

Caregiver Experiences Using Orthotic Treatment Options for Developmental Dysplasia of the Hip in Children

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Background: Developmental dysplasia of the hip (DDH) is a common condition affecting 5 in 1000 newborns. The standard first line of treatment is the use of an orthotic, which has generally high success rates, but can pose substantial difficulties and put undue burden on caregivers. The general experience of caregivers using these orthotics has not been well documented on an orthotic-specific basis. The purpose of this study was to investigate caregiver experience using prescribed DDH orthotics to identify challenges, differences between treatment options, and areas of improvement.

Methods: A survey assessing treatment prescription, respondent demographics, and caregiver experience was distributed online to caregivers whose child/children were treated for DDH with an

orthotic. Seven-point positively phrased Likert scale statements and open-ended questions were included to assess caregiver experience. The results were analyzed using summary statistics and orthotics with more than 30 responses were selected for more in-depth analysis.

Results: A total of 530 survey responses were collected with 63% (334/530) of respondents using a Pavlik harness, 45% (236/530) a Rhino brace, and 13% (67/530) a Denis Browne Bar. The overall weighted average score across all Likert Scale statements was positive for the Pavlik harness, Rhino brace, and Denis Browne Bar at 4.19 (95% CI, 3.83 to 4.54), 4.63 (95% CI, 4.27 to 4.99) and 4.91 (95% CI, 4.58 to 5.24), respectively. In the open-ended responses, all 3 orthotics were perceived as easy to use and not hindering child-caregiver bonding, but raised concerns of discomfort and skin irritation, as well as preventing the ability to cuddle their child the way they desired. The Pavlik harness respondents consistently brought up concerns regarding cleanliness.

Conclusions: The results show that the DDH orthotics analyzed are generally easy to use and perceived positively by caregivers, but have orthotic-specific challenges that should be a focus of future improvement work.

Clinical Relevance: This study evaluated opinions and attitudes of caregivers for children being treated with DDH orthotics, revealing experiences, concerns, and challenges associated with the use of commonly prescribed options.

Key Words: DDH, orthotics, caregiver experience, pavlik harness, rhino brace, denis browne bar

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Developmental dysplasia of the hip (DDH) is a common congenital condition reported to affect up to 5 in 1000 newborns.¹ DDH includes hips that range from unstable to completely dislocated.² Without effective treatment, this condition can lead to hip pain, osteoarthritis, degenerative hip disease, and surgical intervention in severe cases.^{3,4} The primary mode of treatment for DDH is the use of an orthotic device or harness, which positions hips into proper alignment in the joint to provide security and stability during development.

There is a wide range of orthotic devices available for nonsurgical treatment of infantile DDH, from soft

fabric harnesses to plaster casting to stiff braces of various shapes and sizes. Options commonly prescribed include the Pavlik harness, a soft harness with adjustable feet-to-shoulder straps (ages 0 to 8 mo); the Rhino brace, a rigid brace on the hip and waist area that allows crawling and walking (ages 6 wk and older); and the Denis Browne (DB) bar, 2 thigh cuffs spanned by a stiff bar (newborn and older). DDH can also be treated by a multimode approach with various braces used at staggered phases of recovery.

Clinical practice varies widely in terms of method, timing, and duration of orthotic use, even among surgeons practicing within the same country.⁵ Devices like the Pavlik harness are often prescribed for continued at-home use for up to 24 hours per day and up to 24 weeks. These options further rely on caregiver compliance for ensuring treatment efficacy. Studies have linked caregiver non-compliance to both increased duration of treatment and treatment failure.^{6,7}

Caregiver attitudes toward specific orthotics remain relatively unknown, outside of anecdotal evidence gathered on a site-specific^{8,9} or surgeon-specific^{10,11} basis. Assessing the opinions and experiences of caregivers in their use of DDH orthotics can identify treatment gaps, barriers to administering proper treatment, and ways to improve compliance and usability. Previous investigations have demonstrated caregiver noncompliance due to orthotic-related complaints,¹² so applying information on such trends could increase compliance and overall experience using treatment devices.

To determine the current experience of caregivers of children in prescribed DDH nonsurgical orthotics, a survey was developed and distributed online. The purpose of this study was to report current attitudes of caregivers toward orthotic harnesses and braces prescribed for DDH, identify common themes among similar options, and summarize areas for innovation and improvement in orthotics for DDH.

METHODS

We created a survey inquiring about DDH treatment details, respondent demographics, and specific questions about the different orthotics (Appendix 1, Supplemental Digital Content 1, <http://links.lww.com/BPO/A558>). The survey was distributed online through the International Hip Dysplasia Registry (IHDR) and collaborating organizations to caregivers of pediatric patients who were treated for DDH with an orthotic harness or brace. More specifically, survey distribution was

conducted online via IHDR mailing lists and social media groups, and in-person during clinic visits at the authors' institutions. Study data were collected and managed using Research Electronic Data Capture hosted at our institution.^{13,14} Research Electronic Data Capture (Vanderbilt University, Nashville, TN) is a secure web-based software platform designed to support data capture for research studies. All respondents were required to agree to a consent and privacy statement that detailed the protection of their data before proceeding to complete the survey. This research did not undergo Institutional Review Board approval, as it was a Quality Assessment and Quality Improvement Project. The survey was available online for 2 months (May 11 to July 14, 2020).

Survey Structure

The survey consisted of 5 question sections: (1) demographics and treatment history, (2) experience with the Pavlik harness, Rhino brace, or "other" orthotics, and (3) comparing the Pavlik harness and Rhino brace. Respondents were instructed to select all applicable orthotic options. The survey questions were chosen by the authors based on interest, perceived concerns, and important factors for orthotics based on clinical experience. The survey consisted of both closed-ended and open-ended questions and positively framed statements with responses ranging from "strongly agree" to "strongly disagree" (Likert scale) and scored from a maximum of 7 to a minimum of 1, respectively.

Survey Analysis

Surveys were analyzed on a per-question basis, meaning that for each question only the respondents who answered that question were included in the respective analysis. Orthotics with more than 30 responses were chosen for more in-depth analysis. Treatment history was analyzed using summary statistics and 95% CI. The data were first manually cleaned for values outside the allowable range, such as responses with > 24 hours per day. For assessment of the Likert statements, after responses marked "not applicable" were excluded, weighted averages were calculated with 95% CIs. Open-ended questions were analyzed in NVivo 12 (QSR International, Melbourne, Australia).¹⁵ For every open-ended question, 20% of the responses were randomly sampled for review to categorize responses and identify themes. Two independent reviewers analyzed the responses and subsequently categorized them into prevalent themes.

TABLE 1. Treatment History Indicated by Respondents, Reported as Mean (95% CI)

Category	Pavlik Harness (95% CI)	Rhino Brace (95% CI)	Denis Browne bar	All Respondents (95% CI)
Age of DDH diagnosis (wk)	NA	NA	NA	14.6 (12.1–17.2)
Age DDH treatment began (wk)	7.3 (5.8–8.7)	38.6 (32.9–44.3)	21.1 (15.9–26.3)	17.9 (15.1–20.7)
Orthotic treatment length (wk)	7.7 (7.1–8.2)	15.5 (12.7–18.3)	12.3 (10.3–14.2)	NA
Orthotic treatment length (h/d)	23.5 (23.3–23.7)	20.3 (19.5–21.0)	22.4 (21.6–23.2)	NA

NA indicates not asked.

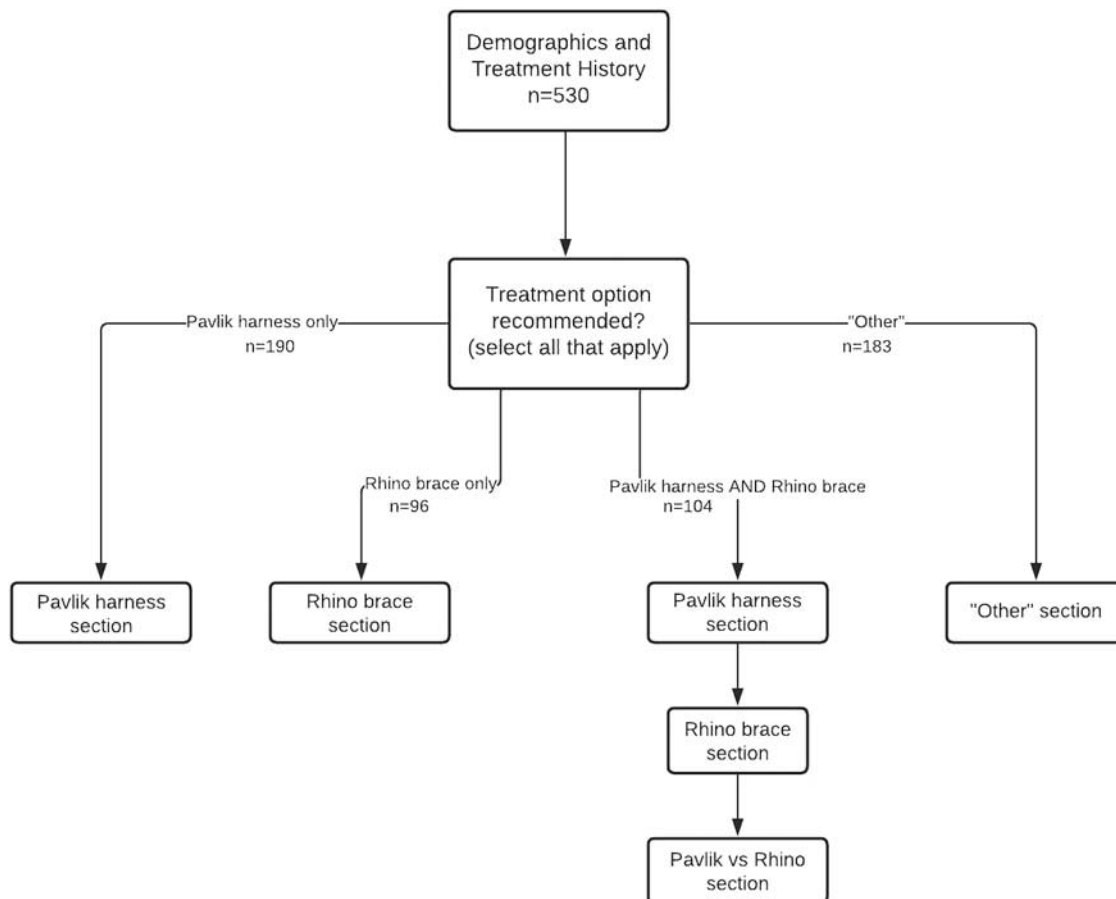


FIGURE 1. Survey structure overview and breakdown of orthotics indicated as recommended for developmental dysplasia of the hip treatment. Respondents were instructed to select all applicable options.

RESULTS

A total of 530 survey responses were collected in the first section, with treatment summary statistics shown in Table 1. The survey included participants from 20 countries, such as Australia (46%, 242/524), the United States (26%, 136/524), the United Kingdom (13%, 66/524), and Canada (9%, 49/524). Among all respondents, 46% (245/530) indicated that more than 1 treatment option was prescribed, 63% (334/530) reported using a Pavlik harness, 45% (236/530) a Rhino brace, and 13% (67/530) a DB Bar (Fig. 1).

Likert Statements

The overall weighted average score (out of 7) across all statements was 4.19 (95% CI, 3.83 to 4.54) for the Pavlik harness, 4.63 (95% CI, 4.27 to 4.99) for the Rhino brace, and 4.91 (95% CI, 4.58 to 5.24) DB Bar. These scores demonstrate a significant difference between the DB Bar and Pavlik harness groups, but no significant differences between the Pavlik harness and Rhino groups or Rhino and DB Bar groups. The weighted average distribution summarizing all Likert scale responses for the Pavlik harness, Rhino brace, and DB bar are presented in Supplemental Figures 2, 3, and 4, Supplemental Digital Contents 2-4,

<http://links.lww.com/BPO/A559>, <http://links.lww.com/BPO/A560>, <http://links.lww.com/BPO/A561>, respectively. Overall, the Pavlik harness had 5 Likert statements that scored negatively (score < 4), Rhino brace had 2, and DB Bar had 1. The highest (most positive) and lowest (most negative) scoring Likert scale statements were the same across each orthotic option analyze.

Open-ended Questions

Analysis of the open-ended questions revealed a number of unifying themes shared across the assessed orthotics (Table 2).

Child comfort was a consistent concern across all the 3 orthotics, with respondents calling for softer materials and increased padding. Improper fit was also raised as a concern, particularly for the Rhino brace. Skin irritation was identified as a major concern for both the Pavlik harness and Rhino brace, arising in the form of rashes and chafing because of material type or improper fit. Respondents indicated that all the 3 orthotics were easy to use, despite the expressing apprehensiveness in an ability to properly adjust the Pavlik harness and DB Bar. They called for more intuitive straps to relieve the anxiety surrounding orthotic adjustments.

TABLE 2. Key Themes Found in Open-ended Questions With (+) Denoting a Positive Response and (–) Denoting a Negative Response

Key Theme	Pavlik Harness	Rhino Brace	Denis Browne bar
Comfort and irritation	(+) “Softer than other harnesses” (–) “Wearing the harness 24 h a day can cause some discomfort to the child such as irritation of skin.”	(–) “I was concerned about her being uncomfortable as a brand new baby” (–) “It also gave my child several rashes and dry skin from rubbing” (–) “Leg foam was also ill-fitting and hot”	(–) “My daughter was not comfortable in it.”
Ease of use	(+) “It is easy to understand how it works and it is pretty easy overall” (+) “It is a simple but effective and non-invasive medical treatment” (–) “It was challenging to make it adjusted correctly at all times” (–) “That it would be too loose or tight and not effective”	(+) “It was easy to use and put on as a parent” (+) “It’s easier than the pavlik because you can’t mess up the fit”	(+) “It seems much easier and less invasive than many other options.” (+) “It was adjustable depending on how my daughter was growing.” (–) “It was difficult to know how tight the straps should be when replacing them with clean ones.”
Cleanliness	(–) “My daughter had reflux and it became so gross and dirty” (–) “very difficult to keep clean, we ended up buying 2 so that we could swap them each week to wash one when the physio changed it over”	(+) “It’s easy to clean” (+) “Easy to keep child clean.”	(–) “[An improvement could be a] Removable cover over bar to help keep clean” (–) “Cleaning my child [was a concern].”
Impediment of daily activities	(–) “Caring for our daughter in the way we intended was interrupted because we had to pick her up, hold her, and change her diaper all significantly different”	(–) “finding car seats/prams/carriers/high chairs/ways to manage shopping trolleys, etc. was really hard. Especially when I needed a double pram to accommodate toddler too.”	(–) “Not being able to cuddle her”

Hygiene of both the child and their orthotic seemed to be important to caregivers. Respondents praised the material of the Rhino brace for being easy to clean and be able to remove for bathing, whereas the Pavlik harness was criticized for the difficulty in cleaning the harness and the child while wearing it. Both DB Bar and Pavlik harness respondents suggested removable covers to facilitate easier cleaning of the orthotics.

All orthotics analyzed were perceived as a burden in terms of impeding daily activities: the Rhino brace was described as bulky and incompatible with sleeping, car seats, and baby carriages (prams), and the Pavlik harness as interfering with feeding and diaper changes, as well as incompatible with standard clothing. All the 3 orthotics were reported by caregivers to impede cuddling and holding of their child.

Pavlik Versus Rhino

When asked to compare the Pavlik harness with the Rhino brace, respondents indicated that they preferred the softer, more flexible material of the Pavlik harness over the Rhino brace. Generally, respondents found the Pavlik harness more difficult to use than the Rhino brace, specifically finding the straps more challenging. Respondents enjoyed that the Rhino brace was removable for certain activities such as baths, diaper changes, or tummy time as opposed to the Pavlik harness. There were no standout negative features reported for the Rhino brace.

DISCUSSION

This study evaluated caregiver experiences and attitudes toward orthotic harnesses and braces prescribed for DDH through a survey consisting of open-ended ques-

tions and Likert scale statements. In terms of weighted average scores across all Likert scale statements, all the 3 analyzed options scored above neutral, suggesting positive perceptions of use. The Pavlik harness scored the lowest (4.19) compared with the Rhino brace (4.64) and DB Bar (4.91). The Pavlik harness also had a greater number of statements that elicited an average negatively scored response; at least 2-fold that of the Rhino brace or DB Bar. These trends could indicate that caregivers perceive the Pavlik harness more negatively or as more difficult to use than the other 2 orthotics included in our study.

Respondents voiced strong concerns about the treatment being uncomfortable for their baby and/or irritating their child’s skin. However, the statement: “My child is happy and/or appears comfortable while wearing the recommended treatment option” scored positively (>4) in all the 3 orthotics. Worries about skin irritation and discomfort from the prescribed use of a DDH orthotic have been consistently reported in other studies, with a majority of respondents voicing similar concerns.^{8–10,16} These concerns may be the unfortunate reality of wearing any orthotic harness or brace for a prolonged time, but remain a documented adverse experience of orthotic use for the treatment of DDH.

Respondents consistently provided the lowest scores to the statement “I can cuddle my child the way I wish while they are wearing the recommended orthotics.” Past research has demonstrated that DDH orthotics present an emotional and physical barrier to cuddling and are perceived to hinder the quality of attachment between parent and child.^{8,10,16} Our study also revealed in both Likert scale statements and open-ended questions that there were difficulties experienced with cuddling and holding during

use of orthotics. Interestingly, negative scores were not found for child attachment or bonding, as the statement “I feel like I’ve been able to bond well with my child throughout their treatment” demonstrated the highest score for all the 3 orthotics analyzed. This is in contrast with previous literature, which described the psychosocial consequences for caregivers when bathing is difficult or forbidden when using a certain orthotic, resulting in feelings of loss of parental autonomy and missing out on a chance to bond with their child.¹¹ However, the discrepancies found may be because of the difficulty distinguishing between the meanings behind the keywords “cuddling,” “holding,” and “bonding.”

Open-ended responses indicated that respondents felt that all the 3 orthotics were easy to use and take on and off, a sentiment further supported by high-scored statements on this subject. These results align with those of a previous study, which found a majority of parents did not report the harness/brace prescribed for their infant’s DDH as difficult to manage.¹⁷ Despite these trends, respondents using the Pavlik harness and DB Bar showed concern in the open-ended questions that the adjustment straps or fit were not correct, either initially or after they took the orthotic on or off by themselves. Rhino brace users were also concerned that the fit was not correct for their child and worried this improper fit resulted in discomfort. Respondents liked that they were allowed to take off the Rhino brace for periods during the day, which is indicative of the treatment stage and nature of prescribed treatment rather than reflective of the design of the device itself. General discrepancies in reported values for time out of brace between orthotic options may be an issue in physician instruction rather than an aspect inherent to the orthotic itself.

Feeding and breastfeeding their child was found to be an interrupted aspect of daily life for respondents using the Pavlik harness. However, Pavlik respondents scored the statement pertaining to feeding their child an almost-neutral score of 4.2. Feeding and breastfeeding were not frequently mentioned concerns or interruptions of daily life for the Rhino brace or DB Bar, which may be because the children being treated with these braces were typically older, on average 38.6 and 21.1 weeks, respectively, compared with 7.3 weeks for Pavlik harness (Table 1). A Swedish study reported significantly lower breastfeeding frequency in infants prescribed a von Rosen splint for DDH when compared with a control group of healthy, nonsplinted infants.¹⁶ Although researchers acknowledged that these differences in feeding may be because of other factors, parents often described issues attributed to the orthotic similar to those mentioned by respondents in our study, such as skin irritation, poor contact, and practical problems like clothing compatibility.¹⁶

Harness cleanliness is important for infant hygiene and caregiver experience; a case study of a mother of an infant diagnosed with DDH described similar concerns of keeping the orthotic clean while changing diapers.¹⁰ Concerns of cleanliness were apparent in the survey results for the Pavlik harness and are especially relevant for the Pavlik

harness, which is made of a soft and flexible textile that is not designed to be water/stain resistant, unlike the Rhino brace, which is made from a stiff plastic shell likely to repel liquids and absorb fewer materials and odors. Many caregivers suggested improving Pavlik harness cleanability by adding removable covers to the straps, allowing the dirty covers to be washed and replaced with clean ones without interrupting the prescribed treatment. Another potential solution is for clinicians to prescribe (and insurers to subsidize) an additional Pavlik harness for patients, enabling uninterrupted wear while the first harness is being washed. Correlating the concerns of cleanliness and hygiene documented in this study with medical conditions like irritation and infection were out of the scope of the study. However, this research lays the groundwork for studying this in the future.

The insights gained from this research can inform future innovation of DDH orthotics based on the specific concerns reported by caregivers. Many of the limitations of this work are inherent to the collection of survey data, including recall bias and selection bias. We used positively phrased Likert statements to improve reliability and construct validity. However, this may have increased acquiescence bias.¹⁸ We did not control for the independent effect of prescribed treatment plan variation among participants and between orthotics. Some of the trends found between orthotics could be because of the differences in typical orthotic treatment prescription or infant age, rather than differences between orthotic design. Infant age at time of prescription, or whether the infant was a first-born child or younger sibling, may have influenced parent responses to many of the questions across the survey. Newer parents still becoming comfortable with caring for their newborn may find dealing with brace wear more stressful than more experienced parents. Consequently, patient age and birth order should be taken in consideration for future research. Finally, the scope of our study prevents conclusions from being drawn beyond between-group comparisons; it could be that some of the concerns raised are innate to an infant wearing any prescribed medical device, and we are unable to comment further on this topic without the use of a control comparison.

CONCLUSIONS

Generally, the 3 DDH orthotics analyzed (Pavlik harness, Rhino brace, and DB bar) were positively scored by respondents and perceived as easy to use and not hindering child-caregiver bonding. However, a closer look at the individual responses and trends within and between groups demonstrated areas for improvement. Caregivers across the 3 options analyzed reported consistent concerns with the discomfort and skin irritation due to wearing of the orthotic, as well as an inability to cuddle their child in the way they desired. Despite being described as easy to use, the Pavlik harness and Rhino brace were perceived as problematic in terms of fit, and specifically in the way of strap adjustments for the Pavlik harness. The cleanability

of the Pavlik harness was also repeatedly voiced as worrisome to caregivers.

The presented study paints a well-rounded picture of caregivers' attitudes toward DDH orthotics on a device-specific basis, allowing for the pros and cons of various options to be identified. This work fills a gap in the current literature for a population that often lacks consideration in orthotic design: the families and caregivers of patients that use these orthotic devices. Our findings elucidate what should be prioritized in future DDH orthotic design and development to optimize caregiver experience, potentially increasing user compliance and positive implications for the clinical setting.

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