



Parent Experience with Ankle-Foot Orthoses for their Young Children with Cerebral Palsy: A Qualitative Study

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Manuscripts

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3 ***Implications for rehabilitation:***
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- 6 1. Clinical practice will be enhanced by empathy and understanding of parent experience
7 with their children's receipt and them learning to use Ankle-Foot Orthoses (AFOs).
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10 2. In collaboration with families, clinicians should seek to establish and review
11 individualized wear-time schedules that align with family routines.
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14 3. Clear guidance and more information about AFOs, including appearance and alternative
15 clothing requirements, should be provided to families in advance of receiving AFOs.
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3 **1 Parent Experience with Ankle-Foot Orthoses for their Young Children with Cerebral**
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5 **2 Palsy: A Qualitative Study**
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3 17 **Parent Experience with Ankle-Foot Orthoses for their Young Children with Cerebral**
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5 18 **Palsy: A Qualitative Study**
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8 19 **Abstract**
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11 20 **Purpose:** This study explored the experiences of parents of young children with cerebral palsy who used
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13 21 Ankle-Foot Orthoses (AFOs).
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16 22 **Materials/Methods:** Parents of children with cerebral palsy (n=11; age range 2-6 years) who used solid or
17
18 23 hinged AFOs participated. Interpretive Description, a qualitative methodological approach focused on the
19
20 24 application of findings to clinical practice, was used. Semi-structured interviews were conducted, and
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22 25 themes were developed using thematic analysis.
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25 26 **Results:** Four themes described parent experience with their children's AFOs: 1) "Hear what I am
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27 27 saying": Collaborative decision-making with families, 2) "Is my child going to be excluded because of
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29 28 AFOs?": Parent and child adjustment was a journey, 3) AFOs created financial and practical challenges,
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31 29 4) The perceived benefits of AFO use.
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34 30 **Conclusions:** Adjusting to AFOs was a challenging and time-consuming process for parents and children,
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36 31 which may have resulted in lower frequency and duration of use than anticipated by clinicians. Clinicians
37
38 32 must be aware of the physical and psychosocial adjustment process as children and families adapt over
39
40 33 time, and work with families to ensure AFO use is optimized and individualized.
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43 34 **Keywords (5-8):** cerebral palsy, ankle-foot orthoses, parent experience, qualitative research, pediatric
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45 35 orthotics
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Introduction

Ankle-foot orthoses (AFOs) are common interventions for children with cerebral palsy for improving gait quality, enhancing stability during standing and walking, maintaining ankle range of motion, preventing deformities (1, 2), and facilitating gross motor function (3). Currently, clinical decision-making about AFO prescription and monitoring practices is often driven by clinical assessments of muscle tone, joint range of motion, and gait pattern (4), all of which are classified as the Body Functions and Structures component of the International Classification of Functioning, Disability and Health (ICF) (5). It has been argued, however, that decisions about AFO prescription and monitoring need more of a dynamic process focused on functional outcomes that requires perpetual evaluation by clinical teams and families to meet clinical and family goals (4, 6). Owen (7) suggested that AFO prescription and use parameters should be driven by the desired goals for AFO use across all components of the ICF, including participation in activities that children find engaging. This perspective aligns with the shift toward promoting daily function, inclusion, and meaningful participation seen more broadly in pediatric rehabilitation (8).

Incorporating family goals in decision-making pertaining to AFO prescription is recommended for optimal treatment outcomes (4). Maximizing child involvement in the process by ensuring they have a voice in their treatment plans may further enhance their motivation to participate (9). Understanding how AFOs impact daily function, participation, and children's routines in their home and community settings will facilitate the alignment of clinical prescription and monitoring practices with parent and child goals. For example, while there are many reports of the positive effects of AFOs (2, 10), there are also some concerns that use of AFOs may limit floor mobility and transitional movements for young children, negatively affecting their daily function (11).

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3 Furthermore, adherence to AFO use by older children may be influenced by the aesthetics of the
4 orthotic device (12), child acceptance, and family perceptions of AFOs (13). Positive family
5 experience with interventions is a key factor in successful AFO management for children (4);
6 however, research exploring the experiences of families is limited (14). In addition, there is a
7 dearth of research evaluating the effects of AFOs on participation for young children with
8 cerebral palsy (14); research exploring parent experiences may explain functional and
9 participation-focused outcomes that are meaningful to families. This study aimed to gain insight
10 into parent experience with AFO use by their young children with cerebral palsy to inform
11 prescription and monitoring practices.
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24 **Materials and Methods**

25 *Study Design*

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28 Interpretive Description, a qualitative approach developed for gaining practical
29 knowledge in applied health disciplines to inform clinical understanding of the phenomenon
30 under study (15), was the methodological framework used for this study. Interpretive Description
31 enables researchers to provide rich descriptions and high-level interpretations of participants'
32 lived experience through a clinical lens (15). This study received ethics approval from the Health
33 Research Ethics Board at the University of Alberta (Ethics ID: Pro00095225). All participants
34 provided verbal consent at the beginning of the interviews. Identifying information was removed
35 from the transcripts prior to extracting any of the quotes for inclusion in publications and
36 presentations.
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52 *Participant Recruitment*

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3 Invitations were distributed among clinician-researchers known to have interest in pediatric
4 orthotics and rehabilitation across Canada to be shared with families of children with cerebral
5 palsy and also via social media platforms. Parents and caregivers were eligible to participate if
6 they spoke English and were parents/guardians or caregivers of a child with: 1) cerebral palsy,
7 Gross Motor Function Classification System (GMFCS) (16) Level I-III, 2) aged 2-6 years, 3)
8 who was currently using AFO(s) for at least one month, and 4) living in Canada.
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18 Twenty-one parents indicated interest in participating in the study from June 2020 to
19 April 2022. In total, six families were deemed ineligible because their child had a diagnosis other
20 than cerebral palsy (n=1), they were older than six years of age (n=2), or they were classified as
21 GMFCS levels IV or V (n=3); four eligible families declined to participate in the interviews due
22 to time constraints. Some of the children wore one AFO (n=4), and the others used them
23 bilaterally.
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32 Eleven parents (ten mothers and one father) participated in individual interviews. A
33 follow-up interview was conducted with one of the parents to clarify some aspects of the first
34 interview. Their children ranged in age from two to six years, and at the time of the interview,
35 they had been wearing AFOs for at least four months. Additional participant information is
36 provided in table 1.
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45 [Insert table 1 here]
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48 ***Data Collection*** 49

50 Interviewing enables researchers to co-construct knowledge by giving voice to participants as
51 they explain the subjective meaning they ascribe to their experiences (17). The initial interview
52 topic guide was pilot tested with a parent of a child with cerebral palsy to verify question clarity
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3 and alignment with the study objective. Minor modifications were made to the guide after the
4
5 pilot interview. Individual interviews (45-60 minutes) were conducted by the first author (PF)
6
7 using a semi-structured guide (box 1) and the automated transcription feature of Zoom (San Jose,
8
9 CA: Zoom Video Communications Inc.) (18). At the beginning of the interviews, the interviewer
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11 informed families that she solely focused on research at the time of conducting this study and
12
13 although trained as an orthotist, she was not currently actively involved in clinical practice. Thus,
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15 families were reassured that the interview was a safe space for communication to share their
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17 experiences and insights. Questions were designed to explore parent experience and perception
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19 of AFO use, including the benefits and challenges and the process of adjusting to AFOs. A
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21 follow-up interview was conducted when more in-depth information was required from the
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23 interviewee.
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32 ***Data Analysis*** 33 34

35 Following each interview, the first author compared the recordings and Zoom-generated
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37 transcripts and edited discrepancies. The six-step inductive thematic analysis process described
38
39 by Braun and Clark (19) was used to analyze the data. Comments were used to identify relevant
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41 text and assign codes within Microsoft Word: Two researchers (PF and LP) 1) familiarized
42
43 themselves with the data, 2) identified codes in the transcripts independently, and 3) developed
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45 themes. The researchers then discussed their coding and preliminary themes to further refine
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47 them, ensuring they were aligned with the aim of this study (Step 4). Researchers discussed the
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49 higher-level concepts within each theme, collaboratively defined the themes, and generated short
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51 descriptions (Step 5). Finally, themes were expanded and edited during manuscript preparation,
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53 and relevant quotes from participants were extracted to substantiate the themes (Step 6).
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Rigor

Strategies described by Sally Thorne to enhance credibility, such as epistemological integrity, appropriate sampling, and providing a thick description of the data were used to inform study design and data collection, analysis, and reporting (15). In addition, verification strategies described by Morse et al. (20), including methodological coherence and collecting and analyzing data iteratively, were also used to enhance study rigor. Methodological coherence (20) was ensured by aligning the research aim and the study methods with the methodological framework, Interpretive Description. Purposive sampling (15) was used to recruit parents who had experience with their young children's using AFOs and who were willing to share their experiences. To engage with the data and ensure that data collection and analysis was conducted iteratively (20), data were analyzed after each data collection session, and the interview guide was modified as needed to ensure exploration of relevant aspects of parent experience.

In addition to the strategies outlined above, peer debriefing (21) was used to enhance the credibility of interpretation of the data. The multi-disciplinary research team was knowledgeable about cerebral palsy, clinical interventions for children with neurodevelopmental conditions, and qualitative methodology. All co-authors reviewed the study protocol and, after the analysis, reviewed the themes and description and the results to assist with the interpretation of data from their various disciplinary perspectives. The researchers primarily involved in the analysis (PF & LP) had clinical experience as an orthotist and a pediatric physical therapist, respectively. While the first author was mindful of her perspective, personal beliefs, and clinical experience during the interviews, peer debriefing encouraged the author to become more aware of how her own perspectives affected the collection and interpretation of data and ensured a focus on participant's voice with the aim to inform clinical practice. Therefore, the first author attempted

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3 to create knowledge that was reflective of the study participants' voice and experience rather
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5 than imposing her beliefs about the topic. Reflexivity was facilitated through discussions
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7 throughout data collection and analysis and by acknowledging how previous clinical and
8
9 research experience affected engagement with data and interpretation of the results in clinical
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11 practice. In addition, the author remained focused on the issues that mattered to families and then
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13 interpreted them through a clinical practice lens. This process contributed to ensuring
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15 epistemological integrity, an important element of rigor in Interpretive Description research (15).
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19 20 **Results**

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22 The analysis resulted in four themes that described parent experience and perception of young
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24 children's AFO use: 1) "Hear what I am saying": Collaborative decision-making with families,
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26 2) "Is my child going to be excluded because of AFOs?": Parent and child adjustment was a
27
28 journey, 3) AFOs created financial and practical challenges, and 4) The perceived benefits of
29
30 AFO use. The themes are described in more detail below.
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35 ***1. "Hear what I am saying": Collaborative decision-making with families.***

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37 While each parent described a unique journey toward accepting AFOs as part of their daily
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39 routine, they often perceived that AFOs were uncomfortable for their children and that they
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41 needed time and more breaks in their wear-time schedule to adjust to AFOs. One parent was
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43 concerned about her child's mental health as the parent perceived AFO use as another therapy
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45 that required dedication and effort:
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50 "I think it's important for him [child], and for all of us, to not only stay physically healthy
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52 but also mentally healthy... to have the recreation time to let his body and his mind
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54 rest... instead of constantly having therapy." (P7)
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3 To facilitate adjustment to AFOs, parents believed that clinical teams should recognize and
4 consider children's tolerance of AFOs when making wear-time schedule recommendations as
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6 "it's a whole kid, it's not just an ankle that we are treating." (P8). Some parents discussed a
7
8 discrepancy between clinicians' recommended AFO dosage, which was variable among study
9
10 participants, and the feasible wear time in their children's daily routines. Although parents
11
12 valued clinicians' opinions and attempted to follow their recommendations, they perceived
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14 instructions "wear AFOs full-time" or "as much as possible" as vague and disconnected from
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16 their children's tolerance and abilities. For example, one parent described her experience with
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18 her child wearing AFOs for the recommended amount of time:
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24 "…It's easy for them [clinicians] to say that – 'wear it all the time, just do it'… But
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26 they're not the ones that have to deal with it [AFO], and have to fight with it… I do listen
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28 to the doctors. We do put them on as much as we can, but they don't have to see him in
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30 pain…." (P1)
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34 The discrepancy between the prescribed AFO dosage and actual wear time became a source of
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36 shame, guilt, and internal struggle for some parents. A parent of a 3-year-old child described her
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38 experience with her child's lack of tolerance for wearing AFOs for the recommended time:
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42 "…we should be doing it, why can't we do it… which is, you know, like guilty and
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44 shameful, but at the same time, I'm trying to be sympathetic too - he's a little boy." (P7)
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47 Another parent who described her child as having a cognitive impairment stated that she was
48
49 unable to explain the reason for wearing AFOs to her child. She also experienced internal
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51 conflict between putting the AFOs on her child, as directed, and observing her pain:
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3 “... It’s hard to explain [to the child], this [AFO] is for your benefit... because our
4 daughter is delayed... and there’s a lot of guilt with it. Even now, when we put it on, it
5 hurts...you don’t want your kids to hurt, and you don’t want to be the cause of the pain
6 either, right?” (P8)
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13 Some parents questioned their parenting skills because of their inability to keep AFOs on their
14 child for the recommended amount of time and assumed they were to blame for adverse
15 outcomes associated with not wearing the AFOs. For example, a mother of a three-year-old boy
16 described her fear about risking her child’s future: “If he doesn’t wear them [AFOs] now, his
17 legs will be messed up forever. He’s never going to walk” (P7). Parents acknowledged that
18 working toward a collaborative and supportive relationship with their clinical teams so that
19 adjustment strategies and barriers to AFO use can be discussed is essential for optimizing AFO
20 outcomes:
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32 “I think kid’s clinical success is really dependent on how effectively you [clinicians] can
33 partner with parents.” (P6)
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37 Parents perceived that an individualized schedule that gradually increased daily AFO wear time
38 was necessary to facilitate adjustment to AFOs. A parent of a 4-year-old child (P5) described
39 how reassurance from the clinical team that allows for some flexibility in the wear schedule
40 would have been helpful in adapting to AFOs: “...it was good to know by this date he should be
41 wearing them [AFOs] all the time, but also kind of let you know that there is going to be a
42 transition period, and it kind of does depend on the kid and their personality.” Another parent
43 emphasized the need for professional input into optimizing dosage for the AFOs: “I wanted to
44 hear how long they [clinical team] wanted us to wear it, and then we figured it out within our
45 lifestyle” (P3).
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3 Parents recognized that there was a need for enhanced and open communication between
4 families and clinical teams, as it was not always convenient for families to share their
5 observations and experiences about AFO use with the team. Some parents found approaching the
6 clinical team to discuss AFO modifications or changes in the wear-time schedule challenging
7 and sometimes felt that they were questioning clinicians' recommendations:
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15 “...it is that part that how do I question without telling you [clinicians] that I think you
16 are wrong, right? So there is that challenge that I have got to balance there ...that
17 uncomfortableness of having some of these conversations....” (P8)
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23 Most families did not have general knowledge about AFOs to prepare children for AFO use.
24 Therefore, lack of knowledge emerged as a barrier to communicating effectively with their
25 children and led to inaccurate assumptions about AFOs: “I didn't realize that it was something
26 that you wear all the time.” (P7). Parents believed that with adequate and reliable information to
27 explain the purpose of wearing AFOs to their children, they would be more successful in
28 convincing children to wear them:
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37 “I think providers really need to highlight the benefits of an AFO, what the overall goal
38 of an AFO is, and what it is helping to prevent as children develop... so that they can
39 have that [information] in their toolkit when they are trying to explain to a toddler and,
40 like in a topic-friendly manner.” (P11)
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47 Receipt of contradictory opinions about AFO use and wear-time recommendations from different
48 clinicians was confusing for families:
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52 “I think the biggest challenge that we face is just going from one provider to the next, one
53 will say this is really beneficial and the next person say... ‘I can't believe you have her on
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3 AFO because don't you know how much muscle weakness that is going to cause her?' So
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5 we're kind of constantly thrown between those two mindsets." (P4).
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9 Conflicting opinions from the clinical team forced some families to independently decide about
10
11 wear-time routines. For example, a mother of a 2-year-old boy (P9) described, "... because we
12
13 got different opinions, we just kind of have used our judgment." While parents articulated many
14
15 challenges related to their children's AFO use, they identified collaborative decision-making as a
16
17 practical approach to mitigating these challenges.
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21 **2. "Is my child going to be excluded because of AFOs?": Parent and child adjustment was**
22
23 **a journey.**
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27 Parents were fearful of the perceived stigma when their children received AFOs, which resulted
28
29 in an initial resistance to AFO use. The internalization of social pressure to look "normal" and
30
31 the perceived stigma associated with wearing AFOs in public made the process of accepting
32
33 AFOs overwhelming for some parents. Initially, some parents expressed embarrassment when
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35 people saw their children wearing AFOs:
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39 "[I feel] embarrassed, and I don't want them [people] to judge him or see that there's
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41 something wrong with him for having them [AFOs]...." (P10)
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44 "...so there is some embarrassment, unfortunately, or some fear that people are going to
45
46 think that we've hurt her, and we worry about that..." (P8)
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49 Parents were also concerned about their children looking different from their peers and the
50
51 potential exclusion that could result from this difference. A parent of a 5-year-old boy (P6)
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53 described how she felt a "shock" because she was not ready to see her child in AFOs: "...I knew
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55 when you look at a kid like that [with AFOs], one of the first things that you register is...that
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3 they have a deficit of some kind.” One parent explained that her husband assumed AFOs would
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5 inhibit their child’s participation because the child would be excluded from group activities by
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7 his peers:
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10 “...he [dad] doesn’t want people to treat him [child] differently because...he doesn’t
11
12 want people to say, oh you’re wearing AFO, so maybe it’s not safe for you to play the
13
14 sport with us...” (P9)
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18 The participants acknowledged that their concerns about stigma and the effects of others’
19
20 perceptions on their child’s participation and inclusion appeared to be primarily a parental
21
22 struggle; their children were accepted in communities and were included in group activities by
23
24 their peers. As one parent described, “three and four-year-olds are such sponges” (P3). Some
25
26 parents also focused on how they could impact society by viewing parental advocacy about
27
28 cerebral palsy and AFOs as an opportunity to enhance awareness about children’s use of
29
30 assistive devices and normalize differences:
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35 “...I want her to grow up in a society where she’s accepted, even though she’s going to
36
37 be different, right? We know she’s going to need help, we know she’s going to be
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39 different, but I don’t want her to be judged negatively for something that’s not her fault.”
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41 (P8)
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45 The perceived stigma shifted over time once parents recognized the positive outcomes associated
46
47 with AFO use. The parent of a 3-year-old boy (P7) explained that the journey of accepting and
48
49 dealing with AFOs was challenging due to the discomfort accompanied by using AFOs, the
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51 effort required to adapt to AFO use, and the need to adhere to the recommended number of
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3 hours. However, she felt positive about the process when she reflected on how much the child
4
5 and family had achieved:
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8 “...You think about where he was at, like a year and a half ago, or whenever he got them
9
10 [AFOs], it was a struggle, it was tough to get through, and now I’m happy and proud of
11
12 him....” (P7).
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16 Parents described the path to AFO acceptance and adjustment as a symbol of success, as they
17
18 overcame the difficulties of the journey and adapted to the new device. However, this success
19
20 was not achieved easily and required patience and practice:
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23 “...it is kind of like a demonstration of something that he’s really worked on with his
24
25 body, that he’s proud of. I think as much as they [AFOs] are pain and they are in place as
26
27 a result of a deficit, they are also like a symbol of success, that he went through a really
28
29 painful procedure.” (P6)
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33 **3. AFOs created financial and practical challenges.**

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36 Parents experienced similar challenges with AFO use, regardless of where they lived. Although
37
38 the majority of AFO costs are publicly funded in Canada, the cost-share portion was unexpected
39
40 for some families. They had to manage their finances accordingly and ensure that they had
41
42 appropriate insurance coverage.
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46 “... it was figuring out where we were going to find the money. Because that is an extra
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48 expense on top of us that we have to come up with every year, we have to pay an expense
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50 for AFOs... we have to pay a \$500 deductible every year. So now we have it figured out.
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52 We budget for it. But that first round was kind of like, oh crap.” (P3)
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3 Parents expressed challenges in finding footwear and clothes that fit AFOs. They were concerned
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5 about finding good quality footwear within their budget, and their children often needed two
6
7 different pairs for use with and without AFOs:
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10 “...because the AFOs make his foot two times bigger. So the shoes that he has is two
11
12 times bigger. So if you just put the shoes on, then they are huge shoes; he is tripping
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14 everywhere. So we have to buy another pair of shoes, so it gets a little expensive.” (P1)
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18 As children outgrow their clothes and footwear more frequently, this imposes costs for adapted
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20 clothing and shoes. Parents believed that some practical challenges, including their lack of
21
22 knowledge about where to buy suitable footwear and pants, types, and brands of footwear, could
23
24 have been mitigated by suggestions from the clinical team:
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28 “I think like a couple of well-chosen blogs and some better pamphlets, a little bit of like
29
30 peer support availability, would go a huge way. So the feelings were like incredible
31
32 frustration on the day that I basically had to carry him around a shopping mall, to find
33
34 socks, like I was definitely near tears.” (P6)
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38 Some families expressed difficulties in keeping the AFOs on when their children learned how to
39
40 take them off. For example, a parent (P8) described that “she [child] learned how to rip the straps
41
42 ...so we usually put a sock over it, we also use medical tape..., and it’s bought us some extra
43
44 time to keep it on her foot longer.” Parents perceived that their children were often
45
46 uncomfortable in their AFOs, particularly in warmer temperatures. Furthermore, wearing long
47
48 socks and running shoes was inconvenient for them during warm weather. Some children were
49
50 able to vocalize their concerns about wearing AFOs; however, in the absence of redness or skin
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52 issues, parents felt it was unnecessary to remove them:
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3 “...I do find that more stressful having him vocalize that he doesn’t want to wear his
4 brace, but there is no redness when we assess his foot, so we know it is not hurting him; it
5 is just more, I think, an independent seeking sort of thing for him right now. And that we
6 just say it helps your foot, and you have to wear it, that’s the end of the story, so that one
7 is a very solid non-negotiable....” (P11)
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14 ***4. The perceived benefits of AFO use.***

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16 Parents perceived that AFOs provided stability, improved their children’s gait pattern and daily
17 function, and played an important role in building their confidence and willingness to try new
18 activities. As such, children were physically active for a longer period of time during play when
19 wearing AFOs. For example, the parent of a four-year-old boy (P5) mentioned that “it has given
20 him enough support that he is able to try things, and his confidence has kind of built from there.”
21 Parents believed that children felt safer and more secure when wearing AFOs because of the
22 increased stability and improved balance:
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35 “...he was falling so much, he was getting a little bit scared of running, so that was a
36 worry for me. So, I would say the AFO was definitely helping with that because he has
37 no fear of anything now...the first time he wore it [AFO], he was like, ‘I’m so excited,
38 I’m having so much fun,’ it was really nice to see...the tripping is gone, and he can still
39 run like, he can keep up with other kids of his age.” (P9)
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47 Parents recognized that children explored more activities while using AFOs, and they were able
48 to keep up with peers more easily.
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51 **Discussion**

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3 The families in this qualitative study reported several perceived benefits of AFO use, such as
4 improved gait pattern, balance, and stability, which have been evaluated and reported in previous
5 studies (22-26). However, some of the positive outcomes reported by the parents in this study
6 were beyond the Body Functions and Structures outcomes typically evaluated in young children
7 (14). For example, parents noted increased child confidence and motivation to try new activities,
8 such as running, which is consistent with previous research (27). Naslund et al. (27) reported that
9 parents of children (4-18 years of age) who used dynamic AFOs experienced improved security
10 and safety, which resulted in increased confidence in some daily activities, such as riding a bike.
11 Confidence and motivation are two important precursors to outcomes that could affect children's
12 participation in multiple environments and are rarely evaluated. The ICF defines participation as
13 involvement in a life situation at a social level (5). Future research could explore how AFOs
14 affect confidence, motivation, and participation. Research evaluating participation as an outcome
15 is limited (14), and the parent focus on participation outcomes in this study suggests that research
16 needs to expand beyond evaluation of outcomes in the Body Functions and Structures
17 component of the ICF. Participation in situations that are enjoyable for children is an important
18 facilitator of child development (28). Therefore, studying if and how AFOs promote children's
19 engagement in situations that are meaningful to them would make an important contribution to
20 the existing literature.
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45 The parents in this study expressed that they deviated from recommended AFO usage
46 parameters because they did not align with family routines, priorities, and their children's
47 tolerance of AFOs. Schwarze et al. (29) reported a significant difference between the
48 recommended dosage of AFO use and the measured wear time among young AFO users,
49 emphasizing a misalignment between clinical expectations and the realities of families. The
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3 authors also identified a difference in children's AFO use between weekdays and weekends,
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5 which may be attributed to environmental factors and children's engagement in different
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7 activities at home and school (29). Optimal wear time and schedules should be individualized to
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9 meet the child and family's goals and routines and incorporate family perceptions about
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11 feasibility (30). Establishing wear-time routines that consider family goals, the clinical objectives
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13 of AFO provision, child tolerance, functional mobility, and activity engagement is also more
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15 likely to optimize AFO use. Kane et al. (4) highlighted the importance of individualized AFO
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17 prescription in collaboration with families to ensure families are partners in decision-making.
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19 This approach to AFO prescription and monitoring may increase the likelihood that families feel
20
21 comfortable discussing any challenges they may experience with AFO use. Collaborative
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23 planning with families, a cornerstone of family centered-care, is associated with a higher rate of
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25 user satisfaction (31). Collaborative, goal-focused planning is also warranted since there are
26
27 currently no consistent, evidence-based guidelines on optimal AFO wear time (29), and optimal
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29 dosage may be variable, depending on the goals of AFO use. Current practice is largely based on
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31 a study conducted by Tardieu et al. (32) in 1988 that recommended wearing AFOs for a
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33 minimum of 6 hours a day to prevent contracture of the gastrocnemius musculotendinous unit.
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35 Future research should explore optimal AFO use parameters that are aligned with outcomes that
36
37 are meaningful to children and families. Parents in our study expressed that optimal adjustment
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39 to AFO use required an initial low dosage that could be increased over time, emphasizing the
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41 importance of incorporating parent and child input and experience into the development of wear-
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43 time schedules.
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52 Clinical expectations about AFO use that misalign with the capacity of families to adhere
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54 to them may result in parental stress and guilt. Parents assigned self-blame for not being able to
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3 follow the wear-time expectations, which was sometimes interpreted as bad parenting. This
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5 experience may be related to a recent diagnosis of cerebral palsy, which may have initial adverse
6
7 effects on the well-being of families (33). Although disability is widely considered to be a social
8
9 construct resulting from the existing gap between family and child needs and resources, services,
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11 and supports (33), families may struggle with the diagnosis and feel unsure about their child's
12
13 future (34). It is important for clinical teams to recognize that individual beliefs about disability
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15 and cultural values and views on disability may shape parents' experience and initial willingness
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17 to use AFOs or any other visible assistive device in public settings.
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23 Conflicting advice from members of multi-disciplinary clinical teams created challenges
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25 for some of the families of this study. Parents noted that they often identified inconsistencies in
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27 the information provided by different clinical team members, which they found confusing.
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29 Clinical teams should make efforts to communicate regularly with each other (35) and deliver
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31 comprehensive and consistent information, working as an interdisciplinary team, to implement
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33 and practice effective interactions with families. Use of a key contact for families may also be an
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35 effective strategy to improve communication. Families indicated that they often had more regular
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37 contact with certain clinicians, often physical therapists, allowing for a more comfortable
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39 environment for open discussion and problem-solving.
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45 Parents struggled with the perceived stigma that they believed AFOs would have effects
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47 on the inclusion of their children. Parrette and Scherer (36) reported an association between
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49 using assistive devices and stigma. Stigma stems from the social symbolism of assistive devices
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51 representing incapability and exclusion (37), which some parents highlighted in their interviews.
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53 Parents' perspectives shifted as they observed improvements in their children's function when
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55 using AFOs, and most parents reported that their concerns about exclusion were not realized as
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3 their children did not experience social isolation at daycare/school and in communities.
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5 Clinicians should be aware that perceived stigma may initially affect parents' willingness to use
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7 AFOs in their communities, and parents may require additional time to adjust. Clinician
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9 awareness of family concerns in this regard will facilitate individualized treatment plans that
10
11 consider family readiness and acceptance of assistive devices. Despite the extensive research on
12
13 the benefits of using orthoses continuously to maintain biomechanical properties (38), it is
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15 crucial to consider how the aesthetics of devices influence children and families and what it
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17 means to them personally (37) when discussing the AFO use plans. Clinician understanding of
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19 parental concerns and practical implications of AFO use with young children on an individual
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21 and societal level may lead to improved alignment of clinical expectations and actual AFO use.
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27 Successful use of an assistive device requires education and guidance to users about the
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29 mechanism, clinical objectives of use, dosage, and associated short and long-term goals set
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31 collaboratively by clinicians and families (7, 35). In this study, families expressed they had little
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33 to no knowledge of what AFOs would look like prior to receiving them, how they would limit
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35 their choice of footwear and clothes, the expected dosage of wear time, and the role of AFOs in
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37 children's functioning when the device was introduced to them. Similar findings were reported
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39 by Zaino et al. (35), who studied the experiences of AFO users with cerebral palsy and their
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41 caregivers in the United States and reported a knowledge gap among users about AFO provision,
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43 such as the rationale for prescribing a specific type of AFO. Their findings also emphasized the
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45 importance of educating families about AFOs to address their challenges and concerns, a
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47 perspective also supported by other research (38). Clinical teams can assist parents with
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49 navigating practical challenges, such as providing advice regarding clothing/footwear brands that
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51 have worked for other families or financial resources to support extraordinary expenses. Also, a
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3 written individualized document with details about the AFO hygiene and maintenance, types of
4 footwear and adapted clothing, wear-time instructions, and eligible activities with AFOs could be
5 useful for families. Clearly, ensuring good AFO fit and parental knowledge of how to monitor
6 skin integrity would also facilitate children's adjustment to the device.
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13 This study highlighted the perceived benefits of AFO use in multiple environments from
14 parents' perspectives, challenges with AFO adjustment that were exacerbated by expectations
15 from clinical teams regarding high frequency and duration of wear time, and parental concerns
16 about stigma that could potentially affect children's inclusion. Future research should focus on
17 the contribution of factors, including cultural values and views about orthotic devices and
18 associated psychosocial concerns in shaping children and families' adjustment to AFO use in
19 public settings. Also, engaging young children in future research studies to address their voices
20 about orthotic devices would provide more insight into practicing collaborative decision-making
21 with families and children about AFO provision and monitoring.
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34 ***Limitations***

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37 One limitation of this study was that we did not collect information about family ethnicity and
38 socio-economic status, which could influence families' access to resources and shape their
39 perception of AFO use in their children. Also, we only received responses from families in four
40 provinces of Canada; therefore, voices of parents from other provinces were not included. Only
41 one father participated in the interview, and including more fathers may have affected the results.
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47 Furthermore, children used different types of AFOs for variable amounts of time, which may
48 have affected parent experience.
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54 **Conclusion**

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3 This study explored parents' experiences of their young children with cerebral palsy using AFOs
4 and provided insight into family challenges and experience. Parents observed their children in
5 home, school, and community environments and have insights that might not be evident during
6 short clinical visits. The findings of this study suggest that interactions with families related to
7 AFO prescription and monitoring may be improved with increased collaborative decision-
8 making with families and the development of individualized AFO use plans that consider family
9 context. Insight into parents' values, goals, and preferences related to AFOs for their young
10 children may contribute to the development of treatment plans that support families' goals and
11 priorities.
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24 Parent perception of AFOs affects children's adherence to AFO use and acceptability of
25 the device. The influence of psychosocial factors associated with AFO use in children and
26 families was prominent in this study, and clinicians should be mindful of psychosocial factors
27 that may affect AFO wear time. Ensuring open communication with families that acknowledges
28 their individual contexts is important for the development of effective therapeutic relationships.
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42 Canada Network, for assisting with recruitment. The authors appreciate the time and effort of the
43 parents who participated in the study and shared their experience.
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51 **Declaration of Interest**

52 The authors report there are no competing interests to declare.
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For Peer Review

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For Peer Review

Table 1. Participant demographic characteristics

Participant	Relationship to child	Child sex	Child age	GMFCS level	Distribution of CP	Type of AFO(s) used currently	Months since receipt of AFO(s)	Province
P1	M	m	5y	II	BL	Hinged	36	AB
P2	F	m	6y, 1m*	II	BL	Hinged	24	AB
P3	M	m	2y, 2m	III	BL	Solid	15	AB
P4	M	f	4y, 11m	I	UL	Hinged	41	AB
P5	M	m	4y	II	BL	Solid	24	NB
P6	M	m	5y, 9m	I	BL	Hinged	4	ON
P7	M	m	3y, 5m	III	BL	Solid	17	AB
P8	M	f	2y, 3m	II	UL	Solid	4	AB
P9	M	m	2y, 9m	I	UL	Hinged	12	ON
P10	M	m	5y, 6m	III	BL	Solid	48	AB
P11	M	m	3y	I	UL	Solid	18	SK

M= mother; F= father; m=male; f= female; y=years; m*= month(s); BL= bilateral; UL= unilateral; AB= Alberta; NB= New Brunswick; ON= Ontario; SK= Saskatchewan.

Box 1. Interview Guide

1. Can you tell me about what it was like when (child) received his/her AFOs?
2. What was it like when (child) first started wearing the AFOs? At the time, how did you feel about (child) using AFOs?
3. Is there anything that would have been helpful to know before your child received AFOs?
4. What were your expectations for AFOs for (child)?
5. You mentioned that you hoped the AFOs would (their expectations). Did that happen? Please explain.
6. What are the negatives associated with using AFOs, if any?
7. What are the positives associated with using AFOs, if any?
8. Are there any activities that your child finds more difficult because of the AFOs? Please explain.
9. Are there any activities that your child finds easier because of the AFOs? Please explain.
10. What was the recommended wear time for AFO use (i.e., hours per day and types of activities)? Did your child wear the AFOs (insert recommended parameters)? If not, why?
11. How did you feel about the recommendation to wear the AFOs (insert recommended parameters)?
12. If parents mentioned that their child experienced challenges: You mentioned that your child (insert any descriptions of barriers to AFO use). What do you think was going on when your child responded this way? How did you feel about it?
13. If there was a discrepancy between actual and recommended wear time: What is it like for you when there is a difference between the wear time expectations from clinicians and your reality?
14. How do you feel about giving your child breaks from AFOs?
15. What would be helpful in regard to wear time recommendations from clinicians?