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ORIGINAL ARTICLE

Understanding frames: A qualitative study of young people's experiences of using standing frames as part of postural management for cerebral palsy

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Abstract

Background: Consensus opinion supports standing frame use as part of postural management for nonambulant young people with cerebral palsy. Although the rationale for standing frame use and the associated challenges have been described, little attention has been given to the users' experiences. The aim of the current study was to explore young people's positive and negative experiences, and attitudes regarding standing frame use.

Methods: Framework analysis informed an open exploration of young people's opinions of standing frames. Using semistructured interviews, 12 young people with cerebral palsy (6 female) were interviewed, providing the data set for transcription and thematic analysis.

Findings: The first theme "attitudes to standing frames" describes the young people's understanding of why they use standing frames. Although standing frames can be painful, some young people believe they should be endured to improve their body structure and function. There were mixed views about the impact standing frames have socially, with some young people feeling excluded from their peers, and others feeling as though standing frames helped them "fit in." Some young people are not offered a choice about how and when they use their standing frame. The second theme "challenges of standing frame use" highlights the issues with standing frame use such as manual handling, interference from siblings, and the lack of aesthetically pleasing standing frame designs.

Conclusions: Young people report benefits related to choice, pain relief, and participation but can also cause pain, discomfort, and reduced independence and participation. Healthcare professionals should have open, informative conversations about potential benefits and challenges of standing frames on all aspects of the young people's lives, including participation and activity.

KEYWORDS

cerebral palsy, child disability, physiotherapy, standing frames

1 | BACKGROUND

Cerebral palsy (CP) is the most common motor disorder of childhood, affecting 1 in 400 children. CP is associated with abnormalities of tone and posture with secondary musculoskeletal complications. These impact on mobility, participation, and function for activities of daily living. Various postural management strategies are recommended to reduce symptoms and maintain body structure, including devices that can be used for standing, sitting, and lying (Gericke, 2006; Hill & Goldsmith, 2009; Pountney, Mandy, Green, & Gard, 2009).

A standing frame is a piece of equipment used for postural management. It is a rigid frame with a wide base that supports a person in the standing position. There are a variety of proposed structural and functional benefits for standing frames, including improved bone mineral density, hip stability, and joint range of movement at the hip, knee, and ankle (Goodwin et al., 2017; Paleg, Smith, & Glickman, 2013), and also those related to enhancing activity and participation. However, the evidence base for their use is limited.

Participation and quality of life are important outcomes for children with CP (Rosenbaum et al., 2007). Using postural management equipment has the potential to impact positively or negatively on a child's life. For example, parents can spend over an hour a day transferring their children from seating systems (Henderson, Skelton, & Rosenbaum, 2008). Also, standing frames can be uncomfortable or painful for young people (e.g., Lyons, Jones, Swallow, & Chandler, 2016). Parents have described the tension that arises when their child must use equipment (such as standing frames) because health professionals promote its benefits, even though their child finds it uncomfortable and is unhappy using it (Lyons et al., 2016). Although young people have been asked to give feedback on the usability of the frames (see Daniels, Gopsill, Armstrong, Pinnington, & Ward, 2005), to our knowledge, there is no published material specifically examined users' "lived" experiences of standing frames. Therefore, the aim of the current paper is to report young people's experiences and attitudes regarding standing frame use.

Key messages

- Young people value their standing frame and perceive benefits such as pain relief and participation. However, standing frames can also cause pain, discomfort, and reduce independence and participation.
- Most young people value having a choice about the type of standing frame they use and the environment they use it in.
- An exploration of each young person's personal goals and experiences as well as therapeutic outcomes is necessary when prescribing standing frames.
- There is a need for high quality research to demonstrate the benefits and the disadvantages of standing frames so that young people, their families, and professionals can make informed decisions about standing frame use.

2 | METHODS

2.1 | Participant identification and recruitment

The research was approved by the East Midlands—Nottingham 1 Research Ethics Committee (15/EM/0495).

Young people were purposively selected to ensure representation from a variety of ages, Gross Motor Function Classification System levels, educational settings, and regions of the UK, with equal numbers of males and females. Participants were young people identified by their parents who had previously completed a survey of standing frame use or through the clinical services of members of the study coapplicant group. Young people were eligible to take part if they were aged 8–18, had a diagnosis of CP, and use or have used a standing frame. Although we aimed to include participants with a variety of experiences and abilities, the sample comprised young people with CP who have the capacity to provide assent and understand questions about their standing frame use.

Interested parents of potential participants were contacted via telephone, and the study was explained to them and their child was screened for eligibility. An information sheet was emailed or posted to them. The parents then received a follow-up phone call, and if the young person wished to participate, an interview was arranged. Each young person was offered an opportunity to meet the interviewer for familiarity and topic planning prior to the interview; however, none thought this was necessary. Assent to participate from the young person and consent from the young person's parent were obtained. The two participants aged 18 consented for themselves, although this decision was made in collaboration with their parents.

Recruitment continued until data saturation, defined as three consecutive interviews not returning new themes by agreement among the research team (Francis et al., 2010).

2.2 | Data collection

A topic guide was developed for the interviews. Topics included (a) when and how the young person uses a standing frame; (b) beliefs about why they use a standing frame and whether it is helpful; (c) what they like and dislike about using a standing frame; and (d) opinions on whether young people should make their own choice about using a standing frame. The researchers reviewed each interview to determine whether the topic guide should be amended, and additional topics addressed at subsequent interviews. Only minor changes were made to capture aspects of the experience not initially considered, for example, whether opinions on standing frames had changed over time and how they would feel if not allowed to use any standing frame.

Interviews were conducted between June and November 2016 at a location of the young people's or carers' choosing for the participants' comfort and ease of access. The young people could bring a selected person for communication or additional support if needed. All interviews were audio recorded for transcription and transcribed verbatim. Pseudonyms have been used to preserve anonymity.

2.3 | Analysis

The qualitative analysis was informed by the Framework Method (Ritchie & Spencer, 1994), which is not aligned with a particular epistemological or philosophical approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013). This allowed systematic data analysis that was accessible for our multidisciplinary research team. Table 1 outlines the stages of analysis. We used a deductive-inductive approach: Certain themes and codes were preselected based on the International Classification of Functioning, Disability and Health: Children and Youth version (World Health Organization, 2007), which is a useful framework for examining the impact of a

TABLE 1 Stages of framework method analysis

Stage	Description
1	Verbatim transcription.
2	Familiarisation with the interview (e.g., reading and rereading transcripts, relistening to the audio recording).
3	Coding as per the ICF-CY. Although deductive coding was used, some open coding took place at this stage to ensure important aspects of the data were not missed.
4	Developing a working analytical framework through discussion and definition of labels after coding the first few interviews.
5	Applying the analytical framework by indexing subsequent transcripts using existing codes.
6	Charting data into the framework matrix. That is, data was summarised by category for each transcript with illustrative quotations.
7	Interpreting the data through discussion, reflection, and writing up.

Note. ICF-CY = International Classification of Functioning, Disability and Health: Children and Youth version.

therapeutic intervention on an individual's health-related functioning. It comprises four components: body structures and functions (anatomical parts of the body and physiological functions), participation and activities (involvement and execution of tasks), and environmental and personal factors (external and internal influences on functioning, such as physical environment or coping styles). However, any new themes that were elicited were added to the framework and codes created. *NVivo 11* (QSR International Pty Ltd, 2015) was used to manage the data.

2.4 | Reflexivity and trustworthiness

All authors are current researchers in disability. A. B., J. C., S. C., A. R., J. P., K. M., and N.K. work clinically with young people with CP who use standing frames. J.S. is a parent of a young person with CP who uses a standing frame. J. G. conducted and analysed the interviews because she was "naïve" to working with standing frames in a clinical capacity. This helped to reduce the impact of potential biases formed through clinical experience; and it was important, participants were introduced to the interviewer as someone impartial to standing frame use. J. G.'s coding of the transcripts was discussed and clarified with the other authors as a means of quality control and rigour check. The transcripts and recordings were continuously referred to, in order to ensure the analysis and interpretation was staying true to the data. Quotes from participants are provided in this manuscript as supporting evidence for the themes. The transparent audit trail in *NVivo* accounted for the systematic examination at each level of analysis.

3 | FINDINGS

Participants were 12 young people with CP who use, or have used, standing frames. All elected to be interviewed at school or home. Their characteristics and experience with standing frames are outlined in Table 2. We have included Tiffany's mother's quotes as she spoke for her, and Tiffany indicated agreement by enthusiastically nodding (in addition to Tiffany using her voice output communication aid). Probing comments from support people included clarification (e.g., "The block… what is it?" [Fred] … "Knee block?" [Support person]), providing more detail to the young people's comments (e.g., "It kind of depends" [Robert] … "It can be a few days a week, or maybe even just once or twice a week. Is that right Robert?" [Support person]), and/or questioning to prompt responses from the young people (e.g., "If you're in it, and you're getting sad, why do you get sad in it?" [Support person]).

The initial codes were divided into two overarching themes to describe the young people's "lived" experience. The first theme *Attitudes to standing frame use* contained three subthemes: *understanding standing frame use*, *experience of standing frame use*, and *choice in standing*. The second overarching theme *Challenges of standing frames* included the subthemes *standing frame design* and *size—lack of space*.

4 | ATTITUDES TO STANDING FRAMES

4.1 | Understanding standing frame use

The young people perceived that standing frames were primarily used for improving aspects of body structure and function. In particular, they suggested that standing frames are beneficial for bone strength, leg strength, growth, posture, and general physical health:

> *(Standing frames help you) to stand up tall and make your legs get straight and not bendy. Make your body stronger, not weaker. [Fred]*

Another reported physical benefit was an extended stretch of their muscles. Some participants really enjoyed this sensation, especially after sitting for long periods. They believed it supported overall comfort, particularly as related to their range of movement (or "flexibility") and contracture prevention. The standing frame was perceived to be the only way to properly stretch their muscles:

> *I'm getting a stretch at every part, your hip flexors, your knees, your hamstrings and because there's no other way … where you can get a better stretch. [Will]*

Standing frames gave participants an opportunity for a change of position, which could be enjoyable for many reasons, including having a "different view of surroundings," "being in the upright position," and "the feeling of being tall." The importance of a position change was also related to pain management. Although participants enjoyed the mobility and independence of their wheelchairs, sitting for long periods was "*uncomfortable*" and could make the young people "*achy and hurty*":

> *I know that if I sat in here 24 hours a day, 7 days a week I would get quite tight and I would get probably a lot more pain than I do if I wasn't in the standing frame. [Bart]*

Despite these benefits, pain was an issue for many of the participants. General pain, knee pain, and foot pain were all reported,

TABLE 2 Participant characteristics

Name	Sex	Age	GMFCS	Predominant motor pattern	School placement	Age of first standing frame use	Currently using a standing frame?	Standing frame setting	Current standing programme	Support person in interview	Communication method
Connor	M	8	IV	Spasticity	Specialist schooling	2	Yes	School	>3/week, 30–60 min	Class teacher	Speech, some comments/probing from support person
Olivia	F	9	IV	Spasticity	Mainstream school	1	Yes	Home	Every day, 30–60 min	Mother and sister	Speech, some comments from support people
Kyle	M	11	V	Dystonia	Mainstream school	1	No, stopped age 9	N/A	N/A	Mother and teaching assistant	Limited speech, comments and probing from support people
Brooke	F	12	IV	Mixed	Mainstream school	2	Yes	Home	>3/week, 30–60 min	Mother	Speech, little input from support person
Will	M	13	IV	Spasticity	Mixed placement	6	No, stopped age 11	N/A	N/A	N/A	Speech
Tiffany	F	13	V	Dystonia	Specialist schooling	1	Yes	Home	>3/week, 30–60 min	Mother and respite carer	Voice output communication aid. Comments from support person, Tiffany indicated agreement or disagreement
Fred	M	14	IV	Spasticity	Specialist schooling	3	Yes	Home	>3/week, 30–60 min	Mother	Limited speech, some comments and probing from support person
Sophia	F	14	IV	Spasticity	Specialist schooling	6 or 7	Yes	Home	? (seems to be as often as possible)	Friend	Speech, little input from support person
Gemma	F	15	IV	Mixed	Mainstream school	5	Yes	School	1/week, <30 min	N/A	Speech
Robert	M	17	IV	Spasticity	Specialist schooling	3	Yes	School	>3/week, 30–60 min	Mother	Speech, some comments/probing from support person
Maddie	F	18	IV	Spasticity	Specialist schooling	6	Yes	School	>3/week, 30–60 min	School physiotherapist	Speech, little input from support person
Bart	M	18	IV	Mixed	Specialist schooling	4	Yes	School	1/week, 30–60 min	N/A	Speech

especially after standing for "*a while*" or "*too long*." Pain did not necessarily dissuade the young people from using (or asking to use) their standing frame. Rather, they were pragmatic about their pain and believed it was something to be endured in order to obtain positive outcomes for their physical health. Participants tolerated the discomfort of standing frames and focused instead on the advantages they believed standing might give them in the long-term:

> *I had an operation on my hip and they said, "Not many people get to 17 without needing the hip done." … For me to get to this age with only needing one (hip operated on) is all to do with standing, so there are benefits to go with the pain. [Bart]*

Bart also commented that he did not always feel this way. When he was younger, he never wanted to use his standing frame. His understanding of the importance of standing frame use had developed with age:

> *…When I was much younger I never wanted to be going in it. I always used to complain… Then I would have to go in. Now that I'm older, I feel the benefit of it. [Bart]*

4.2 | Experience of standing frame use

Being in the standing frame can allow young people to participate in activities that would otherwise be impossible. Compared to a wheelchair, the standing frame gave the young person a different perspective on the world and have freedom to independently engage in different tasks:

> *I had a bit more independence as well because I could actually wash the dishes or stand up… That is incredible how a stand can change how independent a person is. [Will]*

On the other hand, standing frames could be restrictive and inhibit independence. As Olivia comments, "I can't get around in the stander like everyone else can. [The powered wheelchair] is 'sort of my legs' ". A static standing frame limited the young people's mobility, forcing them to rely on others for help:

> *There's not many things you can do in the stander that involves you by yourself… I do a lot of independent things inside my wheelchair that I can't do in the standing frame. [Bart]*

One participant mentioned that using the standing frame was an activity in itself and thus did not facilitate her ability to engage in other tasks. Standing can require a lot of effort and concentration. Brooke did not see the need to do additional activities whilst in her standing frame:

> *I don't like to do something. I just feel like it's already doing something and I'd rather be in my wheelchair or on the floor when I'm doing anything else. [Brooke]*

In addition, standing frame use was associated with discomfort and pain for a variety of reasons, beyond standing for too long (mentioned previously). Sometimes it was due to the young person's predominant motor pattern. For example, Kyle has dystonia:

> *He tends to pull at everything. That is why in those frames he would extend and pull and twist. That is probably why it ended up being uncomfortable. [Kyle's mother]*

Other times, it was related to a specific body part or injury which the standing frame could aggravate. For example, Gemma had particular trouble with her foot, and as such found it difficult to weight bear:

> *I don't want to really force myself to use the stander at the moment, because my foot—it doesn't know how it's going to react to it. Because obviously it is getting really, really painful for me to do anything. [Gemma]*

Participants also mentioned how frightening being in a standing frame can be. Because they spent the majority of their waking day sitting down, standing is an unusual position for these young people. Sophia commented that standing frames were too high, and she was "*scared of heights*." The fears can persist despite cognitive reasoning that they are safe:

> *I must seem like a big baby or scaredy-cat to some people, but I am actually genuinely frightened and nervous. No matter how much people say I'm safe, that doesn't help me because I know I'm safe, but a part of my brain just tells me I'm not safe. [Brooke]*

Although standing can feel quite strange and scary, some young people suggested it was possible to become accustomed to the sensation. For young people using a standing frame for the first time, they emphasised the importance of self-pacing:

> *It is very weird standing at first. But I would say, "If you're uncomfortable just take your time." It does take time to get used to one, so I'd say, "Just take your time and build up the confidence." [Robert]*

4.3 | Impact on peer interaction

Participants often used their standing frames for specific (sometimes solitary) tasks, such as school work. However, their positioning also impacted their social interactions both positively and negatively. Connor found standing frames problematic particularly for peer interaction, describing time in his standing frame as "*boring*" and "*stinky*." Using his standing frame at school meant he was much higher/taller than his peers, who sat at desks. This meant it was difficult to engage socially:

> *Connor's teacher: I think that you like your chair better than your stander because … when you're in your stander you're a bit higher than everyone else… You don't like standing up, separate.Connor: It's really boring, isn't it?*

However, another participant felt that being in a standing frame improved her peer interaction, particularly at mainstream school. Standing allowed her to "*fit in*":

> *The able-bodied children would relate to her differently and she was more like them because she was upright. It's strange just changing position meant that. [Tiffany's mother]*

4.4 | Play

Olivia used her standing frame routinely for many tasks, such as toileting, eating, and drinking. However, it also featured regularly in

her play, especially with her sister, Olga. Olivia stood in her frame to give herself a more dominant role in games, such as pretending to be a school teacher in front of her "class." Her sister sometimes "*wants to be disabled*" during play, so puts herself into the standing frame. Their mother noted that play between the sisters naturally incorporated the standing frame which, as a by-product, then taught Olga about Olivia's care needs. For example, as part of their role-playing games, Olga might strap Olivia in her hoist or position her in the standing frame.

> *I do painting and colouring and marking, like playing schools. [Olivia]*

4.5 | Choice in standing

The young person's choice about standing frame use was a particularly salient issue. One young person was very keen to use a standing frame but did not have access to one at the time of the interview (although he had used one previously). Others were frustrated about having to stand even though they did not want to. Some young people were happy not to have a choice about their standing:

> *I don't mind what they say. I just go in the stander. [Fred]*

Although some participants technically had a choice about when they use their standing frame (e.g., they were asked whether they wanted to stand rather than being told they had to), they received negative reactions from family and therapists when they chose not to stand:

> *It is just the fact that we have to stand it for quite a long time… I can say no, but I always get moaned at for saying no because it is what is best for me. [Sophia]*

Many young people preferred the comfort and independence of their wheelchair over being stationary in a standing frame. Several participants commented on how society has dictated "normal" postural positioning, which did not suit them as individuals:

> *I'm not a big fan of standing and I call it "the fault of life" because I'm like, "Why do we have to?" It's like, "Why was this even invented and why did the world turn out this way?" [Brooke]*

Interestingly, when asked if children should have a choice about using a standing frame, one participant suggested that they should not:

> *Even though it's pretty horrible to say, it's probably the best thing for them, because when I was much younger I never wanted to be going in it … (but) now that I'm older, I feel the benefit of it. [Bart]*

Bart emphasised the need to explain the potential benefits of using a standing frame, even to very young children. This type of pragmatism was again evident, when young people thought about long-term goals, rather that the discomfort of standing. They could weigh up the positive and negative aspects and make their choice about whether to stand:

> *I ask to go in it because I know it will help me with standing, but I'm reluctant to actually. I don't really feel like the whole of me wants to go. [Brooke]*

Although the young people discussed many obstacles, one factor that actually helped them to use their standing frame was emotional support. It was important to have an opportunity to complain every so often, even if the young person was generally willing to use their standing frame:

> *My mum is very good. She listens to me. Even though she might be tired about it and heard it 5 million times, she still goes, "Okay" and still tries to talk me through it because she's my mum and she's very supportive. All my family are really supportive. [Brooke]*

5 | CHALLENGES OF STANDING FRAMES

A major challenge for standing frame use was the manual lifting and handling required. Generally, two people were needed to position the young person properly in their standing frame:

> *It's a right job to get you transferred from the chair into the standing frame, and then out, the standing frame into the chair. [Robert]*

It was also problematic if the person or people positioning the young person did not have the requisite skills. This affected the young person's ability to use their standing frame. The carers required comprehensive training to ensure the young person was comfortable and has their needs met:

> *It hurts because some people ping it so hard and I feel like saying, "Do you want to hurt me? Do you want to?" But I don't… [Olivia]*

This issue was exacerbated for Tiffany, who had to have her voice output communication aid adjusted with the change of position. If it was not set-up correctly, she could not communicate the way she needs to whilst standing:

> *I think the challenge is with the people helping her need to know the equipment well and need to know how to position the communication equipment for her. [Tiffany's mother]*

Another challenge when using the standing frame was interference from siblings. Parts of the standing frame (e.g., the angle adjustments) were at an accessible height for siblings, and this could leave vulnerable the young person in the standing frame:

> *You used to happily be standing in it and then [your brother] used to adjust it and you used to be at a funny angle. Or he would take all your toys away. [Kyle's mother]*

5.1 | Standing frame design

The young people were particularly concerned with the type of standing frame they were using. It was important for them to feel safe and comfortable. As it was also desirable to be able to distract themselves from pain at times, the young people tried to engage themselves in activities to keep themselves occupied. Some types of standing frame

enhanced their ability to do this because of the size or attachments. For example, standing frames with tray attachments enabled them to independently enjoy particular activities:

> *The older ones have a tray or bowl in the middle so you could put cake mixture in it. There was a plastic tray that goes on top of the bowl… it's the world's best invention. [Will]*

Participants suggested having a TV or music player connected to the frame would be beneficial. Aesthetics were thought to be important too, and it was thought that young people would be more enthusiastic about using their standing frames if they could choose the colours and patterns. It would make standing less "boring":

> *(I'd) change the colour of the standing frame because it's boring … It would look colourful and nice. [Maddie]*

Flexibility of positioning when using the standing frame was also valued. Tiffany's sit-to-stand frame allowed the level of stretch she received to be adjusted depending on her tolerance each day. This meant that Tiffany had the independence to control her own standing (and comfort) using the levers:

> *She can say when it's a comfortable stretch. Different days can be different, so she could have a bigger stretch one day and a smaller stretch another day… when she's had enough she can let herself back down for the sitting position. [Tiffany's mother]*

5.2 | Size—lack of space

Another challenge of standing frames was their physical size, requiring a lot of space, and this can cause difficulty with use in different environments, and the standing frame could not always be used as intended (e.g., only at school). Kyle reported not being able to move around in his dynamic stander:

> *The stand was at the back and the back legs came out so far that we couldn't actually move me in it that well. [Kyle]*

6 | DISCUSSION

This study highlighted that young people generally believe they use standing frames for physical benefits. However, there is not robust evidence to support this in the published literature. For example, although using a standing frame to support hip joint development has some scant evidence, more research is needed for guidance on positioning and duration and frequency of standing (Bush et al., 2010). Furthermore, a systematic review suggests that standing frame recommendations for osteoporosis prevention cannot be supported (Fehlings et al., 2012) due to conflicting findings, small sample sizes, short study durations, and variability in weight bearing in the studies available. Young people report that standing frames are primarily useful for body structure and function. However, although they may feel some immediate physical benefits themselves (e.g., getting a stretch and pain relief), it is unlikely they can sense change in areas such as bone mineral density. Therefore, they may be receiving this information from the health professionals who are prescribing the standing frames, and this is then probably reflected by the parents. This is in keeping with findings from Goodwin et al. (2017), where health professionals prescribed standing frames for body structure and function issues, such as preventing hip dislocation. Indeed, Bart's perception that his regular standing frame use delayed his hip surgery was reinforced by his healthcare workers.

Pain was a frequently reported issue for all young people interviewed and is a common experience for nonambulant children. Standing frames can be part of pain management, because if there are no opportunities to change position, the young people report getting stiff and sore; and young people reported pain relief from standing. However, using the standing frame can be a painful experience in itself, particularly if young people are not well positioned or have secondary musculo-skeletal complications, which are painful and exacerbated by standing (e.g., foot pain for Gemma). This may be particularly relevant for older young people using standing frames. It has implications for deciding on how long a young person should stand and ensuring all those supporting the young person are trained in positioning them comfortably.

Although independence specifically related to standing frames has not previously been investigated, independence in general is important to young people with CP. This is associated with mobility, with young people reporting that it is essential for self-sufficiency and making choices (Palisano et al., 2009). Some interviewees in the current study thought that the standing frame limited their mobility and independence, because they had to rely on others for help whilst in the standing frame. Static standing frames take away the young person's ability to move freely and can isolate them from their peers. Therefore, they preferred their powered wheelchairs. This is similar to previous research that highlighted the positive effect of powered wheelchairs in terms of social activities and being able to engage in the environment without constant supervision and assistance from others (Evans, Neophytou, de Souza, & Frank, 2007). However, others thought their standing frame allowed them to participate more in activities such as cooking. Therefore, young people's preferences and self-management are important areas to investigate so that appropriate supports can be provided to help support their independence (Lindsay, 2016). It also important to consider the context in which the standing frame is being used to promote independence and participation. An exploration of the young person's personal goals and experiences as well as potential therapeutic outcomes is necessary. There is a need to understand that young people with CP may have a different understanding of independence, which includes environmental control and being able to direct others, not just individual mobility.

The young people in this study did not always have a choice about how and when they stood. Although some participants in the current study were frustrated by this, others did not mind that they had little choice in when and how they use their standing frame. However, this may change, particularly as they seek more independence as young adults, and their involvement in the decision should be re-evaluated regularly.

Related to choice, the design of the standing frame was important to young people. In a study where young people trialled different

standing frame types, the colour of the standing frame was an important determinant of the young person's feelings about the standing frame (Daniels et al., 2005). They also used their standing frame for specific tasks such as doing homework or using a computer (Daniels et al., 2005). Therefore, the standing frame must have certain features to enable such activities. It is important to consider features in addition to position and comfort. It would be helpful to include young people when designing this type of equipment: They had clear ideas about both functionality (e.g., trays) and aesthetics (e.g., colour choice and comfort). Further, the young people suggested ways to improve the experience of standing, such as having someone to "vent" to and having the opportunity to choose an aesthetically pleasing design.

7 | LIMITATIONS

As a qualitative study, this research does not seek to generalise nor seek cause and effect; hence, no quantitative data regarding numbers of children in each of the themes or potentially identifying sociodemographic information are reported. Experiences of standing frame use may be affected by the young person's cognitive and communicative function, as well as their relationship with the people who "help" them to use it and whether they feel coerced. There may be selection bias because some participants were recruited from families who were already engaged in a wider study regarding standing frame use: They may have self-selected based on their perceptions of their child's ability to be interviewed and/or been more motivated and interested in standing frames compared to the wider CP population. Also, the sample included mainly secondary school age children, and younger children may have different experiences. Therefore, although the current study may not be representative of all young people with CP who use or have used a standing frame, the findings do contribute to the body of knowledge about young people, CP, and standing frames by highlighting both positive and negative impacts on these participants.

8 | CONCLUSIONS

Standing frames are clearly valued by some young people, and can be beneficial with respect to choice, pain relief, and participation, but can also cause pain, discomfort, and reduced independence and participation. This study highlights the need for appropriate use and consideration of how best to use a frame for each individual. Understanding the perspectives of the individual young person will support health and education professionals, families, and young people to ensure standing frames are used at the right time and place for the right person.

Further research is required to determine how young people with CP are informed about health interventions such as standing frames. The United Nations Convention on the Rights of the Child states that children and young people have a right to participate in matters that affect their lives and should be encouraged to be active partners in decisions about their health and care (Coyne, 2008). Further, high quality evidence is needed to demonstrate the benefits and the disadvantages of standing frames so that young people and their families can make informed decisions about whether a standing frame may be appropriate for them. Until such evidence is available, healthcare professionals should have open conversations about potential benefits and challenges of standing frames on all aspects of the young people's lives, including participation and activity.

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DECLARATIONS

The authors declare that the work submitted is their own and that copyright has not been breached in seeking its publication.

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