Stakeholder perspectives of pediatric powered wheelchair standing devices: a qualitative study

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This article is commented on by Lyman on page 893 of this issue.

PUBLICATION DATA

Accepted for publication 19th January 2021. Published online 19th February 2021.

ABBREVIATIONS

Duchenne muscular dystrophy
Powered wheelchair standing
device

AIM To explore and describe the experiences and perspectives of various stakeholders regarding the use of powered wheelchair standing devices (PWSDs).

METHOD The purposive sample included: children aged 6 to 18 years who used a PWSD (n=8; diagnoses: cerebral palsy, spinal muscular atrophy, spina bifida, spinal cord injury), parents of children 18 years of age or younger who used a PWSD (n=12), rehabilitation professionals working with children who used a PWSD (n=12), and professionals working at companies manufacturing PWSDs (n=3). Data were gathered via face-to-face interviews conducted either in person or via Zoom[®] and analyzed using the constant comparative method.

RESULTS Three main themes emerged in the data: (1) 'Stand-on-demand' revealed how participants perceived PWSDs as allowing children to stand whenever and wherever they wanted, thereby increasing participation; (2) 'It's more than weight-bearing' uncovered participants' perceptions of psychological and physical benefits from PWSD use; and (3) 'Ecosystems influencing PWSD acquisition and use' revealed child- and non-child-related factors perceived as influencing children's procurement and use of a PWSD.

INTERPRETATION Use of a PWSD was perceived as providing a unique opportunity for children to stand whenever and wherever they desired. Findings suggest the possible transdiagnostic application of PWSDs.

Standing, an upright position supported by one's feet, is a functional activity many people perform throughout the day.^{1,2} Idioms such as 'stand up for yourself' and 'stand your ground' reinforce standing as a societal norm symbolizing independence, dignity, and autonomy.^{3,4} For children who are unable to stand independently, standing programs, often accomplished using a stationary stander (e.g., a prone, supine, or upright stander), are a common aspect of care.^{2,5,6} Such standing programs have been found to improve muscle length,^{6–8} decrease spasticity,^{6,8} prevent contractures,^{6,7} increase peer interaction,^{6,9} and increase bone mineral density.⁶

For children who use a power wheelchair, a pediatric powered wheelchair standing device (PWSD) may be considered.^{2,6} An evolution of the first adult standing manual wheelchair manufactured in Switzerland in 1975,¹⁰ a PWSD uses a standing mechanism, and, depending on the manufacturer, a seat elevator and anterior tilt mechanism, to electronically allow a child to move between sitting and standing, thereby providing the opportunity to drive in either position.² Standing within a PWSD is designed to meet the unique needs of each child, and, as such, may

vary to include either full or partial extension of the hips and knees leading to either fully upright or partially crouched standing positions.^{2,11}

Although PWSDs for children were manufactured as early as 2003,¹⁰ improvements in design and function have led to a gradual uptake in their use.¹² To our knowledge, existing PWSD research in pediatrics is limited to males with Duchenne muscular dystrophy (DMD).^{11,13–15} The first, a single-case design, investigated the efficacy of a 6- to 12-month home-based standing program using a PWSD.¹¹ Improved hip or knee flexor muscle length was noted in three of the four participants;¹¹ however, none of the participants demonstrated increased bone mineral density.^{6,11} A non-randomized, stepped wedge study involving 14 adolescents with DMD reported mental health benefits and maintenance of musculoskeletal status over the first 20 weeks of PWSD use.¹⁴ A qualitative study exploring PWSD use from the perspectives of 12 adolescents with DMD and their parents and teachers revealed the central theme of 'capacity to be able' wherein introduction of the PWSD coincided with a decline in motor skills and allowed the adolescent to maintain or improve their

independence.¹³ A recent Delphi study regarding the prescription of PWSDs in DMD provides additional details to inform the reasoning processes surrounding provision of PWSDs in DMD.¹⁵

While these studies provide some insights into PWSD use in males with DMD,^{11,13} they do not reflect PWSD use in children with other conditions. To begin addressing this knowledge gap, it is important to gather input from both individuals who are directly affected by PWSD use and those who are involved in the provision of PWSDs. As such, the aim of this study was to explore and describe the experiences and perspectives of various stakeholders regarding the use of PWSDs. Because standing in a PWSD varies amongst users,^{2,11} standing was defined by each study participant based on their perspectives and experiences.

METHOD

This descriptive qualitative study used purposive, snowball, and maximum variation sampling to recruit participants from across the US over a 6-month period.¹⁶ Four participant groups took part in the study: (1) children aged 6 to 18 years who used a PWSD; (2) parents of children 18 years of age or younger who used a PWSD; (3) rehabilitation professionals (professionals) working with children 18 years of age or younger who used a PWSD or other standing power mobility device; and (4) professionals working at companies manufacturing PWSDs (manufacturers). Additional inclusion criteria included the verbal or augmented communication ability to partake in an interview, whilst exclusion criteria included an inability to converse in English. Potential participants were approached by the first author via e-mail or telephone using Institutional Review Board approved recruitment scripts. Ethics approval was obtained from the Institutional Review Board at Grand Valley State University. Informed consent, parental permission, and assent were obtained, as appropriate, for each participant. Written consent/permission were obtained for in-person interviews. Verbal consent/permission were documented for Zoom[®] interviews (as approved by our ethics board). Verbal assent was documented for all children (as approved by our ethics board).

Data were gathered through face-to-face interviews conducted either in person (at a participant's home) or via Zoom[®]. Before the onset of the study, interview guides for each participant group were created using an iterative process. These guides were reviewed by qualitative researchers who were not involved in the study (n=5), piloted with three non-participants (one child, one physical therapist, and one parent), and modified based on feedback. The final guiding questions for each participant group and additional details about the interviews are provided in Table S1 (online supporting information). As data gathering unfolded, additional questions were added to explore emerging concepts in the data. The first author conducted all interviews, audio recorded interviews using a digital recorder, and took field notes during interviews.

What this paper adds

- The ability to stand when desired was unique to powered wheelchair standing device (PWSD) use.
- Participants perceived numerous psychological and physical benefits from PWSD use.
- Child- and non-child-related factors influenced procurement and use of a PWSD.

Demographic details pertinent to each participant group were gathered using a specific form for each group. Recruitment continued until data saturation was reached and novel knowledge was no longer obtained from new participants.

Analysis

Digital recordings were transcribed verbatim. Consistent with naturalistic inquiry,¹⁷ interview data were inductively analyzed using the constant comparative method, wherein units of information within the data were independently assigned a draft code by the first four authors.¹⁷ These same four authors then developed an initial coding guide through discussion of the data and codes. The data were then individually reviewed and coded by each of these authors. Discrepancies were resolved through discussion amongst the researchers until a consensus was reached and a final codebook was created. After all data were coded, codes were amalgamated into themes and main themes through a discussion-based consensus process. MAX-QDA (MAX-QDA: VERBI Software, Berlin, Germany) was used to organize, store, and visualize data. Trustworthiness was addressed through use of a reflexive journal maintained by the first author.¹⁷ Member checks, used to determine whether study findings accurately represented participants' opinions and beliefs expressed during the interviews,¹⁷ were conducted by e-mailing a summary of the study findings to the participants. Participants were asked to comment on whether or not they felt the synthesized results resonated with their experiences. Comments were gathered via e-mail, telephone, or Zoom® based on the participant's preference. Inquiry audits, performed to ensure the analysis was meaningful to those not directly involved in the study,¹⁷ involved presenting the study findings and supporting data to three different individuals on separate occasions.

RESULTS

Thirty-five participants (eight children, 12 parents, 12 professionals, and three manufacturers) from 18 states took part in the study. Participant information is provided in Tables 1–4. Participants who responded to the member check (23 of 35) reported the summary provided was accurate. Based on feedback provided during the inquiry audits, the name and definition of one of the themes was clarified and refined.

Three main themes emerged in the data: (1) 'Stand-ondemand' revealed how participants perceived PWSDs as allowing children to stand whenever and wherever they

Table 1: Participant information: children									
Number of par- ticipants	Sex	Diagnosis	Age, mean; range	Brand of PWSD used	Length of PWSD use, mean; range	Reported time using standing feature/day, mean; range			
8	Male=5 Female=3	CP=5 SB=1 SMA=1 SCI=1	11y 9mo; 6–16y	LEVO® PWSD=2 Permobil® PWSD=6	1y 2.19mo; 1mo–3y	1.37h; 15min–3.5h			

PWSD, powered wheelchair standing device; CP, cerebral palsy; SB, spina bifida; SMA, spinal muscular atrophy; SCI, spinal cord injury.

Table 2: Participant information: parents Number of partici-Child's Child's age, mean; Length of child's PWSD use, mean; Child's diagnosis Mother/father pants sex range range 12 CP=7 Mother=9 Male=8 10y 10.15mo; 6-16y 1y 1.16mo; 1mo-3y Father=3 SB=1 Female=4 SCI=2 SMA=1 Other genetic condition=1

PWSD, powered wheelchair standing device; CP, cerebral palsy; SB, spina bifida; SCI, spinal cord injury; SMA, spinal muscular atrophy.

Table 3: Participant information: professionals

Number of participants and professional background	Practice setting(s) ^a	Diagnoses of chil- dren using PWSDs/ SPMDs	Time in role, mean; range	Length of time working with children using PWSDs/SPMDs, mean; range
Physical therapist=8 Occupational therapist=2 Kinesiologist=1 Pediatric physiatrist=1	Hospital based outpatient seating and mobility clinic=4 Assistive technology clinic=3 Academia=2 Insurance reviewer=1 Early intervention=1 Research=3 Private practice=1 Rehabilitation hospital=1 Clinic in a rehabilitation center=1 Community settings=1	CP=11 SCI=8 SB=8 SMA=4 DMD=3 AMC=1 TBI=1 Other types of MD=2	25y 4mo; 7–40y	14у 5mo; 6mo–25у

^aSeveral professional participants worked in more than one practice setting. PWSD, powered wheelchair standing device; SPMD, standing power mobility device; CP, cerebral palsy; SCI, spinal cord injury; SB, spina bifida; SMA, spinal muscular atrophy; DMD, Duchenne muscular dystrophy; AMC, arthrogryposis multiplex congenita; TBI, traumatic brain injury; MD: muscular dystrophy.

Number of partici- pants and profes- sional background	Clinical settings	Diagnoses of children worked with using PWSDs	Time in role, mean; range	Years working with children using PWSDs mean; range
Physical therapist=1 Occupational therapist=1 Nationwide consultant=1	All 3 provided consultation and services regarding PWSDs in a variety of clinical settings (homes, schools, outpatient clinics, seating and mobility clinics, etc.)	CP=3 SCI=2 DMD=1 Other type of MD=2 SMA=1 Other genetic or neuromuscular disorders=2	16y 10mo; 6y 6mo–32y	10y 10mo; 6y 6mo–16y

PWSD, powered wheelchair standing device; CP, cerebral palsy; SCI, spinal cord injury; DMD, Duchenne muscular dystrophy; MD: muscular dystrophy; SMA: spinal muscular atrophy.

wanted, thereby increasing participation and potentially decreasing caregiver burden; (2) 'It's more than weightbearing' uncovered participants' perceptions of psychological and physical benefits from PWSD use; and (3) 'Ecosystems influencing PWSD acquisition and use' revealed child- and non-child-related factors perceived as influencing children's procurement and use of a PWSD.

Theme 1: 'Stand-on-demand'

All participants perceived the integrated standing feature of the PWSD as giving children the ability to stand when and where they desired, thereby increasing children's independence in performing a variety of tasks (washing hands, reaching for objects, etc.). Performing in a play, singing in a choir, playing with friends, working at a grocery store, partaking in chemistry lab, doing chores at home and in the yard, and eating at restaurants with high-top tables were all cited as situations where children's participation was enhanced through PWSD use.

Participants valued how standing and the ability to independently transition into standing allowed children to feel more involved in certain activities. Child 04, an 11-yearold male with cerebral palsy (CP), expressed this as follows: '(I like to stand at) church ... when all the rest of the people are standing ... (It makes me feel) like I really belong.' Standing to say the pledge of allegiance and during the national anthem were regarded as important functions. Standing in a PWSD reportedly also permitted children to 'see' at museums, sporting events, parades, and other crowded venues.

A majority of participants specifically noted how the built-in standing feature of the PWSD often eliminated the need to transfer to a separate stander, thereby allowing children the choice of standing or sitting without having to transfer into another piece of equipment. Parent 04, mother of a 10-year-old male with CP, noted: '(In the PWSD) ... he (can) sit (with others) ... and not have to worry about "oh excuse me, I have to go get into (a) different piece of equipment (to stand)".' Parent 08, mother of a 14-year-old male with CP, observed the PWSD gave her son independence: 'he doesn't have to rely on his mom to come over and help ... him stand and ... then sit him back down ... He can do all that by himself.' Professional 06, an occupational therapist with 20 years of experience, expressed this aspect of PWSD use as follows: '(the) opportunity to transition between postures (using the same piece of equipment) ... gives the (child) ... independence, and (the) ability to ... be spontaneous.'

Eliminating the need to transfer into another piece of equipment also reportedly benefited caregivers. Parents frequently discussed how transferring children to and from a separate stander became increasingly difficult as their children grew. Such difficulties were felt to result in the children standing less frequently. Parent 08, mother of a 14-year-old male with CP, noted her son was: 'a lot harder to physically transfer ... 'cause he's taller than me now... So (before the PWSD) he wasn't standing as often.' Children observed how their ability to independently transition into standing benefited their caregivers as illustrated by Child 09, an 8-year-old female with spinal muscular atrophy: 'The PWSD helps my mom ... she doesn't have to lift me (into a) stander, strap me in, keep me comfortable for an hour, then have to take me out.'

Theme 2: 'It's more than weight-bearing'

Participants perceived a vast array of psychological benefits as arising from children's use of a PWSD. Many felt standing in a PWSD increased confidence. Child 07, a 14-yearold male with CP, stated the following: 'I feel very confident (when I am standing in my PWSD) ... And it makes me feel more confident as a person. It makes me feel I have more authority ... (when I am) standing up (in my PWSD).'

His father, Parent 09, father of a 14-year-old male with CP, remarked on how his son's confidence had increased since using a PWSD: 'He's more confident ... that's the big thing, the confidence thing. Just being able to feel like he can be just like everybody else.' Participants further reported standing in a PWSD helped children to view themselves as 'able', thereby increasing their self-esteem. Parent 04, mother of a 10-year-old male with CP, described this as follows: 'seeing himself as a person who stands, as a person who's able to stand ... That's just huge.' Parent 07, the mother of a 15-year-old female with CP, indicated that the PWSD helped her daughter to advocate for herself at school, saying: 'she can really, literally stand up for herself (now).'

Many participants felt standing in a PWSD allowed children to stand face-to-face with others. Child 06, a 15-yearold female with CP, noted the following: '(In my PWSD, people) can look (at me) eye-to-eye. And as little as that may seem ... one of the main things in our society is eye contact ... And (not having eye contact is a) constant barrier if I'm sitting down.' Other participants noted how standing in an PWSD may eliminate the height differences imposed by sitting in a wheelchair, possibly further enhancing children's self-concept.

Participants also felt the ability to stand in a PWSD influenced how other people perceived a child using a wheelchair, as exemplified by Parent 07, the mother of a 15-year-old female with CP: 'it is different when the kid comes in, and they're at (eye) level with (their) peers ... It change(s) everyone's perception.' Parent 05, father of a 10-year-old with CP, noted standing in a PWSD may help people to perceive children as more physically and cognitively capable: 'people ... assume a kid in a ... power wheelchair, has cognitive difficulties ... (but) they see him standing, looking (at them) face to face, (and) ... that assumption has diminished.'

All participants perceived health and wellness benefits of PWSD use. Many participants reported perceived musculoskeletal benefits such as maintaining or increasing range of motion, improving posture, and decreasing pain. Child 05, a 12-year-old female with spina bifida, reported: 'standing in my PWSD ... helps me get stronger.' Other perceived health benefits included improved respiratory, cardiovascular, bowel, and bladder function and increased opportunities for pressure relief. Participant groups appeared to be conflicted about the effect of PWSD use on bone mineral density, with professionals and some manufacturers citing a lack of evidence to support this benefit. A few professionals further questioned if standing in a PWSD was equivalent to standing upright in a stationary stander. Professional 02, a physical therapist with 35 years of experience, expressed her concerns as follows:

(To me), standing is ... more than 75% of the (child's) weight going through the bottoms of the feet ... There has never been any evidence gathered about the (actual amount of) weight-bearing on the footplates in a (PWSD) ... (Many children I work with) do not stand all the way up (in their PWSD like they would in) an actual (stationary) stander.

Professional 05, a physical therapist with 23 years of experience, further stated the following: 'the amount of weight ... that you're taking in a (PWSD) is not necessarily the same (as in a stationary) stander'.

Theme 3: 'Ecosystems influencing PWSD acquisition and use'

Participants perceived numerous child- and non-childrelated factors as influencing a child's procurement and use of a PWSD. The funding process and insurance issues were consistently mentioned as barriers to obtaining a PWSD. Participants frequently described a cyclical process of applying for insurance coverage of a PWSD, appealing initial denials, and re-appealing subsequent denials. In discussing her self-described 'fight' for funding, Parent 10, mother of a 7-year-old female with a genetic condition, shared: 'our insurance company would only approve us for a powerchair, but not the standing feature.' Parent 06, mother of a 12-year-old female with spina bifida, had a similar experience: 'insurance kept (coming) back ... and saving ... (Do) you know how expensive this (PWSD) is? Can't we ... do something a little less expensive?' Numerous participants talked about the length of time (often a year or more) needed to obtain insurance approval for a PWSD. Parents worried about their children using an older wheelchair that no longer fit or had safety issues. This prolonged wait often proved too much for some families, and children reportedly had to 'settle' for a regular power wheelchair.

Many participants perceived the size and limited number of companies supplying PWSDs as a barrier to obtaining a PWSD for a child. The base of a PWSD was frequently reported as being larger than the base of a typical pediatric power wheelchair, making transportation and environmental access difficult and increasing the amount of practice needed to achieve driving proficiency. As explained by Manufacturer 05, who had worked for a manufacturer for 12 years: The (base for a PWSD) has to be a little bigger (than in a standard power wheelchair) because of the stability that's required (to stand and) ... to keep it safe for users up to 300 pounds ... It's the same base (for both children and adults with a) different size seating on top.

Participants indicated the increased base size prohibited PWSD use by young children and children of smaller stature. Multiple participants reported wanting to start children in PWSDs at a younger age, but were unable to do so because of the size of PWSDs. Parent 10, mother of a 7-year-old female with a genetic condition, shared that the PWSD had to be modified to fit her child:

I had always wanted a PWSD for her ... but she's very little (we had to wait and then) we had to have the PWSD custom tailored to her ... There was no way for her feet (to reach) the footrests. So (the durable medical equipment provider) basically had to create like an enclosure to bring her more forward but (allow her to) still have back support and have support on the sides.

Therapists' and physicians' lack of awareness and knowledge about PWSDs was another perceived barrier, reportedly forcing multiple parent participants to be the driving force behind their child obtaining a PWSD. Once a PWSD was obtained, parents and therapists reported having difficulties finding individuals who were able to properly adjust, maintain, and repair a PWSD. Child 08, a 16-year-old male with CP, noted: 'everything kind of breaks (on my PWSD).' Participants, however, noted the need for repairs was not unique to PWSDs.

There were also many child-related factors that reportedly needed to come together for a child to procure a PWSD. Some of these factors were safety related, but many child-related factors focused on a professional's perceptions of a child's cognitive status and desire and willingness to use the PWSD. Therapists' perceptions regarding the size of a child's home and whether the child's family and school personnel could effectively support the use of the PWSD were also considered. Many therapists indicated that if these factors did not appear to be in place, a PWSD would not be considered for a child. Many professionals suggested trialing a PWSD over a period of time to determine if it was appropriate for a specific child and family.

DISCUSSION

To our knowledge, this is the first study to explore the perceptions and experiences of PWSD use in both males and females who had conditions other than DMD. Building on the emphasis in the literature on PWSD use in DMDs,^{11,13–15} our findings suggest a possible transdiagnostic application of PWSDs. Our 'Stand-on-demand' theme revealed participants' views of PWSD use as providing the unique opportunity for children to stand whenever and wherever they desired. This same concept was also

recognized in studies involving DMD.^{11,13,15} Similar to previous studies involving PWSD use in DMD,11,13 participants in this study valued children's freedom to choose when and where to stand, noting the positive influence of this freedom on children's participation.^{11,13,15} Participants in both this study and the qualitative DMD study¹³ perceived PWSD use as positively contributing to physical and mental health. Furthermore, perceptions related to eliminating the need to transfer children into a stander, the resultant potential decrease in caregiver burden, and the potential to avoid injuries during transfers emerged in both this study and the qualitative DMD study.^{6,13} Based on this support for the transdiagnostic application of PWSDs, it is conceivable that the quantitative results from both the single-case design¹¹ and stepped wedge¹⁴ DMD studies may also be relevant for children who have conditions other than DMD. Replicating these studies^{11,14} with children who have conditions other than DMD would be beneficial.

Despite this support for the transdiagnostic application of PWSDs, it is also possible that the progressive nature of DMD may influence stakeholders' perceptions and experiences of PWSD use. For example, the qualitative DMD study¹³ reported that some child and parent participants reported negative emotions, such as self-consciousness about standing in the PWSD, and equated the PWSD with the loss of independent ambulation. None of the child or parent participants in the current study described such feelings, and instead appeared to consistently highlight their positive feelings about PWSD use. Similar to the findings of other studies,¹⁸ it is likely that these contrasting emotions stem from differences in the lived experiences of progressive versus non-progressive conditions.

As exemplified by our theme 'Stand-on-demand', participants in this study perceived PWSDs as enabling both participation and autonomy. The ability to stand alongside peers and community members, via the PWSD, while saying the pledge of allegiance or participating in religious services may physically decrease the social distance experienced by many children with mobility limitations and may increase children's sense of belonging.2,19,20 Simultaneously, the autonomy to decide whether to stand or to sit allows children with mobility limitations to control their own positioning, rather than relying on others to do it for them. Such autonomy may contribute to children's quality of life and sense of self-determination, both key factors associated with future educational achievement and employment success in children with disabilities.²¹⁻²³ Research studies exploring these potential benefits of PWSDs are needed.

As illustrated by our theme 'It's more than weightbearing', participants in this study perceived psychological and health and wellness benefits of standing in a PWSD. Such findings resonate with those of other studies and guidelines involving children with a wide range of diagnoses,^{2,6,11,19,24} and have been associated with standing in stationary standers as well as mobile standers.⁶ Arva et al.¹⁹ noted that the integrated standing feature on manual or power wheelchairs increased users' confidence and created a sense of equality by enabling eye-to-eye interactions with non-wheelchair users. The concept in this study of PWSD use influencing people's perceptions of children with disabilities is consistent with other studies involving a child's use of power mobility.^{18,25-27} Yet, as suggested by the single-case design¹¹ involving PWSD use in DMD,¹¹ evidence for use of stationary standers may not be directly applied to use of PWSDs. Future quantitative studies are needed to determine if a causal relationship exists between PWSD use and the objective measurement of the perceived health and wellness benefits reported by participants in the current study. Such studies should consider reporting the amount of weight-bearing achieved when standing in a PWSD, and incorporating inclinometer/internal software or video data to record the PWSD standing angle.14 Furthermore, as standing in a PWSD may not be the same as standing in a stationary stander, future studies directly comparing the effects of standing in a PWSD to the effects of standing in a stationary stander also are needed.

As represented by our theme 'Ecosystems influencing PWSD acquisition and use', participants in this study identified issues related to insurance, funding, professionals' knowledge of PWSDs, and the available sizes of PWSDs. The influence of such factors on the acquisition and use of pediatric power mobility devices is a common theme across the literature, suggesting issues such as funding, insurance, time to obtain equipment, etc., are not limited to PWSDs.^{2,18,19,28–30} As suggested by Schofield et al.¹⁵ for children with DMD, extended PWSD trials would allow professionals to directly assess child-centered and environmental factors influencing safe and appropriate PWSD use. Although the footprint of pediatric power wheelchairs is noted in many studies,^{18,25} the increased footprint of a PWSD may present unique challenges. Investigations concerning the typical use of PWSDs may shed light on whether it would be feasible to decrease the size of the base, thereby possibly allowing younger children and children of smaller stature to use a PWSD. Longitudinal studies involving children who use a PWSD at a younger age are needed to explore potential long-term benefits of PWSDs.

Limitations

This study reflected experiences with PWSDs in the US within the US healthcare system. Including participants from other countries may have yielded different results. The mean of the lower age limit and age range of the child participants (6–16y) and the duration of PWSD use by child participants may have influenced study findings. In addition, participants may have responded in ways they perceived to be socially desirable. The researcher conducting the interviews had previously worked with a few of the participants, potentially influencing these participants'

responses. Although every attempt was made to limit bias, the experiences and viewpoints of the researchers may have impacted the data gathering, analysis, and interpretation.¹⁷

Conclusion

This study highlights stakeholders' views of perceived benefits of PWSDs and identifies factors affecting children's procurement and use of a PWSD. Use of a PWSD was perceived as providing the unique opportunity for children to stand whenever and wherever they desired. Findings further suggest the possible transdiagnostic application of

REFERENCES

- Finke R, Muldoon K. In good standing. *Rebab Manag* 2003; 16: 32–4.
- Dicianno B, Morgan A, Lieberman J, Rosen L. Rehabilitation Engineering & Assistive Technology Society (RESNA) position on the application of wheelchair standing devices: 2013 current state of the literature. *Assist Technol* 2016; 28: 57–62.
- Mulderij KJ. Dualistic notions about children with motor disabilities: hands to lean on or to reach out? *Qual Health Res* 2000; **10**: 39–50.
- Gibson BE, Teachman G, Wright V, Fehlings D, Young NL, McKeever P. Children's and parents' beliefs regarding the value of walking: rehabilitation implications for children with cerebral palsy. *Child Care Health Dev* 2012; 38: 61–9.
- Glickman LB, Geigle PA, Paleg GS. A systematic review of supported standing programs. *J Pediatr Rebabil Med* 2010; 3: 197–213.
- Paleg GS, Smith BA, Glickman LB. Systematic review and evidence-based clinical recommendations for dosing of pediatric supported standing programs. *Pediatr Phys Ther* 2013; 25: 232–47.
- Gibson SK, Sprod JA, Maher CA. The use of standing frames for contracture management for nonmobile children with cerebral palsy. *Int J Rebabil Res* 2009; 32: 316–23.
- Salem Y, Lovelace-Chandler V, Zabel RJ, McMillan AG. Effects of prolonged standing on gait in children with spastic cerebral palsy. *Pbys Occup Ther Pediatr* 2010; **30**: 54–65.
- Bakewell J. Choosing support equipment in children's therapy. Int J Ther Rehabil 2007; 14: 379–81.
- LEVO®. LEVO company history. LEVO Website. Available at: https://levousa.com/history/ (accessed 6 January 2021).

- Townsend EL, Bibeau C, Holmes TM. Supported standing in boys with Duchenne muscular dystrophy. *Pediatr Phys Ther* 2016; 28: 320–9.
- Tally MK, Pope EM. We're still standing. *Rebab Manag* 2020; 33: 6–9.
- Vorster N, Evans K, Murphy N, et al. Powered standing wheelchairs promote independence, health and community involvement in adolescents with Duchenne muscular dystrophy. *Neuromuscul Disord* 2019; 29: 221– 30.
- Bayley K, Parkinson S, Jacoby P, et al. Benefits of powered standing wheelchair devices for adolescents with Duchenne muscular dystrophy in the first year of use. J Paediatr Child Health 2020; 56: 1419–25.
- Schofield C, Evans K, Young H, et al. The development of a consensus statement for the prescription of powered wheelchair standing devices in Duchenne muscular dystrophy. *Disabil Rebabil* 2020; 1–9. https://doi. org/10.1080/09638288.2020.1810786. Online ahead of print.
- Portney L. Foundations of clinical research: applications to practice (4th edition). Philadelphia, Pennsylvania: FA Davis, 2020.
- Lincoln Y, Guba E. Naturalistic inquiry. Beverly Hills, CA: Sage Publications, 1985.
- Kenyon LK, Mortenson WB, Miller WC. "There is power in mobility': parent and therapist perspectives of the experiences of children learning to use power mobility. *Dev Med Child Neurol* 2018; 60: 1012–7.
- Arva J, Paleg G, Lange M, et al. RESNA position on the application of wheelchair standing devices. *Assist Technol* 2009; 21: 161–8.
- Priestley M. Childhood disability and disabled childhoods: agendas for research. *Childhood* 1998; 5: 207–23.
- 21. Shogren KA, Ward MJ, Inge KJ, Wehman P. Promoting and enhancing self-determination to improve the

PWSDs. Future studies investigating the perceived benefits and factors identified in this study are needed.

DATA AVAILABILITY STATEMENT

Data not available due to privacy/ethical restrictions.

SUPPORTING INFORMATION

The following additional material may be found online:

 Table S1: Interview guide for the included stakeholder groups

 and additional interview details

post-school outcomes of people with disabilities. J Voc Rebabil 2018; **48**: 187–96.

- Denham S, Wyatt T, Bassett H, Echeverria D, Knox S. Assessing social-emotional development in children from a longitudinal perspective. *J Epidemiol Community Health* 2009; 63: 37–52.
- Mattson G, Kuo DZ. Psychosocial factors in children and youth with special health care needs and their families. *Pediatrics* 2019; 143: e20183171.
- Taylor K. Factors affecting prescription and implementation of standing-frame programs by school-based physical therapists for children with impaired mobility. *Pediatr Phys Ther* 2009; 21: 282–8.
- Livingstone R, Field D. The child and family experience of power mobility: a qualitative synthesis. *Dev Med Child Neurol* 2015; 57: 317–27.
- Wiart L, Darrah J, Hollis V, Cook A, May L. Mothers' perceptions of their children's use of powered mobility. *Phys Occup Ther Pediatr* 2004; 24: 3–21.
- Guerette P, Furumasu J, Tefft D. The positive effects of early powered mobility on children's psychosocial and play skills. *Assist Technol* 2013; 25: 39–48.
- Kenyon LK, Cohen L, Schmitt J, Otieno S. Providing paediatric power wheelchairs in the USA then and now: a survey of providers. *Disabil Rebabil: Assist Technol* 2019; 15: 708–17.
- Pituch E, Rushton PW, Ngo M, Heales J, Arguin AP. Powerful or powerless? Children's, parents', and occupational therapists' perceptions of powered mobility. *Phys Occup Ther Pediatr* 2019; **39**: 276–91.
- Paguinto S-G, Kasparian NA, Bray P, Farrar M. 'It's not just the wheelchair, it's everything else': Australian parents' perspectives of wheelchair prescription for children with neuromuscular disorders. *Disabil Rebabil* 2020; 42: 3457–66.

PERSPECTIVAS DE NIÑOS/AS, PADRES, Y PROFESIONALES SOBRE LOS DISPOSITIVOS DE BIPEDESTACIÓN EN SILLA DE RUEDAS Eléctrica pediátrica: un estudio cualitativo

OBJETIVO

Explorar y describir las experiencias y las perspectivas de varias partes interesadas, incluido: niños/as, padres, y profesionales - sobre el uso de dispositivos de bipedestación en silla eléctrica (DBSE).

MÉTODO

La muestra intencionada incluyó: niños/as de edades entre 6 y 18 años que utilizaron un DBSE (*n*=8; diagnósticos: parálisis cerebral, atrofia muscular espinal, espina bífida, lesión medular), padres de niños/as de 18 años o menos que usaban un DBSE (n=12=, profesionales de rehabilitación que trabajan con niños/as que usaban un DBSE (n=12), y profesionales que trabajan en empresas que fabrican los DBSEs (n=3). Los datos se recopilaron a través de entrevistas cara a cara realizadas en persona o mediante Zoom[®], y se analizaron usando el método comparativo constante.

RESULTADOS

Tres temas principales surgieron en los datos: (1) "De pie bajo demanda" reveló cómo los participantes percibían que los DBSE permitían a los/as niños/as a ponerse de pie cuando y donde querían, aumentando así la participación; (2) "es más que soportar peso" descubrió las percepciones de los participantes en cuanto a los beneficios psicológicos y físicos; y (3) "Los ecosistemas que influyen en la adquisición y uso de un DBSE" revelaron factores relacionados y no relacionados con el/la niño/a que se percibió como que influyen en la obtención y el uso de un DBSE.

INTERPRETACIÓN

Se consideró que el uso de un DBSE brindaba una oportunidad única para que los/las niño/as se pongan de pie cuando y donde ellos desean. Los hallazgos sugieren una posible aplicación transdiagnóstica de los DBSEs.

PERSPECTIVAS DOS ENVOLVIDOS COM DISPOSITIVOS PEDIÁTRICOS PARA EM CADEIRA DE RODAS MOTORIZADAS: UM ESTUDO QUALITATIVO

OBJETIVO

Explorar e descrever as experiências e perspectivas de vários envolvidos com relação ao uso de dispositivos para em cadeira de rodas motorizadas (DOCRMs).

MÉTODO

Esta amostra proposital incluiu: crianças com idades de 6 a 18 anos que usavam um DOCRM (n=8; diagnósticos: paralisia cerebral, atrofia muscular espinhal, espinha bífida, lesão medular), pais de crianças com 18 anos ou menos que usavam um DOCRM (n=12), profissionais de reabilitação que trabalham com crianças que usavam um DOCRM (n=12), e profissionais que trabalham em uma companhia que produz DOCRMs (n=3). Os dados foram reunidos por meio de entrevistas face a face conduzidas pessoalmente ou via Zoom[®] e analisados usando método comparativo constante.

RESULTADOS

Três temas principais emergiram nos dados: (1) 'Ficar em pé sob demanda' revelou como os participantes perceberam os DOCRMs como permitindo às crianças ficar em pé quando e onde quiserem, aumentando assim a participação; (2) 'É mais do que descarga de peso' descobriu as percepções dos participantes sobre os benefícios psicológicos e físicos do uso de DOCRMs; e (3) 'Ecossistemas influenciando a aquisição e uso de DOCRMs' revelaram fatores relacionados e não relacionados à criança percebidos como influenciando a procura e uso do DOCRM pelas crianças.

INTERPRETAÇÃO

O uso de um DOCRM foi percebido como fornecendo uma oportunidade única para crianças ficarem em pé quando e onde quiserem. Os achados sugerem a possível aplicação transdiagnóstica de DOCRMs.