Does user perception affect adherence when wearing biomechanically optimised ankle foot orthosis – footwear combinations: a pilot study

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Key points:

- Understanding patient adherence is crucial to effective treatment interventions
- The importance of function outweighs the cosmetic element of orthotic treatment
- Results indicate that a holistic approach to orthotic treatment is warranted

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Abstract

Study Design: Pilot study

Background: Ankle foot orthoses (AFOs) and footwear combination (FC) is a commonly prescribed medical device given to children with cerebral palsy (CP) in an attempt to improve their gait. Biomechanically optimising the AFO-FC often requires large adaptations to the sole of the user's footwear. There is currently a dearth of literature regarding the user's perception of wearing biomechanically optimised AFOs and adapted footwear and whether their perception affects their adherence to orthotic treatment.

Objective: This study aimed to investigate perception and adherence to wearing an AFO and FC the participants were asked to wear as part of their orthotic prescription. In particular, whether the visibly modified footwear affected the user's adherence to the orthotic treatment.

Methods: Questionnaire devised for the purpose of this study

Results: All five participants responded to the questionnaire; reporting a high number of positive responses in relation to function, including; an improvement in the way they walked, improved balance and fewer falls. Conversely, there was a high level of negative responses regarding aesthetics, with all participants reporting they did not like the cosmesis of their AFO-FCs. They were conscious that the modification to their footwear was noticeable and therefore different from their peers, yet they adhered to the treatment and in some cases increased the wearing time.

Conclusions: This pilot set of questions indicated that cosmesis is an important factor for children who wear AFOs and adapted footwear. It can be concluded that the impact of the adapted AFO-FC on the participants' function outweighed their opinion on the cosmesis of the device.

Clinical Relevance: It is vital to understand how orthotic prescriptions affect user adherence. Orthotic prescriptions which are not utilised by the user result in a failed treatment intervention, regardless of the scientific application underpinning them.

Key words: Cerebral Palsy; Orthotic Devices; Ankle foot orthosis; AFO; user perception; user adherence; AFO tuning

Introduction

Ankle foot orthoses (AFOs) are commonly prescribed to children with cerebral palsy (CP) in an attempt to improve their gait; they are intended to control motion, correct deformity and compensate for weakness(1) and are defined as "orthoses that encompass the ankle joint and the whole or part of the foot"(2). The term biomechanical optimisation is used to encompass the whole process of designing, aligning and tuning the ankle foot orthosis - footwear combination (AFO-FC)(3–8) and has been recommended as standard clinical practice(9,10). AFO-FC tuning is defined as the process whereby fine adjustments are made to the design of the AFO-FC to optimise its performance during a particular activity(3–7,11). The tuning process involves the manipulation of the shank to vertical angle (SVA) by the addition of wedges to the footwear and in some cases the addition of other modifications including rockers, flares and solid ankle cushioned heels to optimise the entry and exit from mid-stance and influence the ground reaction force in the sagittal plane(12,13).

Thus, a tuned AFO-FC can often have relatively large adaptations to the footwear once the prescription is complete (see Figure 1 – 2). These modifications, along with the AFO itself, are often visible to others.

User perception, self-image and adherence to orthotics

The World Health Organization defines adherence as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a health care provider."(14). This definition differentiates adherence from compliance, emphasising the user's agreement to the recommendations.

A holistic approach to user treatment is widely advocated(15); thus, it is essential to understand the psychosocial impact of orthotic intervention. Orthoses are often prescribed to fulfil several treatment goals, one of which is to improve activities of daily living and enable children to participate in activities by providing improved function. It is widely accepted that improved balance and stability can lead to an improvement in activities of daily living which are important for social development and self-confidence(16). In addition, participation in social activities in children is vital for optimal development and learning(17).

Appearance is a crucial aspect of self-image and of other people's perception of the person. Humans continually construct and interpret appearances as they define, shape, and organise their notions of everyday life. Thus, personal appearances are intertwined with human perceptions of the social order(18). Clothing and appearance are visible elements that we use to identify and differentiate ourselves and others(19). The concept of self-image and the need to fit in with peers are issues which may be affected by the provision of an orthosis, such as an AFO and adapted footwear, which is visible to others and may denote a disability.

Kaiser et al.(21) explored the clothing choice of disabled students. They concluded that disability was disruptive when social norms were breached, that is when people felt they looked different to everyone else.

User perception and adherence with orthoses

Studies which have investigated adherence with prescribed orthopaedic footwear, have reported that as little as 22–36% of users use their footwear frequently(24–26). Studies on the usability of orthopaedic footwear in adults with degenerative disorders of the foot, report a significant association between cosmetic appearance and actual use of orthopaedic shoes. Users who considered their shoes to be cosmetic wore them more often. With users criticising the footwear they were prescribed on the basis of poor cosmetic acceptability, difficulty getting the shoes on and being too heavy and uncomfortable (27,28).

Users often assess the visual appearance of prescribed footwear to determine if the style fits with their perception of the accepted 'norm', reporting a conflict between achieving social inclusion and minimising risk of foot ulceration. Often adapting self-image to take account of therapeutic footwear(29). Resulting in a high level of poor adherence (24,25,31–36).

There are three studies in the current literature which have investigated user satisfaction and adherence with AFOs(23,42,43). Holtkamp and Wouters(20) investigated use and satisfaction with an AFO on users over seven years of age with a mean age of 48.8 years. Respondents under the age of 18 years were deemed the most dissatisfied group regarding the AFO as a whole. The authors concluded that in order to improve user satisfaction, the AFO prescription and delivery process must be identified as an important sub-process of orthopaedics including the tuning process.

The available literature on user perception and adherence primarily focuses on orthopaedic footwear and is based on adults with foot health issues, with a small number of studies investigating AFO adherence and satisfaction, mostly on the adult population. There is currently no research available on the child's perception and adherence of wearing an AFO or adapted footwear as part of a biomechanically optimised AFO-FC prescription. Gaining insight into user perspectives will inform orthotic treatment goal settings and explore challenges associated with AFO use in CP children.

The aim of this study is to use a pilot set of questions to explore the user's adherence to their orthotic treatment with a view to expanding the study to a larger number of paediatric users.

Method

Participants

Five children aged between 7-11 years with a diagnosis of spastic CP and a gross motor function classification system (GMFCS) level of two, as determined by a paediatric physiotherapist, took part in this study. All participants were long-term AFO users (long- term was defined as having worn an AFO for five years or more). See Table 1 for patient anthropometrics. This study was part of a larger study which investigated the effects of non-tuned AFO-FCs on the kinetics and kinematics of gait in CP children, including energy expenditure.

A questionnaire was designed, which consisted of 12 questions (the original questionnaire is available as supplementary material), with a set number of responses and an option to write their own response, should the desired answer not be listed. The responses focused on function, aesthetics and wear time. These categories were chosen to capture the perceived benefit of the treatment: function; what did the treatment enable the participant to physically accomplish; aesthetics; how did the participant perceive the cosmetic aspect of the treatment; wear time; how often did the participant adhere to using the orthosis.

Responses were categorised as either positive or negative, e.g. "I don't like", "I can't", "worse" or "I do like", "I can", "improves". The questionnaire was issued by post to all participants three months after they were issued with their permanently tuned AFO-FC. The participants were asked to complete

the questionnaire and return it in the stamp addressed envelope provided. Questionnaire responses were collated and compared across participants. See Table 2 for the full set of questions and responses.

Ethics and consent

This study was granted ethical approval by the National Research Ethics Service (NRES), Ethics Committee West Midlands South Birmingham (Ref: 12/WM/0378), The Royal Wolverhampton NHS Trust Research (Ref: 12PAE06) and Development Directorate and a local University Ethics Committee. Parents/guardians provided written informed consent and the child's verbal assent was obtained prior to inclusion in the study.

Results

All five participants responded to the questionnaire.

Function

The results indicate a much higher number of positive responses as opposed to negative responses regarding function when wearing a tuned AFO-FC, with all the participants (n=5) reporting they walked better in their tuned AFO-FC, with fewer falls (n=3) and improved balance (n=5).

Aesthetics

The participants reported no positive responses regarding the aesthetic element of the AFO-FC but identified a number of negative responses including not liking wearing their splints (AFOs) and their adapted footwear (n=5) due to the way the splints looked (n=5) and due to other people noticing them (n=5).

In summary, the participants chose 36 positive responses regarding the function of the AFO-FC compared to seven negative responses. In contrast, there were 20 negative responses regarding the cosmetic element of the AFO-FC compared to zero positive responses.

Wear time

The results indicate that the children mainly wore their AFO-FC during school time and for approximately 6-8 hours per days 4-7 days per week. With three participants reporting they now wear the AFO prescription more often than they did when it wasn't tuned. None of the participants reported wearing their tuned AFO-FC less often than their previous non-tuned AFO-FC.

Discussion

This study was the first to look at user perception and adherence when wearing biomechanically optimised AFO-FCs in children with CP. It is clear to see from the results, that all the children who participated in this study did not like the cosmesis of the AFO-FC they were prescribed with and were very conscious of other people noticing the adaptations on their footwear, providing comments such as "*I don't like the way people look at me with the shoes",* "*Because other people keep asking why I wear them*", "*I don't like the style of the shoe*" and "*I don't have a choice of what style of shoes I can wear which makes me quite upset, it's annoying*". This was not unexpected, as self-image and the desire to fit into peer groups has already been described as a dominant driving force, especially in the disabled community(21), along with previous studies on adults which reported that cosmesis played a significant role in whether users chose to wear their prescribed footwear or not(25,28,29,31,33–36,51,52).

Although the participants unanimously agreed that they did not like the appearance of their AFOs and adapted footwear, this did not result in them wearing them less often than when their footwear was un-adapted (non-tuned), with three of the five participants reporting that they now wear their AFO-FC more often than they did before. One reason for this could be an improvement in the child's function, with all participants reporting that the tuned AFO-FC made them walk better and improved their balance. A reduction in falls was also reported (n=3), along with an increase in the number of activities the child was able to participate in (n=3) and an increase in walking distance (n=3). With one participant commenting "*Although I don't like wearing my splint I know that it helps me"*.

These results differ to those studies which examined adherence in the adult population with orthopaedic footwear, which found a significant association between cosmetic appearance and actual use of orthopaedic shoes. This may be because many of these studies involved diabetic patients where the purpose of the footwear is to protect the foot from tissue damage and ulceration and as such, may not be seen by the user as having an immediate effect on their function.

The results of this study are in line with results reported by Parton et al.(29), which stated that the benefit of maintaining function, and being considered by others as functionally normal, often became more important than negative issues relating to self-image and that visual implications of the therapeutic footwear, with regard to obvious disability, were overridden by a desire to lead a functionally normal life. The findings are also in line with a theory of adherence to using assistive technology, which emphasises the perceived benefits of using the technology(53).

There were some contradictory answers in the questionnaire, i.e. participant two reported he "felt no difference" when walking with the adapted footwear, yet later in the questionnaire indicated that the modified footwear made him walk better, increased his activities, reduced his falls and improved his balance. Similarly, participant four reported he didn't like anything about the adapted footwear, yet later reported he could walk further in the modified footwear and walked better. These contradictions may be due to the participants trying to make their feelings known, that they emphatically do not like the look of the adapted footwear.

When studying a group of participants with CP we cannot expect uniform results due to the heterogeneity of the disorder. However, results which were unequivocal included; the dislike of the cosmesis of the AFO-FC, the fact that other people were able to notice the device and the improvement in walking and balance.

It is quite common in clinical practice, especially as children get older, for adherence with orthotic intervention to become problematic. Current literature indicates that AFO use in children tends to decline after the age of five years old, although the reason for this is unclear (54). Often the child does not want to stand out amongst peers because they wear a splint or because their orthotic treatment is visible to others. Therefore, it is essential when discussing orthotic treatment plans, to take this issue seriously and discuss adherence with the user and their family. The orthotic intervention must be acceptable to the user for it to be useable and meet the aims of the treatment.

By exploring the perceptions and experiences of children with CP, issued with AFOs and adapted footwear, we begin to understand how a child's thoughts and feelings can influence their decision to adhere with their orthotic treatment, enabling clinicians to use this information to devise improved treatment goals and better inform clinical practice.

Limitations of the study

Small sample size could be perceived a limitation to this study. However, as the aim was to pilot these set of questions with a view to extending the study to a larger group of participants for further validation; the results highlight the usefulness of these questions. The number of open-ended responses by participants were minimal which indicates that the set responses listed in the questionnaire were adequate. However, an updated version of the questionnaire could include the effect on footwear choice which was mentioned by one participant in an open response.

Conclusion

It is clear that cosmesis is an important factor for children who wear AFOs and adapted footwear, like all children they don't want to stand out as being different to their peers. The participants in this study were conscious that the AFO and modified footwear they were asked to wear, was noticeable to other people, yet they continued to wear them, and in some cases increased the wearing time compared to a previously non-tuned AFO-FC which they wore as part of their previous treatment plan. Which indicates, that for children, the importance of function may outweigh the cosmetic element of the orthotic intervention.

Brief summary

● The current literature lacks research on the effects of patient perception and adherence to orthotic treatment.

● There is no available research on the effects of patient perception and adherence to biomechanically optimised AFO-FCs.

● Patient adherence to any treatment is critical to its success.

● This paper is the first to study the perception and adherence to biomechanically optimised AFO-FCs in children with CP.

● Tuned AFO-FCs are not cosmetically appealing to children.

● The results show that although a user may not like the cosmetic element of an orthotic intervention they may still adhere to the treatment if they feel their function has improved.

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Figure legend

Figure 1 Example of a tuned AFO-FC with an external footwear wedge.

Figure 2: Example of a tuned AFO-FC with a point loading rocker.

Subject ID	CP Classification	Sex	Body Mass (kg)	Age (Years)	Stature (cm)	Passive length of gastrocnemius with knee extended	Bare foot gait classification	AAAFO	AFO	Material	Material Thickness	Optimum SVA
1	Spastic hemiplegic right side affected	F	23.6	8	122	5° dorsiflexed	Group II (Winters (4)	90°	Right solid AFO	Homopolymer Polypropylene	4.5mm	12°
2	Spastic diplegic with right side predominately affected AFO right only	M	55.1	11	145	90°	Group IV (Winters (4)	90°	Bilateral Solid AFO	Homopolymer Polypropylene	5mm	12°
3	Spastic diplegic	F	27.7	7	131	90°	Group IV (Winters (4)	90°	Bilateral Solid AFO	Homopolymer polypropylene	4.5mm	13°
4	Spastic diplegic with left side predominately affected	M	31	10	140	8° plantar flexed	Group IV (Winters (4)	8° Plantar Flexion SAB 90°	Left Solid AFO	Homopolymer Polypropylene	4.5mm	13°
5	Spastic diplegic with right side predominately affected	M	25.8	9	131	90°	Group II (Winters (4)	90°	Right solid AFO	Homopolymer Polypropylene	4.5mm	11°

Table 1: Participant anthroprometric data and AFO design (AAAFO = angle of the ankle in the AFO, SVA = shank to vertical angle) *all AFOs were made from 4.5mm homopolymer polypropylene.

Question	Response	Open responses
Q1. Do you like wearing your splints:	No = 5	
Q1A. If you **don't** like wearing your splints, please tell us why.	I don't like the way they look =5 I don't like how they feel when I wear them =1 They hurt me when I wear them =3 Because other people notice my splints =5 My splints make me tired when I walk =1	"Because other people keep asking why I wear them" "Although I don't like wearing my splint, I know that it helps me. I can run better without my splint; It's awkward to stand straight with it on2 "They make me tired and sweaty and I don't like the style of the shoe"
Q1B. Please tell us what you **do** like about your splints.	They make me walk better =5 I can walk further with my splints than I can without them =3 My splints help me balance better =5 I don't fall over as much when I wear my splints =3 My splints stop the muscles in my leg/s from feeling tight =1	"I like to choose the pattern"
Q2. Do you like wearing the shoes, which we have adapted, with your splints?	No =5	
Q3A. If you **don't** like wearing your adapted shoes, please tell us why.	I don't like the way they look =5 Because other people notice the adaptations on my shoes =5 My adapted shoes prevent me from doing certain activities =2 My adapted shoes make me tired when I walk=1	"I don't have a choice of what style of shoes I can wear which makes me quite upset, it's annoying" "Too small and uncomfortable, I felt no difference"
Q3B. Please tell us what you **do** like about your adapted shoes (compared to shoes and splints without adaptations).	They make me walk better =5 I can do more activities with my adapted shoes and splints =3 I don't have any pain when I wear my adapted shoes and splints =1 I can walk further with my adapted shoes and splints =3 I don't fall over as much when I wear my adapted shoes with my splints =3 My adapted shoes improve my balance =4 I don't feel as tired when I walk in my adapted shoes =1 I don't like anything about my adapted shoes =1	
Q4. Where do you wear your splints?	I wear them whenever I go outside =3 I wear them at home and when I go outside =1 I wear them at school only =5	
Q5. How long do you wear your splints for per day?	I wear them for 6 - 8 hours per day =5	
Q6. How many days per week do you wear your splints for?	I wear them 7 days per week =2 I wear them Monday to Friday only =2 Other =1 (Tuesday – Friday)	
Q7. Since having adaptations added to your shoes do you wear your splints and shoes more or less often?	I wear my splints and shoes more often now =3 There is no change in the amount of time I wear my shoes and splints for =2	

Q7A. If you are wearing your splints and shoes more OR less often since having adaptations added to your shoes, please tell us why.		"I only wear them at school to help my balance" "Because they make walking easier"
Q8. Is there anything else you would like to tell us about the way you feel about your splints and adapted shoes?		"I don't like the shoes the way they look; they're too big for me. They're too heavy. Also, I don't like the way people look at me with the shoes"

Table 2: Questions and responses from the questionnaire