Daily Challenges of Caregivers of Infants Undergoing Treatment for Developmental Dysplasia of the Hip (DDH)

Desafios Diários de Cuidadores de Bebês em Tratamento para Displasia do Desenvolvimento do Quadril (DDQ)
Desafíos Diarios de Cuidadores de Bebés en Tratamiento por Displasia del Desarrollo de la Cadera (DDC)

RESUMO
Objetivo: Investigar os principais desafios enfrentados por cuidadores de bebês em tratamento para Displasia do Desenvolvimento do Quadril e identificar estratégias adaptativas adotadas durante o processo de cuidado. **Método:** Estudo de métodos mistos com análise temática de 50 postagens em três grupos brasileiros de redes sociais sobre DDQ e aplicação de questionário estruturado aos mesmos cuidadores, combinando questões quantitativas e respostas abertas. **Resultado:** As principais dificuldades relatadas envolveram higiene (18%), troca de fraldas (16%) e atrasos no desenvolvimento (32%). Dos cuidadores entrevistados, 54,6% utilizaram o suspensório de Pavlik (58% sucesso) e 36,4% o gesso pelvipodálico (37,5% sucesso). Estratégias incluíram coberturas protetoras e técnicas modificadas de manuseio. **Conclusão:** A falta de orientações específicas e materiais educativos adequados intensifica o estresse dos cuidadores. Os resultados evidenciam a necessidade de programas educativos e dispositivos ortóticos mais ergonômicos e acessíveis.
DESCRITORES: Displasia do Desenvolvimento do Quadril; Ortopedia; Redes sociais.

ABSTRACT
Objective: To investigate the main challenges faced by caregivers of infants undergoing treatment for Developmental Dysplasia of the Hip (DDH) and identify adaptive strategies adopted during daily care. **Methods:** A mixed-methods study combining thematic analysis of 50 posts from three Brazilian social media groups on DDH and a structured survey administered to the same caregivers, including quantitative questions and open-ended responses. **Results:** The main challenges reported involved hygiene (18%), diaper changing (16%), and developmental delays (32%). Among the caregivers interviewed, 54.6% used the Pavlik harness (58% success) and 36.4% used the hip spica cast (37.5% success). Adaptive strategies included protective coverings and modified handling techniques. **Conclusion:** The lack of specific guidance and educational materials increases caregiver stress. Findings highlight the need for targeted educational programs and more ergonomic and accessible orthotic devices.
DESCRIPTORS: Developmental Dysplasia of the Hip; Orthopedics; social networks.

RESUMEN
Objetivo: Investigar los principales desafíos que enfrentan los cuidadores de bebés en tratamiento por Displasia del Desarrollo de la Cadera (DDC) e identificar las estrategias adaptativas adoptadas durante el cuidado diario. **Método:** Estudio de métodos mixtos que combinó el análisis temático de 50 publicaciones en tres grupos brasileños de redes sociales sobre DDC y una encuesta estructurada aplicada a los mismos cuidadores, con preguntas cuantitativas y abiertas. **Resultados:** Los principales desafíos informados fueron higiene (18%), cambio de pañales (16%) y retrasos en el desarrollo (32%). El 54,6% utilizó el arnés de Pavlik (58% éxito) y el 36,4% el yeso pelvipodálico (37,5% éxito). Las estrategias incluyeron coberturas protectoras y técnicas de manejo modificadas. **Conclusión:** La falta de orientación específica y materiales educativos adecuados aumenta el estrés de los cuidadores. Los hallazgos destacan la necesidad de programas educativos y dispositivos ortésicos más ergonómicos y accesibles.
DESCRIPTORES: Displasia del Desarrollo de la Cadera; Ortopedia; red social.

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Paula Ide Coelho de Souza
Biomedical Engineer – Federal University of São Paulo (UNIFESP).
ORCID: https://orcid.org/0009-0005-0222-1012

Natália Aurora dos Santos
Master in Biomedical Engineering – Federal University of São Paulo (UNIFESP).
ORCID: https://orcid.org/0000-0001-7356-5246

Eduardo Keller Rorato
Master in Technological Innovation – Federal University of São Paulo (UNIFESP).
ORCID: https://orcid.org/0009-0009-3755-5820

Thabata Alcantara Ferreira Ganga
Master in Technological Innovation – Federal University of São Paulo (UNIFESP).
ORCID: https://orcid.org/0000-0001-6801-8985

Maria Elizete Kunkel
PhD in Biomechanics – Federal University of São Paulo (UNIFESP).
ORCID: https://orcid.org/0000-0003-1711-9289

INTRODUCTION

Developmental dysplasia of the hip (DDH) is a prevalent condition in paediatric orthopaedics, affecting approximately 1 in 1,000 births without imaging diagnosis and up to 54 in 1,000 with ultrasound confirmation[1,2]. DDH encompasses abnormalities in hip development, including variations in the size, shape, or orientation of the femoral head and/or the acetabulum, resulting in improper joint alignment. These anomalies can lead to joint instability, subluxation, or complete dislocation[3]. In 80% of cases, hip instability detected at birth resolves spontaneously within the first month[4]. However, unresolved cases often progress to subluxation or dislocation, requiring medical intervention[5]. Delayed or untreated DDH can result in lasting complications such as abnormal gait, joint degeneration, chronic pain, and avascular necrosis[1,4].

Successful DDH treatment depends significantly on early diagnosis within the first months of life. As the hip matures, reduction becomes more challenging, complicating treatment and heightening the risk of long-term complications[5]. In Brazil, challenges in diagnosing DDH often arise from inadequate physical examination in infancy[2,6]. Essential tests for early DDH detection include the Ortolani test, which assesses hip reduction for initial dislocation, and the Barlow test, which evaluates dislocation potential in an unstable hip[7]. In addition to physical examination, hip ultrasound is essential for confirming diagnosis in newborns, while radiography is advised only after four months of age, once femoral epiphyses begin ossification, making the femoral head nucleus visible[5,8].

The primary objective of DDH treatment is to reposition the joint and maintain the femoral head centred in the acetabulum, achieved through immobilisation in the Salter human position - hip abduction at 60° and flexed at 110° - until stability is ensured. This positioning promotes healthy hip development[1,4]. Treatment methods depend on age: infants under four months are commonly treated with the Pavlik harness, whereas older infants often require a hip spica cast. The Pavlik harness has a high success rate when used early, allowing some movement while maintaining hips flexion and abduction; however, it presents challenges for infant care[9], as precise positioning is essential for efficacy. Flexion and abduction angles encourage spontaneous reduction of subluxation. While brief harness removal (up to one hour daily) is sometimes allowed for hygiene, many specialists advise against this due to the risk of incorrect repositioning, potentially causing dislocation if the hip extends or adducts improperly[10]. Furthermore, excessive flexion or abduction beyond recommended angles can lead to complications, such as femoral head osteonecrosis from continuous acetabular pressure[1,11].

In case of late-diagnosed DDH or failed Pavlik harness treatment (typically identified before ambulation), the hip spica cast is often employed[12]. This method involves joint reduction followed by immobilisation in the Salter position for up to 120 days. Reduction is performed under anaesthesia, either non-surgical or, if required, via surgical intervention, with immobilisation applied only after verifying correct positioning through ultrasound or radiography. The spica cast extends from the chest to the knee or ankle, restricting pelvic movement. Percutaneous tenotomy of adductor ligaments is sometimes required to prevent muscle shortening and allow greater abduction and exerting undue pressure on the femoral head, which could lead to osteonecrosis. The risk of avascular necrosis increases once the hip joint ossification begins[3]. Plaster casts are frequently utilised in

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orthopaedic immobilisation for their cost-effectiveness, moldability, and mechanical strength. However, their use in DDH treatment poses challenges for healthcare professionals and patient care due to the cast's size, weight, application technique, and limitations regarding water exposure. Cast replacement is often required due to fractures or diminished mechanical integrity from moisture accumulation[13].

Both the Pavlik harness and hip spica cast present significant daily challenges for caregivers and infants, requiring adjustments in feeding, hygiene, transportation, and rest. In paediatric orthopaedics, where extensive immobilisation is common, caregivers often report low confidence in caregiving, which can adversely affect their performance[14]. Building caregiver confidence is most effectively achieved through proper guidance provided at the initial DDH diagnosis and treatment phase by the overseeing healthcare professional.

Despite recognition of these challenges within the medical community[15-16], only two books specifically address caregivers' needs - The Parents' Guide to Hip Dysplasia[17] (2013) and Cast Life[18] (2015). In the absence of formal resources, many caregivers seek online advice to improve their confidence and caregiving abilities during home treatments, leading to the creation of DDH-focused forums where caregivers share experiences, address concerns, and offer mutual support. This study aimed to investigate the specific challenges faced by caregivers managing infants with DDH, emphasising difficulties with conventional treatments to inform the development of enhanced or alternative methods.

METHOD

This research adopted a mixed-methods design, integrating exploratory qualitative research and descriptive quantitative analysis to investigate the challenges and adaptive strategies of Brazilian caregivers managing home-based treatment for DDH. Ethical approval was obtained from the Research Ethics Committee of the Federal University of São Paulo (CAAE nº 76638123.6.0000.5505).

2.1 Phase 1 – Qualitative Data Collection and Analysis

The qualitative phase involved the analysis of 50 posts published by caregivers over one year in three social media groups dedicated to DDH: two WhatsApp groups (Group A, *n*=195; Group B, *n*=190) and one Facebook group (Group C, *n*=4,085). Inclusion criteria comprised posts authored by primary caregivers of infants (0–24 months) undergoing DDH treatment with Pavlik harness or hip spica cast. Posts without personal caregiving experience or unrelated to DDH were excluded. Data were analysed using content analysis of Bengtsson[19] and thematic analysis of Braun & Clarke[20]. The process followed three stages:

1. Familiarisation – repeated reading of posts to identify recurring patterns;
2. Coding – systematic classification of text segments reflecting caregiving challenges and adaptive behaviours;
3. Theme Development – grouping codes into subthemes (e.g., hygiene, diaper changing, rest, feeding, transportation), later synthesised into major themes.

This phase identified the most recurrent obstacles, forming the conceptual basis for developing the structured survey used in the next stage. To ensure reliability, two independent researchers performed the coding, and discrepancies were resolved through discussion and consensus.

2.2 Phase 2 – Quantitative Survey

The second phase used a cross-sectional descriptive survey developed on Google Forms to quantify the frequency and intensity of the challenges identified in Phase 1. Online surveys were chosen for their effectiveness and convenience in data collection[21]. The instrument contained five sections:

1. Informed Consent Form (ICF);
2. Sociodemographic and clinical data (child's age, treatment duration, device type);
3. Challenges during Pavlik harness use;
4. Challenges during hip spica cast use;
5. Feedback and interest in follow-up research.

The survey included Likert-scale questions to transform qualitative responses into quantitative data, enabling statistical analysis[22] (1 = Did not interfere; 4 = Completely changed) and seven open-ended questions on adaptive solutions. Inclusion criteria were caregivers of infants under DDH treatment living in Brazil and members of at least one of the three online communities. Quantitative data were exported to Microsoft Excel and analysed using descriptive statistics (frequency, mean, standard deviation). Qualitative responses were reanalysed thematically to provide contextual depth.

2.3 Ethical Considerations and AI-Assisted Editing

All participants provided digital informed consent before completing the survey. Data were anonymised and stored securely in compliance with Brazilian research ethics regulations (Resolution CNS 466/2012). Artificial intelligence tools were used solely for linguistic refinement (grammar and clarity) and did not influence data interpretation or scientific content.

RESULTS

3.1 Qualitative Data from Social Media Groups

The initial phase analysed 50 posts from caregiver accounts in Groups A, B, and C, describing experiences of Brazilian caregivers managing infants with DDH using the Pavlik harness or hip spica cast (Fig. 1). Table 1 summarises the main challenges reported, grouped by the caregiving activities most affected.

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Figure 1: Flowchart of Phase 1 of the methodology, for qualitative data collection in online caregiver groups

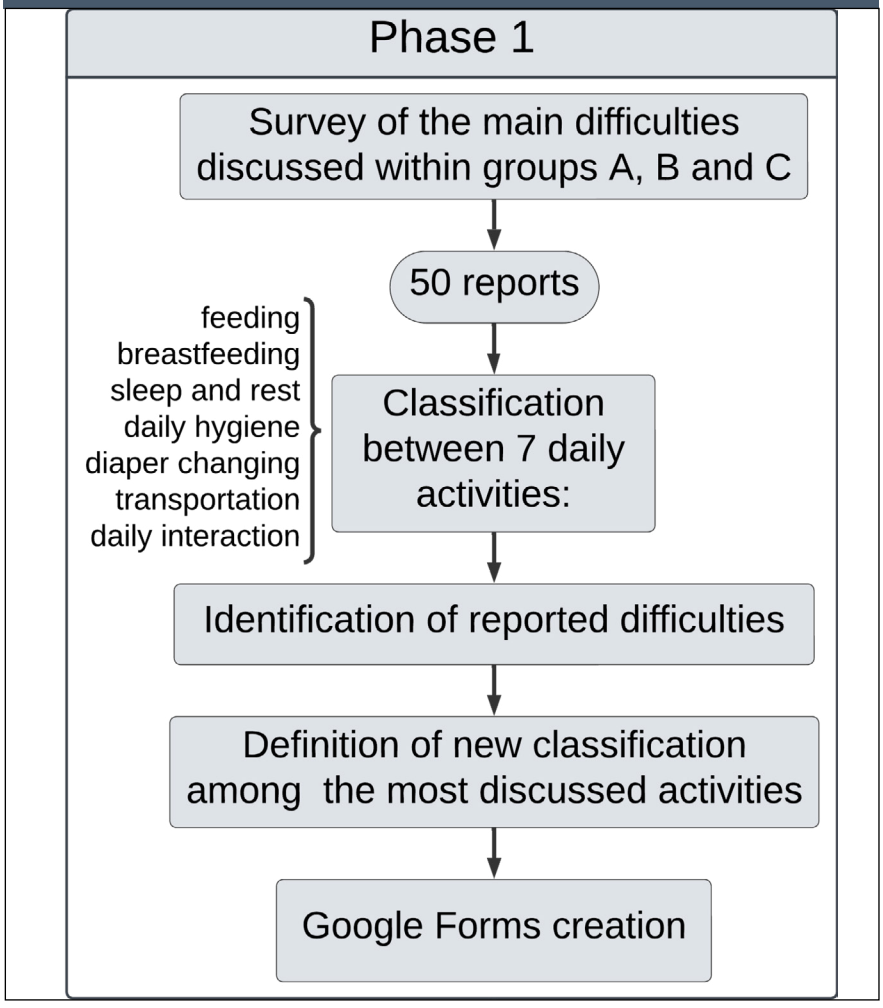

Table 1: Caregiver Challenges in Home-Based DDH Treatment Using Pavlik Harness and Hip Spica Cast

Activity (%)	Main Discussion Points Reported by Caregivers
Feeding (6)	Reports of loss of appetite and constipation during the post-surgical period, requiring feeding schedule adjustments.
Breastfeeding (2)	Difficulties in positioning the infant for breastfeeding and maintaining comfortable holding postures during treatment.
Rest (16)	Challenges in positioning the infant for rest or sleep due to movement restrictions caused by the harness or cast.
Hygiene (18)	Difficulties performing full-body hygiene and preventing skin irritation caused by moisture retention under the device.
Diaper Changing (16)	Strategies developed to prevent leaks, choose suitable diapers, and protect the orthosis or cast from soiling.
Transportation (10)	Concerns about ensuring safe transportation in car seats and developing ergonomic methods for carrying the infant.
Interaction and Play (32)	Worries about developmental delays, impaired motor milestones (e.g., crawling, walking), and difficulties changing clothes or engaging in play.

Interaction and play were the most frequently impacted activities, representing 32% of challenges, mainly related to developmental delays and milestones such as crawling and walking. Hygiene (18%) and diaper changing (16%) were also major concerns. Caregivers often expressed difficulties maintaining cleanliness and preventing skin irritation during treatment.

(I was scared of getting the cast wet, so I would only wash my baby's body with a damp towel. To wash her head, I would lay her down on the bed and use an inflatable baby pool under her head.) (C1) [This excerpt illustrates the caregiver's anxiety about hygiene and the strategies created to avoid water contact with the cast.] Similarly, caregivers expressed tension regarding diaper changes. *(Sometimes, when changing diapers, the cast gets dirty, and I need to change her clothes more than three times a day. I'm afraid of causing skin sores.)* (C2) [This statement highlights the constant concern with hygiene and skin integrity, showing the emotional overload related to basic care tasks.]

The thematic analysis showed that hygiene, diaper changing, and developmental milestones collectively accounted for 66% of posts. Feeding-related issues were less frequent (8%), generally linked to positioning difficulties during breastfeeding or loss of appetite.

3.2 Quantitative Analysis

In the second phase, an online survey was distributed to all participants from Groups A, B, and C, over two weeks, obtaining 18 valid responses (Fig. 2). Table 2 provides detailed information on the survey respondents. Among respondents, 72% initiated treatment before the infant reached four months, and 44% within the first month of life; 28% began treatment after one year. Regarding treatment type, 54.6% used the Pavlik harness (58% success without additional interventions), and 36.4% used the hip spica cast (37.5% success; 50% required additional interventions, such as orthoses or surgery).

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Figure 2: Flowchart of phase 2 of the methodology, for quantitative and qualitative data collection through the online form

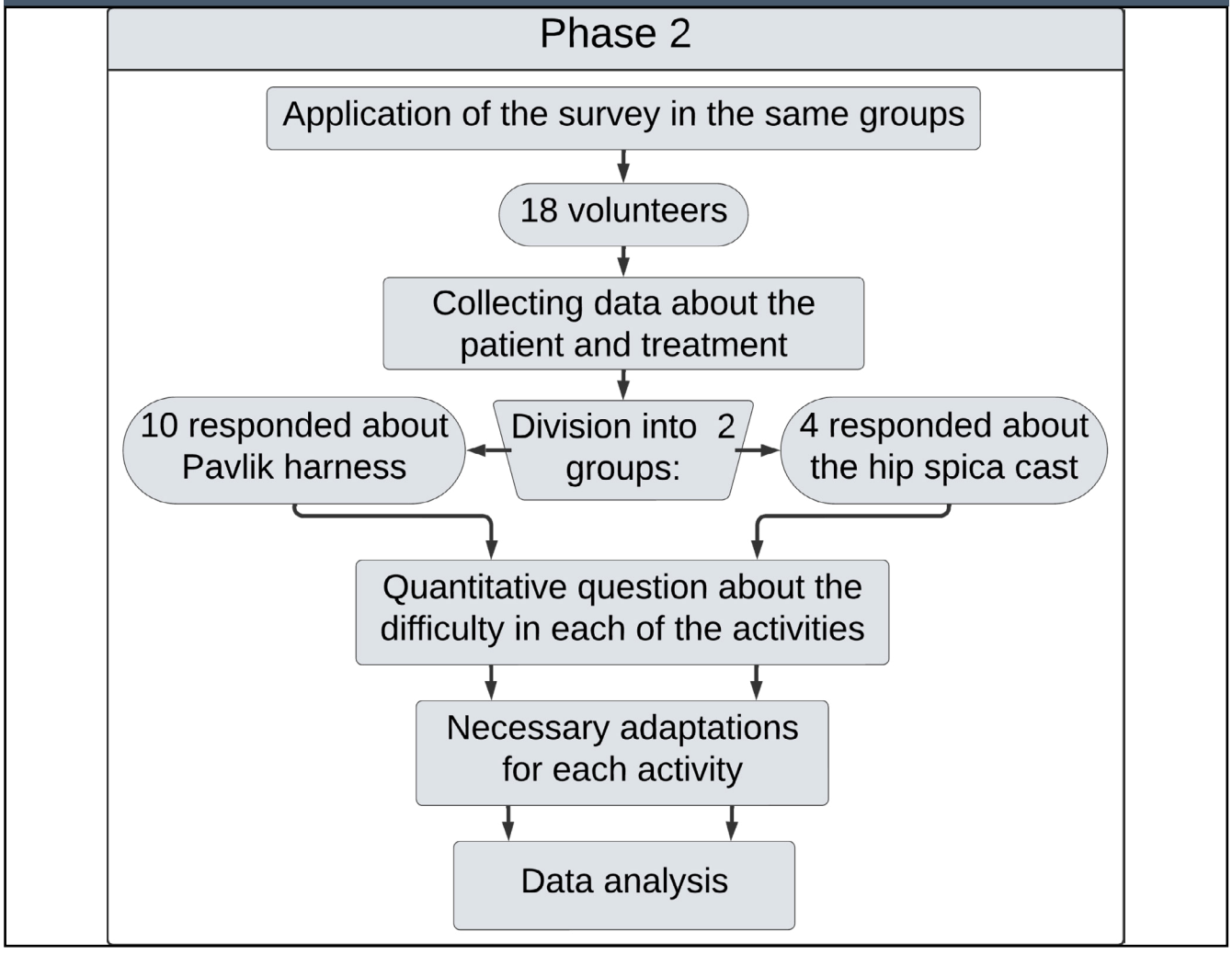

Tabela 2 – Informações das Respostas da Pesquisa de Cuidadores de Bebês em Tratamento Domiciliar de DDQ no Brasil

Treatment Modality	N (% of Total)	Main Informations
Pavlik harness	12 (54.6)	▪ Seven infants achieved treatment success with no additional interventions. ▪ Four infants required transition to a hip spica cast after Pavlik harness failure. ▪ One infant was still undergoing treatment at the time of the survey, awaiting a clinical decision on the next orthosis. ▪ One infant was awaiting corrective surgery.
Hip spica cast	8 (36.4)	▪ Three infants achieved successful outcomes. ▪ Three required subsequent use of an orthosis. ▪ Four underwent tenotomy surgery prior to cast application. ▪ Two required more complex surgical interventions. ▪ Four were still under treatment with a cast or other orthosis at the time of the survey. ▪ One infant was awaiting surgery.
Tübingen orthosis	1 (4.5)	▪ Treatment was successful with no additional interventions required.
Closed Reduction Surgery Only	1 (4.5)	▪ Treatment was successful with no additional interventions required.

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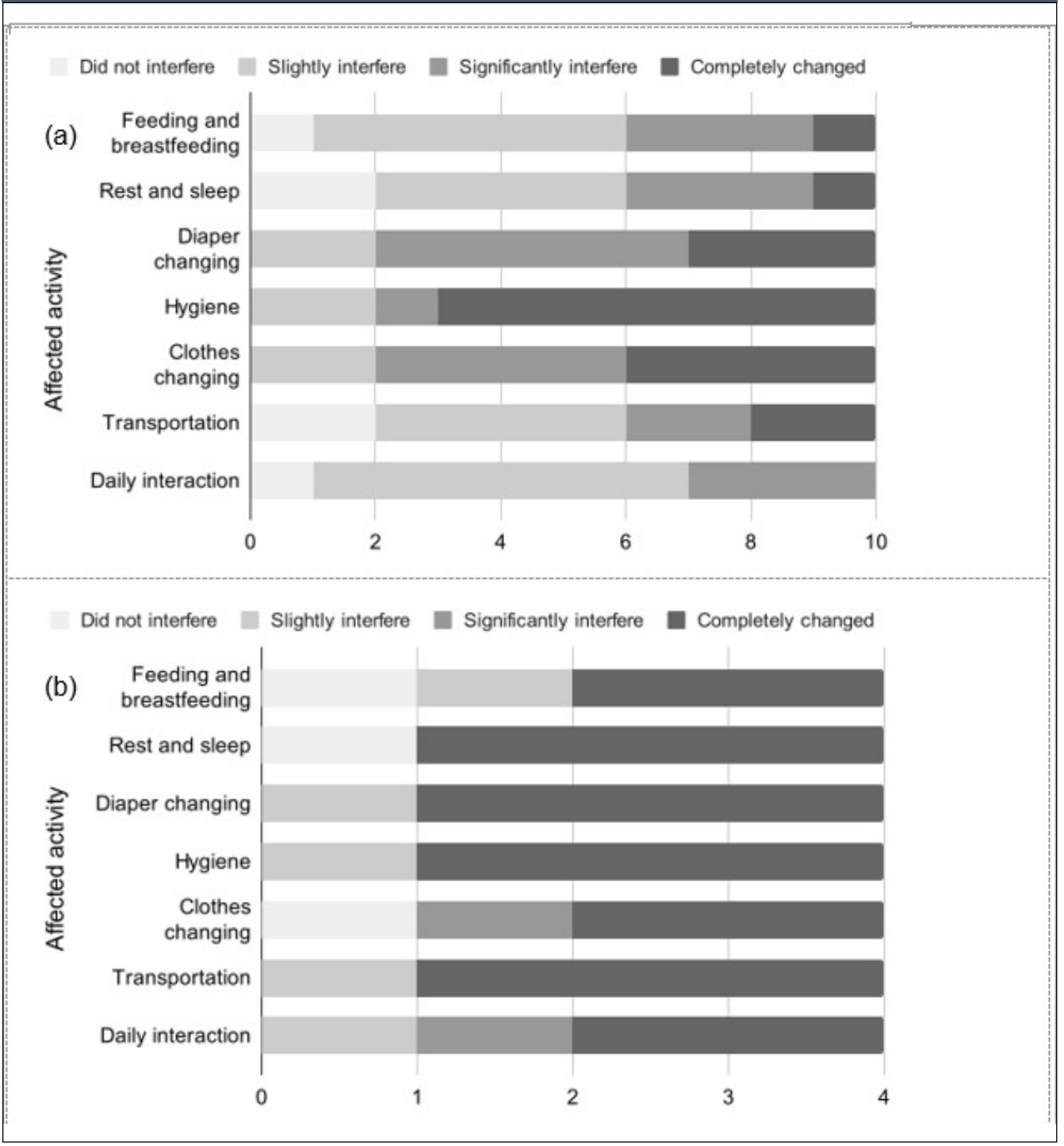
Quantitative analysis showed that hygiene and diaper-changing routines were the most affected activities, followed by interaction and play, confirming qualitative findings (Fig. 3). These activities were most often rated as "Completely changed," revealing significant disruption of daily care practices.

Figura 3: Interferência causada pelo uso do suspensório de Pavlik (a) e do gesso pelvipodálico (b) na realização de algumas atividades diárias segundo os cuidadores.



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3.3 Caregiver Adaptations

Caregivers adopted various adaptive strategies to mitigate treatment-related challenges (Table 3). Reported adaptations included the use of towels or rolled blankets to stabilise the infant's position, *wrap slings (cangurus)* for safe transportation, and modified diapering techniques to prevent leaks.

"I place rolled towels under her legs so she can sleep more comfortably; it helps me keep her in position without straining her hips." (C3). [This adaptation demonstrates practical problem-solving based on comfort and safety.]

Several posts also revealed anxiety related to interpreting medical results and the limited communication with healthcare professionals.

"I get very nervous waiting for the next appointment. When I receive the X-ray, I don't understand what it says, and no one explains it clearly." (C4). [This highlights the emotional stress generated by lack of access to information and medical follow-up.]

Tabela 3 – Diretrizes para atividades diárias de bebês em tratamento de displasia do desenvolvimento do quadril (DDQ) com suspensório de Pavlik ou gesso pelvipodálico

Atividade	Suspensório de Pavlik	Gesso Pelvipodálico
Alimentação e amamentação	Sente o bebê voltado para frente no colo do cuidador ou coloque-o sobre um travesseiro, garantindo que as pernas permaneçam abertas. Mantenha postura ereta durante a alimentação para auxiliar a digestão e o alinhamento do quadril.	Segure o bebê no colo do cuidador ou utilize uma cadeira de alimentação adaptada. Se a amamentação for difícil, considere ordenhar leite ou usar fórmula, mantendo o posicionamento adequado das pernas.
Sono e repouso	Coloque o bebê de costas ou no colo do cuidador, usando travesseiros ou toalhas enroladas para manter as pernas afastadas e prevenir rolamento durante o sono e garantir que o suspensório permaneça alinhado corretamente.	Posicione o bebê de costas com um travesseiro ou toalha enrolada sob e ao redor das pernas para suporte. Evite posições de lado ou prona. Uma rede ou rede-balanço para bebê pode ser utilizada com cautela se aprovada pelo médico.
Troca de fralda	Não remova o suspensório. Coloque um forro limpo por baixo antes de iniciar a troca. Levante o bebê apoiando a região lombar, não as pernas. Use roupas com abertura na região genital para evitar remoção do suspensório.	Use duas fraldas: uma menor, recortada, colocada dentro do gesso e outra maior por cima. Proteja a abertura genital com fita, forro plástico ou barreira impermeável para prevenir vazamentos..
Higiene diária	Limpe o bebê com lenços umedecidos ou algodão; lave apenas a cabeça, evitando o suspensório. Use talco com moderação para prevenir assaduras. O banho de imersão é permitido apenas sob supervisão médica.	Limpe o bebê com pano úmido; lave a cabeça sobre uma bacia ou pia. Cubra o gesso com uma toalha para evitar umidade. Aplique fita de cinesiologia ou barreira impermeável para proteger as bordas; use talco e hidratante (com moderação) para prevenir irritação da pele.
Troca de roupas	Use roupas adaptadas ou tamanho maior. Passe as peças por baixo ou por cima do suspensório. Prefira macacões, bodys ou conjuntos com abertura frontal.	Opte por vestidos ou calças com aberturas laterais ou tamanhos maiores. Permita tempo para o bebê permanecer apenas com gesso e fralda se vestir for difícil.
Transporte do bebê	Use uma cadeirinha de bebê maior com acolchoamento extra ou almofada para posicionamento. Carregue o bebê no colo ou use um sling, garantindo que as pernas permaneçam abertas.	Use cadeirinhas mais largas ou adicione uma almofada macia sob o bebê. Carregue o bebê no colo ou com sling, mantendo conforto e posicionamento correto do quadril.
Interação diária	Dedique tempo para segurar e brincar suavemente com o bebê. Use sling para aumentar o contato enquanto mantém o alinhamento das pernas.	Pratique técnicas seguras de segurar para apoiar o gesso e garantir o conforto. Use sling para facilitar a interação e a conexão emocional.

Overall, despite their creativity and persistence, caregivers frequently emphasised the need for better educational resources and more consistent communication with healthcare providers to reduce anxiety and improve home care management.

DISCUSSION

The findings of this study highlight the considerable physical and emotional burden placed on caregivers of infants undergoing treatment for DDH, especially regarding the adaptation of daily care routines (Erden & Bulut, 2015; Gibbard et al. 2021). Beyond the practical difficulties, such as diaper changing and maintaining hygiene, caregivers experienced anxiety, uncertainty, and exhaustion associated with the complexity of treatment devices (Lourenço, 2017; Batley et al. 2024). These results corroborate previous studies showing that the success of DDH treatment depends not only on the device's efficacy but also on caregiver adherence, understanding, and psychosocial well-being (Ömeroglu, 2018; Pollet et al. 2010; Batley et al. 2024)

Consistent with the literature, the hip spica cast remains one of the most challenging interventions due to its rigidity, weight, and limited mobility (Lourenço,

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2017; Erden & Bulut, 2015), often leading to skin irritation and discomfort (Erden & Bulut, 2015; Schwend et al. 2014; Vaquero-Picado et al. 2019). Caregivers in this study demonstrated remarkable adaptability, developing improvised hygiene and handling techniques that reflect both creativity and the absence of adequate professional support. Similar findings were reported by Lourenço and Erden&Bulut, who observed that inadequate instructions from healthcare providers contribute to unsafe caregiving practices and increased stress levels.

The results also reveal the central role of social media as an informal learning and emotional support environment. Caregivers used these platforms to exchange information, find validation, and share coping strategies, an observation aligned with the growing evidence of digital communities as complementary health-education spaces (Wright, 2005). However, the lack of clinical moderation in such groups can lead to misinformation or unsafe practices, reinforcing the need for healthcare professionals to engage actively in digital communication channels.

A recurring concern among caregivers was the fear of developmental delay, particularly regarding crawling and walking. While these concerns are understandable, studies show that mild delays are often transient and resolve after treatment completion (Schwend et al., 2014; Vaquero-Picado et al., 2019; Ömeroglu, 2018). Providing anticipatory guidance and reassurance through structured educational interventions could mitigate caregiver anxiety and improve adherence to treatment protocols.

The scarcity of culturally and contextually appropriate educational materials emerged as a critical gap. Although international guidelines for DDH management exist (Gibbard et al., 2021; Lourenço, 2017; Vaquero-Picado et al., 2019; Schwend et al., 2014), they rarely consider the socioeconomic and healthcare realities of low- and middle-income countries. Developing locally tailored, evidence-based resources, such as illustrated manuals, video tutorials, and telehealth consultations, could help standardise safe caregiving practices and empower families, especially within the Brazilian public healthcare system (SUS).

From a psychosocial perspective, the caregivers' resilience and mutual support observed in online groups demonstrate significant adaptive capacity. However, this informal support network cannot substitute structured professional follow-up. The integration of digital health strategies, including telemonitoring and virtual support groups moderated by clinicians, could reduce information gaps and ensure ongoing assistance during long treatment periods.

4.1 Limitations and Future Directions

The use of social media groups as the main data source provided valuable insights into caregivers' lived experiences but introduced inherent limitations. Participants were self-selected and likely more proactive or digitally engaged, which restricts generalisability to all DDH caregivers. Additionally, reliance on self-reported data may lead to recall or interpretation bias. Future studies should employ mixed recruitment strategies, including hospital-based samples and longitudinal follow-ups, to capture broader perspectives and evaluate long-term outcomes.

4.2 Implications

This study reinforces the importance of caregiver-centred approaches in paediatric orthopaedics. Strengthening communication between families and healthcare teams, offering practical training, and developing ergonomic orthotic devices could reduce caregiver burden and improve treatment adherence. Furthermore, integrating culturally adapted educational content into telehealth platforms would promote equitable access to information and continuity of care.

CONCLUSION

This study achieved its objective of identifying and characterising the main challenges and adaptive strategies of caregivers of infants undergoing home-based treatment for developmental dysplasia of the hip (DDH) in Brazil. The findings revealed that maintaining hygiene, performing diaper changes, and managing developmental milestones are the most demanding aspects of daily care, often intensified by the constraints imposed by devices such as the Pavlik harness and hip spica cast. These challenges directly impact caregivers' physical and emotional well-being, reinforcing the need for systematic, accessible, and culturally adapted educational support.

Evidence from this investigation demonstrates that caregivers show remarkable adaptability and resilience but frequently lack professional guidance, leading to anxiety and the use of unsafe or improvised practices. These results highlight an urgent demand for structured caregiver education programs, improved communication between families and healthcare providers, and the incorporation of telehealth tools to ensure continuous and reliable support throughout the treatment process.

The study also points to important knowledge gaps, particularly the absence of locally tailored materials and the limited integration of caregiver perspectives in the design of orthotic devices. Future research should include more diverse caregiver populations beyond online support groups, adopt longitudinal approaches to assess long-term psychosocial outcomes, and explore the effectiveness of educational and digital interventions in improving adherence and caregiver quality of life. By foregrounding caregivers' experiences and needs, this study contributes to advancing family-centred care in paediatric orthopaedics and supports the development of more user-friendly and innovative orthotic solutions aligned with real-world caregiving contexts.

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