



## ■ CHILDREN'S ORTHOPAEDICS

# Strategies to optimize the information provision for parents of children with developmental dysplasia of the hip

A QUALITATIVE STUDY

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## Aims

The aim of this study was to identify the information topics that should be addressed according to the parents of children with developmental dysplasia of the hip (DDH) in the diagnostic and treatment phase during the first year of life. Second, we explored parental recommendations to further optimize the information provision in DDH care.

## Methods

A qualitative study with semi-structured interviews was conducted between September and December 2020. A purposive sample of parents of children aged younger than one year, who were treated for DDH with a Pavlik harness, were interviewed until data saturation was achieved. A total of 20 interviews with 22 parents were conducted. Interviews were audio recorded, transcribed verbatim, independently reviewed, and coded into categories and themes.

## Results

Interviews revealed four fundamental information topics that should be addressed in the different phases of the DDH healthcare trajectory: general information (screening phase), patient-specific information (diagnostic and treatment phase), practical information (treatment phase), and future perspectives (treatment and follow-up phase). To further optimize the information provision in DDH care, parents wished for more accessible and trustworthy general information prior to the first hospital visit to be better prepared for the diagnosis. Furthermore, parents wanted more personalized and visually supported information for a better understanding of the nature of the disease and the reason for treatment.

## Conclusion

This study offers novel insights to optimize the information provision in DDH care. The main finding is the shift in information need from general information in the screening phase to patient-specific information in the diagnostic and treatment phase of DDH. Parents prefer visually-supported information, provided in a timely fashion, and tailored to their child's situation. These recommendations potentially decrease parental anxiety, insecurity, confusion, and increase parental empowerment and treatment adherence throughout the diagnostic and treatment phase of DDH.

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## Introduction

Developmental dysplasia of the hip (DDH) is the most common orthopaedic disorder in newborns.<sup>1</sup> It encompasses a wide spectrum

of abnormalities to the paediatric hip joint, ranging from mild acetabular dysplasia to a dislocated hip.<sup>2</sup> Early diagnosis and treatment are essential to prevent early adulthood

hip osteoarthritis as DDH is responsible for approximately 29% of the primary hip arthroplasties in people aged up to 60 years.<sup>2,3</sup> Infants are initially treated with an abduction device (e.g. Pavlik harness) for a minimum of six weeks until the hip ultrasonographically normalizes. As the majority of this treatment takes place at home, parents play an essential role in diagnostic and treatment process of DDH.

Adequate information provision is one of the key elements in patient-centered care.<sup>4</sup> Systematic and trustworthy provision of medical information is a complex process. It is demonstrated that 40 to 80% of the medical information provided by healthcare professionals is forgotten immediately, and approximately 50% of the medical information is remembered incorrectly.<sup>5</sup> Forgetting and misinterpreting medical information can have various causes, ranging from difficult medical terminology and low patient education level to the way the information is shared.<sup>5</sup> Understanding and memory of medical information are prerequisites for treatment compliance.<sup>6</sup> In this context, it is important to understand the information needs and preferences of parents of children with DDH.

Inadequate information on medical and practical issues can precipitate a variety of problems. A previous qualitative study on experiences of parents caring for a child with DDH revealed major challenges with insufficient pre-hospital information and an unclear overview of the patient journey.<sup>7</sup> As a result, parents felt compelled to use the internet as primary source of information. The broad amount of unfiltered online information on different treatment options for DDH led to insecurity and anxiety among parents.<sup>7</sup> Parental anxiety due to inappropriate and incomplete information was also reported in chronic ill infants. Additionally, inconsistent and contradictory information led to insecurity and confusion, which undermined confidence in the healthcare professional's expertise.<sup>8</sup> Beside, adequate information provision to parents in paediatric oncology also contributed to parents' feeling of control and reassurance.<sup>9</sup> This indicates that improving information provision for parents of children with DDH potentially affects parental anxiety, insecurity, confusion, loss of confidence, feeling of control, and treatment compliance.

Parents of children with hip dysplasia are uniquely positioned to offer first-hand insights in suggestions to optimize the information provision in DDH care. The aim of this study was to identify the information topics that should be addressed according to the parents of children with hip dysplasia in the diagnostic and treatment phase of DDH during the first year of life. Second, we explored parental recommendations to further optimize the information provision in DDH care.

## Methods

**Study design.** This study is part of a broad qualitative research project on hip dysplasia performed at the Máxima Medical Centre, the Netherlands. Individual interviews were performed in the same group of parents that were interviewed in a preceding paper.<sup>7</sup> For the purpose of the present study, parents were specifically interviewed on parental needs and recommendations on information provision. The qualitative research approach facilitated parents to extensively report their personal information needs and recommendations in DDH care. The study was performed and reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (Supplementary table i).<sup>10</sup>

### Participants

Parents of children with DDH, who were treated with a Pavlik harness, with a maximum age of one year were included. A purposive sampling strategy was adopted to ensure diversity of parents, resulting in a representative cross-section of the DDH population. Selection was both infant-based (sex, DDH grade, and Pavlik harness treatment duration) and parent-based (education level). Parents were excluded if their child was treated by an abduction device different from a Pavlik harness, cast immobilization, or underwent surgery. Final sample size was determined based on data saturation, which was considered when no new codes emerged from the latest interviews.<sup>11</sup> A total of 30 parents were approached by phone by the paediatric orthopaedic PhD candidate (WT). Additional written information on the study was sent to 22 parents of children with DDH willing to participate. Participants gave their written informed consent before the interviews took place.

### Setting

Participants were recruited via the Máxima Medical Centre, which is a large, tertiary referral centre for paediatric orthopaedics in The Netherlands with approximately 425 new DDH patients a year. DDH care at the Máxima Medical Centre is provided by a team of healthcare professionals consisting of two paediatric orthopaedic surgeons (FvD, AB), one fellow paediatric orthopaedic surgery, two paediatric orthopaedic clinical nurse specialists (EvH, ZN) and residents orthopaedic surgery. The local DDH care pathway is depicted in Figure 1.

### Data collection

A semi-structured interview guide was developed by a mixed group of stakeholders in the DDH healthcare trajectory, consisting of: one representative of the board of the Dutch patient association for DDH (Vereniging Afwijkende Heupontwikkeling (VAH)) (MvV), two paediatric orthopaedic surgeons (JT, FvD), one paediatric orthopaedic PhD candidate (WT), and one orthopaedic researcher (MvdS). The interview guide was used to

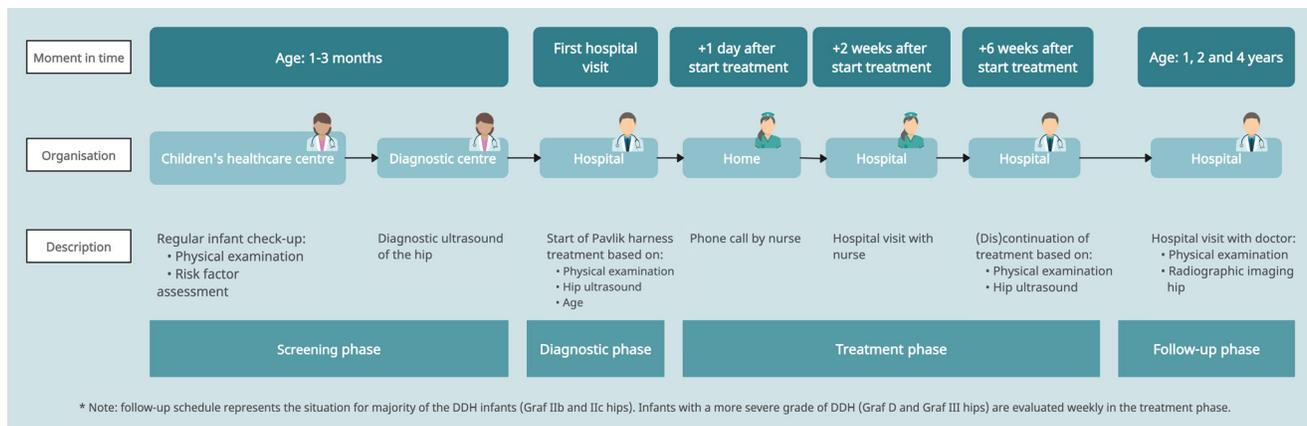


Fig. 1

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

facilitate the discussion and was iteratively modified in response to evolving study findings (Supplementary table ii). All interviews were conducted by the paediatric orthopaedic PhD candidate (WT), who was extensively trained in qualitative research methodologies. The interviewer had no prior relationship with the study participants and briefly introduced himself at the start of the interviews. Interviews were digitally conducted via a secured video consultation system: Webcamconsult (Bergen op Zoom, the Netherlands). Anonymity of the parents and infants was secured in the interview transcripts. Interviews were audio recorded and transcribed verbatim in the native language (Dutch) by an independent, professional transcription agency (TiptopGlobal, the Netherlands).

### Data analysis

Qualitative data analysis was performed using ATLAS.ti version 9.0 (Germany). Thematic analysis was used to analyze the data, according to the six step model of Braun and Clark.<sup>12,13</sup> Inductive coding of the interviews was independently performed by two researchers (WT, MvdS). After each five interviews, discrepancies and new codes were discussed and refined until consensus was reached. Following the coding process, categories and themes were developed with input from a third researcher (JT). Final codes, categories, and themes were interactively discussed by the research group and consensus was reached. Representative quotes were listed during the interviews to illustrate the themes. Quotes were translated into English by a third researcher (JT). One representative of the board of the Dutch patient association for hip dysplasia was actively involved in reviewing the results to support interpretation of the data.

### Results

A total of 22 parents of children with DDH were interviewed between September and December 2020. Overall, 20 interviews were conducted (18 involving only

the mother and two involving both parents). Mean age of parents was 34 years (standard deviation 3.0). Interview duration ranged from 12 to 52 minutes with a mean of 30 minutes. Characteristics of participating parents are listed in Table I.

**Fundamental information topics.** Interviews revealed four fundamental topics that should be addressed according to the information needs of the parents of children with DDH (Figure 2). Representative quotes were used to illustrate these parental information needs (Table II).

#### Theme 1: General information in screening phase

Interviews highlighted that the active parental information need emerged with a positive screening for DDH at the children's healthcare centre or with abnormalities on the hip ultrasound at the diagnostic centre (Figure 1). From that moment on, parents wanted general information on what is hip dysplasia, what does it entail for my child and what are the potential treatment options (Table II, quotes 1 to 2). Parents repeatedly stated that they wanted to remain in control of their child's health status and that insufficient knowledge about risk factors and preventive measures undermined this feeling (Table II, quotes 3 to 4). The role of the different healthcare organizations and healthcare professionals in the DDH healthcare trajectory was unclear to parents (Table II, quote 5). They lacked an overview of the DDH patient journey.

#### Theme 2: Patient-specific information in diagnostic and treatment phase

Once a child was officially diagnosed with DDH by a paediatric orthopaedic surgeon, the information needs of parents changed. Instead of general information on DDH, parents were mainly interested in patient-specific information, which was applicable to their child. General information as provided on the internet was not sufficient (Table II, quote 6). Parents wanted to be precisely informed on why treatment is indicated and what kind of treatment is needed for their child (Table II, quote 6).

**Table I.** Characteristics of study participants.

Interview		Parent				Child			
#	Duration (minutes)	Sex	Age	Home situation	Education level *	Sex	DDH grade	Treatment duration	
1	50	♀	30	Two parent household	HVT	♀	IIb	6 weeks	
2	43	♀+ ♂	29,31	Two parent household	HVT	♀	III	12 weeks	
3	20	♀	29	Two parent household	HVT	♀	D	6 weeks	
4	21	♀	34	Two parent household	IVT	♂	IIb	6 weeks	
5	20	♀	33	Two parent household	IVT	♂	IIb	6 weeks	
6	24	♀	33	Two parent household	University	♂	IIb	6 weeks	
7	24	♀	29	Single parent household	IVT	♂	IIc	6 weeks	
8	38	♀	29	Two parent household	IVT	♂	D	6 weeks	
9	52	♀	29	Two parent household	HVT	♀	IIb	6 weeks	
10	30	♀	31	Two parent household	HVT	♀	IIb	6 weeks	
11	35	♀	28	Two parent household	HVT	♀	III	12 weeks	
12	37	♀	41	Two parent household	IVT	♂	IIc	6 weeks	
13	22	♀	35	Two parent household	IVT	♀	IIb	12 weeks	
14	32	♀	28	Two parent household	University	♀	D	6 weeks	
15	29	♀+ ♂	29,31	Two parent household	IVT	♂	IIb	6 weeks	
16	25	♀	28	Two parent household	IVT	♀	IIc	6 weeks	
17	12	♀	31	Two parent household	University	♂	D	12 weeks	
18	33	♀	30	Two parent household	University	♀	IIc	6 weeks	
19	21	♀	29	Two parent household	HVT	♂	IIb	6 weeks	
20	27	♀	31	Two parent household	HVT	♀	IIb	6 weeks	

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

Additionally, a strong wish for an indication on the duration of Pavlik harness treatment existed (Table II, quote 7).

### Theme 3: Practical information in treatment phase

Parents explained that there was a need for adequate practical information on living with a child in a Pavlik harness, which was often underexposed. In addition to the demonstration on how to apply the abduction device by the paediatric orthopaedic clinical nurse specialist, a strong wish for a hands-on session on applying the Pavlik harness to their child under supervision of the paediatric orthopaedic clinical nurse specialist was mentioned in the interviews (Table II, quotes 8 to 9). In the home situation, parents would like to have clear instructions on which physical movements a child is allowed to make in a Pavlik harness, and movements and activities that should be prevented (Table II, quote 10). Also practical issues with clothing was a recurring topic in the interviews (Table II, quote 11). Multiple parents expressed the desire for information on safe transportation options with specific car seats for a child in a Pavlik harness (Table II, quote 12). Difficulties regarding hygiene of caring for a child in a Pavlik harness was a frequently heard complaint. Parents needed clear instructions on showering, bathing, changing a diaper (Table II, quote 13), and washing instructions of the Pavlik harness (Table II, quote 14). A large group of the interviewed parents were interested in experiences from other parents of children with DDH,

who went through the same process. Parents appreciated practical tips from other parents, which were easily accessible on the Facebook page of the Dutch patient association for DDH (Table II, quote 15).

### Theme 4: Future perspectives in treatment and follow-up phase

Once Pavlik harness treatment was started, parents wished for information regarding what impact the Pavlik harness would have on their child and development (Table II, quote 16). They wanted information on how to deal with a child in a Pavlik harness at home. Parents were concerned about how the Pavlik harness would affect their daily life and would lead to potential sleeping problems (Table II, quote 17). Once Pavlik harness treatment was discontinued, parents lacked guidelines on milestones and red flags regarding the development of their child. Parental worries arose especially on the motor development after successful treatment of DDH (Table II, quotes 18 to 19). They needed information on the ability to walk, weightbearing, which movements of the affected leg are allowed, and when to contact the hospital in case of lagging development or striking movements (Table II, quote 20). During and after the treatment, parents were in doubt which healthcare professional or organization to contact with questions; whether it was the general practitioner, children's healthcare centre doctor, paediatric orthopaedic clinical nurse specialist, or the paediatric orthopaedic surgeon (Table II, quote 21).

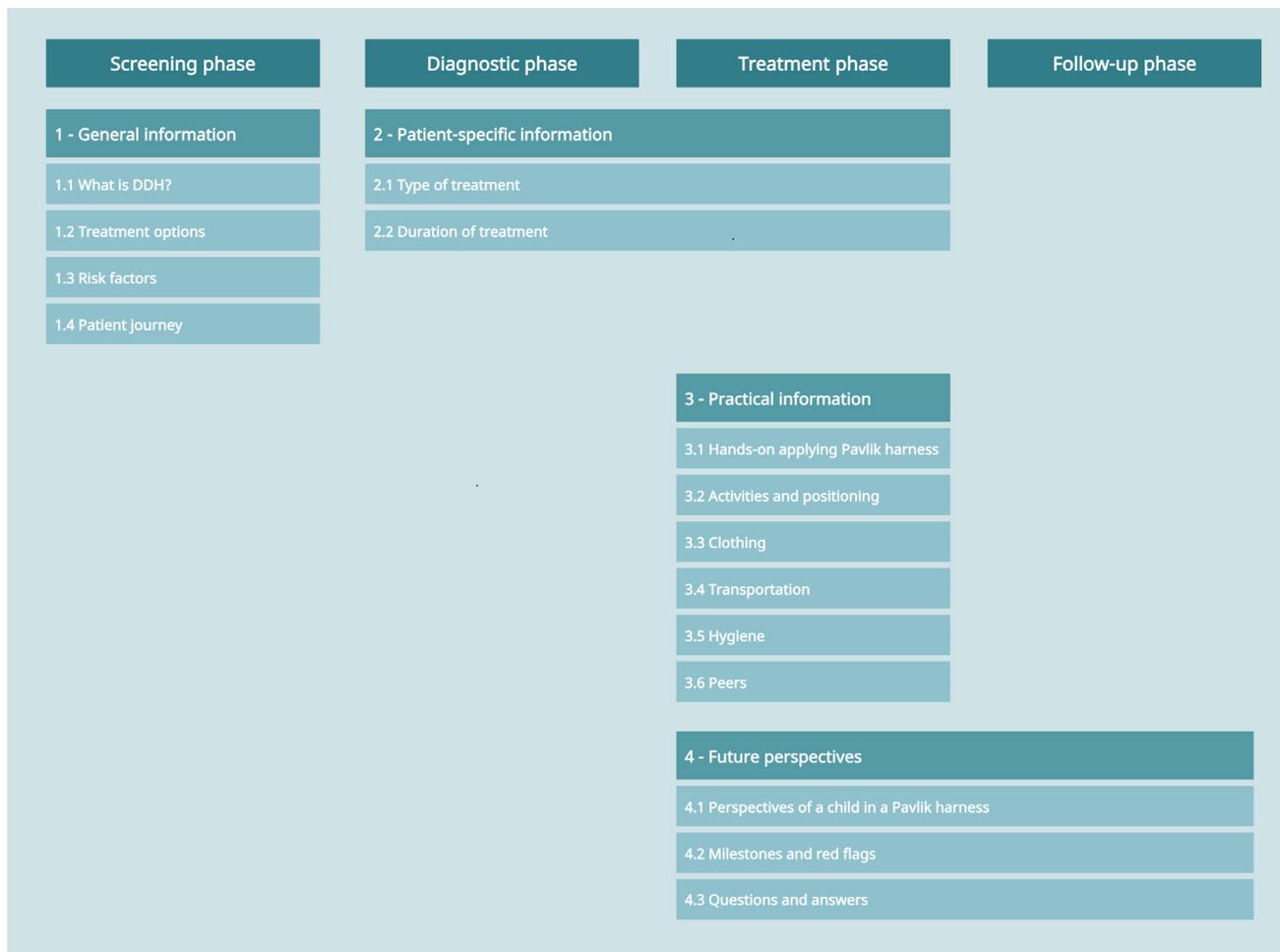


Fig. 2

Overview of the four fundamental information topics in developmental dysplasia of the hip care.

### Recommendations on information provision

Interviews yielded five recommendations that parents of children with DDH have, to further optimize the information provision in the DDH healthcare trajectory: 1) availability of pre-hospital information; 2) personalized information; 3) visual explanation hip ultrasound; 4) presence of both parents; and 5) centralization of care (Figure 3 and Table III).

#### Theme 1: Availability of pre-hospital information

Majority of the interviewed parents suggested that information should be available earlier during the DDH patient journey (Table III, quote 22). Prior to the first hospital visit, where the official diagnosis is made, parents wished to receive trustworthy general information on DDH (incidence, risk factors, diagnosis, treatment, and overview patient journey) as they want to be prepared for the first hospital visit to ask more specific questions on the disease and treatment. In the current DDH healthcare trajectory, parents are fully dependent on online DDH information

prior to the first hospital visit, which is often inaccurate, not applicable, and difficult to read.

#### Theme 2: Personalized information

A strong desire for personalized information was expressed by multiple parents (Table III, quote 23). Information on DDH on the hospital website and information leaflets was often too general, and not accurately applicable to the situation of their child. Parents lacked patient-specific information which was provided in a timely fashion. A few parents wished for an interactive smartphone application, which provided information tailored to their child.

#### Theme 3: Visual explanation hip ultrasound

Although individual differences exist, the majority of the parents preferred visual information over written information. Parents indicated that visual information would make it easier to understand and to recall the newly acquired information (Table III, quote 24). Parents

**Table II.** Overview of themes, categories, and quotes on the main topics of information in DDH care.

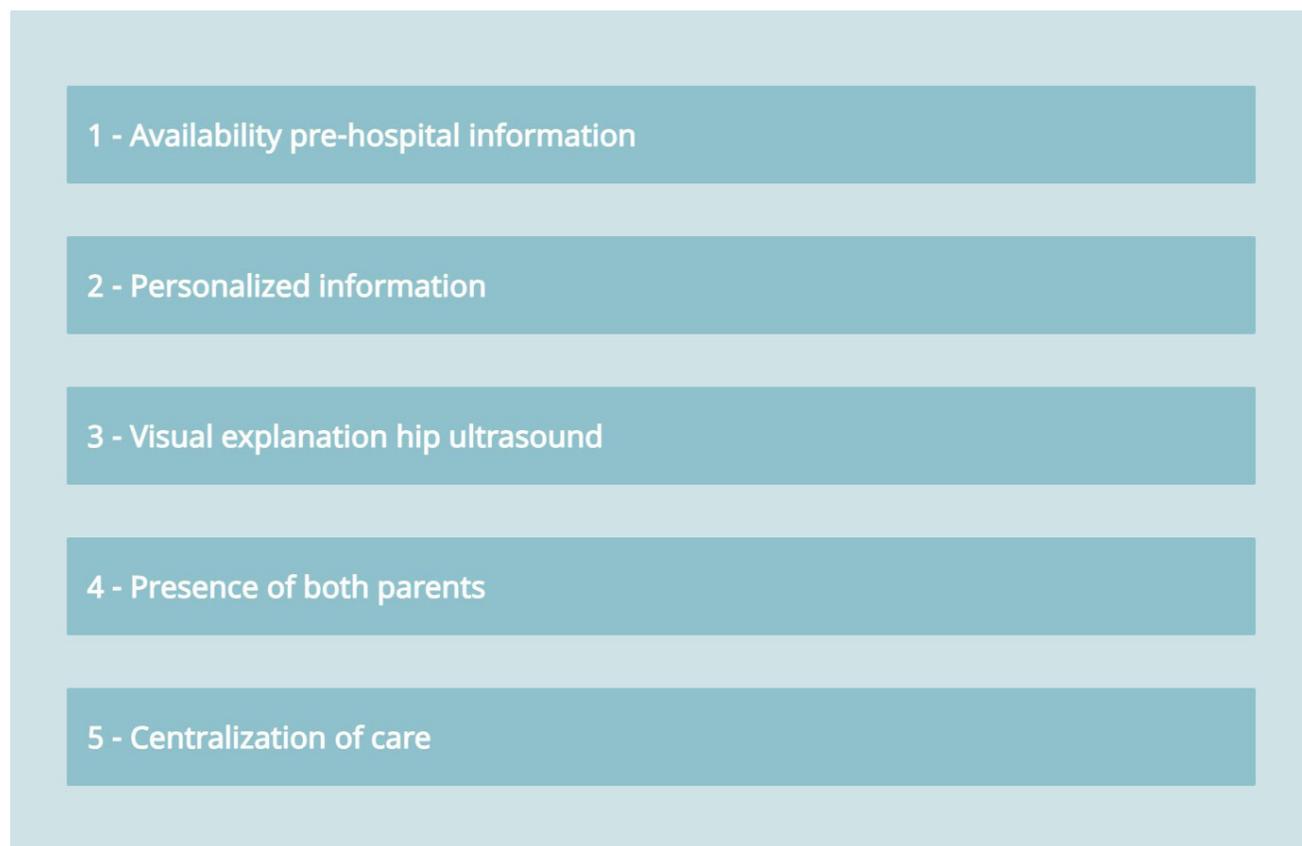
Theme	Category	Quote [quote number; interview number]
<b>Theme 1: General information</b>	1.1 What is DDH?	I was curious about what hip dysplasia was and what it meant for my child? [q1;i2]
	1.2 Treatment options	We did not know if they were going to start treatment. Whether it was necessary or not. We were curious about that. Then I started searching the internet for possible treatment methods. [q2;i5]
	1.3 Risk factors	It is important that parents themselves feel in control. Should I pay attention to something with my child? Maybe I can do something myself to prevent hip dysplasia? [q3;i12] It would have helped, if they told me on forehand that it is good for his hips to put him in a infant carrier. [q4;i6]
	1.4 Patient journey	The relationship between the children's healthcare centre, the diagnostic centre and the hospital was not clear to me. How do they relate to each other? Why did we have to go to all these organizations? [q5;i12]
<b>Theme 2: Patient-specific information</b>	2.1 Type of treatment	The information you find on Google is not your child's situation. Ultimately, you want information that applies to your own child. Especially when it comes to treatment. Will it be a Pavlik harness, cast or surgery? [q6;i11]
	2.2 Duration of treatment	As a parent, of course you want to know for the treatment duration of the Pavlik harness. That is the first question you want to know. You want an indication of how long it will take. [q7;i5]
<b>Theme 3: Practical information</b>	3.1 Hands-on applying Pavlik harness	I think it would be nice if the nurse measures and demonstrates the applying of the Pavlik harness and that you as parent can also give it a go. So, you know for sure that you are doing everything right and someone has checked it. [q8;i1] For example, I would have liked it if I had tried it myself in clinic. The nurse had explained it once, but when you are at home you usually do not remember that anymore. [q9;i10]
	3.2 Activities and positioning	I would have liked to know; is he allowed to roll over, creep or crawl with the Pavlik harness on? The first time I put him on his stomach, I found it quite tense. Maybe you could give some advice on this. What is allowed and what is not allowed? [q10;i5]
	3.3 Clothing	Questions arose on the clothing. For instance, should the Pavlik harness go under the clothes or on top. What is pleasant for a infant? [q11;i11]
	3.4 Transportation	Something I quickly found out myself when I heard that my oldest was getting a harness; I started looking for special car seats or a Maxi-Cosi. I did not hear that from the children's healthcare centre, not from the hospital, but I found out myself. It helped me a lot because we quite regularly spend a little longer in the car than half an hour. [q12;i20]
	3.5 Hygiene	How should we go about taking a shower? I think it was allowed to take it off for an hour a day and I thought to myself: should I be very strict and well change the diaper and take a quick bath? [q13;i11] Also washing the harness. Maybe trivial, but we did call for advice because it was on the Pavlik harness that you could only wash it by hand, but it had a very long drying time and you were not allowed to put it in the tumble dryer and still you should actually try to keep it on twenty-four hours a day. [q14;i13]
	3.6 Peers	Tips and tricks on the Facebook page for parents of infants with DDH were very helpful. How they experienced the treatment and how they dealt with this was useful. Some practical tips of other parents on the harness were very handy. [q15;i18]
<b>Theme 4: Future perspectives</b>	4.1 Perspectives of a child in a Pavlik harness	The prospects of what the future will bring, how does such a trajectory go. That would have been nice. [q16;i8] What would happen after the treatment had started? I think most of the fear was: "will she still sleep?" [q17;i6]
	4.2 Milestones and red flags	There is quite a long period in between [between the end of Pavlik harness treatment and 1 year follow-up appointment] during which I wondered whether my child would continue to develop well in motor skills. Especially with a child who has a hip disorder. I found it stressful to leave such a long period in between [clinic visits after the harness was discontinued]. [q18;i2]

Continued

**Table II.** Continued

Theme	Category	Quote [quote number; interview number]
		Because it is my first child, I had no idea what to expect and what is normal in terms of development. I was particularly unsure, because I did not know what to look out for and when it would be too late or cause problems. [q19;i9]
	4.3 Questions and answers	It is useful to know what you should pay attention to at what age and what you can expect in terms of movements that are allowed. When should she walk? [q20;i4]
		When we were at home, we felt like; who should we contact? In case we should have had questions, were can we go to? Can we call the hospital, or do we send an email or go to the children's healthcare clinic? [q21;i12]

DDH, developmental dysplasia of the hip.

**Fig. 3**

Parental recommendations on information provision in developmental dysplasia of the hip care.

explicitly stated they had a better understanding of the nature of the disease and the treatment effect, once ultrasound images of the hip were shown and explained with additional schematic explanatory drawings by the paediatric orthopaedic surgeon (Table III, quote 25). Drawings of the differences between the ultrasound image before and after treatment with increased acetabular coverage of the hip, provided reassurance according to parents (Table III, quote 26).

#### Theme 4: Presence of both parents

One of the COVID-19 restrictions, which allowed the presence of only one parent during the outpatient hospital visit, demonstrated that parents deeply care about the presence of both parents at the hospital visit. They repeatedly pointed out the value of attending a vital moment in their child's life with the two of them, rather than being alone (Table III, quote 27). Another benefit of

**Table III.** Overview of themes and quotes on recommendations to optimize the information provision in DDH care.

Theme	Quote [quote number; interview number]
<b>Theme 1: Availability of pre-hospital information</b>	I would suggest to give general information on DDH at the children's healthcare centre. That is the first moment you hear that something is wrong with your child. I was totally unaware of what DDH was. So, when I was home I went straight to the internet to see what DDH was and I saw all kind of scary images there on casting and surgery. If they would have given me an information leaflet or a trustworthy website with information on DDH, it would have prevented this scary time between the children's healthcare centre and official diagnosis in the hospital, which took one week. [q22;i2]
<b>Theme 2: Personalized information</b>	The information in the information leaflet is very general. If your child has something specific, it is not in the leaflet. An information tool with more specific information for my child would make it much better. A smartphone application for instance, that specifically adapts to your child's situation, that would be ideal. [q23;i16]
<b>Theme 3: Visual explanation hip ultrasound</b>	The children's healthcare centre provides you with an infographic about nutrition for an infant: at 6 months and at 12 months and without a lot of text. That is also very helpful and easy to understand. I am visually oriented, so such an infographic makes really helpful. It makes it easier to remember and understand. [q24;i12] What I liked, is that the hip ultrasound was explained with a drawing, showing how the hip should look like and what it did look like in our son. That was very enlightening. [q25;i17] Verbal explanation by the doctor was nice, because that is what you want to hear as a parent. Explanation of the ultrasound images can be an addition and even more reassuring. Especially when you see the differences between the beginning and the end of treatment. Seeing the improvement visualized would reassure me even more. [q26;i2]
<b>Theme 4: Presence of both parents</b>	When you visit the hospital alone as a parent, you have to report the information to your partner once you are at home. I was unsure whether I had mentioned everything to my partner. I think you deliver better care when both parents just get the information firsthand. [q27;i10]
<b>Theme 5: Centralization of care</b>	I think it would have been better if the appointment with the paediatric orthopaedic surgeon directly followed the hip ultrasound. In our situation, we went to the diagnostic centre for the hip ultrasound and had to wait one week before the appointment with the paediatric orthopaedic surgeon in the hospital. That was not the easiest time to go through. [q28;i20]

DDH, developmental dysplasia of the hip.

both parents attending, was the capability of recalling information.

#### Theme 5: Centralization of care

The clinical care pathway for children with DDH at the Máxima Medical Centre is arranged in a way that the hip ultrasound is made at a diagnostic centre and only children with abnormal findings on the hip ultrasound are referred to the paediatric orthopaedic surgeon in the hospital (Figure 1). Some parents reported this infrastructure as an unpleasant experience as parents had to wait a few days between the hip ultrasound and the hospital visit. One mother preferred a 'one stop shop' principle, where the hip ultrasound is made at the hospital with immediately following the appointment with the paediatric orthopaedic surgeon (Table III, quote 28).

## Discussion

This study offers novel, in-depth insights into the information needs and recommendations of parents caring for a child with DDH. The research project focused on the parental view of optimizing information provision in DDH care, rather than focusing on the healthcare professionals view. Together with the input from the Dutch patient association for DDH, we were able to provide an extensive overview to optimize the information provision in DDH care.

In paediatric orthopaedic care, little is known about the information parents want to receive and how this is related to the information the paediatric orthopaedic surgeon provides. In the field of general surgery, it has been shown that information delivery is based on the healthcare professional's view of what information should be provided.<sup>14</sup> Building a patient information system solely based on healthcare professionals ideas, potentially leads to a discrepancy between the information patients receive and the information patients need. Our qualitative study on information needs and recommendations of parents of children with DDH tries to fill this gap.

A previous study on parental experiences in DDH care showed that parents had concerns with insufficient information provision prior to the first hospital appointment with their child.<sup>7</sup> A study by Gordon et al<sup>15</sup> highlighted that one quarter of parents of children aged six to ten years did not receive adequate information prior to the hospitalisation for surgery. Our study findings underline the importance of information provision prior to the first hospital visit. Parents are in need of general information on what is DDH and what does it mean for their child? Consequence of suboptimal pre-hospital information, is the search for online information. In paediatric care, it is reported that 21% of the parents use internet before the

first outpatient clinic appointment to inform themselves on the reason for consultation.<sup>16</sup> Parents of children with DDH expressed a strong interest in online health information.<sup>17</sup> Quality and readability of the online information on DDH varies significantly and is generally written at a level above that recommended for publically distributed medical information.<sup>18</sup> A study on online DDH information revealed that of 63 websites with information on DDH, only 1.6% was below the recommended level for medical information (sixth grade), and 12.7% below the USA average reading level (eighth grade).<sup>18</sup> We previously showed that the complex maze of unfiltered online information on different treatment options for DDH led to insecurity and anxiety among parents.<sup>7</sup> Thrustworthy and verified general information earlier in the patient journey would reduce the online search for information on DDH, potentially preventing anxiety due to the broad spectrum of unfiltered online information. This underlines the importance of reliable and understandable online information on DDH to prevent these negative side-effects.

The beneficial effect of adequate pre-hospital medical information provision was acknowledged in previous studies. In hip and knee arthroplasty surgery, it is shown that supplemental web-based patient education, in addition to information by the orthopaedic surgeon alone, significantly increases the confidence in knowing what questions to ask the doctor and the appropriateness of patient questions.<sup>19</sup> In a paediatric population, it has been shown that parents often do not know the right questions to ask and that information prior to the consultation might be helpful to prepare better for a first consultation.<sup>20</sup> By providing parents general information on DDH prior to the forthcoming hospital visit, parents will be better prepared which potentially creates a more equal partnership between the parents and paediatric orthopaedic surgeon, which is one of the key concepts of patient-centered care.<sup>21</sup> Furthermore, it has been shown that the recollection of medical information is better when newly provided information fits into the previous knowledge.<sup>22</sup> Better general knowledge on DDH prior to the first hospital visit could potentially enhance the memory of the medical information that is provided when official diagnosis is set by the paediatric orthopaedic surgeon in the hospital.

Another important issue is the format in which information is provided to parents of children with DDH. In most cases, medical information is given verbally.<sup>5</sup> Yet, an important role is played by written and visual information. Difficulties for patients with low education or low literacy have been reported with written information.<sup>23</sup> These patients benefit more from visual information in the form of pictographs. In cancer and HIV research, medical information was correctly recalled in 14% with verbal information and in 80% when pictographs were used.<sup>24,25</sup> Our studies results underline these results as

majority of the parents preferred visual information in addition to the verbal information. This preference for visual information was independent of the educational level or age of parents.

Over the last couple of decades, a paradigm shift from disease-centered care to patient-centered care has been made. An important component of patient-centered care is respecting patient and family preferences.<sup>4</sup> Ultimate goal of this concept is to improve individual health outcomes and satisfaction rates instead of population health outcomes.<sup>4</sup> This study underlines that parents wish for more than solely information on the medical part. Interviews highlighted that both practical information and experienced based information from peers was underexposed. A literature review emphasized the need for social support for parents, as 30% of parents used emotional support groups and 35% used the internet for communication with other parents.<sup>26</sup> The importance of closed online communities where parents can get advice and share thoughts with other parents, who went through the same treatment, is valuable for many of them and potentially leads to a feeling of solidarity.<sup>27</sup> Parents feel free to say whatever they think in these closed communities, which potentially brings some questions forward that parents will not ask in the hospital. Quality of the shared information in the closed online communities in DDH care in the Netherlands is guaranteed by board members of the Dutch patient association for DDH, who are actively involved in the private Facebook page (2,288 members) for parents of children with DDH.

**Limitations.** Our study has a few limitations that should be considered when interpreting the findings. First, this study was performed at a large tertiary referral centre for children with DDH in the Netherlands. This may limit the transferability of our results to other contexts and regions, particularly due to the local infrastructure of DDH care in our hospital. Second, fathers were under-represented in the present study. Paternal under-representation is a known phenomenon in paediatric research and contributed to: a lack of time, a lack of research interest, and a lack of accessibility according to mothers.<sup>28</sup>

The future goal is to implement the parental needs and preferences in our DDH healthcare trajectory to further optimize the care for infants with DDH. As the diagnostic and treatment process of DDH is a dynamic process, with constantly interchanging situations depending on the disease trajectory and individual differences, information needs changes over time and differs between parents. Therefore, present-day verbal and written information is not ideally fit to comply with these information needs. A more prominent role for technological aids, such as smartphone and computer aided information systems, lies ahead as these information tools are perfectly suited to customize the information to the needs and preferences of each individual child and parent at a specific

moment in time. Development of a DDH patient smart-phone application with tailor-made, visually supported and time specific information and a combination of both medical and practical information is a potential solution.

In conclusion, parents prefer reliable and understandable general information on DDH prior to the first hospital visit to be better prepared for the official diagnosis. Once diagnosed with DDH, parents wish for patient-specific, visually-supported, and time-specific information on their child with DDH. By shifting from a 'one size fits all' to a patient-specific, tailored approach, a potential decrease in parental anxiety, insecurity, confusion, and increase in parental empowerment and treatment adherence can be established throughout the diagnostic and treatment phase of DDH.



### Take home message

- Parents want to be better prepared for the diagnosis by receiving trustworthy general information on developmental dysplasia of the hip (DDH) prior to the first hospital appointment.
- Parental information need shifts from general information in the diagnostic phase to patient-specific information in the treatment phase of DDH.
- Building a patient information system solely based on healthcare professionals ideas leads to a discrepancy between the information parents receive and the information parents need.

### Twitter

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### Supplementary material



Consolidated criteria for REporting Qualitative research (COREQ) checklist, and interview guide.

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