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A Global Survey of Patient and Caregiver Experiences Throughout Care for Developmental Dysplasia of the Hip

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Background: Diagnosis and treatment for developmental dysplasia of the hip (DDH) varies greatly depending on condition severity, age at diagnosis, and professional opinion. Little is known about patient experiences across the globe. We aimed to characterize global patient and caregiver experiences during DDH care and to highlight patient-identified priorities.

Methods: We developed a cross-sectional survey in collaboration with 7 DDH outreach organizations. DDH patients and/or their caregivers (above 18 y old) were invited to complete an international online survey about their experiences. Participants were recruited through web media of all collaborating organizations. Data collection took place over 3 months. Descriptive statistics were used to analyze quantitative results. Qualitative content analysis was used to categorize open-ended responses.

Results: A total of 739 participants completed the survey, representing 638 (86.3%) parents/guardians of DDH patients, and 101 (13.7%) patients. Three hundred eighty-six (52.2%) participants received diagnosis by 3 months of age; mean age of diagnosis was 15.96 months (90% confidence interval = 12.04, 19.91). Of 211 participants with family history of DDH, 68 (32.3%) did not receive DDH screening. Of 187 patients born breech, 82 (43.9%) did not receive DDH screening. In total, 36/94 (38.3%) participants with both family history and breech birth did not receive DDH screening. Most participants reported treatment (696/730, 95.3%), including bracing (n = 461) surgery (n = 364), and/or closed reduction (n = 141). A total of 144 patients reported > 1 surgery; 82 reported > 3 surgeries. Participants reported a range of 1 to 400 visits to health care professionals for DDH care across 1 to 66 years. Lack of information and resources on treatment practicalities and timelines, along with emotional burden of diagnosis, were greatest challenges reported.

Conclusion: Results demonstrate that DDH diagnosis and treatment can pose significant burden on patients and caregivers. Reliable public information is needed to support those affected. Global educational efforts are needed to raise awareness of DDH risk factors, signs, and symptoms among care providers, to increase awareness and improve identification, screening, and monitoring of at-risk children.

Key Words: DDH, survey, global, hip, experience, swaddling, breech, Pavlik, rhino, brace, hip dysplasia

(*J Pediatr Orthop* 2021;41:e392–e397)

Developmental dysplasia of the hip (DDH) is a common pediatric hip disorder with a wide spectrum of severity. DDH has an incidence of ~6.6 of 1000 children in Canada,[1] and reported incidence of up to 1 in 100 internationally.[2] Consequences of DDH include pain, hip-replacement later in life, and general mobility issues affecting quality of life.[3] Diagnosis and treatment during childhood varies greatly depending on severity, age at diagnosis, and professional opinion.[2]

Screening and surveillance programs established for DDH identification at early stages of presentation mitigate challenges that arise with later diagnosis; late diagnosis complicates clinical outcomes and quality of life.[4–6] The Canadian Task Force on Preventative Healthcare, regarding the screening and management of DDH in newborns, considers diagnosis of DDH in an infant after the age of 3 to 6 months to be delayed.[7] We used the 3-month mark as our threshold for delay in our study, as

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The authors would like to thank all members of the IHDR Knowledge Translation Advisory Board for assistance designing and interpreting this study: Sarah Twomey, Nancy Muir, Bridget Watts, Loredana Guetg-Wyatt, Natalie Trice, Charles Price, Regina Wilken, and Jennifer Farr. The authors thanks the collaborating organizations: Health Hips Australia, Miles4Hips, Spica Life, Steps Charity Worldwide, DDH UK, International Hip Dysplasia Institute, and I'm A HIPpy. Thanks to Ash Sandhu and Jeffrey Bone at BC Children's Hospital Research Institute for assisting with data analyses.

No external funding for this manuscript.

The authors declare no conflicts of interest.

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Supplemental Digital Content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's website, www.pedorthopaedics.com.

DOI: 10.1097/BPO.0000000000001813

opposed to a value within the 3 to 6 months period, as earlier identification provides quicker referral to appropriate care and improved outcomes.

Unifying guidelines for DDH surveillance and treatment[2,8] were published in 2014 by the American Academy of Orthopedic Surgeons, and adopted by the International Hip Dysplasia Institute on a global scale.[2,7,9] These guidelines recommend screening for DDH at birth, with clinical hip evaluation until a child is walking and close observation of newborns presenting with clinical markers of DDH. Close follow-up through imaging is recommended if potential for DDH is recognized.[2,8] These guidelines seek to standardize diagnosis and treatment of DDH; however, implementation varies greatly on a global scale with respect to patient populations, accessibility and availability of resources.[2,8]

DDH treatments vary globally, but most common is abduction therapy using supports such as the Pavlik harness.[7] In Canada, a typical patient diagnosed between 1 and 6 months with hip dysplasia in 1 hip undergoing treatment may expect regular health care visits, potentially on a weekly basis for a period of up to 18 weeks, yet this varies even within Canada.[10] Treatment experiences across the globe remain unknown[3] and every patient's treatment journey is unique. Characterizing global patient experience and gaps in care delivery is a critical first step to inform DDH practice guidelines that reflect patient needs. Thus, further investigation of experiences of DDH patients and their caregivers is needed. The objective of this study was to help characterize patient and family experiences across the globe during diagnosis and treatment for hip dysplasia.

METHODS

All procedures were approved by the Research Ethics Board at our institution. A cross-sectional survey design was used for this study. We developed an international online survey in collaboration with representatives of 7 hip dysplasia outreach organizations (International Hip Dysplasia Institute, Healthy Hips Australia, I'm A HIPpy, Steps Charity Worldwide, DDH UK, Spica Life, and Miles4Hips). The survey included quantitative and qualitative questions to capture participant demographics and experiences during DDH diagnosis, treatment, and management. Questions were developed through consultation with each organization to capture global data where existing knowledge was lacking. The survey was designed to explore a participant's personal experiences based on known risk factors and recommended care processes across the world. The survey was offered in 2 modalities: a full-length comprehensive questionnaire and an abbreviated version (Appendix A, Supplemental Digital Content 1, http://links.lww.com/BPO/A344). Participants chose which to complete based on their time and interest.

Participants were recruited online through email lists at a pediatric tertiary care center, and web media of all collaborating organizations. Patients with DDH and caregivers of patients with DDH were invited to participate. Participants were included if they were over 18 years old and consented. Participants were excluded if they could not read or write in English. Data were collected and managed using REDCap electronic data capture tools[11,12] hosted at our center's Research Institute. REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies.[11,12] The survey link was available online for 3 months.

Descriptive statistics were used to analyze quantitative results. Qualitative responses were randomly sampled (n = 100 per question), and qualitative content analysis was performed to categorize responses and identify themes. Qualitative data were analyzed by 2 members and cross-compared. Discrepancies were discussed with a third team member until agreement was reached.

RESULTS

A total of 739 participants completed the survey (full, n = 553; abbreviated, n = 186), representing 638 (86.3%) parents/guardians of DDH patients, and 101 (13.7%) patients reporting their own experiences. Participants reported hip dysplasia diagnosis in the right hip (n = 114/737, 15.5%), left hip (n = 227/737, 30.8%) or both hips (n = 396/737, 53.7%). Most births took place at a hospital (n = 542/551, 98.4%); participants reported vaginal (n = 315/547, 57.6%) or cesarean (n = 232/547, 42.4%) delivery, and 187/729 (25.6%) patients were born breech. Participants reported receiving care in the same country as birth.

Age of diagnosis ranged from day of birth to 49 years (Table 1). Mean age of diagnosis was 15.96 months (90% confidence interval = 12.04, 19.91), while median was 2 months. A total of 407/737 (55.2%) patients reported receiving screening for hip dysplasia through newborn hip check (n = 318), ultrasound (n = 137), clinical assessment (n = 80), and/or x-ray (n = 37). A total of 271/737 (36.8%) participants did not receive any screening, and 59/737 (8.0%) were unsure. Table 2 shows age of diagnosis, screening, and treatment by country of birth.

Risk Factors

Participants reported on risk factors for hip dysplasia. Swaddling experiences are described in Table 3. Parents primarily learned about hip-healthy swaddling

TABLE 1. Patient Age at Developmental Dysplasia of the Hip Diagnosis

Age	N (%)
0.00-3.00 mo	386 (52.2)
3.01-12.00 mo	138 (18.7)
1.01-2.00 y	100 (13.5)
2.01-3.00 y	16 (2.2)
3.01-4.00 y	7 (0.9)
4.01-5.00 y	2 (0.3)
5.01-10.00 y	5 (0.7)
10.01-15.00 y	3 (0.4)
15.01-45.00 y	12 (1.6)
Over 45.00 y	2 (0.3)
Missing age data	67 (9.1)

TABLE 2. Country of Birth and Differences in Age at Diagnosis, Screening, and Treatment for Developmental Dysplasia of the Hip Patients

Variables	Country of Birth, n (%)				
Total Responses	UK	Australia	USA	Canada	Other
N (%)	267 (36.1)	201 (27.2)	168 (22.7)	46 (6.2)	55 (7.4)
Age of diagnosis					
0-3 mo	124 (46.4)	125 (62.2)	92 (54.8)	21 (45.7)	24 (43.6)
> 3 mo	116 (43.4)	66 (32.8)	57 (33.9)	21 (45.7)	24 (43.6)
Missing data	27 (10.1)	10 (5.0)	19 (11.3)	4 (8.7)	7 (12.7)
Received screening					
No	114 (42.7)	63 (31.3)	52 (31.0)	20 (43.5)	22 (40.0)
Yes	137 (51.3)	127 (63.2)	96 (57.1)	22 (47.8)	24 (43.6)
Unknown	16 (6.0)	11 (5.5)	20 (11.9)	4 (8.7)	9 (16.4)
Received treatment					
No	9 (3.4)	11 (5.5)	4 (2.4)	4 (8.7)	6 (10.9)
Yes	252 (96.6)	189 (94.5)	163 (97.0)	42 (91.3)	49 (89.1)
Missing data	6 (2.2)	1 (0.5)	1 (0.6)	0	0

from online DDH organizations (n = 265), pediatricians (n = 81), midwives (n = 26), and family doctors (n = 18).

A total of 187/729 (25.3%) patients were born in the breech position, and 82/187 (43.9%) of these participants reported that they did not receive screening for DDH. In total, 211/728 (29.0%) participants reported a family history of hip dysplasia from the patient's parent (n = 73), cousin (n = 62), aunt/uncle (n = 50), sibling (n = 46), grandparent (n = 19), and/or other relative (n = 27). Table 4 describes participants with known family history. Of 94 participants that reported both a known family history and a breech birth, 36 (38.3%) reported that they did not receive screening for DDH. For parents with known family history who reported swaddling their child, 51/102 (50.0%) said they were unaware of hip-healthy swaddling techniques at the time of their child's birth.

Treatment

Most participants reported receiving treatment (696/730, 95.3%). Only the full survey modality captured additional treatment details: 146/520 (28.1%) began treatment by 6 weeks, 106 (20.4%) by 3 months, 108 (20.8%) by 1 year, and 106 (20.4%) began treatment after 1 year of age. Treatments included bracing (n = 461) surgery (n = 364), and/or closed reduction (n = 141). Type of treatments based on age of diagnosis are presented in Appendix B1 (Supplemental Digital Content 2, http://links.lww.com/BPO/A345). For those who did not receive treatment, age of diagnosis ranged from 1 week to 49 years.

Most common braces were the Pavlik harness (n = 221), rhino cruiser (n = 152), and/or Denis Brown brace (n = 50). Bracing duration varied, with reports of fewer than 6 weeks (n = 37), 6 to 12 weeks (n = 102), 13 to 18 weeks (n = 56), > 18 weeks (n = 131), or an unknown amount of time (n = 23). Surgeries were open reduction only (n = 86), open reduction with femoral osteotomy (n = 63) and/or open reduction with pelvic osteotomy (n = 78). Age at first surgery varied widely (Appendix B2, Supplemental Digital Content 2, http://links.lww.com/BPO/A345). In total, 144 patients reported > 1 surgery; 82 of these participants reported 3 or more surgeries. One participant reported 41 surgeries and procedures (eg, pin removal) over 22 years of treatment.

Participants visited multiple health professionals, including orthopaedic surgeons (n = 653), family doctors (n = 265), pediatricians (n = 302), physical therapists (n = 208), occupational therapists (n = 66), chiropractors (n = 30), and/or massage therapists (n = 16). Participants estimated their number of visits to health care providers across for DDH care and timespan of these visits (Fig. 1). Number and timespan of visits differed based on age at diagnosis (Table 5).

TABLE 3. Parent's Use and Knowledge of Hip-healthy Swaddling Techniques

Variables	Yes, n (%)	No, n (%)	Unknown/ Missing, n (%)
Swaddled their child (developmental dysplasia of the hip patient) as a baby	319 (43.7)	360 (49.3)	51 (7.5)
Aware of hip healthy swaddling techniques at time of child's birth	237 (35.4)	432 (64.6)	70 (9.5)
If not aware at the time of birth (n = 432), aware of hip healthy swaddling techniques now	323 (74.8)	109 (25.2)	0
Total aware now (n = 739)	560 (75.8)	109 (14.7)	70 (9.5)

Family Experiences

Participants responded to open-ended questions describing what they found most challenging and most helpful during care. Participants noticed there was something wrong in themselves (eg, pain) or their child (eg, unusual gait), and sought care accordingly. Yet, many reported needing to visit multiple health care professionals before assessment was pursued: "*[we] were ignored and were told it was growing pains*". This postponed diagnosis and affected families emotionally: "*that was most difficult, knowing something was wrong yet no one was doing anything*". Others described early diagnosis after standard screening, with quick action from care providers.

Lack of information and resources from health care providers was the biggest challenge for most participants. They described significant difficulty adjusting to braces, harnesses, and casts, with little guidance. Participants lacked practical information such as where to find appropriate clothing, furniture and car seats, and how to breastfeed or change diapers for children undergoing treatment. "*I didn't know anything about the harness… simple things like her clothes would no longer fit*". Emotional burden and shock were also challenges. Participants reported uncertainty and worry surrounding treatment types, outcomes, and timelines. "*[We were] not aware after initial treatment we had to continue with yearly checks. We were cleared at 7 months then diagnosed at 19 years requiring surgery*".

Nearly all participants identified online information and support communities as most helpful, along with

TABLE 4. Risk Factors and Diagnosis Processes for Participants With Family History of Hip Dysplasia (n = 211)

Age of Developmental Dysplasia of the Hip Diagnosis	0-3 mo, n (%)	> 3 mo, n (%)	Missing Data, n (%)
N (%)	121 (57.3)	68 (32.2)	22 (10.4)
Variables	No	Yes	Unknown
Swaddled as a baby	93 (44.1)	102 (48.3)	16 (7.6)
Parent was aware of hip-healthy swaddling at time of child's birth	116 (55.0)	75 (35.5)	20 (9.5)
Born in breech position	164 (77.7)	47 (22.3)	0
Received screening	68 (32.2)	129 (61.4)	13 (6.2)
Referred to orthopaedic specialist	29 (18.5)	128 (81.5)	54 (25.6)

support from specialists when available. They relied on these resources for emotional support, to relate to experiences of others, and to clarify unanswered questions. "*Without [online organizations], I wouldn't have known where to start*". Some participants also turned to nurses or community health workers for additional support that specialists could not provide.

DISCUSSION

Our study highlights the variable experiences of patients and caregivers across diagnosis and treatment for hip dysplasia even within the same countries, as a first step to formally understand burden of the disease from the family perspective. We found substantial variation in age, number of visits to health care providers, timespan of care, and type and duration of treatments. Despite variation, our results demonstrate that DDH diagnosis and treatment can pose significant burden on patients and caregivers, necessitating multiple surgeries and procedures, many health care visits, and lengthy care duration. These findings underscore the worry and uncertainty that many participants reported.

Family history of hip dysplasia, breech birth, swaddling, and female sex are known risk factors for DDH.[5] Despite reporting risk factors, many participants still received diagnosis after 3 months of age, and many reported they did not receive screening. These findings highlight potential knowledge gaps, where health care providers may be unaware of DDH risk factors that necessitate monitoring or screening,[2] or gaps in resources where at-risk children are unable to receive recommended care. Participants identified another important issue: dismissal of patient concerns by health care professionals. This phenomenon has been documented across many medical disciplines; physician communication and listening skills are repeatedly highlighted by patients as critical components of establishing a trusting rapport with their healthcare provider.[13,14] Together, these results emphasize the importance of global knowledge translation activities and educational efforts to raise awareness of DDH risk factors, signs, and symptoms among primary care providers, to increase physician awareness and improve identification, screening, and monitoring of at-risk children.

Most participants received treatment. Patients may not have received treatment due to mild diagnoses undergoing observation, very late diagnosis in adulthood and awaiting surgery, or awaiting first treatment at time of survey.[15] Participants who reported diagnosis before

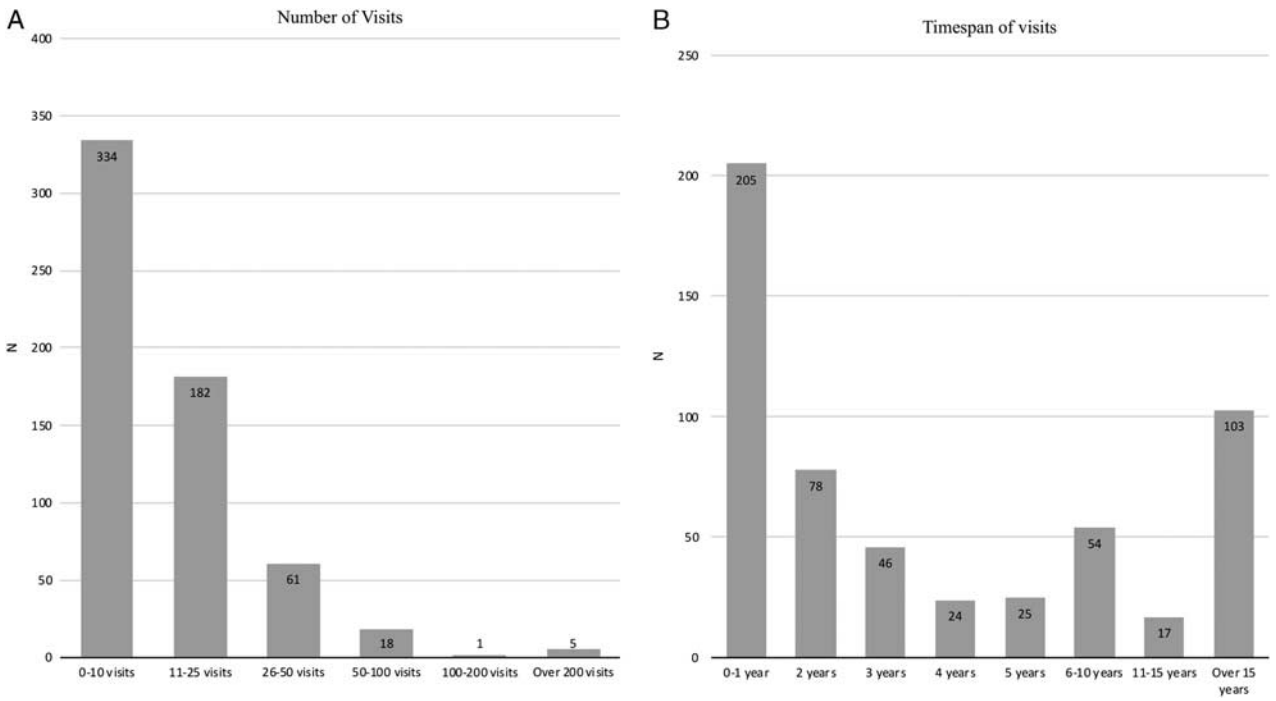

FIGURE 1. A and B, Number and timespan of visits to health care providers. Timespan of visits is reported in years.

TABLE 5. Differences Between Number and Timespan of Visits (Years) to Health Care Providers Based on Age at Developmental Dysplasia of the Hip Diagnosis

Variables	Age at Diagnosis, Mean (SD)		Mean Difference; *P*	90% CI
	0-3 mo	> 3 mo		
No. visits with health care providers	17.01 (21.1)	20.76 (41.5)	−5.61, −1.77; 0.001	15.92, 20.44
Timespan of visits (y) with health care providers	3.17 (5.45)	5.63 (9.43)	−2.92, −2.00; < 0.001	4.04, 5.14

CI indicates confidence interval.

3 months old more often reported treatment with bracing only or with bracing and closed reduction only, compared to those with delayed diagnosis. Bracing is often the first line of treatment for uncomplicated cases, especially in infants below 6 months of age, as it is less invasive, and use during a less-mobile developmental period results in high success rate.[16] Conversely, participants were more likely to report surgical management for older patients. Complications from surgery can be serious, and surgical intervention is typically used when nonoperative techniques are unsuccessful or due to decreased efficacy of bracing in older children.[17] Our findings align with existing knowledge that later diagnosis may require more invasive treatments.[4–6] Participant-reported age at first surgery suggests a lapse between diagnosis and surgery where other treatment options were employed.[17]

Participants reported knowing little about DDH before diagnosis, and burden of navigating treatments on their own while relying on online resources. Thus, our results suggest knowledge translation efforts among the public and new parents are needed to address the reported emotional shock and lack of knowledge throughout diagnosis and care. Others have reported similar needs, emphasizing educational resource development.[18,19]

Global Relevance

Most countries represented in our survey have national medical guidelines to inform screening and treatment for DDH. These countries are well-positioned to identify and treat patients early in life, and host well-known online outreach organizations. Despite this, our results suggest that hip dysplasia can still be a significant burden on patients and caregivers. Experiences of patients in developing countries or regions without large outreach groups were underrepresented; it is plausible that these patients may feel even greater burden of the condition due to limited medical resources and community supports. Thus, our findings cannot be generalized beyond a "westernized" health care context.

The international uptake of this survey, and the willingness of most participants to complete the long version, demonstrates significant engagement of patients and families across DDH communities. Collaboration of 7 outreach organizations to help design and share this survey is an unprecedented approach in hip dysplasia that catalyzed further collaborative efforts and formation of a Knowledge Translation Advisory Board to advise and inform research priorities for an international multicenter registry. We captured significant challenges in regards to treatment with braces/harnesses, and the group has already begun formal investigation of parent experiences with braces to inform development of a better solution.

Limitations

This study has several limitations. Recall bias is a factor as we relied on self-reported experiences over many years; many participants were patients reporting their own experiences across the lifespan. Notably, self-reported screening could reflect participant misconceptions of screening processes rather than actual practice. Furthermore, patients diagnosed in late adolescence/adulthood are sometimes considered to have a different condition; we were unable to quantify which participants had issues during childhood without diagnosis in comparison to those with later presenting issues. We also did not capture severity of hip dysplasia diagnosis and were unable to differentiate between hip dysplasia and full dislocation. We offered an abbreviated survey, so not all data points were collected for each participant, notably on types of surgeries, which can indicate treatment invasiveness. Thus, some samples were small and differences were not powered to assess significance. Selection bias may be another limitation, as participants with eventful or burdensome experiences may have been more likely to participate. Patients with bilateral hip dysplasia were over-represented in our sample, at 53.7%, compared to typical incidence of < 40%.[20] Our sample primarily represented developed nations; results cannot be generalized beyond a westernized health care context. Larger-scale epidemiologic studies are needed to capture treatment experiences with hip dysplasia on a global scale. Finally, this study did not include a formal quality of life measure; further studies involving validated quality of life measures are needed to fully characterize burden of developmental hip dysplasia across the lifespan.

CONCLUSIONS/FUTURE DIRECTIONS

It is clear that pediatric hip dysplasia can impose a large burden of disease, and families identified substantial gaps in their own needs and what is presented by health care providers. As such, global knowledge translation activities are needed to raise awareness of DDH risk factors, signs, and symptoms among care providers, to increase awareness and improve identification, screening, and monitoring of at-risk children. Our findings are the necessary first step to inform development and implementation of these activities. Physicians and medical societies can work alongside DDH outreach organizations to develop reliable educational resources and better utilize existing resources that provide

support to the public. Patient and caregiver priorities must be at the center these efforts.

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