perspectives arose both in the pre-treatment and post-treatment phase with a Pavlik harness.  
18  
19 270 [quotation 22]  
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## 21 272 Theme 4: Difficulties parenting

### 22 273 *4.1 Mother child relationship*

23  
24 274 A recurring theme among the interviews was the disturbed relationship between mother and child.  
25  
26 275 Mothers reported a change in perception of the relationship with their child, once Pavlik harness  
27  
28 276 treatment was initiated. They felt that the Pavlik harness functioned as a physical barrier between  
29  
30 277 them and their child. [quotation 23-24] The sudden onset of treatment combined with an abduction  
31  
32 278 device that was worn 23-24 hours a day interfered with the normal upbringing they had in mind once  
33  
34 279 they became parents.  
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### 36 281 *4.2 Interference with work*

37  
38 282 A child in a Pavlik harness in the home situation led to a need for additional care. For parents  
39  
40 283 working at home (due to COVID-19), more than usual attention and care for their child was needed.  
41  
42 284 This interfered with the daily work the parents had. [quotation 25]  
43

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### 44 286 *4.3 COVID-19 isolation*

45  
46 287 As in all healthcare services, the COVID-19 pandemic affected DDH care. In contrast to the normal  
47  
48 288 situation, only one parent was allowed to accompany the infant during the outpatient clinic visits.  
49  
50 289 Some mothers wished for the presence of their partner and were afraid to miss crucial information  
51  
52 290 which the paediatric orthopaedic surgeon shared with them. [quotation 26] In the home situation,  
53  
54 291 the majority of the parents felt isolated and had the feeling of being left alone in the treatment  
55  
56 292 phase due to the COVID-19 isolation. [quotation 27]  
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## 58 294 Theme 5: Emotional burden

### 59 295 *5.1 Overwhelmed by diagnosis*

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3 296 Some parents reported that paediatric orthopaedic surgeons should acknowledge that the official  
4 297 diagnosis of DDH had a big impact on the parents' and child's life. They felt that this was not fully  
5 298 appreciated by the paediatric orthopaedic surgeon during their clinic visit. Parents felt overwhelmed  
6 299 once diagnosis was made and often required more time being adequately informed on diagnosis and  
7 300 treatment by the paediatric orthopaedic surgeon. [quotation 28]  
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12 301  
13 302 *5.2 Wearing a Pavlik harness*  
14 303 In the early days of treatment, many parents found it a distressing sight to see their three-month-old  
15 304 child restricted in a Pavlik harness. They were worried whether their child was comfortable and  
16 305 reported that it was unpleasant to see their child's movements restricted. This feeling was reported  
17 306 to resolve during treatment at least partially by most parents, as the majority saw their child quite  
18 307 rapidly accepted the Pavlik harness. [quotation 29]  
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25 309 *5.3 Reactions from others*  
26 310 Parents emphasised that they continuously had to deal with reactions from other people in their  
27 311 environment (e.g. family, friends, neighbours and strangers) on their child in a Pavlik harness.  
28 312 Parents sometimes got the feeling of having a child with a handicap instead of a healthy child.  
29 313 [quotation 30] A lot of attention was paid to the aberrant looking position of the child's legs in a  
30 314 Pavlik harness.  
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35 315  
36 316 *5.4 Expectation management*  
37 317 Expectation management was a recurrent subject among the interviews. In particular expectations  
38 318 that were created in the pre-hospital phase, which had to be disproved at the hospital. This  
39 319 discrepancy between expectations and reality led to confusion for parents. Parents often went to the  
40 320 hospital with wrong expectations on treatment type and duration, partially caused by the suboptimal  
41 321 information. It is noteworthy that parents link words like 'severe grade DDH' - that was mentioned  
42 322 several times in the pre-hospital phase - to heavy treatment options like 'surgery, cast immobilization  
43 323 or traction treatment'. [quotation 31]  
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50 324  
51 325 *5.5 COVID-19 delay in diagnosis*  
52 326 As for many healthcare services, DDH screening had to be temporarily halted and postponed in The  
53 327 Netherlands during the first wave of the COVID-19 pandemic. Many parents raised concerns about  
54 328 the consequences of the delay in screening and diagnosis of DDH regarding their child's hip.  
55 329 [quotation 32]  
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3 330 Discussion

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5 331 This study offers a novel view on parental experiences on care for children with DDH treated with a  
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7 332 Pavlik harness in the Netherlands during the first year of life. The qualitative research approach  
8  
9 333 identified new insights and leads from the patients' perspective, which can be used to further  
10  
11 334 optimise care for children with DDH. The present study highlights the complexity of DDH care and  
12  
13 335 the need for increasing awareness for medical, practical, and emotional support for parents of  
14  
15 336 children with DDH.

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17 337  
18 338 Parents were generally satisfied with the DDH care provided by the hospital. The collaboration  
19  
20 339 between the paediatric orthopaedic surgeon, who provided medical information, and the clinical  
21  
22 340 nurse specialist, who provided practical information and emotional support, was particularly valued  
23  
24 341 by the parents. On top of that, accessibility of the clinical nurse specialist during the treatment phase  
25  
26 342 on medical and practical issues was appreciated by parents. These responses are in line with  
27  
28 343 previously identified predictors for recommending a paediatric orthopaedic hospital to other  
29  
30 344 parents[22]: collaboration between paediatric orthopaedic healthcare professionals, friendliness of  
31  
32 345 healthcare providers, patient-healthcare provider relationship and provided medical information.[22]  
33  
34 346 Furthermore, parents highly appreciated the practical help and emotional support by peers.[16]  
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36 347 Based on these results, collaboration between paediatric orthopaedic healthcare professionals and  
37  
38 348 involvement of peers is crucial.

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40 349  
41 350 In the pre-hospital phase, most concerns by parents of children with DDH were expressed on  
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43 351 insufficient information provision prior to the first hospital appointment and unfiltered online  
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45 352 information. Due to the insufficient information provision, parents felt unprepared and surprised by  
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47 353 the sudden onset of treatment which led to insecurity. The importance of information prior to the  
48  
49 354 first outpatient appointment was previously shown in parents of children with a craniofacial  
50  
51 355 condition. These parents were curious about what would happen during and after their appointment  
52  
53 356 and wanted to be able to prepare questions to ask.[23] Because parents felt that the information  
54  
55 357 they received on DDH prior to the first hospital appointment was insufficient, they felt forced to use  
56  
57 358 internet as primary source of information. The quality and reliability of the online information varies  
58  
59 359 substantially and as a result patients may be misinformed about their medical condition and  
60  
61 360 treatment options.[24] Our findings suggest that due to the broad amount of unfiltered and non-  
62  
63 361 patient specific information on DDH treatment, parents may become unnecessarily anxious. Previous  
64  
65 362 studies showed that in general the online information on DDH is written on a level above the  
66  
67 363 recommended level for medical patient information.[25] This may lead to misunderstanding and  
68  
69 364 misinterpretation of the information, which is associated with worse healthcare outcomes.[25]

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3 365 Orthopaedic healthcare professionals must be aware of the variability of the level of quality,  
4 366 reliability and understandability of the online information. Parents should preferably be referred to  
5 367 pre-screened and trustworthy online sources by the youth healthcare physician and orthopaedic  
6 368 surgeon. Besides general information on DDH, parents experienced a lack of overview on the DDH  
7 369 patient journey. Patient perspectives on the healthcare process are increasingly used to optimise the  
8 370 patient journey. Data provided by the patient experiences can help to improve the quality or efficacy  
9 371 of the clinical management towards the activities most valued by patients.[26] In our qualitative  
10 372 study unawareness of the different organisations involved in the diagnostic and treatment process, a  
11 373 global overview of the treatment process and future perspectives were recurrent features that  
12 374 resonated across most of the interviews. By incorporating these aspects in the patient information in  
13 375 a timely fashion, parental experiences might be improved.[27]

14 376  
15 377 Although anxiety and psychosocial problems on diagnosis of DDH have been reported by parents in  
16 378 previous research, these studies were not able to grasp the detailed nature of these problems.[2,15]  
17 379 A better understanding of the underlying causes of parental anxiety and psychosocial problems on  
18 380 diagnosis and treatment of DDH is essential to optimise DDH care and support during this process.  
19 381 Our qualitative research was able to identify a spectrum of these underlying reasons: concerns on  
20 382 acceptance of Pavlik harness by child, effect of Pavlik harness treatment, distressing to see child in  
21 383 Pavlik harness, reactions from others on a child in a Pavlik harness and future perspectives regarding  
22 384 ability to walk, leg length difference and hip stability. Mothers were specifically concerned on their  
23 385 mother child relationship as the Pavlik harness functioned as a physical barrier between them and  
24 386 their child, which interfered with the maternal attachment they had in mind. These parental  
25 387 concerns are at least partly supported by recent research on maternal attachment in infants,  
26 388 showing that deprivation of mother's tactile and proximity related signals leads to biobehavioural  
27 389 dysregulation.[28] Practical difficulties is a recurring theme among parents of children with DDH.[29]  
28 390 A lack of practical information on clothing, transportation, breastfeeding and furniture is a  
29 391 recognised problem.[16] Parents require information on future perspectives and additional practical  
30 392 information and guidance on the application of a Pavlik harness in daily life.

31 393  
32 394 Despite the strengths of this study, our study has some limitations. The local infrastructure and  
33 395 involvement of multiple healthcare organizations for children with DDH at the Máxima Medical  
34 396 Centre potentially influences parental experiences during the patient journey. Yet, the experiences  
35 397 on Pavlik harness treatment are presumably universal, as the principles of abduction splinting with a  
36 398 Pavlik harness are generally similar worldwide.[30] Despite this, additional research is needed to  
37 399 verify the generalisability of our study results to other DDH care settings. Secondly, fathers were

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3 400 underrepresented in the interviews. Low levels of father participation in paediatric research is a  
4 401 known phenomenon[31] and is attributed to a lack of time[32], a lack of interest[32], a lack of  
5 402 accessibility[32] and not being asked to participate.[31]  
6  
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9  
10 404 The current findings suggest that future interventions should focus on optimisation of (online)  
11 405 information, optimisation of the patient journey overview, better understanding of future  
12 406 perspectives and guidance with practical and emotional support for parents of children with DDH.  
13 407 Specific attention should be given to understandable information for parents in all layers of the  
14 408 society to minimise misunderstanding or misinterpretation of information.[25] Communication with  
15 409 pictures, videos, diagrams [33,34] and electronic patient specific information [35,36] can be used as  
16 410 these initiatives may improve parents' preparedness, reliability of patient care and enhance the  
17 411 value of healthcare.  
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24  
25 413 The novelty of this qualitative study is the focus on parental perspectives of the healthcare process,  
26 414 rather than the healthcare professional perspectives.[37] This allowed parents of children with DDH  
27 415 to share their detailed experiences from a personal point of view and facilitated the expression of  
28 416 beliefs that may be left undiscussed in previously performed studies with close-ended  
29 417 questionnaires.[2] As such, this study improves our understanding of parental experiences on care  
30 418 for children with DDH and serves as first step to improve the patient journey. The results of this  
31 419 qualitative research document numerous opportunities for improvements in current DDH care. Pre-  
32 420 hospital information, trustworthy online information, overview of the patient journey and guidance  
33 421 with practical and emotional support are the main points of improvement.  
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3 422 Figures legend

4  
5 423 Figure 1

6 424 Overview of the patient journey of a child with Developmental Dysplasia of the Hip at the Máxima  
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8 425 Medical Centre.

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10 426

11 427 Figure 2

12  
13 428 Schematic overview of 5 themes and categories.

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15 429

16 430 Supplementary file

17  
18 431 File 1: Topic guide

19  
20 432

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22  
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24  
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26  
27 436 extremely valuable work in the DDH trajectory at the Máxima Medical Centre.

28 437

29  
30 438 Authors Contributions

31 439 WT: prepared study protocol, conducted interviews, coded data, analysed data and wrote the  
32  
33 440 manuscript. MS: prepared study protocol, coded data, analysed data and wrote the manuscript.  
34  
35 441 MVV: analysed data and wrote the manuscript. FVD: critical reviewer of study protocol and  
36  
37 442 manuscript. MW: critical reviewer of study protocol and manuscript. JT: initiator study design,  
38  
39 443 prepared study protocol, analysed data and wrote the manuscript.

40 444

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43  
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46 448 interpretation or reporting.

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50 450 Competing Interests

51 451 None declared.

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55 453 Data Sharing Statement

56 454 No additional data are available.

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60 456 Ethics Approval



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3 457 The Medical Ethics Committee of the Máxima Medical Centre assessed the study and judged that  
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5 458 ethics approval was not required under Dutch National Law, METC number N20.077.  
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For peer review only

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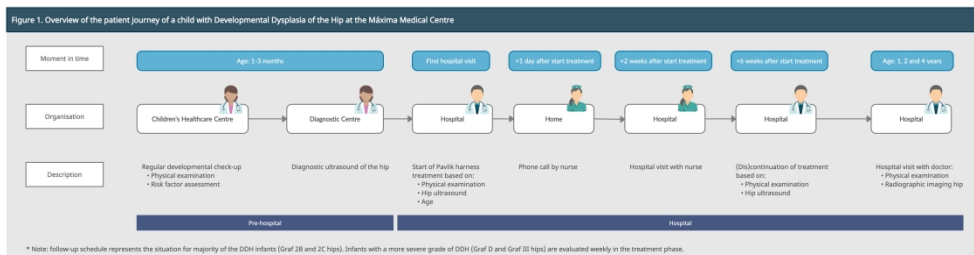


Figure1  
Is illustrated by 1st author Theunissen  
669x181mm (157 x 157 DPI)

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 by others
	2.4 Practical issues			5.4 Expectation management
				5.5 COVID-19 delay in diagnosis

Figure2

148x104mm (400 x 400 DPI)

**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.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	



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

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

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**