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Research Article

INVESTIGATION OF PARENTAL EXPECTATIONS REGARDING ANKLE–FOOT ORTHOSIS USE IN CHILDREN DIAGNOSED WITH CEREBRAL PALSY: THE CASE OF ŞANLIURFA PROVINCE

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Keywords

Ankle–foot orthosis,
Cerebral palsy,
Family expectations,
Orthosis compliance,
Pediatric rehabilitation.

ABSTRACT

Purpose: The aim of this study was to evaluate the expectations of families of children with cerebral palsy (CP) who use ankle–foot orthoses (AFOs). Additionally, demographic characteristics of children with CP, socioeconomic status of their families, awareness levels regarding CP, expectations from treatment and orthosis use, and perceptions of orthosis appropriateness were investigated.
Methods: This cross-sectional study included voluntary parents of children aged 3–18 years with a diagnosis of CP who had been using an AFO for at least four months and were receiving treatment at special education and rehabilitation centers in Şanlıurfa, Türkiye. A total of 120 parents participated. Data were collected using a researcher-developed Parent Questionnaire Form including demographic information, socioeconomic status, knowledge about CP and orthosis use, orthosis compliance, satisfaction, and perceived benefits. Descriptive statistics and appropriate parametric and non-parametric analyses were performed using SPSS software.
Results: Night AFOs were used significantly longer than walking AFOs ($p < 0.05$). The majority of children (79.19%) used their orthoses regularly. The most commonly reported reasons for irregular use were discomfort, pain, sweating, and child reluctance. Parents demonstrated limited knowledge about CP and the context-dependent pain-reducing effects of AFOs, rather than a general analgesic effect. Overall, AFOs were found to meet family expectations at a moderate level.
Conclusion: Family–rehabilitation center collaboration is essential to minimize problems related to orthosis use in children with CP. Increasing parental knowledge regarding CP rehabilitation and AFO use may improve treatment compliance and outcomes. These findings may contribute to the development of clinical guidelines for physiotherapists.

INTRODUCTION

Cerebral palsy (CP) is one of the most common physical disabilities observed in early childhood. CP is defined as a permanent disorder characterized by posture impairment, loss of motor skills, and movement limitations resulting from disturbances that occur during the prenatal, perinatal, or postnatal periods (1). In CP, movement, posture, and balance are affected. Orthoses are used to support walking functions and standing abilities in children with CP.

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Children who benefit most from orthotic interventions are those with mild to moderate quadriparesis, diparesis, and spastic hemiparesis. Studies have demonstrated that children exhibit more stable movements when using orthoses. In general, the use of orthoses in children is important in terms of preventing deformities and providing support during sitting (2). One of the most commonly used orthoses to prevent postural disorders and increase mobility in CP is the ankle–foot orthosis (Ankle Foot Orthosis [AFO]) (2).

In clinical settings, physiotherapists recommend the use of AFOs for children with CP in order to improve gait parameters such as walking speed, step length, and cadence. AFOs have also been found to be highly important in improving joint movements in children (3–5). For the treatment of children with CP, the appropriate use and follow-up of orthoses are of great importance in rehabilitation. Regular use and necessary individual adjustments are essential for orthotic effectiveness. Monitoring the suitability of orthoses and variables such as family-related factors, making modifications to orthoses when necessary, and evaluating the effectiveness of orthoses are crucial for the progression of disease management. It is particularly important that orthoses designed for children are selected by taking into account the developmental changes of the child. In addition to variables such as the diagnosis, age, height, body weight, joint range of motion, and muscle strength of the child with CP, family and child expectations, perceptions regarding orthosis use, and financial resources should also be investigated, as reported in the literature (6–8).

The existing literature indicates that studies investigating family expectations regarding orthosis use in children with CP are limited and insufficient. Therefore, this study was conducted to evaluate the expectations of families of children diagnosed with CP who use ankle–foot orthoses (AFOs). Within the scope of this study, the demographic characteristics of children with CP, the socioeconomic status of their families, their levels of awareness regarding the disease, expectations from treatment and the orthosis use process, and perceptions regarding the appropriateness of the orthoses used were also examined. It is anticipated that the findings obtained from this study will contribute to the development of future guidelines for physiotherapists.

METHODS

This study was conducted to investigate the expectations of families of children with cerebral palsy (CP) who use ankle–foot orthoses (AFOs) and reside in the province of Şanlıurfa. Voluntary parents of children diagnosed with CP, aged between 3 and 18 years, who had been using an AFO for at least four months and were receiving treatment at different private special education and rehabilitation centers in Şanlıurfa were included in the study. Exclusion criteria included parents of children who: were younger than 3 years or older than 18 years, had a diagnosis other than cerebral palsy, had been using an ankle–foot orthosis for less than four months, were not receiving ongoing rehabilitation or special education services at the time of the study, had undergone orthopedic surgery or botulinum toxin injections within the previous six months, which could affect orthosis use or parental expectations, had severe cognitive or communication impairments that could limit the parents' ability to reliably report expectations related to orthosis use, whose parents were unwilling or unable to provide informed consent.

The study was approved by the Non-Interventional Research Ethics Committee of the Faculty of Health Sciences, Hasan Kalyoncu University, with the decision dated 27.04.2021 and numbered 2021/058. An informed consent and volunteer information form explaining the purpose and content of the study was presented to the participants, and written informed consent was obtained from the parents who agreed to participate in the study. The study was conducted in accordance with the Helsinki Declaration.

A power analysis was conducted to determine the sample size of the study. The minimum required sample size was calculated as at least 102 children diagnosed with CP, based on an 80% power, 95% confidence level, $\alpha = 0.05$ An a priori power analysis was conducted to estimate the required sample size. Assuming a moderate effect size (Cohen's $d = 0.5$), an alpha level of 0.05, and a statistical power of 80%, the minimum required sample size was calculated. The confidence level was set at 95%. (9). The study was completed using data obtained from 120 parents of children diagnosed with CP.

In this study, the "Parent Questionnaire Form" developed by the researchers was used as the data collection tool. The questionnaire administered to parents included questions regarding the children's demographic characteristics, parental education level, family socioeconomic status, levels of knowledge related to cerebral palsy and the purpose of orthosis use, information about rehabilitation processes, whether the children had orthosis usage habits, reasons for not using orthoses if applicable, parents' comments and criticisms regarding orthosis use, and overall family satisfaction with the orthosis. Responses to the questions were provided in yes/no, multiple-choice, and open-ended formats. For some questions, participants were asked to rate their responses using a Visual Analog Scale (VAS) ranging from 0 to 10 (with 0 indicating the lowest score and 10 indicating the highest score).

Although several clinical variables such as CP type and distribution, GMFCS level, comorbidities, spasticity severity, and AFO characteristics (e.g., solid, hinged, or ground-reaction; night-time versus walking use) may influence family expectations regarding AFO use, these variables were not systematically assessed or included in the present study. The primary focus of the study was to explore parental expectations and perceived knowledge related to AFO use, rather than to examine clinical or functional determinants of these expectations.

Statistical Analysis

The Statistical Package for the Social Sciences (SPSS) software program was used for data analysis. Analyses were expressed using frequency, percentage, mean, standard deviation, standard error, skewness, and kurtosis values. Depending on whether the data showed a normal distribution and homogeneity of variances, parametric analyses were applied. For demographic variables divided into two groups, such as yes/no or present/absent. Depending on the normality of distribution, the Paired t-test or Wilcoxon signed-rank test was applied to numerical (continuous) variables. Categorical variables (e.g., yes/no, present/absent) were analyzed using chi-square test. The study group consisted of a single group, and comparisons were made between two different conditions as sub-dimensions of a demographic characteristic within the same group. Similarly, for demographic variables with more than two categories within the same group—such as place of residence, income status, and education level—one-way analysis of variance (ANOVA) and post-hoc analyses were conducted and reported in the findings. The Chi-square Test was used to examine the distribution of qualitative data between groups. In all statistical analyses, the p-value was accepted as 0.05. Accordingly, analyses were limited to descriptive evaluations of parental expectation and knowledge scores. No stratification or adjustment based on clinical characteristics was performed (10).

RESULTS

A total of 120 children with cerebral palsy (CP), aged between 3 and 18 years (age: 91.8 ± 48.6 months; height: 118.6 ± 24.5 cm; body weight: 28.7 ± 12.8 kg), including 53 females and 67 males, were included in the study.

When the caregivers of children with CP were examined as n (%), it was observed that mothers, fathers, sisters, and brothers were involved in caregiving; however, the caregiver role was predominantly assumed by mothers (Table 1).

Table 1. Caregiver Information for Children with CP

Caregiver	n	%
Mother	93	77.5
Father	20	16.7
Sister	4	3.3
Brother	3	2.5
Total	120	100

When the sociodemographic characteristics of parents were examined, it was determined that the majority were primary school graduates, had a monthly income below 5,000 TL, predominantly resided in urban areas, and 55% had social security coverage (Table 2). The number of individuals living in the household ranged between 2 and 13, with an average of 5–6 individuals.

Table 2. Sociodemographic Characteristics of Parents

Variable	Category	n	%
Education level	**None**	17	14.17
	Primary school	76	63.33
	High school	18	15
	University	9	7.5
Monthly family income	**Below 5,000 TL**	105	87.5
	5,000–10,000 TL	14	11.67
	Above 10,000 TL	1	0.83
Place of residence	**Village**	12	10
	District	17	14.17
	City	91	75.83
Social security	**Yes**	66	55
	No	54	45

Table 3. The Characteristics of AFO Use Children with CP

Variable	n (%) / Mean ± SD
Duration of AFO use	
< 1 year	18 (15.0%)
1–4 years	91 (75.8%)
≥ 5 years	11 (9.2%)
Type of AFO used	
Night orthosis	48 (40.0%)
Walking orthosis	59 (49.17%)
Both night and walking orthoses	13 (10.83%)
Daily duration of AFO use (hours)	
Night orthosis	4.84 ± 1.97
Walking orthosis	3.85 ± 1.87

The characteristics of AFO use among children with CP are summarized in Table 3. Eighteen children had been using AFOs for less than one year, 91 children for 1–4 years, and 11 children for five years or longer. Regarding orthosis type, 48 children (40%) used night orthoses, 59 children (49.17%) used walking orthoses, and 13 children (10.83%) used both walking and night orthoses, with walking orthoses being the most frequently used type. When daily usage duration was evaluated, night orthoses were used for a longer period (4.84 ± 1.97 hours) compared to walking orthoses (3.85 ± 1.87 hours), and this difference was statistically significant ($p < 0.05$).

In the evaluation of whether children used their orthoses regularly, it was found that regular or irregular orthosis use did not differ between night and walking orthoses. However, 26.66% of the children were reported not to use their orthoses regularly. Accordingly, it was determined that 79.19% of the children used their orthoses regularly.

When parents were questioned regarding the reasons why children with CP did not use their orthoses regularly, 32 parents reported various reasons. These reasons included pain caused by the orthosis ($n = 3$), the orthosis pressing into the foot and causing wounds ($n = 2$), excessive sweating ($n = 6$), the child crying, being irritable, becoming bored, unwillingness, removing the orthosis when angry, lack of acceptance, inability to adapt, and discomfort ($n = 18$), parents being unable to allocate sufficient time to their child with CP ($n = 1$), and the inability to achieve the desired joint range of motion in the child with CP despite AFO use ($n = 2$).

Fifteen parents participating in the study reported experiencing various problems while their children with CP were using AFOs. These problems were listed as follows: “The orthosis causes pain, creates discomfort by squeezing the foot, and the child cries and does not want to use it" (5 parents); "Loss of balance and fear of falling associated with orthosis use" (1 parent); "The orthosis has become too small" (1 parent); "Sweating, pain, and minor injuries" (3 parents); "The orthosis feels heavy" (1 parent); "The child does not want to wear the orthosis" (1 parent); "The orthosis causes wounds" (1 parent); "The foot slips inside the orthosis" (1 parent); and "The orthosis hits the heel" (1 parent).

It was observed that among 72 children using walking AFOs, the orthosis was used more frequently while walking both at home (81.94%) and outdoors (61.11%), with higher usage rates observed at home.

When parents were questioned about what actions they took when problems occurred with the orthoses used by their children with CP, it was determined that the rate of taking the orthosis back to the manufacturing center was high (Table 4).

Table 4. Solutions Implemented When Problems Occurred with Children's AFOs

Orthosis-related action	**n**	**%**
Immediately taking it to the manufacturing center	67	55.83
Attempting to solve the problem themselves	10	8.33
Continuing to use it for a while and then taking it to the center	23	19.67
Doing nothing	12	10
Consulting the physiotherapist	1	0.83
Did not experience any problems	7	5.83

To evaluate both parental knowledge regarding orthoses and children's adaptation to orthosis use, parents were asked to rate their level of knowledge regarding rehabilitation, cerebral palsy, the benefits of AFO use, the purpose of orthosis use, expectations from AFOs, and the perceived effects of AFOs on body balance, deformity prevention, and context-specific pain-related outcomes (e.g., contracture-related pain, fatigue-associated discomfort, and discomfort secondary to abnormal biomechanical loading), as well as the prevention of unwanted body movements by the AFO used. Parents were asked to score these items on a scale ranging from 0 to 10. Based on these ratings, it was observed that parents had limited knowledge regarding CP, and the scores related to the context-dependent pain-relieving effects of AFOs were low (Table 5).

Table 5. Findings Related to Parental Knowledge About Orthoses and Children's Adaptation to Orthosis Use

Item	Mean	Standard Deviation	Minimum	Maximum
How much knowledge do you have about rehabilitation?	5.17	2.30	0	10
How much knowledge do you have about cerebral palsy?	4.38	2.46	0	10
How beneficial is AFO use for you?	5.51	1.89	1	10
Do you know the purpose of the orthosis being used?	5.35	2.25	0	10
To what extent does the AFO used meet expectations?	5.86	1.91	1	10
To what extent does the AFO affect body balance?	5.23	2.08	0	10
How effective is the AFO in preventing deformity (explained to the family)?	5.70	2.00	0	9
How effective is the AFO in reducing pain?	3.60	2.05	0	8
How effective is the AFO in preventing unwanted body movements?	5.45	1.86	0	9

DISCUSSION

In this study conducted to examine the expectations regarding ankle–foot orthosis (AFO) use among families of children with cerebral palsy (CP) living in the province of Şanlıurfa, it was observed that night orthoses were used more frequently than walking orthoses and that AFOs generally met family expectations to a large extent.

In recent years, the number of studies related to orthosis use has been steadily increasing. Research indicates that orthosis use combined with rehabilitation treatment processes provides significant benefits for children and positively affects their gait. In a study examining the effects of ankle–foot orthosis use on children with CP aged between 3 and 18 years, the problems experienced by parents during their children's orthosis use were investigated. Compliance with night orthoses was found to be lower than compliance with daytime orthoses. Significant differences were identified regarding the presence of problems associated with the use of both orthoses. Discomfort was reported as the main reason for unwillingness to use night orthoses, whereas restriction of movement and discomfort were identified as the reasons for unwillingness to use daytime orthoses. While the regularity and duration of night and daytime orthosis use were found to be similar, an increase in parental education level was associated with increased knowledge regarding rehabilitation and CP. The importance of children's adaptation to orthoses and the need for enhanced parental education were emphasized (11,12).

Parents of children with CP bear a considerable burden in terms of orthosis use and rehabilitation follow-up. It has been observed that parents' quality of life and sociocultural characteristics may positively or negatively affect their children's treatment processes. Therefore, it is crucial that parents receive support from healthcare professionals or other family members at home (13). In the present study, parents with lower education levels were also found to have lower monthly incomes. Due to financial difficulties, some families were observed to use the same AFO for extended periods, which resulted in unmet expectations regarding orthosis use.

In our study, night orthoses were used more frequently than daytime orthoses. Accordingly, a difference was observed between the usage durations of night and walking orthoses. The literature indicates that further studies are needed to improve orthosis use and compliance (14,15). In a study conducted with children with CP, the effects of AFO usage duration were investigated. While CP subtype influenced the duration of walking AFO use, it had no effect on the duration of night AFO use. Additionally, parental knowledge regarding rehabilitation was found not to affect the usage duration of either night or walking orthoses. Other factors influencing daily walking orthosis use included the type of CP diagnosis, children's Gross Motor Function Classification System (GMFCS) levels, and families' levels of rehabilitation knowledge (9).

In a study investigating whether orthosis usage duration was effective for treatment in children with CP, questionnaires administered to parents compared orthosis usage data and recovery status of eight children over a one-year period. Significant differences were identified between orthosis usage durations recorded by sensors and those reported by parents. Consequently, it was suggested that parental reports should be considered as maximum estimates. The study emphasized the importance of using different methods to measure orthosis usage duration more accurately and highlighted the need for careful and regular orthosis use, which is a critical factor in children's recovery (16).

In a study conducted on children with CP who experienced sleep disturbances associated with night orthosis use, parental competence and experience levels were compared. Research conducted on 82 children aged between 10 months and 9 years found no significant difference between children who used night orthoses and those who did not; however, a positive association was identified between parents' adequate involvement and interest in orthoses and the absence of sleep-related problems. The study concluded that parents who were consistent in treatment experienced a lower caregiving burden and that enhancing parents' sense of competence in orthosis use and treatment processes could further improve outcomes (9).

In the present study, the primary reasons reported for irregular orthosis use by children included sweating, pain, and children's unwillingness to wear the orthosis. Identifying problems encountered during orthosis use and determining their underlying causes are important for guiding both physiotherapists and parents. When the reasons for irregular orthosis use were examined in the literature, irritation, children's unwillingness, and cosmetic inadequacy of orthoses were reported as the main factors (17). In another study, commonly encountered problems were identified as heel lift-off, excessive flexion at the knees and hips, and excessive lumbar lordosis of the trunk (18). In a qualitative study conducted with parents of children with CP using dynamic AFOs, orthosis effectiveness was evaluated in children aged between 4 and 18 years. In this study involving 15 parents, participants reported that improvements in physiological conditions, functional activities, and psychosocial status were complementary variables contributing to treatment compliance and outcomes in children using orthoses (14).

In the present study, parental inaction or attempts to resolve orthosis-related problems independently were observed in a subset of participants. Although these behaviors may potentially influence children's treatment processes, the available data do not allow for a direct conclusion regarding their impact on treatment outcomes. Nevertheless, these findings highlight the importance of providing parents with more comprehensive and structured information regarding orthosis use, emphasizing the need for close communication between families, physiotherapists, and other healthcare professionals.

Although the present study did not directly assess parental psychological well-being, previous research has shown that having a child with CP may negatively affect parents' psychological status and overall family quality of life. For example, studies have reported associations between the severity of a child's condition and maternal psychological well-being, which may indirectly influence families' experiences with rehabilitation processes. In this context, improvements in children's rehabilitation outcomes may be associated with positive psychosocial effects on families; however, this relationship should be interpreted cautiously, as it was not directly examined in the current study (19).

In the present study, parents' levels of knowledge regarding orthoses were found to be moderate. We believe that implementing interventions aimed at increasing parental knowledge would enhance the efficiency of treatment processes. In a study with similar findings, a significant difference was identified between parents' education levels and their knowledge about CP. Similarly, a significant relationship was observed between parental education levels and understanding the reasons for orthosis prescription (12).

In another study, parents were asked the question, “What do you think is the main problem with your child’s orthosis use?” and the reasons for non-use were investigated. Based on the numerical data derived from parental responses, it was revealed that children with CP were unwilling to use AFOs because the orthosis restricted movement. The rigidity of the material used in AFO construction was suggested as the underlying reason for this issue (12). It is considered necessary to develop structured measurement tools in order to obtain more objective data regarding AFO use and compliance processes in children with CP.

In a study conducted by Dilek et al., it was emphasized that identifying factors affecting orthosis usage duration in children with CP—where orthosis use is highly prevalent—is important for guiding future research. Since treatment adherence is a subjective concept that is difficult to evaluate, the study highlighted the need for more objective investigations into factors influencing orthosis use. Furthermore, it was concluded that more comprehensive studies are needed using questionnaires with established validity and reliability and appropriate cultural adaptation to assess orthosis compliance in CP (10). Another study in the literature has also addressed the evidence regarding orthotic/assistive device satisfaction in chronically disabled individuals (20).

The limitations of the present study include the fact that the majority of participating caregivers were mothers, although fathers and siblings also assumed caregiving roles for some children. Considering that mothers typically bear the greatest caregiving burden, not exclusively selecting mothers as caregivers at the outset of the study may be considered a limitation. CP subtype and GMFCS level were not assessed. This is acknowledged as a major limitation of the study, as the absence of CP-specific motor function measures limits the clinical interpretation and comparability of the findings.

Based on the findings of the present study, it was observed that parents’ knowledge regarding the CP rehabilitation process and orthosis use was insufficient. Increasing knowledge levels and improving family education in this regard is a shared responsibility of all professionals involved in the rehabilitation team. However, the role of physiotherapists—who play a central role in the rehabilitation of children with CP—is particularly critical. We believe that sharing the results of this study with physiotherapists and special education centers throughout the province of Şanlıurfa will raise awareness and facilitate the initiation of future studies.

CONCLUSION

This study evaluated patterns of ankle–foot orthosis (AFO) use, parental knowledge, and problem-management behaviors among families of children with cerebral palsy in Şanlıurfa. The findings showed that walking AFOs were the most frequently used orthosis type, while night orthoses were used for a significantly longer daily duration. Although the majority of children used their orthoses regularly, more than one-quarter did not, mainly due to discomfort, pain, sweating, skin problems, and difficulties with acceptance and adaptation. When problems occurred, most parents preferred to take the orthosis directly to the manufacturing center, whereas consultation with physiotherapists was rarely reported.

In addition, parental knowledge regarding cerebral palsy and orthosis use was generally limited. In particular, parents reported low perceived effectiveness of AFOs in relation to context-specific pain-related outcomes, compared with other expected benefits such as balance support, deformity prevention, and control of unwanted movements.

Based on these findings, improving structured parental education and strengthening communication between families, physiotherapists, and orthosis providers appear essential. Clear information regarding the purpose of AFO use, realistic expectations, potential sources of discomfort, and appropriate problem-solving pathways may support better adaptation to orthosis use. Future studies incorporating detailed clinical characteristics and longitudinal follow-up are warranted to further clarify factors influencing parental perceptions and orthosis adherence.

Ethics Committee Approval:. Non-Interventional Research Ethics Committee of the Faculty of Health Sciences, Hasan Kalyoncu University, with the decision dated 27.04.2021, numbered 2021/058

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