Permobil White Paper

A summary of the evidence on power standing wheelchairs

Update 2023

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CONTENTS

LIST OF ABBREVIATIONS

ADL = Activities of Daily Living

BMD = Bone Mineral Density

CP = Cerebral Palsy

DMD = Duchenne Muscular Dystrophy

MS = Multiple Sclerosis

PWC = Power Wheelchair

ROM = Range of Motion

SB = Spina Bifida

SCI = Spinal Cord Injury

ABSTRACT

AIM:

To describe the impact that standing can have on an individual who uses a power standing wheelchair.

METHODS:

The primary source was a systematic literature review. A total of ten original scientific publications on power standing wheelchairs were identified, of which five were clinical trials.

Other sources were:

- Scientific publications on other standing devices
- A survey amongst 137 individuals who use a Permobil power standing wheelchair and answered questions about how they use power standing and which impact they experience.
- Motion capture data to indicate displacement of individual body markers representing the way that movement occurs when going into a standing position and returning to a seated position.
- Three interviews with individuals using a power standing wheelchair.

RESULTS:

Identified benefits for using a power standing wheelchair supported with higher quality evidence include:

- Pressure redistribution
- Bladder, bowel, digestive functions
- Range of motion and muscle length
- Activities of daily living, personal/medical care, and leisure activities
- Functional reach
- Communication
- Participation in social, work, and educational settings
- Independence

Identified benefits for using a power standing wheelchair supported by lower quality evidence include:

- Bone health
- Spasticity
- Mental health

Additional discussion included how power standing leads to more benefits compared to standing with other non-powered standing devices (such as a stander or standing frame) because of less limitations in daily use, including e.g., that there is no need to transfer between devices. The results from the additional survey performed add unique findings in a relatively large group of individuals using a power standing wheelchair, and include outcomes that are not commonly reported on in the literature. Findings on quality of life show that 80% of individuals reported that their quality of life is higher with power standing function compared to without.

Considerations include that health-related benefits can be dependent on the amount of time spent in standing, shear forces may be of concern when moving in and out of stand, pain needs to be monitored when individuals start standing and when children grow, and some individuals may perceive that they “stand out” when they use the standing function.

CONCLUSION:

The impact that power standing wheelchairs can have include multiple health-related benefits, as well as what activities people can participate in and how independent they are.

IMPLICATIONS FOR CLINICAL PRACTICE:

Based on the comprehensive nature of this white paper and all the resources presented, clinicians can utilize this paper to support their clinical decision-making when matching individual needs with the benefits and considerations of power standing wheelchairs. In addition, the connection between self-reported experiences and the clinical evidence can provide confidence in setting goals and expectations throughout the evaluative process.

INTRODUCTION

BACKGROUND

Health risks of sitting for long periods of time are widely acknowledged[1]. In the most recent guidelines, people with mobility impairments are recommended to limit the amount of time spent sedentary (sitting or lying down), because an increasing level of evidence shows that replacing sedentary behaviour with an activity of any intensity provides health benefits[2]. Studies in different population groups confirm that standing can be considered as a light activity for people with mobility impairments and is, therefore, suited to break up long intervals of sitting [3–6].

Evolution of power standing wheelchairs

Over the last half-century, technology has been available to integrate standing with an individual's mobility device. Historically, power standing wheelchairs included characteristics such as a system that can be controlled by a wheelchair drive input that allows the seating system to move to a vertical position while at the same time extending the lower extremities through legrest and backrest extension[7]. Devices that operated on this principle may have created limitations as to who can benefit from their use, since the pattern of movement may not be comfortable or compatible for everyone.

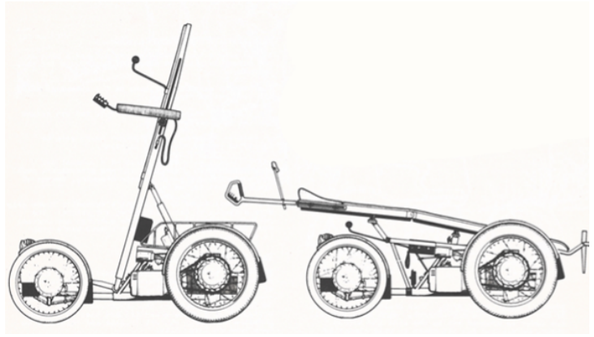


Figure 1. *Permobil power standing wheelchair model, circa 1979*

Devices of the past may have presented limitations that may have influenced the decision on what type of individual was the perfect candidate for a power standing wheelchair. Some of those limitations included: the seating solutions that were compatible, the achievable total standing angles, the ability to drive while in a standing position, the pattern of which someone can sit to stand, as well as the environments where they can be used. Many of these concerns can now be reduced and/or eliminated with improved compatibility, mechanical adjustability, and programming considerations to allow individualized fit to maximize outcomes. Misconceptions such as the idea that only people with functional upper extremities can use a power standing wheelchair can now be minimized as it is easier to maintain positioning and/or access to input devices.

In addition, in the past there have been some power standing wheelchairs that would limit the use of other power seat functions due to the capacity of the power mobility base itself. This created a challenge in that if a person was unable to stand for a few days due to health complications, they also lost the ability to change their position for pressure management. With current technology, neither the clinical decision making, nor the client choice needs to be compromised for one power seat function over another as standing can be used alongside all other functions throughout the day.

As a result of the advances and choices that are available, individualized clinical evaluation can now match the person with the technology that works for them to provide benefits that extend to all facets of life. Power standing can provide flexibility with when and how someone can stand as well as expand from just physical therapeutic benefits into psychological and sociological impact[8]. Healthcare policies on the provision of power standing wheelchairs differ between systems, countries, and regions. Additionally, although the body of evidence is growing, limitations exist regarding funding support for power standing wheelchairs, which may be seen as not medically or functionally necessary, or even an item of convenience[9].

METHODOLOGY

Aim of this white paper

The aim of this paper is to describe the impact that standing can have on an individual who uses a power standing wheelchair. A broad impact was assessed on body functions and structures, activity, participation, quality of life and independence. Furthermore, environmental and personal factors were discussed. The intention of this white paper is to serve as a resource to inform clinical practice.

This version of the white paper is an updated version in 2023 from the original version that was published in 2021. Additions and revisions in the new version are described below in the overview of sources in this white paper.

Sources

1. Systematic literature review

A systematic literature review was performed to identify the impact of standing on all outcomes of the ICF model for individuals who use a power wheelchair (PWC). A broad search was performed using PubMed/Medline. The PICO framework was used to define the search and used the following key words, for Population: wheelchair, disability, handicap, impairment, or non-ambulatory; for Intervention: stand/standing (in PubMed: stand*), upright, frame, table, stander, power seat, weight-bearing, passive loading, prolonged muscle stretch, long leg braces, standing box; the search was not limited to any comparison or outcome.

In the first published white paper on this topic, the evidence was summarized into clinical, functional, and psychosocial impact. This is revised in the current white paper to be summarized in the ICF framework (International Classification of Functioning, Disability and Health)[10]. Furthermore, the literature has been updated to include the latest publications up to March 2023. In this new body of literature, a growth in the body of evidence specifically to standing in PWCs (rather than in other devices) was noted; therefore, the summary was rewritten with a primary focus on

these studies. Studies on standing with devices other than PWCs were described as a secondary source of evidence. A total of 519 publications were found and systematically screened by title, abstract and full text. Out of these, a total of ten original research publications on power standing wheelchairs were identified, which included five clinical trials[11–16], one qualitative study on stakeholder perspectives[8], one retrospective chart review[17], one consensus statement based on a Delphi study [18], and two experimental lab studies[6,19]. A detailed description of these ten research publications is available in Appendix A. Furthermore, two position papers[7,20] and one policy analysis[17] on power standing were identified and were included as supporting articles.

2. Permobil standing survey

The previous version of the white paper included a questionnaire that was filled out by Permobil employees based on their observed experiences with power standing wheelchairs. This was now replaced with a survey amongst individuals using a power standing wheelchair. Quantitative and qualitative results from the survey are described as additional evidence in this white paper. More detailed results of the survey are provided in Appendix B.

In the beginning of 2023, Permobil performed a web-based survey of individuals using a PWC to get a better understanding of the impact of standing, needs, and experiences. An invitation to the survey was shared via an email list of 1075 individuals using a Permobil F5 Corpus VS worldwide. A total of 171 participants started filling out the survey, and 140 persons answered at least 40% of the survey which was set as the minimum amount to be included in the analysis. From the group of 140, 10 were under 18, and were thus not asked any questions deemed sensitive. The survey was discontinued for participants without standing functionality. A total of 137 participants included their power standing experience and their demographic characteristics are presented in Table 1. The majority identified as male and had been using a power standing wheelchair for at least 1 year. There was a wide range of ages represented with most participants being adults. Regional distribution of participants included: North America (63%), Asia Pacific (6%), Europe/Middle East (29%).

Table 1. *Proportion of Permobil standing survey participants by gender, age, and experience with power standing wheelchairs*

Gender (n=137)	Female	27%
	Male	72%
	Prefer not to say	1%
Age (years) (n=137)	71-80	9%
	61-70	12%
	51-60	28%
	31-50	31%
	18-30	13%
	5 to 17	6%
	Prefer not to say	1%
Time using a power standing wheelchair (n=137)	Less than 1 year	18%
	1-5 years	55%
	>6 years	26%

3. Motion Capture Data

An addition in this update of the white paper are results of motion capture data to give insights into the displacement of an individual in a PWC after standing. Movement in a three-dimensional space can be tracked and recorded using reflective markers. These small markers are secured to a moving subject and filmed from numerous angles. Using specialized software (such as Vicon Nexus), the movement of the reflective markers can be translated from the video footage into numbers that can be tracked digitally. This creates a robust model in three-dimensional space as seen in Figure 2. Using the motion capture laboratory at Flinders University (Adelaide, Australia), the movement of a non-disabled participant in a Permobil F5 Corpus VS was recorded while the chair was moved from a seated position into stand and back to seated again. The motion capture data measured the participant's body position and the chair position throughout this sequence to a mm resolution. This provided accurate insight into how well the wheelchair maintained the participant's posture after the sit-to-stand-to-sit transition. The methodology is explained in more detail in Appendix C. Displacement: motion capture data.

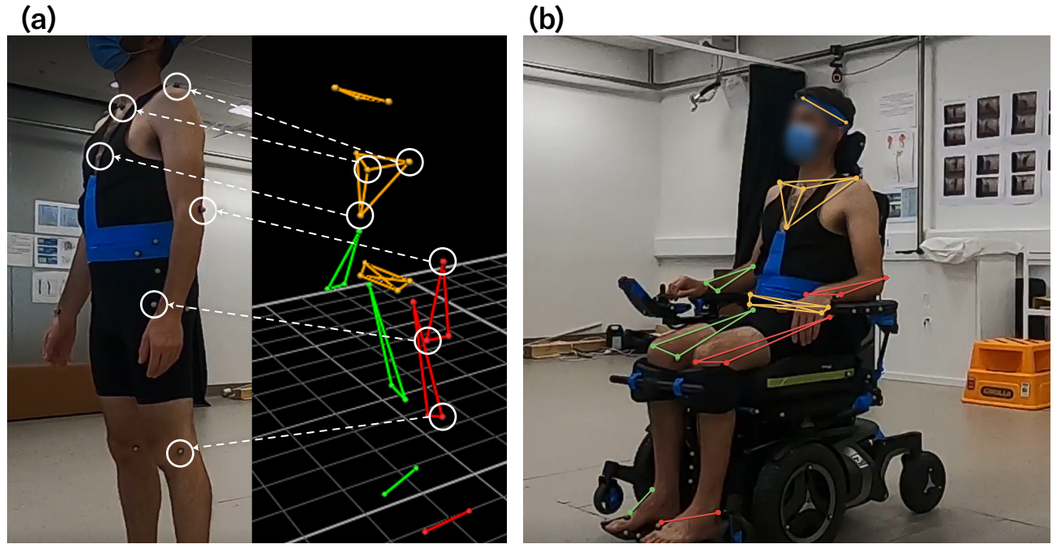


Figure 2. *The photo and screen capture in (a) was taken during initialisation of the motion capture analysis to ensure sound results. The diagram shows the translation of physical markers on the non-disabled participant to the computer-generated model in three-dimensional space created by the specialized software. The model was created with the use of 10 cameras surrounding the participant and wheelchair. (b) shows a representation of the model overlaying a photo of the participant during testing.*

4. Clinical applications

In this update of the white paper, three interviews with individuals using a power standing wheelchair were added. Pictures and quotes from those individuals are used to visualize and explain the

scientific evidence provided. Key words that relate to areas of evidence were identified. Clinical applications compiled based on these are presented in Appendix D.

5. Supporting articles

This includes articles on standing devices other than PWCs and supplemental publications for areas such as background information, considerations, and clinical support. All articles are available in the reference list.

APPLICATIONS

International Classification of Functioning, Disability and Health (ICF)

This white paper used the ICF framework when describing the overview of the evidence (Figure 4). This framework maps an extensive set of considerations with regards to body functions and structures, activities, and participation, and how these interact with environmental and personal factors[10]. In a modified version, quality of life was added as a concept that encircles all the individual aspects of the framework[21]. The ICF framework was developed by the World Health Organization (WHO) to shift discussions from a medical model focused on diagnosis and disability to one highlighting the social model with function as its primary purpose. According to the WHO, the ICF creates a standard language to describe health and health-related states. The ICF framework can be used in many different ways, but the main purpose is as a tool when making decisions around health plans and health policies[10]. Additional information is provided in Appendix E.

Health conditions

Power standing wheelchairs may be useful and beneficial for individuals with a variety of mobility impairments; this is best determined via an evaluation performed by a care team. This may include a person with upper and/or lower extremity impairments, coordination difficulties, and anyone who is unable to stand independently and functionally. Power standing devices are compatible with a wide range of seating solutions and drive controls. If a person has more complex needs, it is even more critical to have a comprehensive wheelchair service provision process in place.

All health conditions have been considered when composing this white paper. Some health conditions, such as Duchene Muscular Dystrophy (DMD), Cerebral Palsy (CP), and spinal cord injury (SCI) have been more extensively studied than others. When there is limited or unavailable research related to a specific mobility impairment, it does not automatically mean that a power standing wheelchair may not be beneficial. If there are specific differences between populations or types of mobility impairments, this will be discussed when appropriate.

Definitions

Standing power mobility has traditionally been described in a multitude of ways; power standing, integrated standing mobility, and power standing mobility are just a few. Currently, there is no global consensus on the term to use when defining the combination of a PWC base and standing system in current research, the authors of this white paper will use the term power standing to refer to a PWC with standing functionality built in.

Power standing is defined as a system that encompasses the ability for a standing system (consisting of multiple actuators and power seat functions such as tilt, recline, elevating legs, and seat elevate) to be utilized in its full capacity upon a PWC base. This combination of seat functions and power base allow the individual using the wheelchair to optimally achieve both a seated and standing position within the system, while enabling access to his/her environment with the use of mobility.

Standing duration recommendations

Recommendations on the duration of standing have been presented separately for different outcomes. A dosage of 40-minutes, five times per week has been proposed to have a positive impact on most outcomes such as self-care and standing balance, ROM, cardio-respiratory strength, spasticity, pain, skin and bladder and bowel function, while 60-minutes four to six times per week has been proposed for an impact on bone health and mental health[5]. For individuals with DMD it was recommended to use power standing approximately 60-minutes for four to five days per week. Furthermore, it was recommended that, if reasonably possible, to avoid periods without standing longer than four weeks[18].

Results from the Permobil standing survey provide additional insights into clinician recommendations that individuals received for the duration of power standing and how frequently individuals were standing in their PWC. Almost half of the participants of this survey had been given clinical recommendations for standing duration. These recommendations were mostly to stand for as long as tolerated (38%), for weight shift (20%), for an activity (11%), or for a specific time (23%). Of the latter, recommendations ranged from 12 minutes two times per day to 180+ minutes per day.

Permobil standing survey results further showed that 42% of 137 participants reported to use their power standing function every day, 31% at least two times per week, 17% a few times per month and 9% did not use it at all. One-third (34%) of these participants remained in stand for 16-30 minutes per day, 23% spent less than 15 minutes per day, while 22% used stand for 30-60 minutes, 12% for 1-2 hours, 6% for 2-4 hours, and 4% for over 4 hours. More information can be found in Appendix B. Permobil standing survey results.

This survey data on the amount and duration of use were combined to form three subgroups of varying frequency which gives an indication of the amount of power standing use (Figure 3). Of the original 137 participants, 19 participants could not be categorized as they used their power standing function for long durations but infrequently. Of those included in the frequency analysis (n=118), 40% were considered highly frequent users, standing more than 31 minutes per day, more than two days per week. Middle frequency users made up 34%, standing between 16 and 30 minutes per day, more than 2 days per week. Only 26% of survey participants spent less than 15 minutes per day in standing. These three subgroups will be referred to in subsequent analyses as high frequency, middle frequency, and low frequency groups. As this survey specifically concerned power standing, it can be

surmised that the respondents are more likely to use this functionality often. As such, there is risk of bias within the proportion of participants using stand frequently. Furthermore, it must be noted that this was self-reported use of power standing and may, therefore, not be fully reliable.

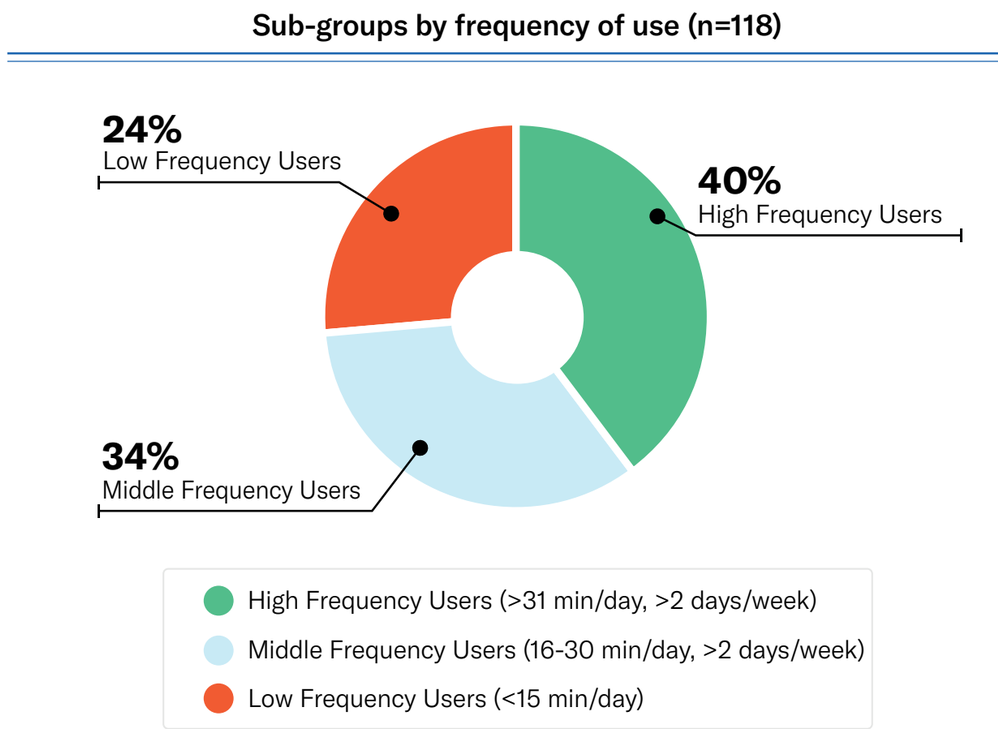


Figure 3. Survey respondents grouped by power standing frequency. *Three subgroups of participants from the Permobil standing survey were categorized by standing frequency. The groups were determined by combining data of how many days were spent in stand per week, and the duration spent in stand per day.*

OVERVIEW OF THE EVIDENCE

Figure 4 represents the summary of the research review findings as to the influence of power standing on all aspects of the ICF framework as well as and on independence and quality of life. Each outcome is color coded to describe the level of evidence. When determining the level of evidence, we considered the amount, type, and quality of evidence available. The strongest sources of evidence were considered to be the findings from five clinical trials on power standing identified in the systematic literature review, directly followed by the five other original research publications that studied power standing (Appendix A. Characteristics of power wheelchair research publications). Evidence from the literature on standing with other devices and results from the Permobil standing survey were considered as supporting sources to the PWC publications.

In the sections that follow, the evidence will be described for each component of the ICF framework: body functions and structures, activities, participation, and quality of life and independence. Subsequently, environmental factors and personal factors will be discussed.

Each section will be organized using the same structure:

Background: Provides an introduction with supporting literature on the importance and evidence of each part.

Summary statements: Summary of all available evidence per topic. Concluding statements are printed in blue.

Considerations: Positive and negative factors that can be important to consider for the implication of the findings.

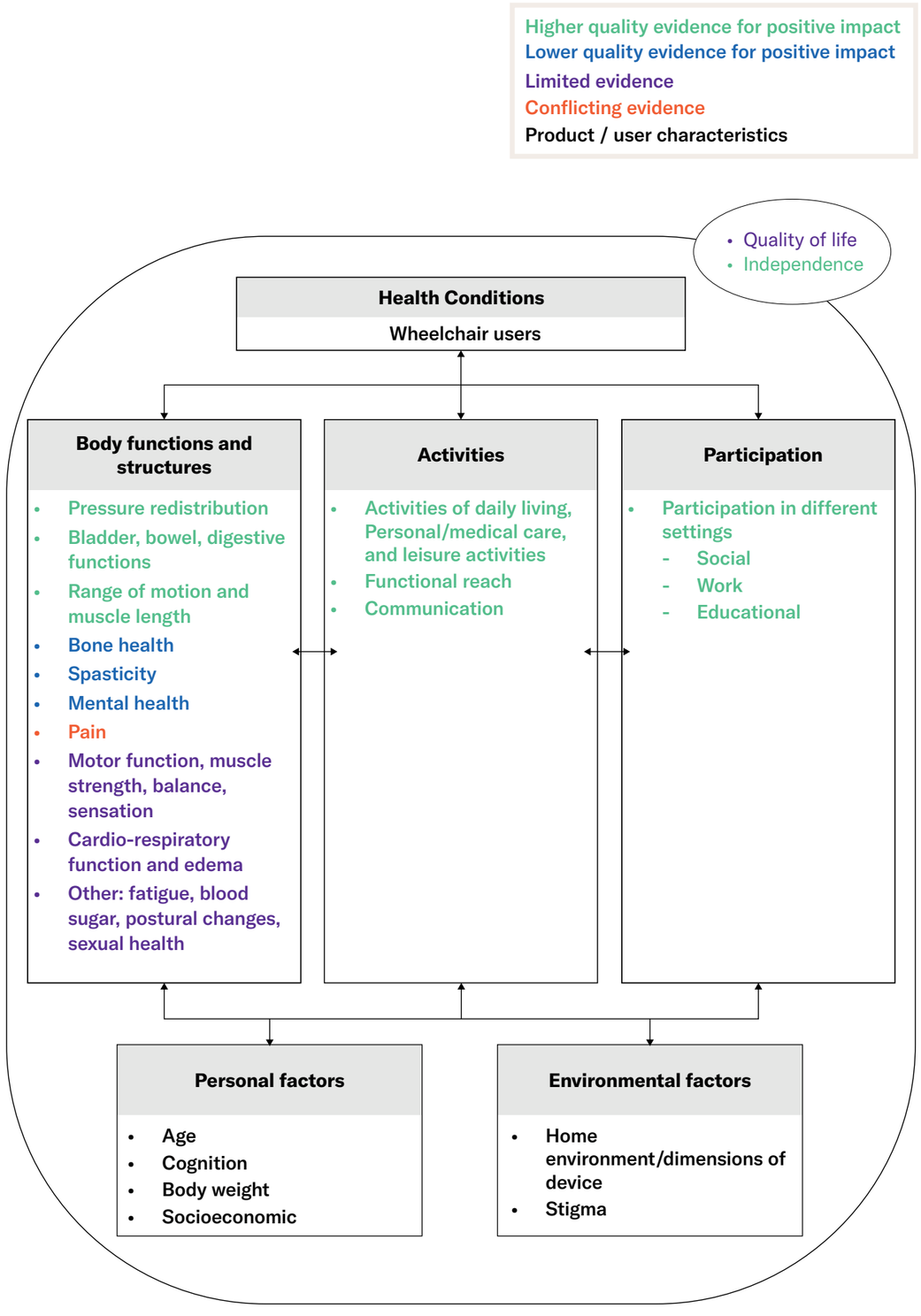


Figure 4. *Overview of the evidence on the impact of power standing wheelchairs in the ICF framework.*

Body functions and structures

Pressure redistribution

BACKGROUND

Pressure injuries and skin/tissue breakdown occur when an individual has risk factors including, but not limited to; absent or limited sensation, muscular atrophy, impaired nutrition, advanced age, limited mobility and activity, circulation and oxygenation deficits[22]. Individuals who utilize wheeled mobility devices are at an increased risk of pressure injuries due to factors such as prolonged sitting activities, inability to redistribute pressure independently, postural asymmetries, and spasticity. In a retrospective data review study of medical charts, 50% of individuals using PWC had a history of wounds from pressure injuries[23]. Therefore, managing pressure and protecting skin and tissue integrity are critical.

SUMMARY STATEMENTS

Power standing enables pressure redistribution and thereby mitigates the risk of pressure injuries.

Direct evidence for the prevention of pressure injuries is not available. However, based on experimental studies and self-reported findings, it can be concluded that standing enables pressure redistribution and thereby mitigates the risk of pressure injuries.

An experimental study showed that standing leads to significant offloading of the seat and backrest, and as load equals the pressure multiplied by the area, standing has the potential to decrease the risk of pressure injuries[6]. Standing and recline offered similar seat load reductions[6]. Compared to tilt and recline load redistribution, standing was the only configuration that decreased loads off the seat and backrest simultaneously[6].

A systematic review noted that three survey studies amongst individuals with SCI suggest that standing (not device-specific) may help decrease the risk of pressure injuries[5]. There is no reason to assume that the working mechanism of offloading the sitting surface and the relation to pressure injury prevention would be different for adults, adolescents, and children. One qualitative study amongst adolescents with DMD[12] and another study in children[8], reported that power standing was used for pressure redistribution.

Results from the Permobil standing survey, shown in Figure 5 found that 50% of participants perceived a favourable impact on skin health related to power standing, while 42% reported on no impact, and the remaining 4% an unfavourable impact. The additional analysis performed to get insight into whether the amount of standing had an impact on these results showed that those that were in the low frequency standing group had the largest proportion of participants perceiving an unfavourable impact (20%), although it must be noted that this group had a lower number of participants responding (n=15).

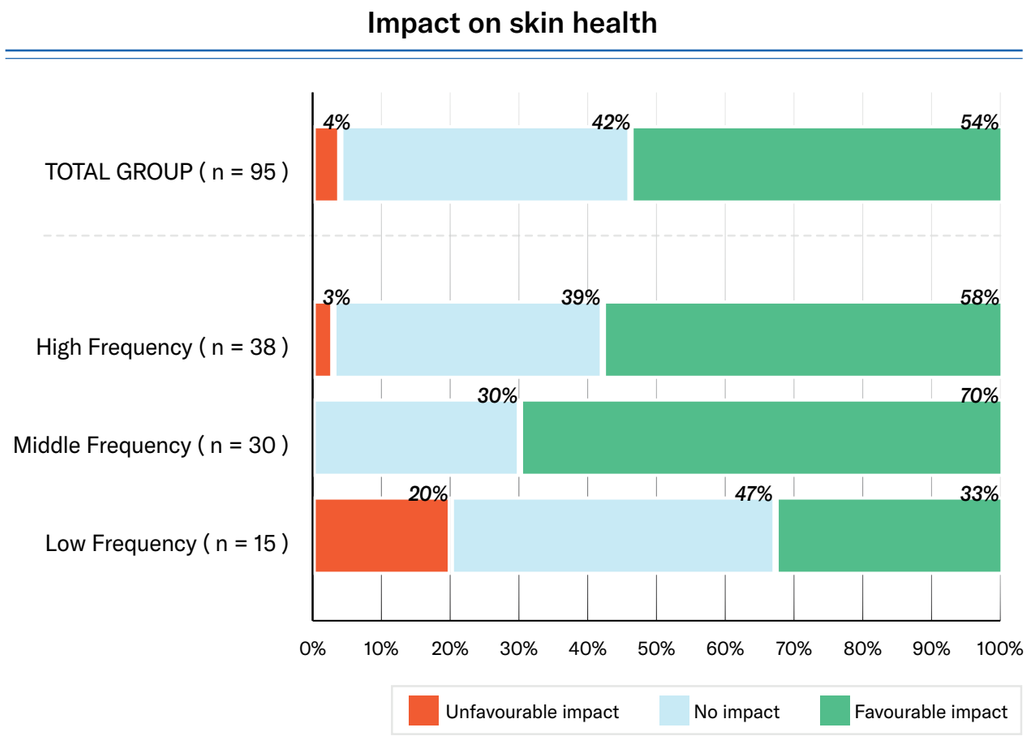


Figure 5. Impact of standing frequency on skin health. *This figure shows how Permobil standing survey participants rated the impact of power standing to their skin health. The 95 participants who submitted a response are displayed regardless of standing frequency. Subsequent results are displayed as three subgroups depending on standing frequency. The graph shows the percentage of participants who reported an unfavourable impact, no impact, or favourable impact in each subgroup respectively.*

Scott is demonstrating the use of power standing for pressure management.

Ignacio uses power standing to reduce the risk of a new pressure injury post-surgical closure.

CONSIDERATIONS

Displacement

One lab-based study reported on displacement between the body, the back support, and seat surface in 24 individuals with SCI. In the PWC that was tested in this study, which did not have an anti-shear mechanism, the shear displacement was approximately nine cm between the individual's body and the back support and seat surfaces. During the sit to stand phase, the individual's back slid down and the thigh was displaced rearward, but they moved in opposite directions when the wheelchair returned to a sitting position[19].

Motion capture data that were collected from a non-disabled person moving in and out of standing in a PWC (full description and results available in Appendix C. Displacement: motion capture data), showed only limited displacement between the person and the wheelchair; as displayed in Figure 6. The maximum displacement was seen at the iliac crest which moved 16 mm (0.63 inches) down towards the floor when returning to seated after standing. Displacements were less than 10 mm (0.4 inches) for 73% of the marker locations measured. For example, the forehead moved 7.8 mm (0.3 inches) downwards and 3.4 mm (0.1 inches) backwards, indicating that the cervical spine was able to maintain its resting or normalized curvature and position once returned to sitting.

Body displacement during sit-stand-sit sequence

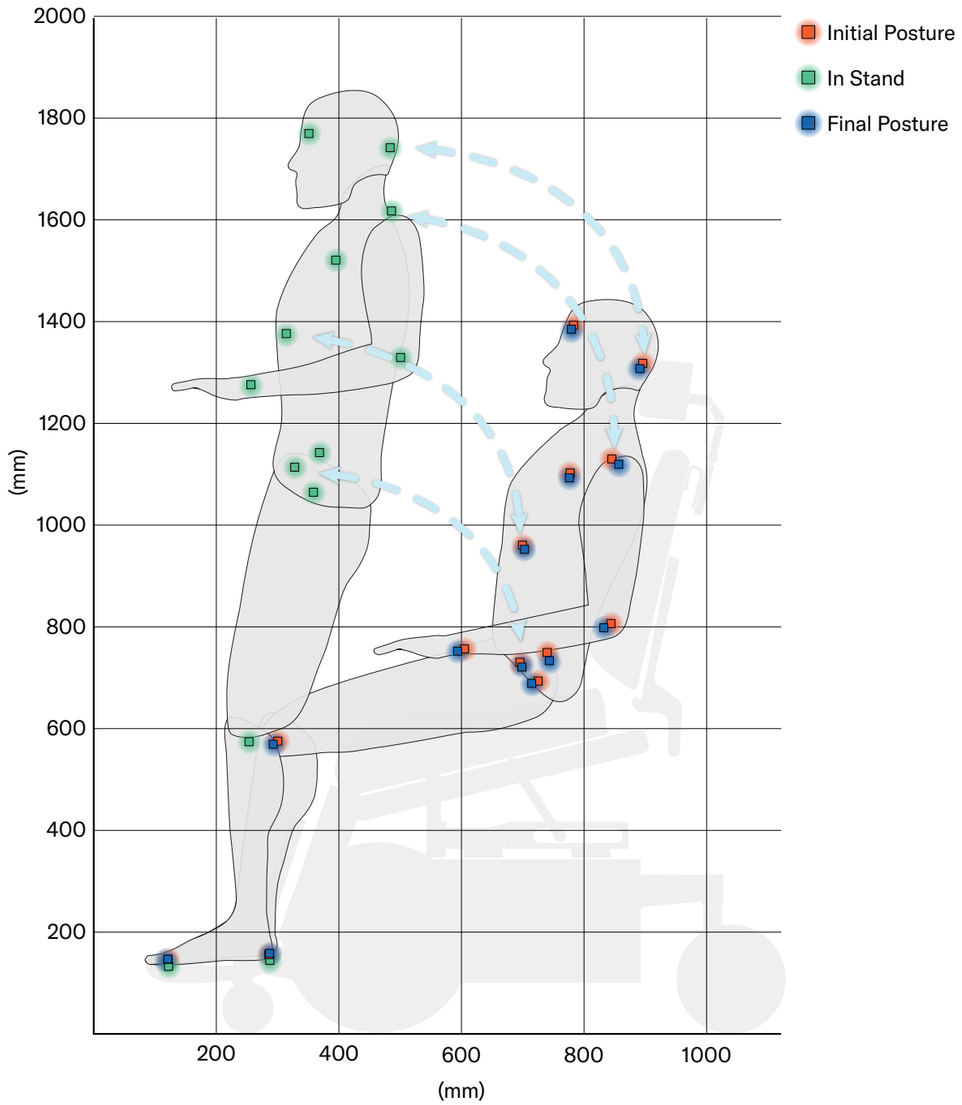


Figure 6. Body displacement during sit-stand-sit sequence. *This figure shows the body position of a non-disabled individual as tracked by motion capture. The individual was seated in a Permobil F5 Corpus VS power standing wheelchair and moved from a seated position into a full stand, and then returned the wheelchair to seated. The red markers show the individuals' initial position to a mm accuracy prior to moving into stand. The green markers show the position of the individual once in stand and the blue markers show the position of the individual once returned to seated.*

Shear forces

Sliding between the body, seat, and back support might occur while transitioning from sitting to standing and vice versa in a PWC, and this may cause shear displacement[19]. During the sit to stand movement, shear forces are generated on the seat and on the back support[24]. Without an anti-shear mechanism there is an increased risk of shear forces both when standing up and sitting down. Shear forces can potentially increase the risk of pressure injuries and therefore require careful attention[19].

> *It is very beneficial for pressure relief, spasticity, activities and communication.*
>
> - Male, 51-60

> *It's a good thing physically, shifting weight, stretching hamstrings, etc.*
>
> - Male, 11-17

> *Generally l sit too much and find that I need to be able to stand, to relieve my bottom.*
>
> - Male, 71-80

Bladder, bowel, and digestive functions

BACKGROUND

Incontinence, bowel issues, and digestive issues are common comorbidities among individuals using a PWC[23].

Bladder dysfunction is an abnormality of either the filling or emptying of the bladder. It may be caused by involuntary muscular activity in the muscles of the bladder wall, the muscles that control the starting or stoppage of the flow of urine out of the body (sphincters), or the muscles of the pelvic floor. Neurological impairment and certain medications can contribute to bladder dysfunction, and many individuals who use a wheelchair have diseases or injuries to their nervous system. Common urological dysfunction are incontinence and infection, and the risk of infection becomes further increased in cases when there is incomplete emptying of the bladder[25].

As is the case with the urinary system, the gastrointestinal system might be impaired in many individuals using a wheelchair, particularly those with neurological disorders. Both immobilization and paralysis contribute to the common problem of constipation[26]. For example, for individuals with SCI, neurogenic bowel dysfunction can include both the failure to eliminate or the failure to store. The inability to manage bowel function due to central nervous system disruption, impaired mobility and hand dexterity not only results in physical limitations but can also result in psychosocial challenges[27].

For individuals with SCI, the inability of the bowel or bladder to empty can cause pain which can trigger autonomic dysreflexia, which is considered a medical emergency[27]. When an individual cannot empty their colon, conditions can occur such as fecal impaction and bowel obstruction, which can require surgery[28].

Studies in able-bodied individuals without bowel dysfunction show that food empties from the stomach best when individuals alternate between sitting and standing and worst when individuals just sit, stand or lie down[29].

SUMMARY STATEMENTS

Power standing may improve bladder and bowel function.

Four studies among individuals using power standing wheelchairs support a positive impact of power standing on bladder and bowel function. One case-series found that four participants (CP, Multiple Sclerosis (MS) and two SCI) reporting constipation before having a power standing wheelchair all showed improvements after using a power standing wheelchair on the constipation quality of life measure[14]. A retrospective data review of records including 13 individuals using a power standing wheelchair (77% diagnosed with SCI) that compared the amount of urinary tract infections before and after the power standing wheelchair evaluation, found a lower incidence of urinary tract infections the year after compared to the year before (8% vs 23%)[17]. A qualitative study reported that parents of adolescents with DMD observed improved digestive function after using a power standing wheelchair[12]. Another qualitative study reported that different stakeholders, including children using PWC, their parents and clinicians, agreed that power standing wheelchairs have a positive effect on bowel and bladder function[8].

> *I guess the biggest thing is being able to stand up helps my bowel programs so much. If I stand up a little while before programs, they do so much better, and I empty out a lot easier. It also helps with gas and gas pains. I have a really hard time getting rid of gas and being able to stand up and to get that gas moving so I can expel it it's very helpful.*
>
> - Male 31-51

The Permobil standing survey (Figure 7) showed that of 49 participants indicating to have bladder function impairments, 61% perceived a favourable impact due to standing. Participants with digestive function impairments (n=44) had a larger majority of 80% rating the impact of standing as favourable to their digestive function. Bowel function was also seen as improved by the majority (78% of 58 participants). An unfavourable impact was seen by 10%, 5%, and 5% of each group respectively.

> *When I stand, it stretches out my stomach to help my digestion.*
>
> - John, Age 11

CONSIDERATIONS

Systematic reviews have reported on positive self-reported outcomes of standing in different devices on bladder and bowel function[5,30,31] Two studies that used more objective quantitative measurements of bladder and bowel function, such as bowel frequency and time to first stool, did not find any positive effects[32,33]. However, in both studies the individuals with MS and SCI were also asked for their perceived benefits which indicated that the standing did help bladder and bowel function. When interpreting results from quantitative outcomes of bladder and bowel function it should be considered that these functions are difficult to quantify and are, therefore, difficult to measure[33]. Another consideration is that the response to standing may also be affected by neurological status, diet, and other lifestyle habits.

The Permobil standing survey results suggest that frequency of standing may impact the impact of standing on bowel, bladder and digestive function as seen in Figure 7. Standing was perceived to have a favourable impact on bowel and bladder function for 88% and 71% of the high frequency standing users, respectively. Furthermore, 100% of survey participants rated the impact of standing on digestive function as favourable in the high frequency group. The favourable impact seen in the low frequency groups was lower; 33% for both digestive and bladder function, and 57% for bowel function. However, it must be noted that there were very few participants with bladder, bowel, or digestive function impairments in the low standing frequency groups.

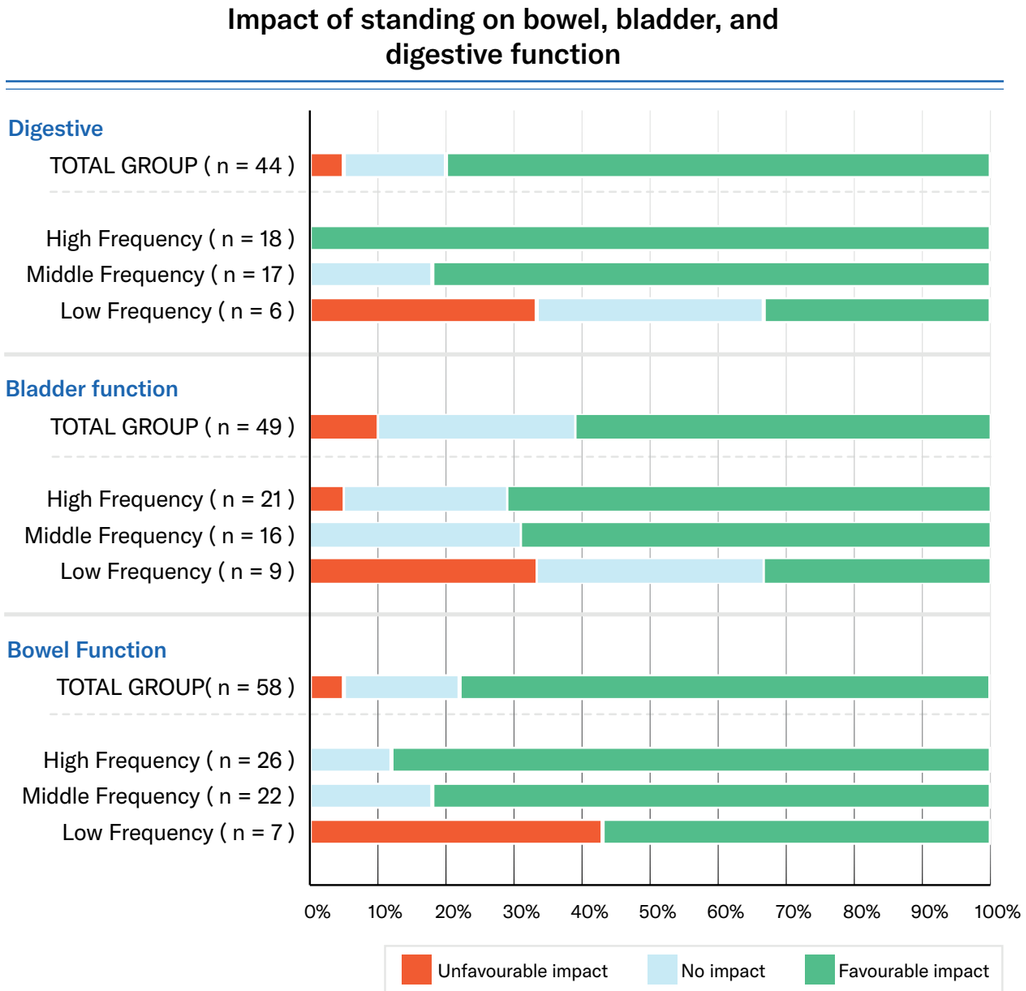


Figure 7. The Impact of standing frequency on bowel, bladder, and digestive function. *This figure shows how the Permobil standing survey participants with bowel, bladder, and digestive related diagnoses rated the impact of power standing on these functions respectively. The figure displays how all participants responded regardless of standing frequency and subsequently how participants responded within each frequency subgroup.*

Range of motion (ROM) and muscle length

BACKGROUND

Range of motion (ROM) can be defined as the range of full flexion through full extension that a joint must move through for mobility[34]. Several factors may decrease ROM, e.g., joint inflammation, paralysis of the muscles acting across the joint, spasticity, etc. One or several of these factors commonly occur in individuals using a wheelchair. When limitations of ROM are present, the joint, muscles, and tendons can shorten and cause deformity; the deformity is called a contracture[34]. Each joint has optimal passive and active mobility to assist with movement. When a joint or joints in the human body move or are moved through the full available ROM on a consistent basis, limitations in movement and contractures can be avoided.

Loss of ROM in individuals that utilize wheeled mobility can potentially result in a variety of difficulties including pain and discomfort, reduced positioning abilities, challenges with completing self-care tasks and limited functional independence. Thus, for those individuals using a wheelchair who experience limited standing or walking function, keeping their existing ROM is important to support function and independence. For individuals who are non-ambulatory, a power standing wheelchair can provide movement through their available ROM.

> *Standing helps to keep my muscles from shortening and if I don't stand, I feel like [my diagnosis] will progress faster.*
>
> - Andy, 22 years old

> *I use my standing wheelchair to stay on top of my leg stretches, usually about 20 minutes at a time, twice a day.*
>
> - John, 11 years old

> *This has helped my son put off a hamstring surgery and gives him a better quality of life.*
>
> - Parent answering for son, Male, 11-17

SUMMARY STATEMENTS

Power standing may increase range of motion and muscle length.

Evidence that was gathered from studies on standing in PWCs indicate a favourable effect on ROM. Six out of seven participants (four adults and three children with SCI, MS or CP) who received a power standing wheelchair, showed increases in passive ROM of their lower limbs, and five persons showed a gain of between 5 and 40 degrees of passive knee flexion at one or both knees[14]. An observational study assessed muscle length after power standing use and noted improvements in hip and knee flexor muscle length in those with DMD without marked ankle equinovarus contractures and in the early non-ambulatory phase[15]. In another observational study amongst individuals with DMD, power standing wheelchair use was associated with no change of videoed joint angles in standing. In standing, hips were slightly more extended over time, slightly more pronounced knee flexion was observed, and ankle angles were maintained. It was, therefore, concluded that there is some evidence to suggest that power standing use protected against the development or worsening of contractures[11]. Furthermore, in a qualitative study amongst different stakeholders, including children using PWCs, their parents and clinicians, many participants reported on perceived musculoskeletal benefits such as maintaining or increasing ROM[8].

A recent systematic review on supported-standing interventions for children and young adults with non-ambulatory CP, reporting on studies using power standing wheelchairs and other devices, concluded that findings support the favourable impact of standing on ROM and contracture prevention[30]. Two other reviews reported on moderate to high qualitive evidence, and support was in particularly found for adults with stroke and SCI[5,31].

Of the 72 Permobil standing survey participants to indicate ROM and muscle length related impairments, 75% reported a favourable impact due to standing, 21% reported no impact and 4% reported an unfavourable impact (see Figure 8). Additional analysis to assess whether the amount of standing impacted the outcomes, showed that standing was rated to have a favourable impact on ROM and muscle length in 85% of the high frequency group, 73% of the middle frequency group, and 71% of the low frequency group. Of the high frequency group and the middle frequency group, none reported an unfavourable impact, while within the low frequency group 21% reported an unfavourable impact. However, it must be noted that especially in this last group, there was a low number of participants with ROM and muscle length related impairments.

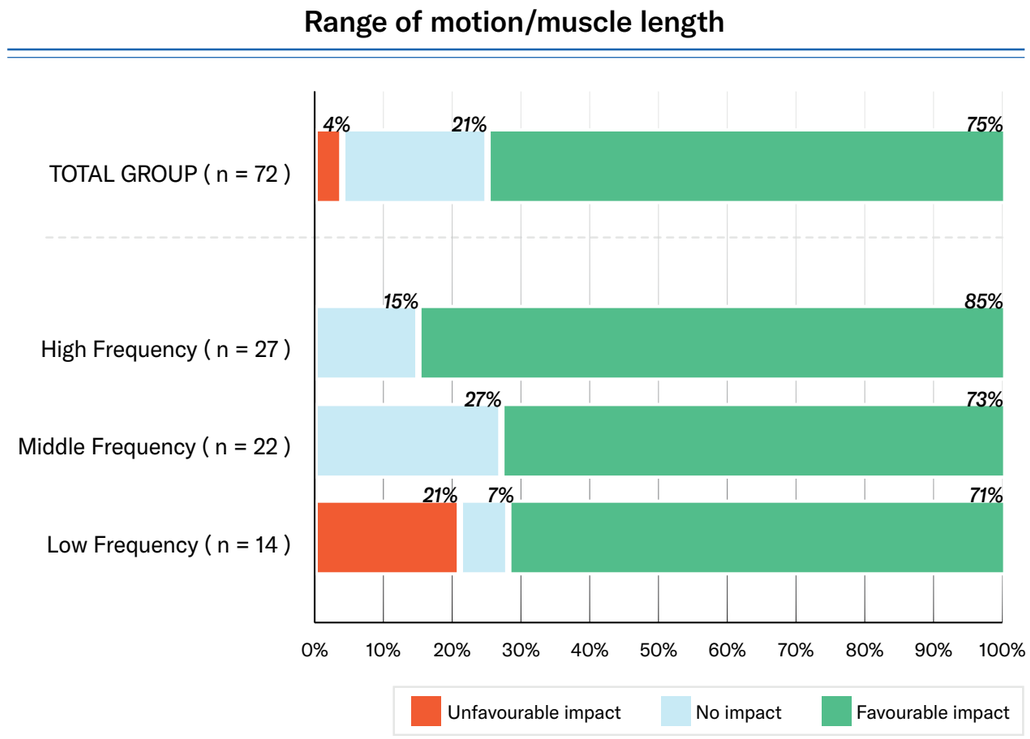


Figure 8. Impact of standing frequency on range of motion/muscle length. *This figure shows how Permobil standing survey respondents with range of motion/muscle length related diagnoses rated the impact of power standing on their range of motion/muscle length. The figure displays how all participants responded regardless of standing frequency and subsequently how participants responded within each frequency subgroup. The figure also shows the percentage of participants who reported an unfavourable impact, no impact, or favourable impact in each frequency group respectively.*

CONSIDERATIONS

In an agreement amongst experts with regards to the prescription of power standing wheelchairs to persons with DMD, hip and knee flexion contractures up to 20 and 30 degrees, respectively, were considered to not preclude the use of power standing, and there was consensus that up to 10 degrees plantarflexion contracture was allowable with power standing wheelchair use if supported with appropriate ankle foot orthotics and standing was without pain[18]. It may, therefore, be beneficial to start standing as early as possible, if that would mean that contractures of this extent would not develop.

Bone health

BACKGROUND

The human skeletal system is comprised of large amounts of minerals that make up the structure of our bones. These minerals provide the strength and structure to not only support the human body, but also to assist the skeletal frame for mobility and function. Interruption in the production of bone minerals, often due to age and/or disease, can compromise our skeletal system, resulting in osteopenia or osteoporosis, both of which may place individuals at risk of fracture. For a non-disabled individual, weight bearing and vigorous exercise is associated with an increase in bone mineral density (BMD) when performed more than one-hour per week[35]. The loss of weight-bearing activities such as standing can increase the speed at which the density of the bone decreases[36,37].

SUMMARY STATEMENTS

There are indications that power standing promotes bone health

Standing wheelchairs promote weight bearing (average of 75% of body weight) comparable to those of other standing devices[19]. This amount of load redistribution changing from sitting to standing implies that there is potential to improve bone health.

One of the clinical trials on power standing reported on the effect on BMD, and in this study amongst four boys with Duchenne muscular dystrophy (DMD), three reported on decreased lumbar BMD between baseline and early to mid-intervention of a six to 12 months standing program[15]. This decrease was transient in two boys and sustained in one boy. BMD was stable in the fourth boy who participated in this study. In a qualitative study with regards to paediatric power standing wheelchair devices, conflicting results were reported by the children, parents, rehabilitation professionals and company representatives who participated[8].

A recent systematic review considering evidence on power standing and standing with other devices amongst children and adolescents with non-ambulatory CP concluded the evidence reported to date is mainly positive and should be interpreted in light of the fact that children who do not have the ability to walk are anticipated to develop osteoporosis and show decreasing BMD with age[30]. Conclusions from systematic reviews on the evidence of standing with different devices in adults had similar conclusions, reporting on studies that showed either maintenance or improvements in BMD[5,31,38].

The results from the Permobil standing survey (Figure 9) show that the majority (77%) of participants (n=92) rated the impact of standing on bone health and density as favourable. The participants who perceived no impact of standing on bone health and density represented 17% of the group whilst 5% perceived an unfavourable impact. An additional analysis evaluated the impact of standing duration and frequency on the outcome. This showed that within the high and middle frequency subgroups respectively, 86% and 85% of survey respondents reported a favourable impact to bone health/density. Comparatively, only 50% reported a favourable impact in the low frequency group. The results, shown in Figure 9, also show a higher proportion of participants (17%) reporting an unfavourable impact in the low frequency groups compared to the high and middle frequency groups (3-4%).

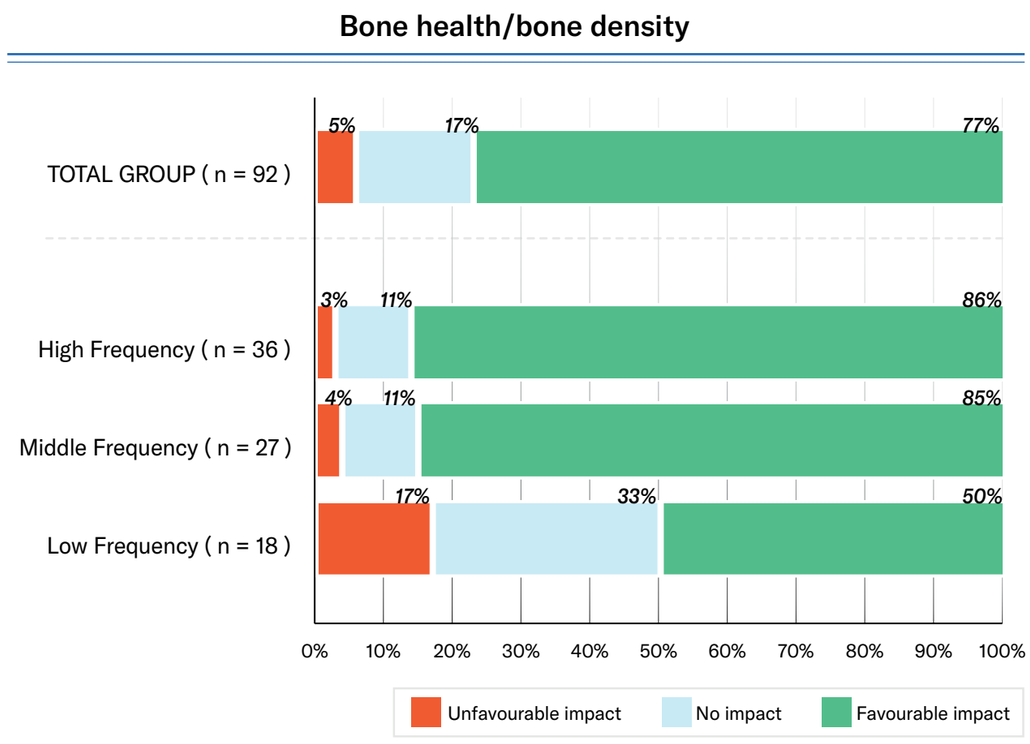


Figure 9. The impact of standing frequency on bone health/density. *Permobil standing survey participants are displayed regardless of standing frequency and subsequently within each frequency subgroup. All participants were asked about the impact of standing on bone health/density. The graph shows the percentage of participants who reported an unfavourable impact, no impact, or favourable impact in each frequency group respectively.*

CONSIDERATIONS

The effect of standing may be impacted by the dose of standing; that is, the amount of standing per day; whether someone has reported to start early after injury; and whether someone has been standing for longer periods of time[5]. This conjecture was supported by the Permobil standing survey results. The survey results suggest that those who use power standing frequently are more likely to perceive a positive impact on bone health; whereas those who do not stand often and for longer time periods are more likely to perceive an unfavourable impact.

Spasticity

BACKGROUND

Spasticity is a condition that occurs as a result of an impaired neurological system where there is a disruption in movement patterns. Spasticity can cause stiffness or tightness in the musculature which limits fluid movement patterns. In addition, it has been defined as a velocity-dependent increase in the tonic stretch reflex as a result of hyper excitability of the reflex[39]. This can result in increased muscle tone, clonus, muscle spasms and involuntary movements. Spasticity is a common comorbidity amongst individuals using a power wheelchair[23]. Many different types of medical conditions or diagnosis can experience spasticity, such as individuals with a SCI, traumatic brain injury and CP[5,40,41].

There are occasional circumstances where individuals may use patterns of spasticity or increased muscle tone for functional activities. However, when spasticity is not monitored or managed, it can have a negative impact on posture, balance, comfort, coordination, ROM, transfers and activities of daily living (ALDs). In addition, there is a correlation with several other factors discussed in this paper and the influence on spasticity such as pressure injury, infection, pain, as well as the inability to empty the bowel and bladder[42].

SUMMARY STATEMENTS

There are indications that power standing may decrease spasticity in the lower extremities.

No studies were found that specifically looked at the effect of standing in a power standing wheelchair on spasticity. All available systematic reviews on standing in other devices indicate that the evidence is weak, but that the evidence available points towards a positive effect of standing on spasticity[5,30,31,38]. Studies amongst children with CP using clinical assessments such as the Ashworth Scale point towards positive effects of standing on reducing spasticity[30], and surveys amongst those with SCI indicate a potential positive impact[5].

The Permobil standing survey results in Figure 10 show that 71% of participants (n=69) reporting to have spasticity observed a favourable effect on spasticity. Meanwhile, 26% reported no impact on their spasticity due to standing, and only 3% (2 participants) reported that there was an unfavourable impact. These two participants were grouped as low frequency standing individuals (n=11), making up 18% of this smaller subgroup. The high frequency subgroup (n=30) had the largest proportion of participants rating the impact of standing on their spasticity as favourable at 87%.

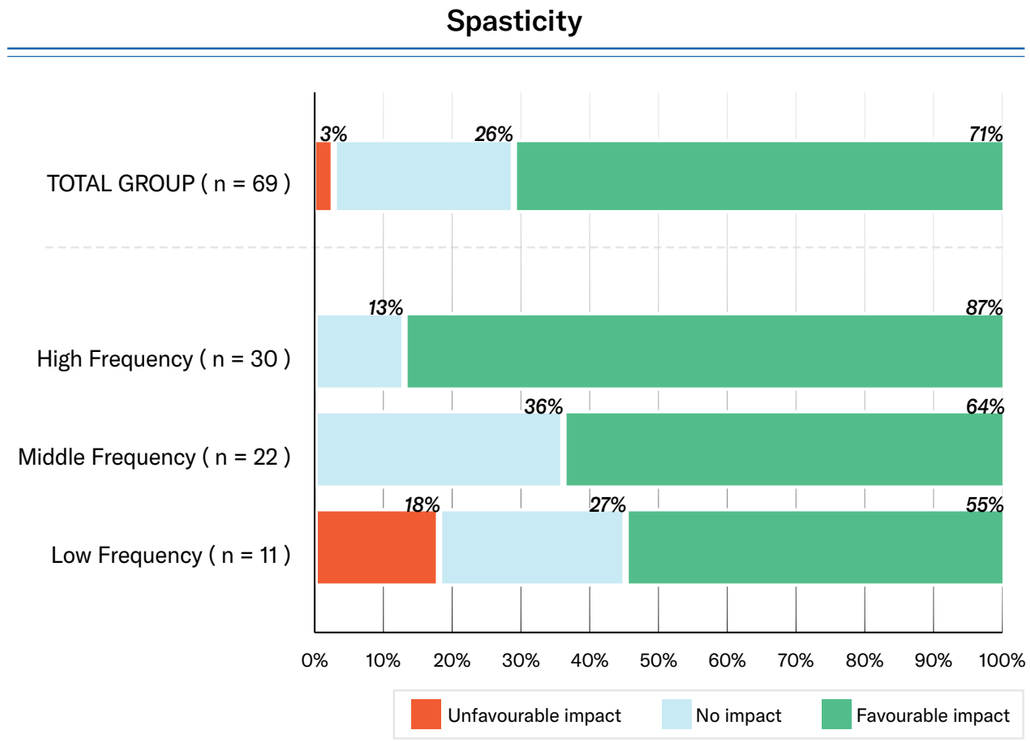


Figure 10. Impact of standing frequency on spasticity. *This figure shows how Permobil standing survey respondents with spasticity associated diagnoses rated the impact of power standing on their spasticity. The figure displays how all participants responded regardless off standing frequency and subsequently how participants responded within each frequency subgroup. The graph shows the percentage of participants who reported an unfavourable impact, no impact, or favourable impact in each frequency group respectively.*

> *I can maintain independence and healthy posture, weightbearing helps reduce spasms, and its functional.*
>
> - Female, 51-60

CONSIDERATIONS

For individuals with MS, when there was a high occurrence of self-reported spasms, there was more improvement with standing frame use[32]. Furthermore, the reductions in spasticity may only be temporary[30], and therefore, may need to be combined with other therapy. As will be discussed later in the activities section, compared to standing with other devices power standing does not require an individual to increase their number of transfers and therefore may allow more frequent standing, which in turn, may allow for more beneficial management of spasticity.

Mental health

BACKGROUND

One third of persons with SCI are known to have moderate to severe mental health disorders, when followed five years after leaving the hospital[43]. Mental health disorders among those with CP are prevalent[44]. Depressive disorders and symptoms are extremely common among individuals with MS, and contribute to overall disease burden and detract from quality of life[45].

Mental health concerns in individuals who use a mobility device are multifactorial; in addition to experienced physical impairments, other factors such as lower physical activity levels and unmet healthcare needs may also play a role[46].

> *Clean the top of my refrigerator. Danced with a friend. Hugged my brother without him bending over. I can see things from a normal angle as opposed to always looking in an upward angle. Strangely, I feel somewhat normal. I feel stronger mentally and physically. Although I have only had my chair for approximately 7 months, and the improvements have been small, I feel the more I work with it, the more improvements will occur. So, it has given me hope for a better life. One that is better, easier to accept, and participate in.*
>
> - Female, 61-70

> *My chair helps my physical and mental health as well as helping me function more independently.*
>
> - Male,31-50

SUMMARY STATEMENTS

There are indications that power standing may have a positive impact on mental health.

Several studies reported that the ability to stand in a PWC was associated with better mental health. This includes opportunities to stand at school, an important setting for the establishment and maintenance of positive social relationships and friendships which consequently may serve to promote mental health. At a time when mental health often declines, adolescent-reported scores improved when using the power standing wheelchair and reflected more positive mood, reduced hyperactivity and better peer relations[11]. When receiving a power standing wheelchair, most adolescents reported to feel happy or excited and enjoyed doing things without seeking help from others. Parents observed that standing increased confidence and improved self-esteem amongst adolescents with DMD. They observed their children as happier and more content, more mature, and self-confident. Parents also described fewer episodes of grumpiness, frustration, and anger. Additionally, being able to drive fast while standing may make adolescents feel extremely special[12]. In a qualitative study focusing on children with different diagnoses using a power standing wheelchair, parents noted increases in self-esteem and described the benefits of being able to stand face-to-face with others[8].

Self-consciousness, self-esteem, and happiness were all seen to be favourably impacted by the majority of Permobil standing survey participants (Figure 11). Respectively, 67%, 78%, and 84% of the participants rated the impact of standing as favourable. Furthermore, the qualitative analysis of the Permobil standing survey further supported that standing improves confidence by being able to look someone in the eye, which allows individuals to be heard and taken seriously.

> *When I stand, I feel like myself.*
>
> - Andy, 22 years old

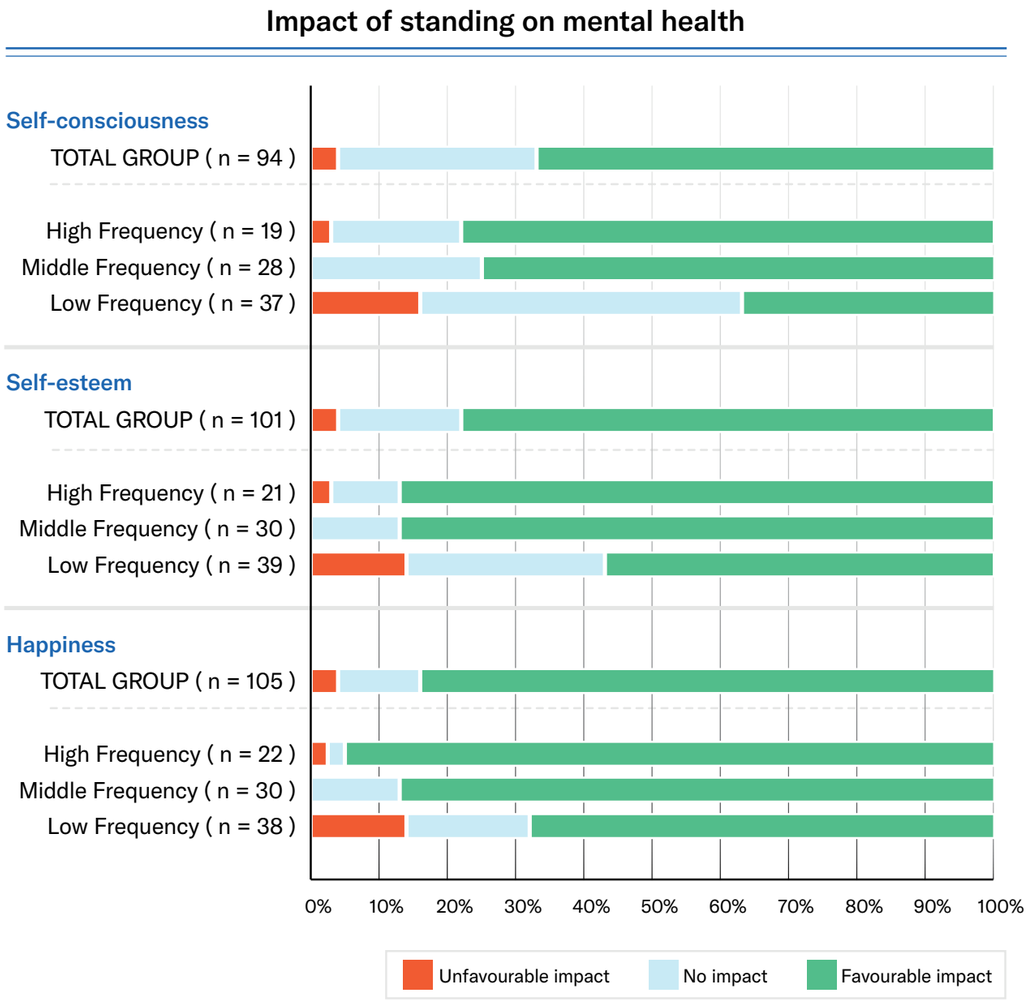


Figure 11. The Impact of standing frequency on mental health. *This figure displays the impact reported by survey respondents for three components related to mental health. Within each cluster, survey respondents are displayed the total group and subsequently as three subgroups depending on standing frequency. Each bar shows the percentage of participants who reported an unfavourable impact, no impact, or favourable impact in each frequency group.*

CONSIDERATIONS

Adolescents with DMD reported to be self-conscious of standing in front of others and did not always enjoy appearing different and being the center of attention. These negative emotions were confirmed by the parents. Teachers also noted that for some adolescents, initial anxiety, apprehensiveness, and embarrassment needed to be overcome. Whilst some adolescents were extremely self-conscious of standing, most reported that the capacity to stand independently was useful in social settings with family and their peers at school, who in return responded positively. Individuals who received the power standing wheelchair after they became non-ambulatory appeared to derive less benefit, possibly because they were more self-conscious and less comfortable standing after a period of no upright activity[12]. In another study one of the mentioned reasons for a boy with DMD to stop using the power standing wheelchair was not wanting to draw attention to himself when getting into standing[16].

Results from the Permobil standing survey indicate that the impact of power standing on self-consciousness seem to be influenced by the amount persons were standing (Figure 11). The participants who did not use their standing function frequently were the only subgroup that did not have a majority rating the impact of standing as favourable on self-consciousness. Within this group (n=19), only 37% perceived standing to have a positive effect, whereas 47% perceived no impact.

Pain

BACKGROUND

Pain was found to be the most common comorbidity amongst individuals using a mobility device, impacting 91% of individuals[23]. Pain management is a complex topic for people with and without a disability. For individuals with a disability where there is an impairment with how the body either receives or responds to pain, this management gets increasingly more challenging. Individuals with damage to their nervous system not only experience orthopedic pain from circumstances such as immobility or overuse, but also from neuropathic pain. Neuropathic pain can be described as burning, itching, or tingling, as well as hypersensitivity or sensing pain in response to something that would not result in pain for someone with an intact neurological system[47]. Both neuropathic and orthopedic pain can have a negative impact on an individual's quality of life, in addition to complexities and co-morbidities associated with pharmacological management[48].

SUMMARY STATEMENTS

There is conflicting evidence of the impact of power standing on pain.

Of the four trials that studied power standing wheelchairs and reported on pain, two reported on favourable effects of pain[11,14], and two reported unfavourable effects of pain[15,16].

Favourable effects of pain included no reports of pain or discomfort for children with CP, or even reduced pain levels after 6 months use of a power standing wheelchair in adults with SCI or MS[14]. Another trial which included adolescents with DMD reported that although participants reported to have pain, this was not associated with standing in the PWC[11]. Self-reports of the same adolescents indicated that power standing provides the opportunity to independently manage pain and comfort by standing[12]. The standing wheelchair provided opportunity for independent pain management while allowing fuller functioning and participation and could be considered an adjunct to pharmaceutical pain management methods. In one qualitative study, reduced pain levels were mentioned, but no further details were provided[8].

> *My pain level and physical function vary day to day; I utilize standing independently to find what feels comfortable.*
>
> - Danielle, 34 years old

> *Allows greater family participation, provides exercise, circulation, and comfort.*
>
> - Male, 71-80

Unfavourable effects of pain included having pain while standing in the PWC amongst adolescents with DMD. Pain locations included ankles, knees and calves, and pain was presented in 15-44% of the standing occasions[16]. In another trial among those with DMD, standing time within a session had to be reduced because of pain in the foot, anterior knee/shin related to pressure from support pads, and back pain. Others reported standing less often because of back pain and ankle pain. It was noted that physical discomfort which occurred during power standing did not last beyond the daily standing times[15].

From a total of 102 Permobil standing survey participants reporting to have pain and answering how power standing impacted their pain (Figure 12), 54% perceived standing to relieve pain, 35% reported on no impact and 11% perceived power standing to cause pain. When asked what type of pain was relieved, 61% stated orthopedic pain (joints, muscle, bones), 37% neurological (burning, tingling, phantom pain), and 3% did not know. The additional analysis on the impact of the amount of standing on this outcome showed that the proportionality of participants in low (n=22), middle (n=28), and high frequency (n=38) groups rating the impact on pain as favourable was 36%, 64%, and 66% respectively. The low frequency group had the largest proportion of participants who perceived standing to cause pain at 27%.

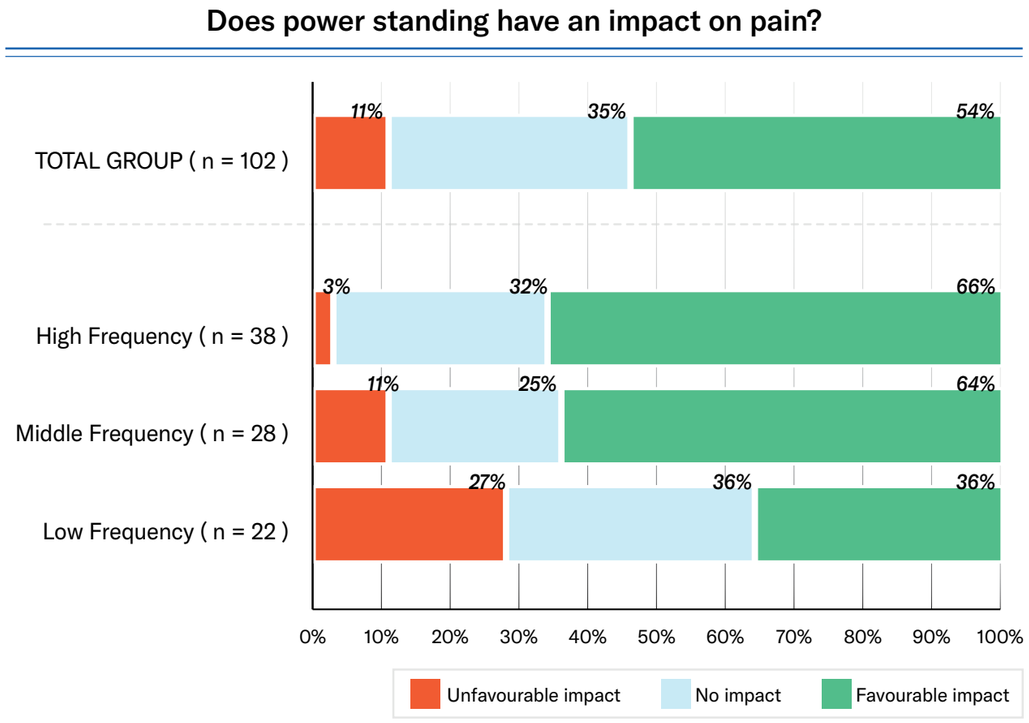


Figure 12. The Impact of standing frequency on pain. *This figure displays how Permobil standing survey participants responded to the question "does power standing have an impact on pain?". These results exclude participants who answered: "I do not have pain" (n=15). Participants were displayed as a total group and subsequently as subgroups depending on standing frequency. Each bar shows the proportion of participants in the subgroup who reported standing causing pain, no impact or pain relief.*

CONSIDERATIONS

It is important to monitor pain and comfort, particularly in the initial stages of standing and when children are growing[12]. Self-reports show that when first using a power standing wheelchair, some adolescents experienced foot discomfort. Others experience knee pain, but this could be solved with adjustments to knee pads and leg blocks[12]. A study among those with MS using a standing frame also reported that with continued standing, pain might ease[32].

Motor function, muscle strength, balance, sensation

BACKGROUND

Motor function is the ability to perform activities utilizing the neurological system. Related to motor function are other outcomes such as muscle strength, balance and sensation. Standing can be considered as a light physical activity for people with mobility impairments[3–6] and is, therefore, hypothesized to have an impact on motor function, muscle strength, balance and sensation.

SUMMARY STATEMENTS

There is little evidence of an impact of power standing on motor function, muscle strength, balance, and sensation.

None of the studies on power standing reported on motor function, muscle strength, balance and sensation. The evidence that is available on standing with other devices is inconclusive, and systematic reviews indicate that very few studies are available. Most studies included those who have had a recent stroke or have MS, and the majority are of low quality. In several studies, standing was not the only intervention, and it was, therefore, hard to interpret whether the effects found were due to standing[5,30].

Results from the Permobil Standing Survey (Figure 13) showed that 73% of participants (n=102) reported a favourable impact of power standing on muscle strength compared to 62% and 51% reporting a favourable impact on balance (n=65) and sensation (n=47) respectively. Furthermore, the qualitative analysis of the Permobil standing survey also found individuals reporting on improvements in muscle strength in their legs and core. In addition, several individuals reported that they no longer have a fear of falling while standing where either themselves or a caregiver could become injured.

> *I used a walker when I was young at school and then I moved to an [manual wheelchair with power assist] and then found the F5 VS because we noticed that I was getting weak and needed to stand.*
>
> - Male, 18-30

> *She is supported in her standing chair and there is no risk of falling causing harm to herself or support workers/parents.*
>
> - Female, 18-30

> *I use the standing function to varying degrees (angles) depending on the situation… constantly… throughout the day. A major benefit from using the standing function is that I no longer seriously have to worry about falling… from standing."*
>
> - Male, 51-60

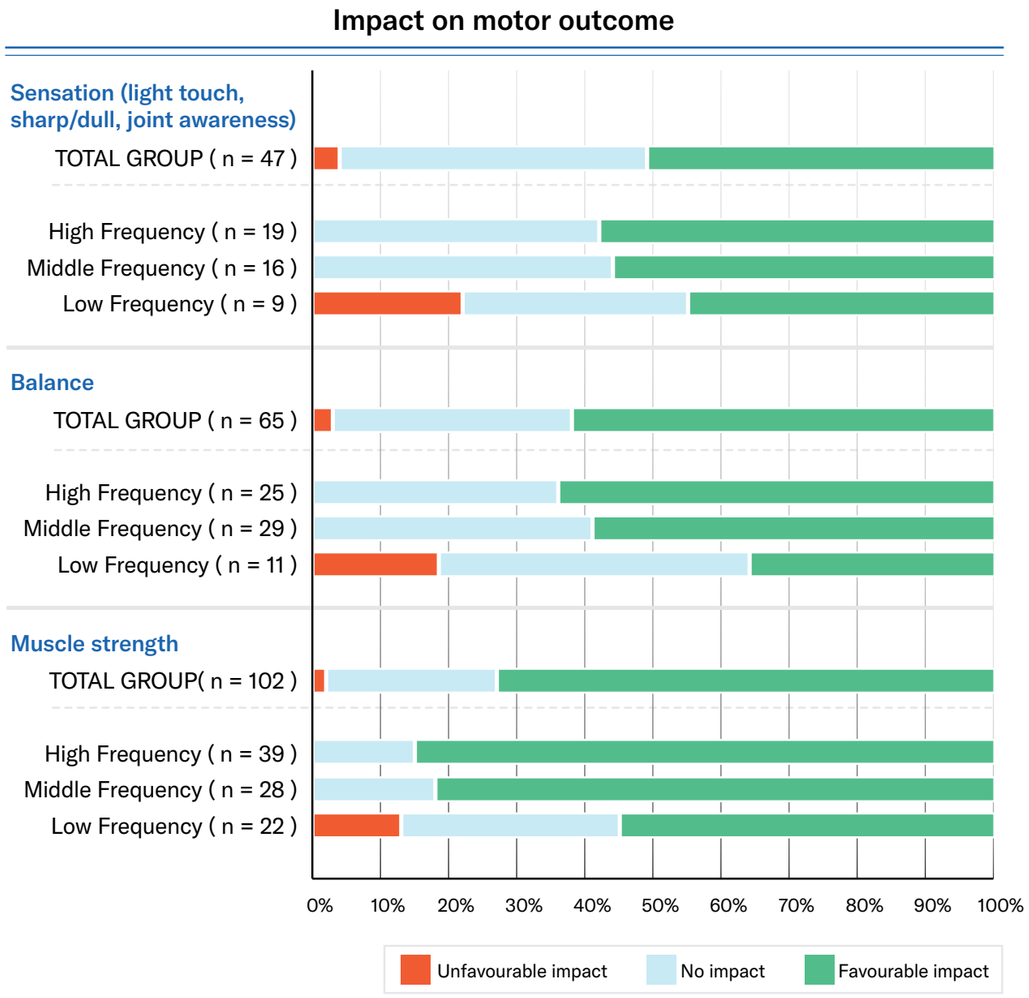


Figure 13. The Impact of standing frequency on motor outcomes. *This figure displays the impact reported by Permobil standing survey participants for three conditions related to motor outcomes. Muscle strength was rated by all survey participants. Balance and sensation were rated by those respondents with an associated diagnosis. Within each cluster, participants are displayed as a total group and subsequently as subgroups depending on standing frequency. Each bar shows the percentage of participants who reported an unfavourable impact, no impact, or favourable impact in each frequency group.*

CONSIDERATIONS

Comparable to effects of exercise on muscle strength, a certain amount of dosage and intensity is needed for standing to impact motor function, muscle strength, balance, and sensation. Longer standing times amongst those with MS have found to be related to greater improvements in motor function, which indicates that there may be a dose-response relation[49]. Similar results were seen in the Permobil Standing Survey (Figure 12) with a large proportion of people reporting to stand more frequently showing favourable impact of power standing on muscle strength, balance, and sensation. Decreased functional reach has long been a marker of having an increased risk to fall. It has been validated in a wide variety of patient populations and has been modified for individuals who use manual wheelchairs for mobility[50]. When functional reach even with an ambulation aid is limited either due to muscle weakness, coordination, paralysis, muscle imbalance, fatigue or even vision impairments, a person can become fearful that they will fall and either injure themselves or their caregivers. Across the globe, falls along with road injuries (such as motor vehicle accidents) are the leading cause of both SCI and Traumatic brain injury (TBI)[51]. As stated previously, several individuals self-reported that using their power standing wheelchair eased their fear of falling.

Cardiorespiratory function and edema

BACKGROUND

When injury occurs to the central nervous system, the cardiorespiratory system can become impaired as well. With loss of functional muscle and damage to the sympathetic nervous system, the system struggles to move fresh oxygenated blood from the heart and lungs to the body, as well as return the non-oxygenated blood waste back. As this process slows, the blood pressure will lower leading to difficulty with regulation such as orthostatic hypotension[52]. Orthostatic hypotension is when blood pressure suddenly drops when changing positions. Symptoms include dizziness, light-headedness, or blurred vision.

Airway volumes between standing, sitting and lying positions have been found to differ in non-disabled individuals, in that the inspiratory and expiratory volumes from the trachea, bronchi, and bronchioles increased in sitting and standing. Although not statistically significant, there was an increase in overall pulmonary function test in standing compared to supine[53]. The effect of body position on pulmonary function may, however, be dependent on the health condition of the individual[54]. Individuals who are in a prolonged seated position for their mobility can develop postural impairments which can result in respiratory capacity limitations. Because the same muscles are used for respiration and postural support, when these muscles become impaired due to a neuromuscular impairments or oxygen transport deficit, positioning for effective breathing can become a challenge[55].

Physical impairments, immobility, and dependent positioning can contribute to lower extremity edema. For individuals with a disability, when the venous system is unable to pump blood back to the heart and lungs, venous pooling occurs resulting in swelling, or edema. When edema is not managed, it can result in fatigue, pain, skin, and soft tissue compromise, as well as increasing risk of blood clots and infection.

SUMMARY STATEMENTS

There is little evidence of an impact of power standing on cardiorespiratory function and edema.

Very little is known about the effects of standing on cardio-respiratory function. It was sometimes reported by parents of adolescents with DMD that were using a power standing that their child showed easier breathing, however this was not further quantified[12]. In one qualitative study, respiratory and cardiovascular were mentioned amongst perceived health benefits but no further details were provided[8]. None of the other studies on power standing reported on these outcomes. Amongst the studies of standing in other devices, a few studies in adults reported on cardio-respiratory function[5]. Amongst those were survey studies reporting on improved circulation and decreased edema. However, all available evidence was weak.

Permobil standing survey results on the impact of power standing on cardio-respiratory function and edema is presented in Figure 14. Of the 55 participants with edema, 73% experienced a favourable impact of standing. For cardiovascular function (n=38), 79% rated the impact of standing on cardiovascular function as favourable. Within the group of participants with breathing function impairments (n=43) 74% perceived a favourable impact. For all of these outcomes, a smaller proportion of participants in the low frequency group reported on a favourable outcome but it must be noted that there was a low number of participants with cardiovascular or breathing related impairments.

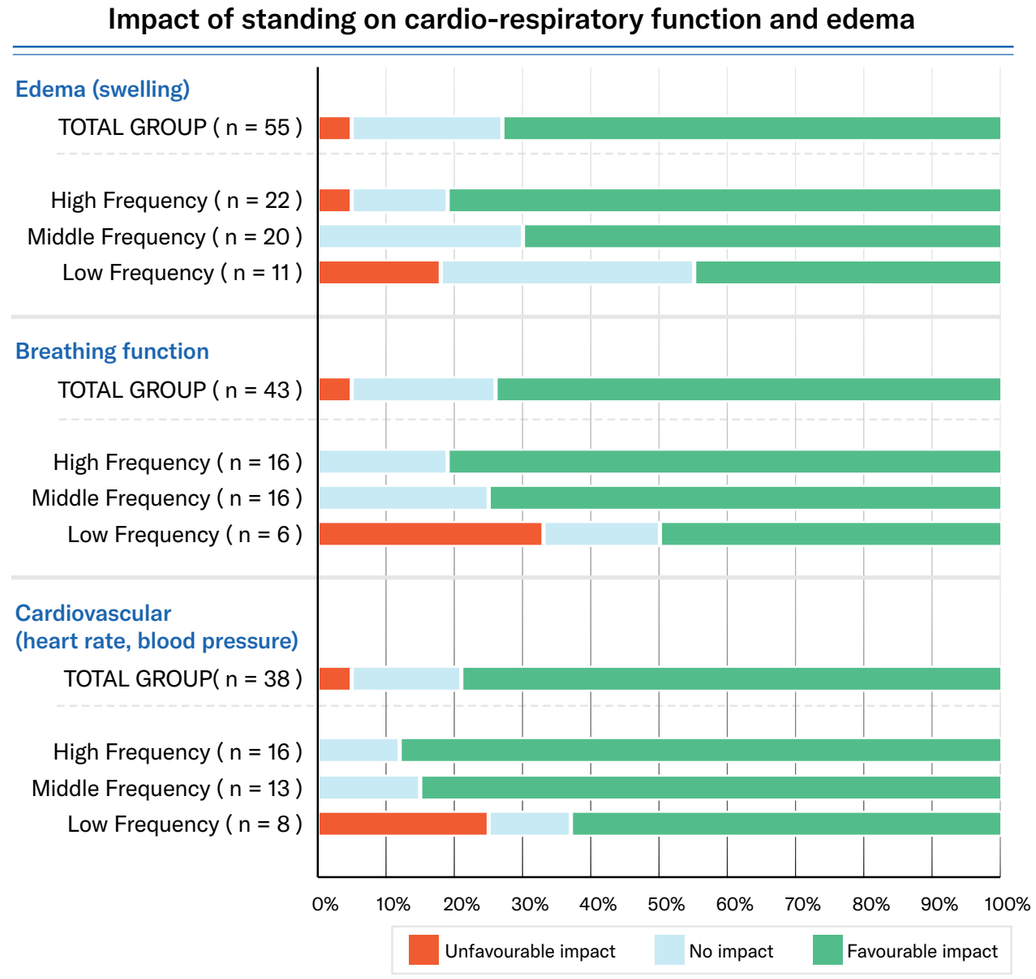


Figure 14. The Impact of standing frequency on cardio-respiratory function and edema. *This figure shows how Permobil survey respondents with cardiovascular, breathing function and edema associated diagnoses rated the impact of power standing on these cardio-respiratory functions and edema respectively. Within each cluster, survey respondents are displayed as three subgroups depending on standing frequency. Each bar shows the percentage of participants who reported an unfavourable impact, no impact, or favourable impact in each frequency group.*

> *My blood pressure has the tendency to lower more often in the standing frame than when I stand in the power chair.*
>
> - Male, 51-60

> *Promotes blood function, reduces edema. Promote bowel and bladder function. Passive stretching just by standing.*
>
> - Male, 31-50

CONSIDERATIONS

Orthostatic hypotension may occur when starting with standing and should therefore be carefully monitored[5]. To assist with this, it could be helpful to consider the programming an individual standing sequence on a power standing wheelchair. This provides the opportunity to transition into a standing position in a slow and controlled manner that may allow the cardiovascular system to accommodate the transition to upright. From clinical experience, some individuals have less orthostasis if they stand from a supine or laying down position and some benefit from a more immediate sit to stand pattern.

> *Being able to breathe easier when using my standing power wheelchair was unexpected.*
>
> - Danielle, 34 years old

Other: fatigue, blood sugar, postural changes, sexual health

BACKGROUND

There are multiple other impacts of standing that have been mentioned in the literature, by individuals that are standing or reported by clinicians, including fatigue, blood sugar, postural changes, and sexual health.

Fatigue has been defined as an overwhelming sense of tiredness, lack of energy and often a feeling of total exhaustion[56]. Persons with mobility impairments are at a greater risk to experience fatigue and this risk increases with age[57]. Fatigue is a multifactorial problem, but in persons with mobility impairments there are indications that part of it has a physical origin[58,59], and that being more physically active may be able to lower fatigue[60].

Impaired fasting glucose, insulin resistance, and diabetes mellitus have all been reported to be common amongst those that sit most of the day and in those with mobility impairments[61–63]. In non-disabled persons, substituting sitting or lying down with light physical activity has been found to have beneficial effects on glucose regulation[64,65].

When an individual is seated for a majority of their awake hours and has co-morbidities such as paralysis, weakness, muscular imbalance, amputation, and visual field impairments, seated posture can deviate from what is typically considered a midline and neutral posture. While this may be functional for some individuals, there is a risk that postural impairments, especially if there are changes in a baseline posture, can increase the risk for skin impairments, digestion and respiratory restrictions, pain and discomfort, and limited mobility[66].

Individuals with mobility impairments have been shown to be at increased risk for sexual dysfunction[67,68]. Physical activity interventions, such as aquatic exercise, have shown to have potential to improve sexual function including arousal, lubrication, orgasm, and sexual satisfaction in women with MS[69]. Furthermore, in individuals with SCI locomotor training showed a potential to include sexual desire[70]. It may therefore be hypothesized that standing could influence sexual function in those using a PWC.

SUMMARY STATEMENTS

There is little evidence of an impact of power standing on fatigue, blood sugar, postural changes, and sexual health.

None of the studies on power standing reported on these outcomes. The only exception was one clinical trial reporting on potential fatigue management. In this study amongst adolescents using a power standing wheelchair, most adolescents used the power standing wheelchair to adjust their position both for comfort and to manage fatigue. Furthermore, teachers of the participants reported that adolescents would manage fatigue and discomfort in the classroom by adjusting the wheelchair

to a reclining position in both standing and sitting so that they did not tire as quickly during the school day[12]. More research is needed.

As shown in Figure 15, participants in the Permobil standing survey largely perceived no impact of standing on sexual health (70%), whereas 26% did report on a favourable impact.

With regards to posture, Permobil standing survey results showed that power standing was perceived to have a favourable impact in a majority of participants, with 78% of all participants (n=103) reporting on a favourable impact. The additional analysis on whether the amount of standing impacted these results showed that the middle and high frequency subgroups had no participants perceiving an unfavourable impact on posture while the low frequency subgroup had 17% perceive an unfavourable impact. The qualitative results of the Permobil standing survey gave further insights into what types of postural impacts individuals experienced, which included overall better posture, the ability to maintain a healthy posture while in their wheelchair or to perform functional activities.

The Permobil standing survey further shows that power standing was perceived to have a favourable impact on fatigue by 53% of participants (n=95), whereas 40% reported on no impact and 7% on an unfavourable impact. Interestingly, the high frequency subgroup (n=37) had the largest proportion of participants who perceived a favourable impact (62%) but also had 11% who perceived an unfavourable impact. Meanwhile, the middle frequency subgroup (n=27) had no participants who perceived an unfavourable result. Qualitative results also included a participant reporting that they were not able to stand as much as they were recommended due to fatigue.

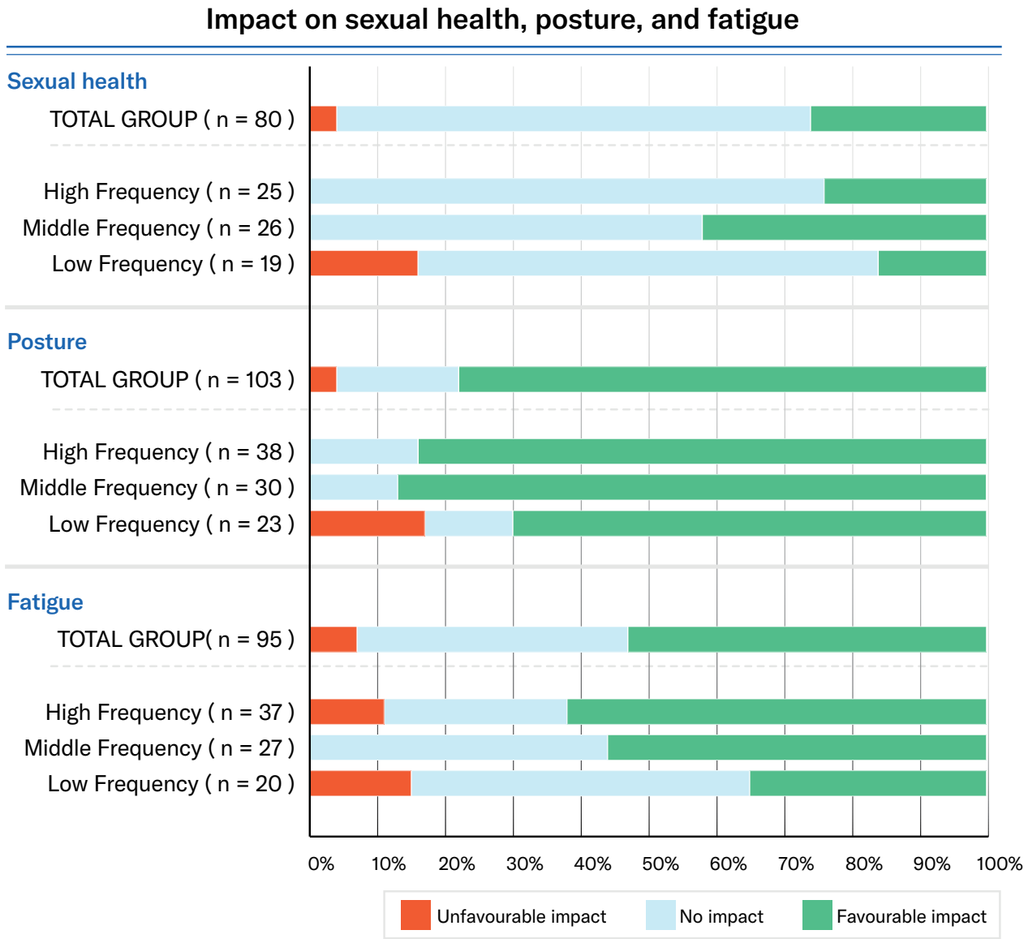


Figure 15. The Impact of standing frequency on sexual health, posture, and fatigue. *This figure shows how the Permobil standing survey participants rated the impact of power standing on these functions respectively. The figure displays how all participants responded regardless off standing frequency and subsequently how participants responded within each frequency subgroup.*

> *I access things in my classroom cupboards I have never been able to reach before. Also, In the hallways if it is crowded, I do a half stand allowing me to move at normal pace and see around me. Similarly, it has helped with posture, and I find I can more authentically reach things in any space I am in.*
>
> - Female, 31-50

CONSIDERATIONS

In those with newly acquired injuries, such as after a recent stroke, fatigue may be a barrier to participate in additional standing practice[71].

Activities

BACKGROUND

Activities include ADLs, personal and medical care, leisure, functional reach, and transfers in/out of the chair. Furthermore, it includes ways to communicate, i.e., visual orientation by line of sight and voice production. The benefits of increasing reach and improving visual orientation are comparable to those mentioned for seat elevation as for both standing and elevation it will change the position of the individual making it possible to be closer to higher placed objects and to visualize the items at the same height [72,73]. Furthermore, a reduced need for over-shoulder reaching may also contribute to less shoulder pain or injuries[74]. Aside from standing having a direct impact on the activities performed, there may also be indirect benefits. For example, when standing leads to a decrease in spasticity, this might lead to improvements in ADLs such as bathing[75].

> *Standing with the chair makes it easier to get undressed for bed or shower.*
>
> - Response from qualitative survey

> *As a voice actor, being able to stand in the recording booth has not only encouraged me to stand frequently throughout the day but perform better as well.*
>
> - Response from qualitative survey

The impact on activities can be extrapolated from knowledge which is not specific for individuals who use a wheelchair. For example, office workers are known to spend 60% of their time sitting, 28% standing, and 12% walking, with minimal differences in how the time is spread between time at the workplace, working days, and non-working days[76]. It was found that most of the day is spent sitting because it is a habit, which implies that the remaining time (40%) is organised into activities which need to be performed in an upright position or because the environment is built for standing. One could therefore hypothesize that power standing makes it easier to be a part of these kind of activities which require individuals to be in an upright position.

Most benefits to activities from power standing do not extend to standing with all other devices. Power standing increases the ability to independently move into and out of a standing position, complete tasks while standing, drive while standing and increases the ability to sustain a standing regimen[7]. Consequently, power standing may be easier to perform multiple times per day for shorter periods.

Images of Jason transitioning his power wheelchair from a seated position to standing to improve his line of sight to work on his vehicle.

In a study that provided power standing wheelchairs to four adults and three children with SCI, MS, and CP, device-measured data from wheelchairs (Permobil Connect data) was used to analyse how frequently participants were standing. This study showed a large variation in use. The average minutes of standing time per session ranged from four to 15 minutes. Power standing seemed to be mostly used for short periods of time, likely to be to perform activities[14]. These results are in line with the results from the Permobil survey showing a large variability in power standing use.

SUMMARY STATEMENTS

Power standing enhances independent ADL, personal/medical care, and leisure activities.

Power standing in children and adults with a variety of diagnoses has shown to lead to improvements in activities such as giving someone a hug, stirring a pot on the stove, turning on the water in the kitchen sink, working out, and cleaning the house. Individuals commented that driving in standing also allowed to assist with chores more easily and increased independence in several tasks[14]. Furthermore, amongst adolescents with DMD, personal care routines were generally faster and required less use of hoists and transfers when power standing. The most discussed personal care activity was using the standing function to pass urine. The standing function enabled adolescents to manage toileting independently for longer and passing urine in standing was easier and faster[11,12]. Another study amongst boys with DMD also mentioned that the main activity power standing was used for in boys that were non-ambulatory was independent toileting[16]. Other than toileting, activities performed while standing included classroom activities, sports, dance, playing outdoors, cooking and countertop activities[16]. Furthermore, power standing was used in physical education activities such as table tennis, archery and golf[12].

A qualitative study focusing on children with different diagnoses using a power standing wheelchair

also stressed that giving children the ability to stand when and where they desired increased children's independence in performing a variety of tasks, such as washing hands. Furthermore, it was also valued how standing and the ability to independently transition into standing allowed children to feel more involved in certain activities[8].

> *I can move and change my posture to access my environmental controls, which increases my independence.*
>
> - Agustin, 52 years old

> *I like to stand when I am cooking or baking with my mom. I usually do about 20 cookies or brownies or I do the mixing.*
>
> - John, 11 years old

Scott demonstrating how his choices at the grocery story increase when he uses his power standing wheelchair to go shopping.

Power standing increases functional reach.

The impact of standing on reach has been a consistent finding in multiple studies. Power standing in children and adults with a variety of diagnoses has shown to lead to improvements to be able to reach items on a shelf at home and reach for groceries on high shelves in the store[14]. In a study amongst boys with DMD, participants reported on increased access to higher height shelves, cabinets, and counters[15]. Furthermore, a qualitive study focusing on children with different diagnoses also mentioned the increased ability to reach things[8].

Images of Landon reaching his water from his power upright chair compared to getting a cup from the cabinet when in a standing position.

> *Reaching things on shelves or desks used to be a struggle. He could not even get a glass of water by himself, instead he had to always wait for someone to come and help.*
>
> - Landon's mom

> *It is possible to get my own glass of water because I can stand up and reach the sink and not be so low to the ground like previously with other chairs.*
>
> - Landon, age 15

Power standing facilitates communication.

Multiple studies have described the benefits of power standing to facilitate face-to-face communication with non-disabled individuals[12,13,15]. It was noted as a benefit in social settings such as with family and with peers at school. More specifically, power standing was mentioned as an advantage to be able to look at friends while talking, hear conversations, be able to see more clearly, and feel better able to cope in crowded situations. Parents also observed that the power standing function facilitated communication with others and that better hearing was facilitated[12,13].

> *"It is easier to socialize and get people's attention when looking at somebody face-to-face and not looking up at them. Unlike if you are sitting down and have to look up at the person, it just doesn't feel the same cause you are not looking right at them. It feels more natural when you are looking right at a person rather than looking up at them."*
>
> - Landon, age 15

> *"When we go out or are at a party, I like that he has the choice to be included, to stand up and join in the group conversation.*
>
> - Mom of John, Age 11

> *"Standing at the same line of site has increased my confidence in communication.*
>
> - Male, 31-50

Charlotte demonstrates how power standing helps her communicate when she arrives at a hotel, assisting to overcome environmental barriers.

Landon talking with his family while on a walk

Participants in the Permobil standing survey were asked to indicate which activities they typically performed while power standing. As shown in Figure 16 the most frequently selected option (16%) was pressure management and relief. Socializing (13%), training and exercise (13%), and household chores (11%) were also highly selected. Within the "other" category (6%) participants specified activities such as walking the dog, cooking, and sexual activities.

What type of activities or tasks do you typically do when standing in your power wheelchair? (n=117)

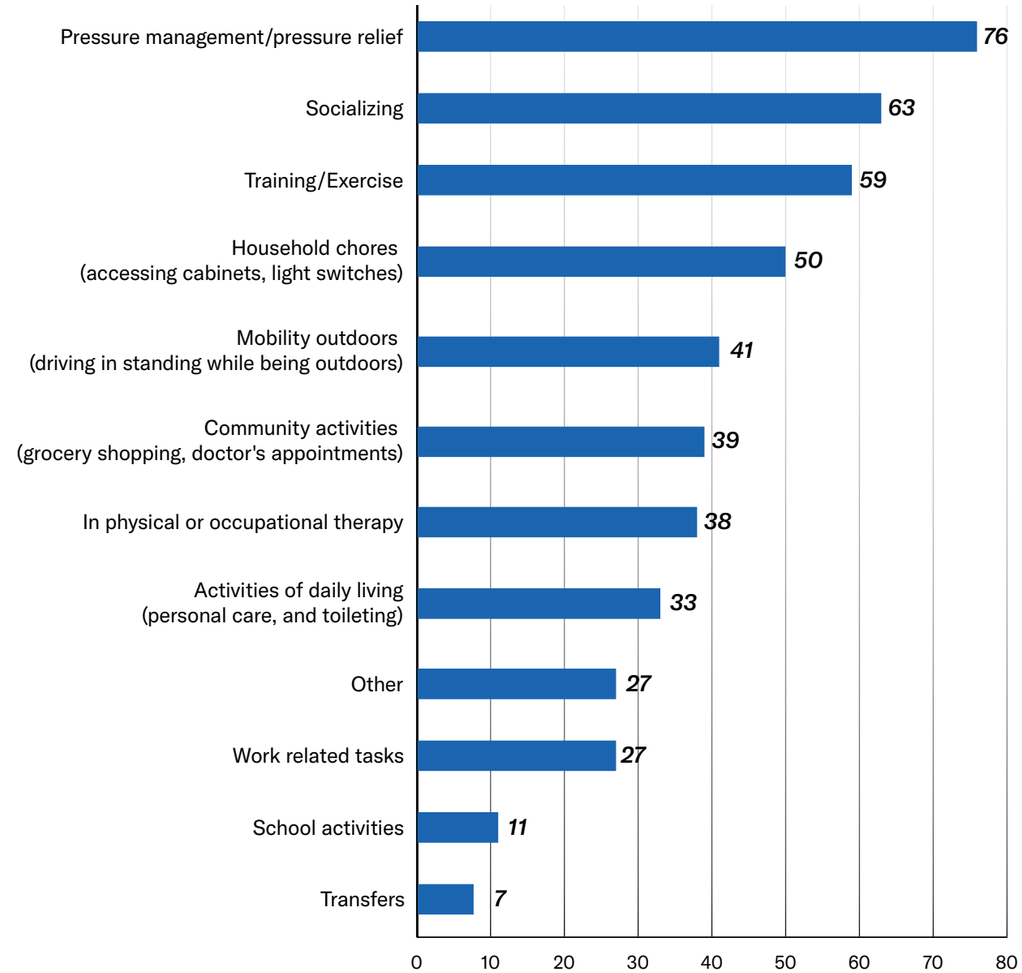


Figure 16. Common activities while power standing. *This figure shows the activities typically performed by Permobil standing survey participants while power standing. Participants were asked to select all options that applied.*

The qualitative analysis of the Permobil standing survey further explored the types of activities that individuals perform while in their power standing wheelchair. This included functional activities in the home and in the community. Activities completed in standing while at home included: household chores, gardening, preparing a meal, accessing a work bench in the garage and performing car repairs and maintenance. Outside of the home individuals reported that they can spend more time outdoors without being uncomfortable or tired. The participants reported that they use their chair for dancing, shipping, playing music, standing up at church, and accessing more public and portable restroom facilities.

CONSIDERATIONS

Anterior tilt may also be beneficial for reach and performance of ADLs[77]. When a PWC is anteriorly tilted, it changes the seat angle orientation in relation to the ground in the sagittal plane and angles the seat forward (definitions used: up to -45 degrees is anterior tilt, and standing is >-45 degrees of anterior tilt). As anterior tilt is activated, the seat-to-back angle can adjust to place the individual in a semi-standing position and the leg rests can articulate to a comfortable and functional position. However, the safety and/or positioning components needed for anterior tilt, in particular a chest strap, might cause some limitations to reach in the horizontal direction[77]. The same may apply when someone enters a standing position (> 45 degrees of anterior tilt) related to the chest support and other positioning and safety components.

Including new behaviours in everyday life seem to be easier when started early on, in childhood or in a sub-acute phase after injury, compared to changing behaviours in adulthood or in the chronic phase after injury[78–80]. This implies that individuals might benefit from having a power standing wheelchair as their first chair to achieve most functional benefits.

One area where transfers may be secondarily impacted is when there is an observed or reported change in an individual's quality of transfers or the amount a person is able to participate in a transfer activity after the use of a power standing wheelchair. One example was self-reported through an interview where a young man with CP used a power standing wheelchair for 6 months after his previous mobility equipment which included a power upright wheelchair and posterior rolling walker. Comparing his stability after the 6 months with a power stander, he was able to remain more upright and stable with his stand pivot transfer.

> *[H]e stands up more solid now when he does the transfers."*
>
> - Caregiver of Landon, 15 years old

> *Since using the standing wheelchair we don't have to use a hoist [lift] to transfer from his chair to his bed. He is able to support his weight better during transfers.*
>
> - Caregiver of John, 11 years old

The Permobil standing survey (Figure 17) found that while the majority (63%) of participants perceived a favourable impact of power standing on visual orientation (n=83), voice production showed a favourable impact in a smaller proportion of 35% (n=89). The results further show that for both visual orientation and voice production slightly more individuals that were standing frequently experienced a favourable effect on these outcomes.

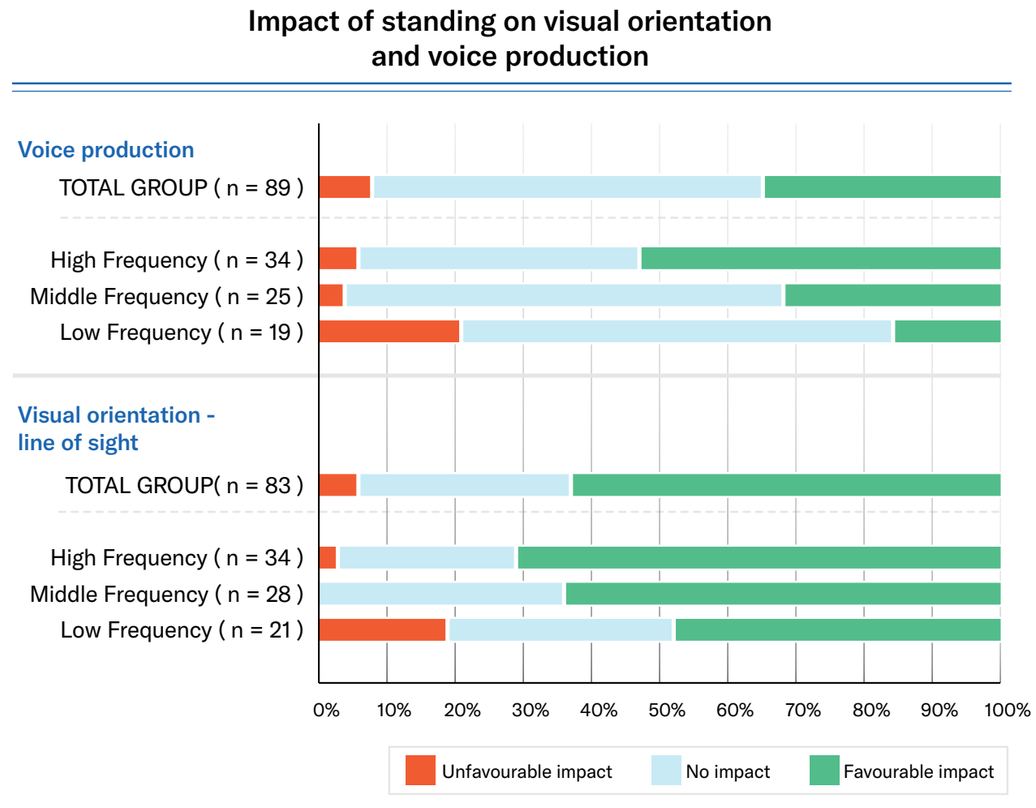


Figure 17. The Impact of standing frequency on visual orientation and voice production. *This figure shows how the Permobil standing survey participants rated the impact of power standing on these functions respectively. The figure displays how all participants responded and subsequently how participants responded within each frequency subgroup.*

Participation

BACKGROUND

Traditionally, the designs of living environments and workspaces are based on the assumption an individual is completing an activity from a standing position, e.g. kitchen bench/counters and cooking heights, bathroom sinks, storage cupboards, handles, and light switches. While there have been advancements in understanding universal design and aging in place, this is still not a widespread standard practice. As many individuals with a disability function from the seated height of a wheelchair, this consequently means that typical living and workspaces are inaccessible. Power standing may allow an individual to access a wider range of unmodified spaces[7]. Individuals using a power standing wheelchair may, therefore, be able to benefit in a variety of (unmodified) community settings to enhance their independence, improve vocational, and enable recreational activities. For example, the ability to access vending machines, high elevator buttons, coffee shop counters, stand up to access drawers and other necessities at work, enable certain jobs which need to be performed from a standing position, and enhance recreational activities, such as standing up with others for a ball game[7].

SUMMARY STATEMENTS

Power standing can be beneficial in social, work and educational settings.

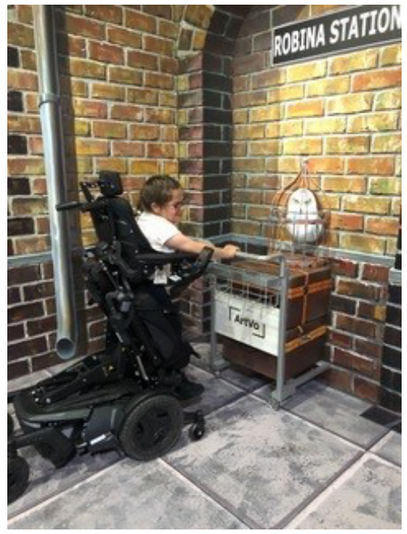
Multiple studies have shown that power standing can be beneficial to participation in multiple settings and environments.

A study amongst children (7-18 years, with CP or Spina Bifida (SB)) who received a power standing wheelchair and were evaluated three months after wheelchair delivery showed that all participants increased their satisfaction with meaningful self-identified participation outcomes in daily life. In-home participation goals included preparation of food and drinks, leisure pursuits, household chores and personal care routines. Out-of-home participation goals included going for walks with friends or family, shopping, and school activities. Younger participants valued outdoor play[13].

In a study amongst individuals with DMD, standing was beneficial for both teaching and ceremonial activities at school. Furthermore, power standing enabling faster toileting at school which also meant less time missed from class[12]. Another study in persons with DMD mentioned that power standing was used in both home and school environments and although it was not directly measured in this study, the potential to improve participation was mentioned[16].

A study on power standing in children and adults with a variety of diagnoses has shown to lead to improvements in participation in social and physical activities and performing tasks at work[14]. 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 mentioned as situations where children's participation could benefit from power standing[8].

Ivy, 11 years old, receiving an award from school,



Ivy, 11 years old, interacting with a museum exhibit

> *I can stand to march with the band during parades and dance with my friends. It gives me the opportunity to participate in the community in ways I never could before.*
>
> - Male, 18-30

> *When I was at a friend's barbeque birthday party at a park, I was able to help cook the steak and sausages. I got to stay with all the men while they were cooking.*
>
> - John, Age 11

> *Writing in board at school. Petting animals. Participating in more games at school.*
>
> - Male, 5-10 years

> *Freedom of independence in performing tasks and expands what I'll attempt to participate in.*
>
> - Male, 51-60

The Permobil standing survey (Figure 18) found that 58% of participants responded that they could perform or participate in an activity with their power standing wheelchair that they were unable to do without. Figure 19 shows that 13% reported that power standing had a favourable impact on participation at school and 20% on a favourable impact at work. It is worth noting that of the participants to answer this question, only seven participants had previously described themselves as students which can explain the relatively small proportion of participants reporting on a positive impact at school. Out of the seven, only one reported that power standing had no impact. The participants noticing an impact at school selected participation in class discussion (29%) and school-based activities (29%) as two of the most common impacts resulting from their power standing wheelchair. At work, increased overall opportunity for employment had the largest impact (38%).

Furthermore, the Permobil standing survey summarized tasks that individuals were able to perform while at work, which included writing on a smart board as a teacher, standing while completing voice acting work and any task requiring reaching overhead. The possibility of standing while at work also allowed individuals to stand more frequently. One unique comment related to life's unique events was when a participant reported they were able to be face to face with their partner when getting married.

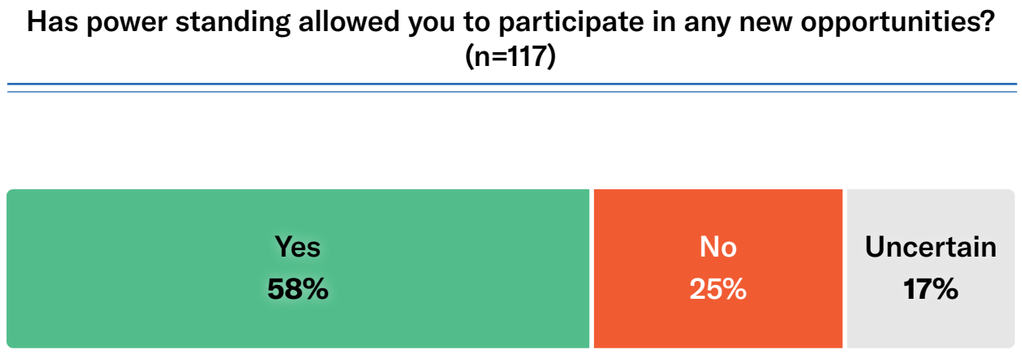


Figure 18. Impact of standing on participation. *Permobil standing survey participants were asked the question "Has the standing functionality with your power wheelchair given you the opportunity to perform an activity or to participate in an activity that you were not able to do before you had power standing wheelchair?".*

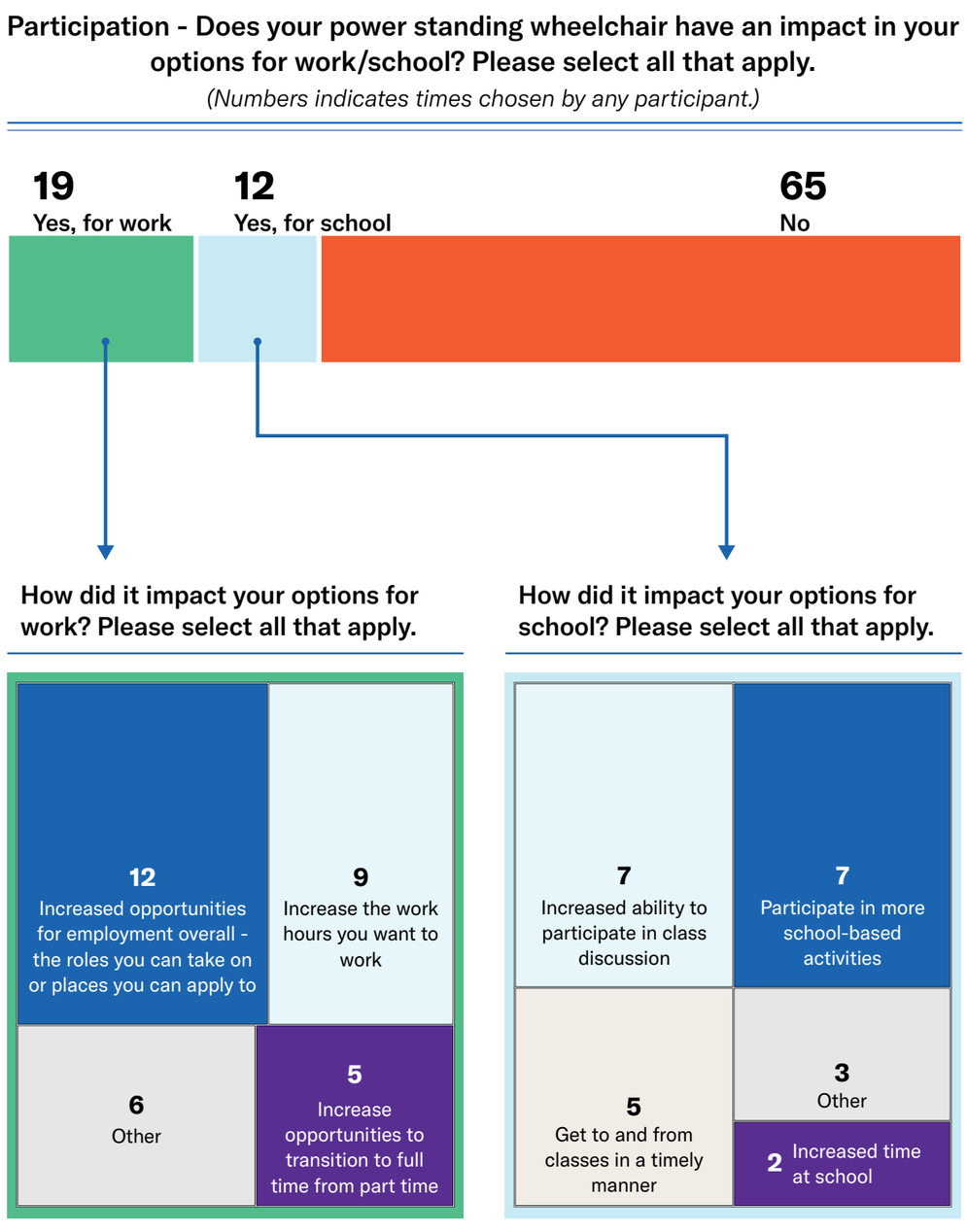


Figure 19. Impact of standing on school and work participation*. Permobil standing survey participants were asked a series of questions concerning impact of their power standing wheelchair on work and school. The original questions and answers were kept verbatim except for the option marked with an asterisk. This was shortened, the original reading "Increased ability to participate in class discussion". Please note that the n value is not representative of the number of participants answering each question as multiple options could be chosen by each participant.*

Furthermore, results on a question in the Permobil standing survey with regards to the impact of power standing on participation in enjoyable activities (Figure 20) found that 42% of participants reported an increase in enjoyable activities, and 32% somewhat increased their participation in enjoyable activities. Part (b) of Figure 20 showed that these activities largely consist of socializing (28%), family activities (21%), and leisure (19%).

(a) Has the use of the standing power wheelchair increased your participation in enjoyable activities? (n=117)

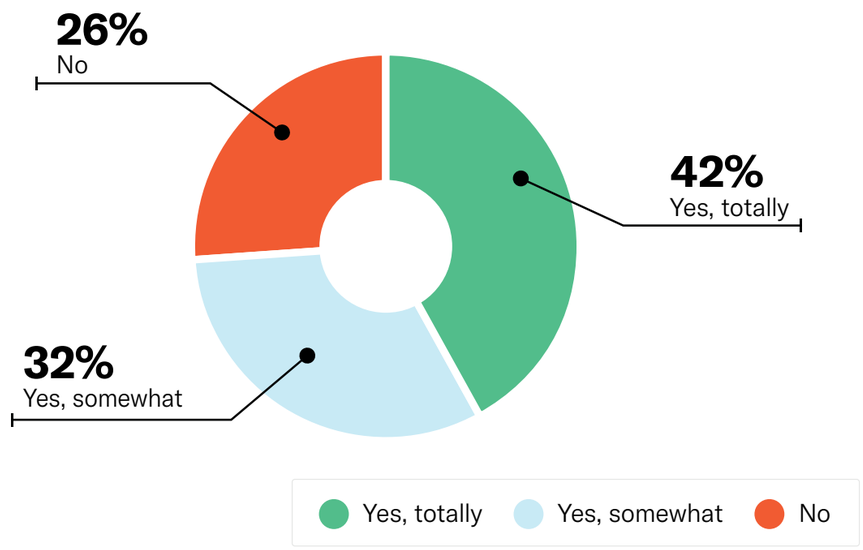


Figure 20. Part (a) Impact of standing on participation in enjoyable activities. *This figure shows how Permobil standing survey participants rated their increase in enjoyable activities due to their power standing wheelchair.*

(b) What type of activities can you enjoy more with the standing function on your wheelchair? Select all that apply. (n=117)

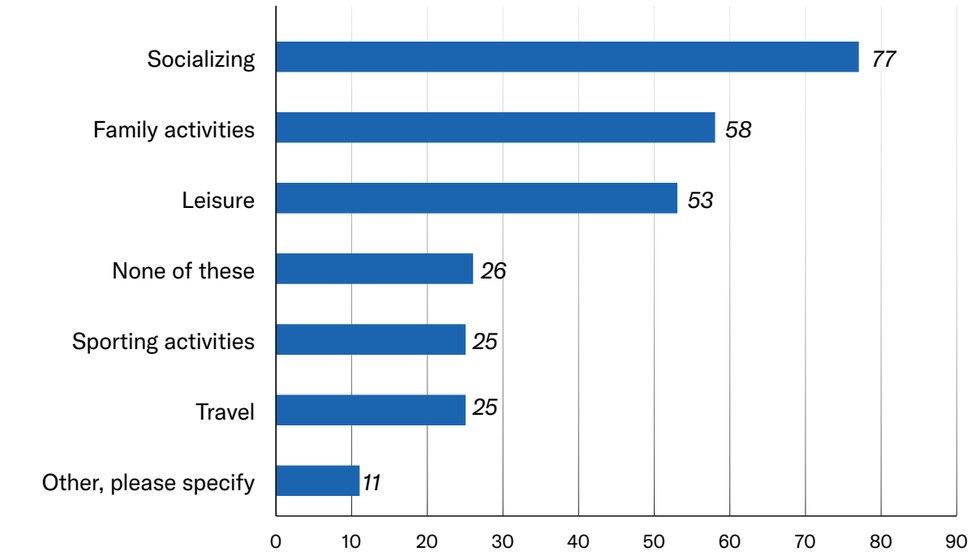


Figure 20. Part (b) Activities enjoyed with power standing. *This figure shows the activities most enjoyed by survey participants due to their standing wheelchair.*

CONSIDERATIONS

Individuals who use wheelchairs typically require home modifications which can be accompanied by high costs[81]. In considering a power standing wheelchair and its costs, it may be worth considering the long-term health economics (or economic impact) of a power standing wheelchair compared to home modifications.

Quality of life and independence

BACKGROUND

Requiring a wheelchair for mobility can come with its challenges. Physical environments need to be accessible, the community culture needs to be understanding of disability, and people who use wheelchairs for mobility still do not have full inclusion when it comes to activity participation[82,83]. These limiting factors can have a negative impact on quality of life and independence, and the solutions to overcome these challenges may not be quick or simple. Quality of life and independence may be favourably impacted by an increased understanding of the individual's needs, values and goals when providing mobility solutions. The impact of standing on quality of life is often overlooked as part of funding guidelines.

SUMMARY STATEMENTS

There is limited evidence for the impact of power standing on quality of life.

Only one study on power standing wheelchairs followed up on the impact of power standing on quality of life. In this study amongst children and adults with a variety of diagnoses, quality of life outcomes showed varied results both within and between persons, and no overall conclusions could be drawn[14].

The Permobil standing survey (Figure 21) showed that out of 107 participants, 80% perceived their quality of life to be higher with power standing compared to without. No great impact was reported by 16% and 4% reported that quality of life was lower.

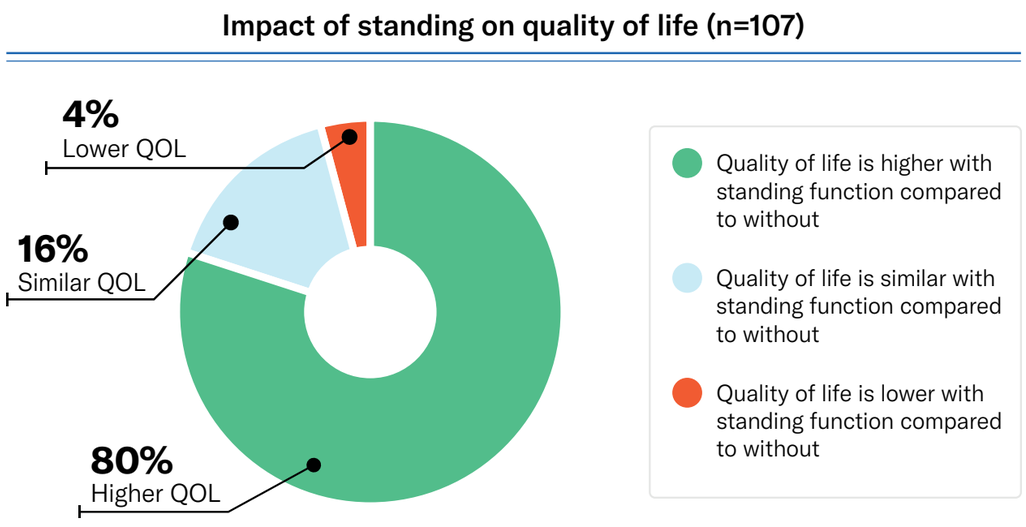


Figure 21. Impact of standing on quality of life. *This figure shows how Permobil standing survey participants responded to the question "Compared to having a power wheelchair without standing function, does the standing function on your wheelchair impact your quality of life?". The legend shows the verbatim selections from this multiple choice question.*

Power standing may have a positive impact on independence.

Results from a study amongst power standing in adolescents with DMD showed that both quantitative and qualitative findings supported a higher level of independence[11,12]. A PWC allowed continuing independence for daily tasks or components of daily tasks, including providing the individual with control over the decision of when to stand[12]. Power standing enabled more autonomous participation in physical, social, and educational activities. In particular, being able to do things without having to ask for assistance in all everyday tasks, of which cooking is one example. Parents also noted a decreased demand for their care, and teachers more time to focus on teaching. Independence in personal care was noted using the standing function when toileting. Other personal care routines were generally faster and required less use of hoists and transfers[12].

Two studies on power standing in individuals with DMD showed that participants reported a host of new functional abilities associated with power standing, which enhanced independence[15,16].

When asked about the impact of power standing on independence (Figure 22), Permobil standing survey participants (n=105) primarily responded that they are more independent with power standing than without (70%). Only 7% responded that they were less independent with power standing compared to without while 23% perceived no change.

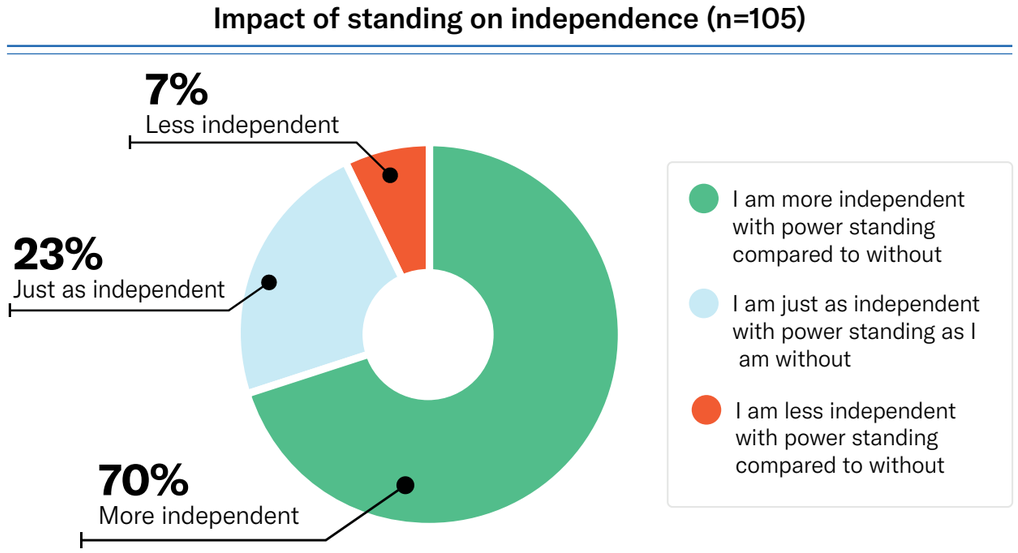


Figure 22. The impact of standing on independence. *This figure shows how Permobil survey participants responded to the question "Does the standing function on your wheelchair impact your independence?"*

Image of Molly Kate, playing basketball with her father

> *When I was standing [i]t made me feel good as I did not need help with the microphone or anything. It made me have a purpose and not feel like a little dot!*
>
> - Ivy, 11, Student, when doing a speech for her 8th grade class

> *The big thing is that he has a choice to be more independent and increase his social abilities. Because without it, being restricted to a regular seated position, it takes his choice away. So the standing feature gives him that choice back. That's the biggest benefit for me*
>
> - Mom of John, age 11

> *The key difference between a standing frame and the power standing function is that I can use the power standing function any time during the day without use of any further help from caregivers. I could use a standing function without having to be use a lift to get me in the standing frame.*
>
> - Male, 71-50 years

> *The standing frame difficult to transfer me into and out of. Also, it took up a lot of space and I was stuck in one place and in one position once I was in it.*
>
> - Male, 18-30

> *I got my F5 in March of 2020… just 4 hours before my state, WV, went into lockdown, 8 pm. My Attendant immediately stop working for me. So, until July of 2021, I was performing 99% of his duties myself. That literally would not have been possible, without the standing function. Also, my spasticity wasn't as bad… over time. as well as my leg cramps.*
>
> - Male, 51-60

CONSIDERATIONS

Power standing leads to more benefits compared to standing with other non-powered standing devices (such as stander) because of fewer limitations in daily use.

Compared to standing with other devices, standing with a PWC may be more independent and therefore might lead to more benefits on activities and participation compared to other standing devices because of less restrictions in daily use[8,12].

While a power standing wheelchair provides the individual with control over the decision of when to stand, the acceptance and utility of other standing devices can be limited by the burden of transfers into the separate standing device[12]. For caregivers, power standing reduced the need for transfers that can be particularly difficult when in confined spaces in the community. Thus, an additional benefit of the standing wheelchair includes possible protection of caregiver health and safety. In agreement with this study, another study noted how power standing can eliminate 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[8]. The same study also stressed that eliminating the need to transfer to be able to stand also benefits caregivers. It was stressed by parents that transferring children to and from a separate stander became increasingly difficult as their children grew, which resulted in the children standing less frequently[8].

Using a standing frame in the educational setting can be complex, including priorities regarding therapy versus education, young people's autonomy, working within logistical boundaries and the competence and confidence of classroom staff[84]. One barrier for frequent standing with a frame is that a child has a standing frame at nursery/ school, but not at home. Another study stressed

the importance for children to integrate the standing in a meaningful activity, otherwise it would be perceived as too boring[85]. Integrating shorter periods of standing might be easier in a power wheelchair compared to standing with another device.

Of the Permobil survey respondents, the majority (71%) had only experienced power standing while 15% reported experience with a standing frame and 4% with a standing table. Those who had experience with alternative standing devices conveyed a preference for power standing due to increased independence, convenience, and mobility. The decreased risk of falls and lack of transfers was also noted.

> *The key difference between my chair and my crutches is that standing in my chair maintains body mechanics and is functional (I am a teacher I can write on the white board; I can carry out chemistry demos, I am not concerned about falling).*
>
> -Female, 31-50

> *... My standing wheelchair allows me to enter a standing position without having to transfer. It also allows me to choose how straight the chair goes, meaning I can work up to the stretch of standing gradually.*
>
> - Female, 11-17

> *My standing wheelchair is more convenient because I don't have to transfer to stand, which results in more standing.*
>
> - Male 18-30 years

> *I have ALS and standing is important to my health and reduces the load on my caregiver.*
>
> - Male, 51-60

Standing training in a walker

Standing in Permobil F5 Corpus VS

Environmental and personal factors

Factors that have come up in the different sources that were used in this white paper are described below.

Age

Of the five clinical trials on power standing that were included (Appendix A), only one study included adult participants[14]. However, the results from the Permobil survey included 129 adults and 8 children, and therefore can serve as support to confirm the findings in the adult population. Furthermore, for the impact on body functions and structures there is a body of evidence that support the summary statements from standing with other devices[5,20]. With regards to activities, participation, independence, and quality of life, there is no reason to believe that the extend of the impact will be different for children and adults, however, it is likely to impact participation in different type of activities performed[14].

> *There are really no words to explain the feeling of being able to stand up again up after so long. You really learn to live with what you have but you really take standing for granted after an extended period of time.*
>
> - Male 31-50

Cognition

Cognition is an important component to consider with regards to the safe use of power seat functions including standing. In a consensus amongst experts with regards to power standing in individuals with DMD it was agreed that the child must be able to learn how to manoeuvre the power standing wheelchair safely, and the child must be able to communicate pain and discomfort. It was also agreed that the child must be able to consent using the power standing wheelchair or show enjoyment and should not have excess fear and anxiety while standing[18]. Related to the benefits that standing may have for individuals with cognitive impairments, there is literature to show that supportive standing can provide early mobilization following an acquired brain injury to facilitate alertness and arousal levels, especially for individuals with severe disorders of consciousness[86].

Body weight

All power standing wheelchairs have weight capacity limitations, which can be a consideration that needs to be made for those with a higher body weight.

Socioeconomic factors

The funding process and insurance issues are frequently mentioned as barriers to obtain a power standing wheelchair[8,9]. The requirements to qualify for a power standing wheelchair as well as

the provision method and potential out of pocket costs will vary by region, province, state, and governmental policies. In addition, topics related to coverage of power standing equipment may create opportunities to challenge current policies and create new standards of care.

> *It is taken for granted and not "prescribed" by medical specialists but rather seems to be an after thought when progression has damaged body systems. Stand and MOVE early at start and during progression of paralysis. PRESCRIBE standing!*
>
> - Male, 51-60

> *Standing is the best part of the chair it should be standard feature.*
>
> - Male, 51-60

Health economic evaluations of power standing wheelchairs are not available. One can, however, speculate about potential cost savings with the use of a power standing wheelchair. First, by using a power standing wheelchair less caregiver assistance may be needed. Another consideration is that the independent standing may lead to more frequent redistribution of the pressure which may decrease the risk of pressure injuries and associated health costs. Furthermore, power standing may also lead to more active participation in the community or workplace[18]. Lastly, as mentioned previously, with a power standing wheelchair less adaptations in the house may be needed[81].

Home environment / dimensions of device

The size of the wheelchair base was a barrier to carrying out regular everyday activities, e.g. resulting in limited access to a small kitchen. This was particularly noted by adults, who had adapted their homes, ADLs and habits to accommodate the dimensions of their previous wheelchairs[14]. In another study discussing power standing wheelchairs for children, the size was also mentioned as a barrier. The base of a power standing wheelchair was frequently reported as being larger than the base of a typical pediatric PWC, making transportation and environmental access difficult and increasing the amount of practice needed to achieve driving proficiency[8].

Based on the qualitative feedback from the Permobil standing survey, having an integrated standing function in the power wheelchair means less equipment in the home and to bring along when traveling.

Stigma

When society projects negative assumptions and beliefs towards the behaviour or personal attributes of an individual, the concept of stigma or stigmatization is created and perpetuated. For an individual living with a disability, this can result in marginalization, being discredited, having a lower status in society as well as unwarranted stereotypes, misconceptions, and labels. Stigma can be internalized where a person takes on and agrees with some of the stereotypes placed upon them; however, the most prevalent type of stigma is from external sources creating the misconceptions surrounding an individual's disability[87].

There are layers to stigma, but as an example for a person with a SCI, stigma can influence by how obvious their limitations or impairments are, how much assistance is needed, and in the case of mobility equipment, the use of a PWC carries it's own perceptions[87]. One study reported that it was observed that power standing positively influenced how other people perceive a child using a wheelchair[8].

> *In standing you can get a real hug; you can look over a crowd and you feel like a human being.*
>
> - Female, 31-50

> *I blend in with the church choir when I'm standing in my chair and no one thinks of me as different. before I was put on a regular seating chair on the side from everyone else which made me stand out a lot.*
>
> - Female, 31-50

> *I'm just able to live more of a normal life that I could before.*
>
> - Male, 31-50

Appendix A. Characteristics of power wheelchair research publications

Study: Clinical trials	Design	Participants	Power standing	ICF category	Measurements	Outcomes
Bayley et al. 2020[11] (quantitative results) **Vorster et al. 2020[12] (qualitative results)**	Stepped wedge design	14 children with DMD (9-16 yrs) 12 of 14 participated, and their parents and teachers	6-18 weeks Standing Recommendation: 60 minutes/day	• Body functions and structures: Pressure redistribution, bladder/ bowel/ digestive, ROM/muscle length, mental health, pain, Respiratory function, fatigue • Activities: ADL/care/leisure, communication • Participation • Independence	• ROM/muscle length with a video assessment. Pain via survey to adolescents and mental health via survey to adolescents and parents. • Semi-structured interviews on pressure redistribution, bladder/bowel/digestive function, mental health, pain, breathing, fatigue, ADL/ care/leisure, communication, participation, and independence.	• Power standing was not related to changes in ROM or muscle or joint pain, but it did lead to advantages in mental health. • "Capacity to be able" was defined as a central theme. Positive impact and considerations with regards to independence, health, comfort, and community belonging and involvement.
Field et al. 2022[13]	Interrupted time-series	6 children with CP or SB (7-18 yrs)	3 months Standing Recommendation: not reported	• Activities: Communication • Participation: Self-identified task	Wheelchair outcome measure (WhOM) and accelerometer on wheelchair to measure distance and speed (amount of standing not reported)	All participants increased overall satisfaction with meaningful self-identified participation outcomes in daily life after using a power standing wheelchair.
Gohlke & Kenyon 2022[14]	Case-series	5 adults (24-74 yrs) and 3 children (8-17 yrs) with SCI, MS, or CP	4 participants for 12 months, 3 for 6 months and 1 for 2 months Standing Recommendation: at least 5x/week for 30-60 min	• Body functions and structures: Bladder/bowel/digestive, ROM/muscle length, pain • Activities: ADL, care, leisure, functional reach • Participation • Quality of life • Environmental and personal factors	• Constipation quality of life survey, Lower extremity ROM measured as joint mobility in degrees (LE PROM) • Activities and participation with Canadian Occupational Performance Measure (COPM), and quality of life including pain/discomfort with EQ-5D survey • Semi-structured interviews • Device-measured data on amount of standing	• 3 of 4 participants with constipation showed improvements, and almost all participants showed increased ROM • Improvements in activities and participation were found. • Quality of life showed varied results
Townsend et al. 2016[15]	Single-subject design	4 children with DMD (12-15 yrs)	6-12 months Standing Recommendation: 5 to 7 days per week, with aim of 5 to 7.5 hrs/week	• Body functions and structures: ROM/muscle length, bone health, pain • Activities: Functional reach, communication • Independence	• Lower extremity muscle length with goniometry, BMD with Dual-energy x-ray (DXA) • Self-reported outcomes for pain, activities, and independence	• Improved hip flexor muscle length in 3 out of 4 participants, improved knee flexor length in 2 out of 4, and stable ankle length in all 4 • Decrease in lumbar BMD in 1 participant whose lost ability to functionally ambulate. • In 3 out of 4 participants BMD stayed stable from baseline to 12 month follow-up
Young et al. 2021[16]	Descriptive study	7 Children with DMD (11-17 yrs)	24 months Standing Recommendation: not reported	• Body functions and structures: Pain • Activities: ADL / care/ leisure • Participation • Independence	Survey with reports of pain, reasons for using standing, activities in which standing was used, social environments in which standing was used, and other perceived impact	• 3 participants reported no pain and 4 reported pain during standing • Toileting was the most common activity reported, with many other activities listed as well as environments in which standing was used

Study: Other original research	Design	Participants	ICF category	Measurements	Outcomes
Kenyon et al. 2021[8]	Qualitative: Stakeholder perspective	8 children (6-18 yrs) using a power standing wheelchair; 12 parents, 12 rehabilitation professionals and 3 professionals from manufacturers	• Body functions and structures: Pressure redistribution, bladder/ bowel/digestive, ROM/muscle length, bone health, mental health, pain, cardio-respiratory • Activities: ADL /care/ leisure, functional reach • Participation • Environmental and personal factors	Face-to-face interviews	• Power standing allows children to stand whenever and wherever they wanted thereby increasing participation • Power standing was perceived to be more than weight-bearing with multiple physical and psychological benefits reported • Factors influencing the procurement and use of a power standing wheelchair identified
LaBerge et al. 2021[17]	Retrospective medical chart review	13 power standing wheelchair users (mean age 53 yrs)	Body functions and structures: bladder	Reported urinary tract infections	23% had at least one urinary tract infection in the year prior to device evaluation, and 8% in the year after
Schofield et al. 2020[18]	Delphi expert consensus	9 persons with DMD using a power standing wheelchairs and 38 clinicians	Environmental and personal factors	Consensus on prescription for power standing wheelchair for those with DMD	• Before trial of power standing wheelchair it is necessary that there is tolerance and comfort in standing for at least 10 min, ankle contractures less than 10 degrees and motivation to stand • For continued use of power standing wheelchair; family, therapist and service support considered critical
Sprigle et al. 2010[6]	Experimental lab-study	10 adults with SCI and 6 non-disabled	Body functions and structures: pressure redistribution	Load measured with pressure maps on seat and back support during sit, tilt, recline and stand	• Standing and recline reduced load on the seat to 40% of load, and tilt reduced load to 55% of maximum • Standing was the only configuration that decreased loads off the seat and back support at the same time
Yang et al. 2014[19]	Experimental lab-study	24 adults with SCI	Body functions and structures: pressure redistribution	Shear displacement between body and back support/ seat and force on the lower limb joints during sit-stand-sit transitions in a PWC (without anti-shear mechanism)	• Shear displacement was 9 cm between user's body and backrest/seat surfaces • During standing up the user's back slid down and the thigh was displaced rearward but moved in opposite directions when wheelchair sat back down • Forces on knee restraints could reach 24% of body weight

Appendix B. Permobil standing survey results

The Permobil standing survey results were primarily viewed as three subgroups based on frequency of wheelchair use presented in Figure 3. These subgroups were defined on the combination of two questions, and the individual results of these questions are described in Figure 23.

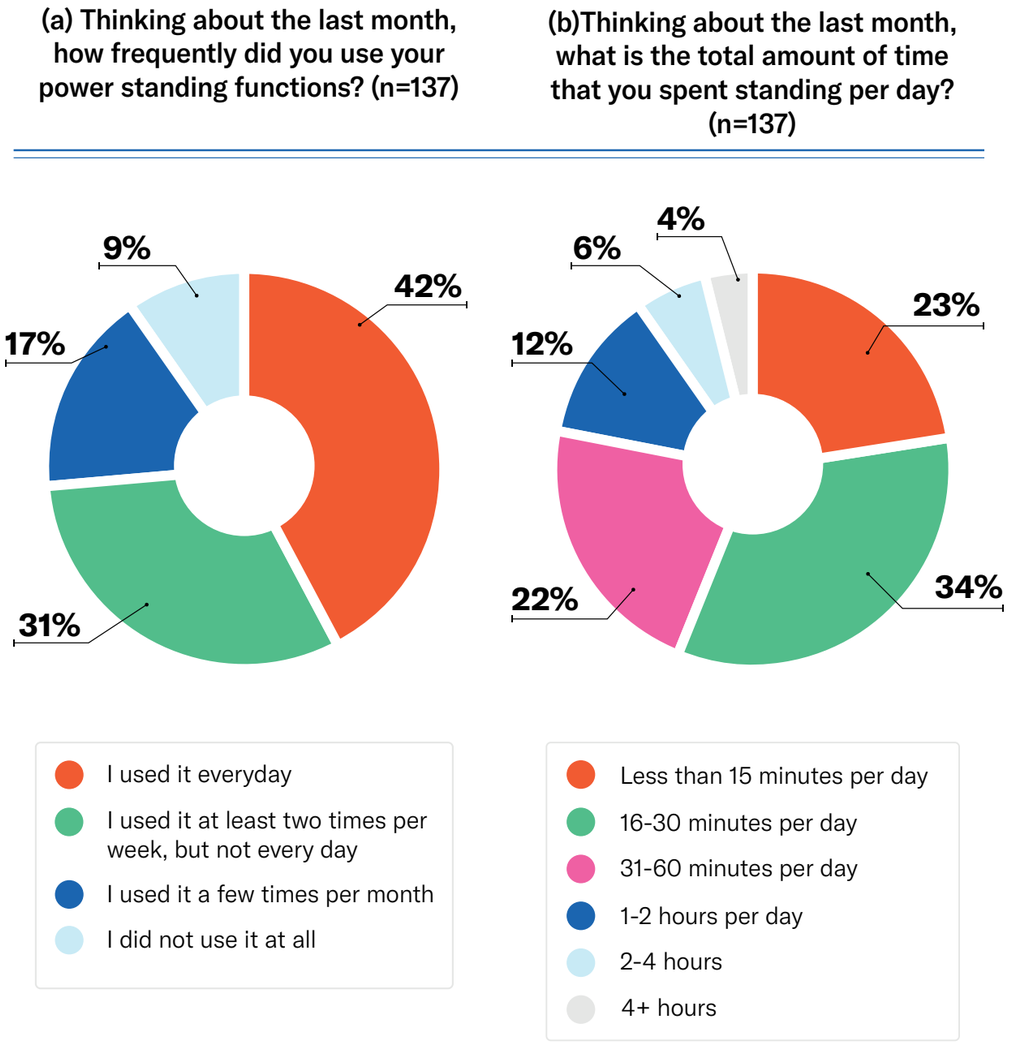


Figure 23. Frequency of standing by month/week and day. *This figure shows how frequently Permobil standing survey participants use their power stand functionality. In Figure (a) participants selected how many times a month they used their power standing function. Part (b) shows the duration of time that participants typically remain in stand.*

Table 1 reports on the characteristics of the Permobil standing survey participants, including their age, gender, and experience with a PWC. As an addition to this, Table 2 describes these characteristics within high frequency, middle frequency and low frequency subgroups. Gender was comparable between the frequency groups. With regards to age, it was interesting that the middle frequency subgroup had the highest proportion of participants aged 71-80 years (13%), whilst it also had the lowest within the 61-70 age bracket (5%). No participants aged 5-17 used their power standing function infrequently. Lastly, with regards to the time participants were using their PWC, those who had owned a standing wheelchair for less than 1 year had the highest proportion within the low frequency group (26%). Those with a standing wheelchair for 1-5 years were most likely to be within the high frequency subgroup (66%). Meanwhile, those with a standing wheelchair for more than 6 years had the highest proportion of participants within the middle frequency group (43%).

Table 2. Participant demographics by frequency of power standing use. *Permobil standing survey participants are split into three subgroups to demonstrate the participant demographics for each subgroup. The total participant demographics are shown in the last column.*

		High Frequency (n = 47)	Middle Frequency (n = 40)	Low Frequency (n = 31)	Total Group (n = 137)
Gender	**Female**	26%	25%	26%	27%
	Male	70%	75%	70%	72%
	Prefer not to say	4%	0%	0%	1%
Age	**71-80**	6%	13%	4%	9%
	61-70	16%	5%	15%	12%
	51-60	29%	35%	21%	28%
	31-50	39%	33%	32%	31%
	18-30	10%	8%	19%	13%
	5 to 17	0%	8%	8%	6%
	Prefer not to say	05	0%	0%	1%
Time using a power standing wheelchair	**Less than 1 year**	26%	15%	13%	18%
	1-5 years	58%	43%	66%	55%
	>6 years	16%	43%	22%	26%

Figure 24 shows an overview of the overall impact of power standing on various aspects of health, taking into consideration all participants. Figure 25 shows the impact of standing connected to previously established self-reported health conditions. Note that these results are described in separate figures divided in the different ICF-model sections throughout this white paper.

With regards to health (Figure 24) this overview clarifies that in most cases more than 50% of survey participants reported a favourable impact of power standing on the different aspects of health or related to health. Only voice production (n=89) and sexual health (n=80) had a higher proportion rating no impact at 57% and 70% respectively. Voice production also had the highest negative impact due to standing (8%). The highest favourable impact due to standing was seen in well-being (85%) and happiness (84%).

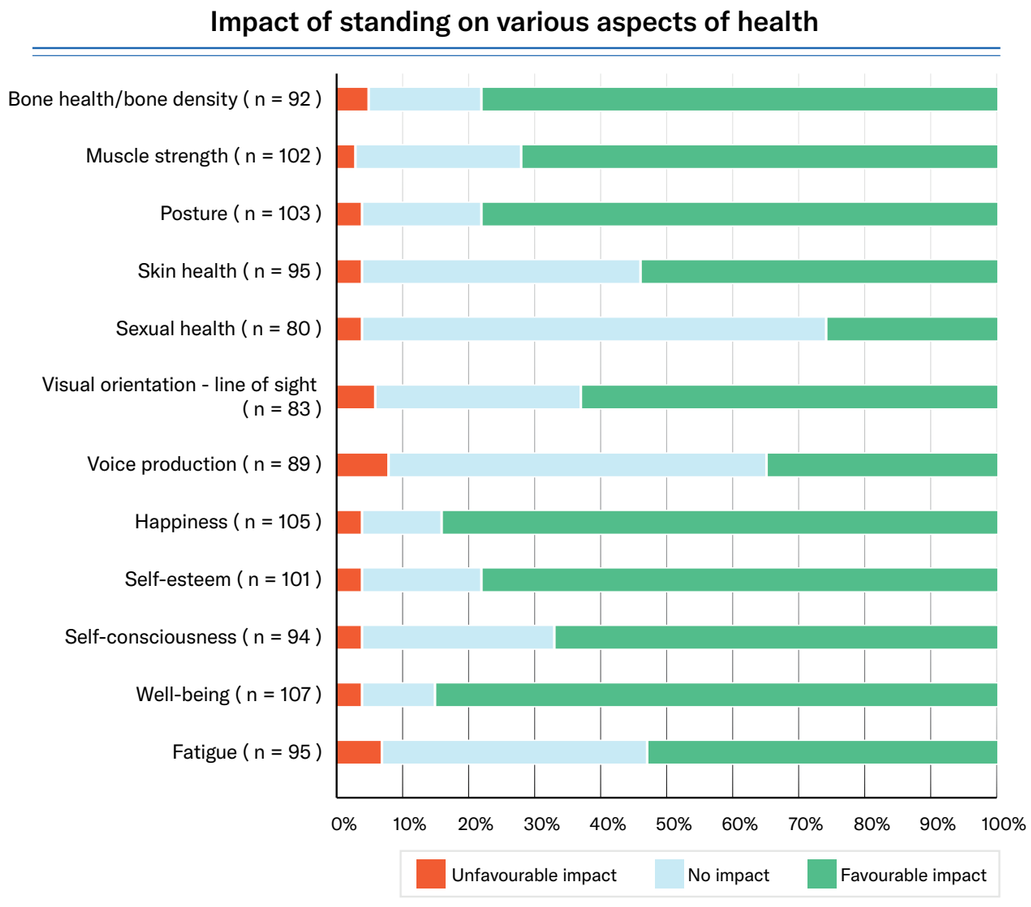


Figure 24. The Impact of standing on various aspects of health. *This figure shows how Permobil standing survey participants rated the impact of power standing on various aspects of health. Participants were asked to rate the impact as unfavourable, no impact, or favourable.*

Figure 25 shows that with regards to health aspects related to diagnoses, on average, 5% of participants rated the impact of standing as unfavourable, 26% reported no impact, and 69% reported a favourable impact. Sensation (n=47) had the lowest proportion of participants who reported a favourable impact (51%) due to a large proportion (45%) reporting no impact. Interestingly, bladder function (n=49) had the largest proportion of participants who reported an unfavourable impact (10%).

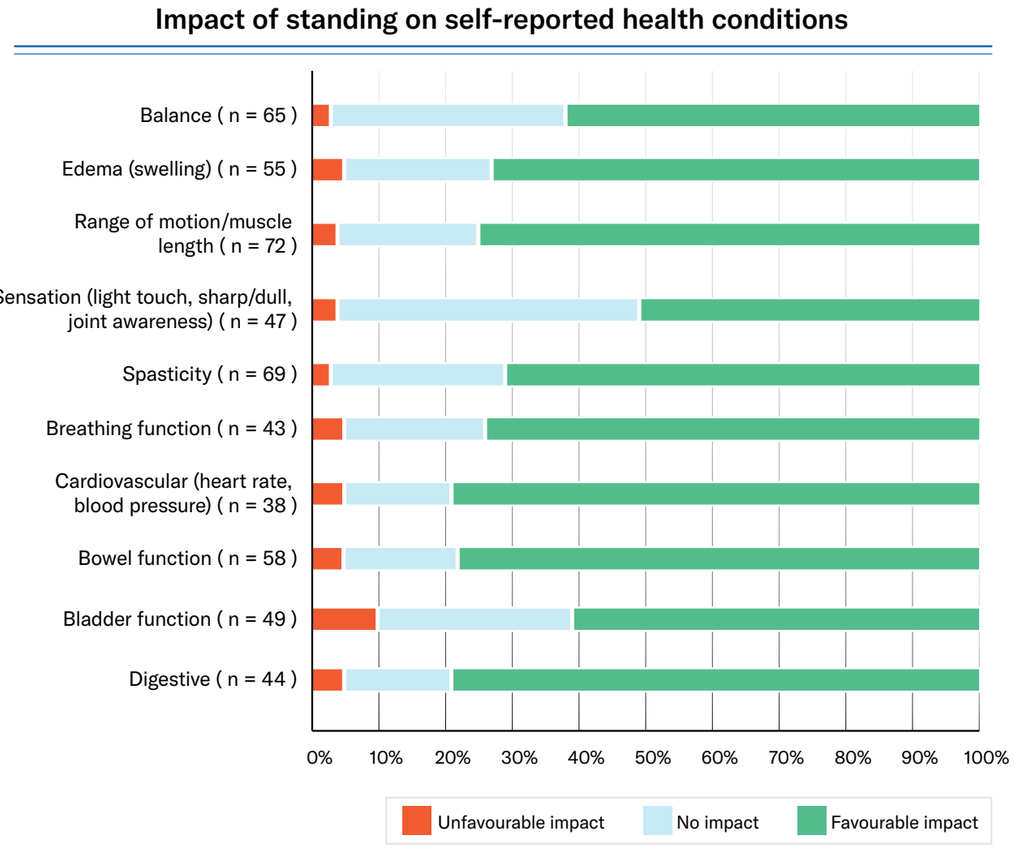


Figure 25. The Impact of standing on self-reported health conditions. *This figure shows how Permobil standing survey participants with various conditions related to their diagnoses rated the impact of power standing on the relevant condition. For example, only participants who selected spasticity as part of their diagnoses were included in the results detailing the impact of standing on spasticity. Participants were asked to rate the impact as unfavourable, no impact, or favourable.*

Appendix C. Displacement: motion capture data

METHODOLOGY

Tests were performed in a motion capture gait analysis laboratory (Flinders University, Australia). A total of 74 reflective markers were secured to a PWC and the non-disabled participant. The movement of these markers was tracked within 3-Dimensional space (x, y, z) by 10 cameras in a circle surrounding the space where the wheelchair was positioned. Vicon Nexus Software was used to record the data and output position data for analysis.

Markers were placed on the participant in areas where pressure concentrations are common and shear forces can increase the risk of pressure injuries. Additional markers were placed in locations such as the forehead, sternum, and shoulders to track body position and posture. The tracking software allowed each of these locations to be precisely measured as the wheelchair moved between configurations.

PARTICIPANT AND EQUIPMENT

The participant was a 178 cm, 68 kg, non-disabled man. Participant body dimensions are shown in Table 3. No shoes were worn, and clothing was well-fitted to prevent any movement or occlusion of markers. The wheelchair was a Permobil F5 Corpus VS Series 1 PWC with an 19’ x 19’ Ergo Stretch Air Cushion with air insert. The wheelchair was configured to fit the participants body dimensions. The seat was 19’ x 19’ with a 18’ x 25’-28’ Stretch Air Cushion back support.

Table 3 Motion capture participant measurements

Measurement	Value (cm)	Measurement	Value (cm)
Hip width	34	Seat to elbow	20
Top of head	89	Upper leg length	48
Top of shoulder	62	Lower leg length	40

PROCEDURES

The participant began by standing still in front of the wheelchair, allowing the system to initialize. Then the participant seated himself in a standard sitting posture within the wheelchair and fixed the knee supports in place. With minimal muscle activation and arm movement, the wheelchair was moved into standing using the standard Permobil S1 sequence. After pausing in standing, the wheelchair was brought back down to a seating position. The data was recorded at 100 Hz and all position data was exported as a CSV file.

DATA ANALYSIS

To create a manageable data set, the raw data was cut to only include position points from the sit-stand-sit sequence. Three discrete position points for each marker were calculated by taking the average of 100 samples from when the chair was initially seated, when it had risen to stand, and when it had reached its original seated position again. This was done separately for the markers on the participant and for each corresponding marker location on the wheelchair.

To ensure that the final body position markers (once the wheelchair had returned to seated) were not impacted by any possible chair displacement, the following calculations (Equation 1) were performed for each discrete marker point. In this equation a_p denotes the participant after movement, $b_w$the wheelchair before movement, and a_w the wheelchair after movement.

$$Final\ marker\ displacement = a_p + (b_w - a_w) \quad (1)$$

All calculations were performed with positive axes values. To achieve this 800 mm was added to all y values. This did not change the final displacement; it merely shifted the y axis. Thus, the displacement of the chair was factored into the final reported displacement of the participant.

RESULTS

To get 3-Dimensional positional data, three coordinate points (x, y, z) were given for each marker for each point in time. The x axis represents lateral translation (left/right movement), the y axis shows anterior/posterior displacement (forwards/backwards), and the z axis shows translation upwards/downwards. Thus, the x axis corresponds to the frontal axis, the y axis to the sagittal axis, and the z axis to the vertical axis.

As expected, displacement seen in the wheelchair was typically low; the largest translations occurring in the y axis. These consisted of backwards movement in the headrest (23.0 mm or 0.9 inches) and the back support cushion (13.1 mm or 0.5 inches).

Figure 6 presented the results of body displacement during the sit-stand-sit sequence. More detailed information about the data presented in this figure, is shown in Table 4. As no changes were expected in the x axis, these were not included. The x coordinates typically had less than 5 mm (0.2 inch) displacement. The two largest outliers of lateral displacements (20.3 mm, 18.3 mm or 0.8 inches, 0.7 inches) were found in the right forearm which was controlling the joystick.

Furthermore, to graphically represent the results, the lefthand side was chosen to be presented as there was no expected difference between the left-hand side and the right-hand side. Although no bias towards one side was found, minor differences were found between the left and right markers such as 4 mm (0.16 inches) difference between the left and right acromioclavicular in the z axes and 1.8 mm (0.07 inches) in the y axis. This could be due to errors within the system such as marker slippage.

Table 4 Marker displacement. *This table shows the locations of the markers chosen for graphical representation in Figure 6. The values displayed are the y and z coordinated whilst initially seated (initial position) and the coordinates once the chair had returned to seated after standing (final position). The difference shows the displacement that occurred between these two positions. A positive displacement in the y axis corresponds to forward movement. Positive displacement in the z axis corresponds to downward movement (towards the floor).*

Marker Location	Axes	Initial Position	Final Position	Difference (mm)	Difference (“)
Forehead	Y	782,62	779,18	3,43	0,14
	Z	1388,04	1380,23	7,81	0,31
Above Ear	Y	895,87	891,28	4,59	0,18
	Z	1313,31	1303,09	10,22	0,40
Acromioclavicular	Y	845,33	856,62	-11,29	-0,44
	Z	1126,12	1115,66	10,45	0,41
Clavicle	Y	777,17	775,83	1,34	0,05
	Z	1098,59	1089,09	9,51	0,37
Sternum	Y	699,00	702,37	-3,37	-0,13
	Z	957,19	949,00	8,19	0,32
Lateral Elbow	Y	843,83	832,11	11,72	0,46
	Z	803,68	795,51	8,17	0,32
Lateral Wrist	Y	604,20	593,03	11,17	0,44
	Z	754,05	749,67	4,38	0,17
Illiac Crest	Y	739,43	743,10	-3,67	-0,14
	Z	747,14	730,92	16,22	0,64
ASIS	Y	694,98	698,18	-3,21	-0,13
	Z	727,91	718,48	9,43	0,37
Greater Trochanter	Y	724,76	714,20	10,56	0,42
	Z	691,06	686,54	4,53	0,18
Lateral Knee	Y	298,76	291,23	7,53	0,30
	Z	573,39	567,34	6,05	0,24
Lateral Heel	Y	284,15	285,31	-1,16	-0,05
	Z	155,14	157,81	-2,67	-0,11
Big Toe (2nd Knuckle)	Y	119,10	119,00	0,10	0,00
	Z	145,88	146,56	-0,68	-0,03

Appendix D. Clinical applications

CLINICAL APPLICATIONS

These portraits reflect a virtual interview session that was conducted by the Permobil clinical education team using an interview guide for consistency. They are intended to provide clinical applications of power standing wheelchairs for each individual so that evidence can be connected with clinical outcomes. The results are all self-reported and vary from person to person.

CLINICAL APPLICATION 1:

Meet Danielle:

Danielle is a 34-year-old female who has used a PWC since the age of 14. She works full-time as a care coordinator for a state funding agency which requires multiple skills including speaking engagements. Danielle has a medical diagnosis of CP, a diagnosis acquired at birth. For her, she has motor limitations associated with spasticity in both arms, hands, and legs. In addition, she reports having pain, digestion issues, trouble with sleep, difficulty taking deep breaths, as well as trouble with bowel and bladder function.

Danielle at work demonstrating how she can use her power standing wheelchair

Equipment history:

In childhood, Danielle was able to ambulate short distances but primarily utilized a manual wheelchair for functional mobility. As she moved into her adult years, ambulation became more taxing and she was unable to self-propel functionally, so she was evaluated and provided a PWC. She has been using her power standing wheelchair for 7 months at the time of the interview. To achieve a standing position in her PWC, she uses a sit to stand pattern that she likes to change the angles from day to day to match her needs. She now is able to stand in her power standing wheelchair on a daily basis, typically at least one hour per day out of the 16 hours that she spends in her wheelchair.

Main goals of power standing

Body functions and structures

When Danielle first thought about how she would use a power standing wheelchair, her primary goals were to manage and decrease her pain as well as to be able to achieve weight bearing independently. She was participating in a standing program; however, she relied on caregiver assistance to help her get set-up and into a comfortable standing position. She also would like to see improvements in her ability to manage her comfort, pain, and stiffness throughout her workday.

Activities and Participation

Danielle wants to be able to improve how she can take care of herself in her home and with chores and daily tasks, even if they are small changes. She plans to use the power standing wheelchair for a wide variety of work-related tasks. She also wants to improve how she communicates with her co-workers and improve how she can project her voice.

Impact on body functions and structures

Related to her body functions and structures, Danielle has seen a change in her breathing allowing her to breathe easier and communicate with less strain and effort. In addition, she reports that fatigue is a symptom associated with her medical diagnosis that not only impacts her physically but also with her ability to focus. When using her power standing wheelchair, she has seen an improvement with how her fatigue is managed, allowing her to work a full 8-hour day. One additional major area she has experienced improvements include bowel and bladder function. She reports that since her bowel function has improved, she also has less urinary urgency. Pain was one of the other primary goals that she expressed when having her evaluation and she reports that she does experience pain relief when standing and when being able to make changes in her standing position from day to day. Of course, she also achieved her goals of being able to perform weight bearing activities independently, which she feels has really helped with stretching her body and allowing her to remain at work and in her chair for a longer period of time.

Impact on activities and participation

Danielle describes being able to use power standing function when performing several self-care activities such as household tasks and getting dressed. In her home, she also describes that she can reach items in her apartment when in standing that she would not be able to reach at a typical seated position. Danielle also has noticed that she can speak at a louder volume with her colleagues at work and when performing speaking engagements.

Impact on quality of life

Not only has Danielle seen an influence on her ability to be more involved in her work setting, but she has also seen a change in her participation in social events with family and friends, septically when they are seated at tables that are at a taller height. When asked how having a power standing wheelchair impacts how she feels about herself, Danielle replied “I feel more confident professionally and personally. I am able to bring my voice louder and advocate more strongly for individuals with severe [physical] and mental illness and individuals with disabilities.

Experienced power standing limitations

The primary limitation expressed by Danielle is the lack of accessible transportation that limits her ability to use her PWC more in the community.

Key areas that are reflected in the systematic review:

Fatigue, Pain, Bowel, Bladder, Respiratory, Weight bearing, Quality of Life

CLINICAL APPLICATION 2:

Meet John:

John is an 11-year-old boy who attends primary school and loves video games online with his friends. He enjoys playing video games with other boys his age with a similar diagnosis in different states. He enjoys playing power soccer as an adaptive sport. His favourite food is a poke bowl, which he feels is very advanced for his age. John loves learning about new things in science class. He has a family dog named Peanut who creates lots of fun in his life. John presents with Duchene Muscular Dystrophy, which he describes as “a gap in his DNA”.

Equipment history:

When he was younger, John used a manual wheelchair when he had difficulty walking independently. He also had a portable mobility scooter that he would use for going out in the community. They had to take it apart every time they got in and out of the car and it became more difficult for John to transfer as well. At the time when he started having a few falls, it was determined he could use a PWC, so then he got a loan chair for a short time. Quickly after that, John and his mom attended a conference where other boys who were a bit older than him with the same medical diagnosis had standing PWCs, and they knew that he could also benefit. John has been using a power standing wheelchair for approximately 2 years and has a manual wheelchair just as an emergency back-up device.

Main goals of power standing

Body functions and structures

The main goals that John had when he got his power standing wheelchair was to help him get the sensation of still being able to stand while stretching out his muscles. John’s mom states that his positioning was very important because they were discussing having to do another tendon release surgery on his hips, knees, and angles. Right now, he is on a waiting list to have surgery but he has to maintain the ROM he does have otherwise he won’t be a candidate if he loses more ROM.

Activities and Participation

John would like to be able to help his parents with cooking in the kitchen, participate in family activities, play his video games while he is standing. Some of his therapy goals at school may also include standing, depending on his classroom setting.

Impact on body functions and structures

As stated, John’s main goals for improving his physical health was to manage his ROM. He felt like he is getting used to being in a standing position and enjoys how the stretching feels on his legs. He can also participate in more physical fitness sports activities at school when he has support to make the accommodations. When he starts high school, he feels that they are more inclusive as there have previously been other students who have use PWCs.

John’s mom also observed that once the lateral trunk supports were adjusted correctly, they did hold him straighter, which was a concern at first because he was starting to get a slight scoliosis as he always favoured one side. But they feel like the support while standing will help manage this.

At the time of the interview, John’s mom said that they started to see he was having a bit more fatigue and wanted to get up and out of bed earlier because he was not as comfortable. So being in his wheelchair, he can adjust to a variety of positions to get more comfortable.

John has also noticed that standing has helped his digestion because it “stretches out his stomach”. He feels that when he lays back or sits upright, he can’t digest his food as well.

Impact on activities and participation

Currently, John is seated in his wheelchair about 12 hours per day, depending on when he goes to bed. He usually stands for about 20-30 minutes, at least twice a day for stretching. He does stand for other reasons, but that is the longest he stands at one time. At school, he does have some environmental barriers to use his chair in a standing position but when he first received the chair he would stand to go up to the board when he was called on by the teacher just like the other kids. John says that his therapists and teachers encouraged him to stand when he went to the canteen on the playground, but he typically would use power seat elevate if it wasn’t part of his school plan.

When he is at home, John’s favourite activity is to cook and bake with his family. His mom states that while he is mixing brownies or muffins and getting everything ready at the counter, John really enjoys this activity and will stand for 15-20 minutes without hesitation.

Although John initially tried managing his bladder from a standing position, they found that the clothing management was more difficult as he got older and that unless he had on modified tracksuit pants, it was more difficult for him to stand to use the restroom while standing in his wheelchair.

One other area that they noticed was even though John was not able to walk as much at the time he started using his PWC, he was able to sit, stand and support his weight during transfers more than before. They stopped using their hoist (lift) because he would bear more of his own weight during the transfer.

John’s mom states that one area she has really appreciated about the standing PWC is that he has options now. He can improve his independence like reaching things out of cupboards, but most importantly, when we are out at a party and everyone else is standing, he can be included in the

conversation and be given back the choice to stand or not, and choice was something that felt like it was being taken away when John first started using a wheelchair.

Impact on quality of life

Since John's favorite hobby is cooking (and getting into the raw cookie dough) he is really happy that he gets to enjoy that with his family. As John is just 11 years old, he is happy playing video games and being with his family, but as he starts to go to high school, he may want to use his standing wheelchair more to get more of the social benefits.

One benefit that was very meaningful to John comes back to cooking, but this time when his friend was having a bar-b-que in the park, he noticed the kids going off and playing but he enjoyed staying at the grill with all the other men to cook the steaks and sausages. Even though he was hanging out with adults, they felt that it was positive that he could stand and interact and be social.

As John is still in early adolescence, he does sometimes feel a little bit self-conscious at first with his PWC, but then once he shows other kids what the chair can do, and it helps to make him feel more comfortable. He does feel more empowered and that it makes him feel stronger because he can decide if he wants to stay in a situation or change his mind and go somewhere else.

Experienced power standing limitations

When John first received his power standing wheelchair, there were several adjustments that needed to be made to accommodate his posture. Because he was growing and changing and trying to maintain his ROM, there were some adjustments needed to be made with the hip guides, knee supports, and footplates. He also wears ankle foot orthoses (AFOs) so they had to accommodate the position that his ankles are in with the braces. It took several visits to get John comfortable but now they are at a good place.

They do hope that as John gets a little older, he will feel more comfortable explaining how and why he uses his PWC and become a little less self-conscious. Managing his emotional health has also been challenged because he feels that people don't pay attention to what is going on around them because people are always on their phones. John hopes that scientists invent the ability to become invisible so that he can drive around in his wheelchair without bothering other people and without worrying about the size of the wheelchair running into things in his house.

Key areas that are reflected in the systematic review:

Range of Moton, ADL, Balance, Participation, Socialization, Communication, Independence, and Quality of Life

CLINICAL APPLICATION 3:

Meet Ivy:

Ivy is an energetic young lady who states that she is 11 years old but will be 12 in 3 days after the interview took place. At the time of the interview, she was very excited for her Wednesday Addams themed birthday party. Ivy was diagnosed with CP who goes to school, likes to swim, rides horses, enjoys playing with her iPad and being social with her friends. She also has made good friends with her manufacturer representative, who says has really helped her with some tricky situations with her equipment and considers him a good friend.

Equipment history:

Ivy has had a variety of equipment throughout her almost 12 years, including a manual wheelchair and a pediatric PWC, a Permobil Koala. She does still use her posterior walker at home before going to school, and once she gets to school, she uses her chair for the first 3 hours and then again for a few hours at the end of the school day, for a total of about 8 hours a day. She did have a manual wheelchair she used as a back-up, but it is quite small now and they may need to look into renting one if she ever needed it to access a location that is not accessible for her PWC.

Main goals of power standing

Body functions and structures

Ivy does get uncomfortable when she sits in one position and would like to be able to manage that better. Also, she would like to conserve her energy so that she can improve her tolerance to do more activities at school and after school. She also hopes that standing will help her ROM in her legs and hips as well as keep her muscles strong.

Activities and Participation

Socializing and interacting with her peers was really important to her as well as helping her to become more independent. She also states that she has difficulty keeping up with other kids and participating in sports when she has her walker. She also likes using her iPad when she is standing and would like to get homework done while getting in some extra standing time. Ivy wants to access different height tables more independently like at the café, restaurant, or library.

Impact on body functions and structures

Ivy likes to change positions when she feels uncomfortable and because of the different power seat functions and standing she can really adjust to what works for her. She is able to still walk with her walker for exercise, but she feels that the power standing wheelchair does help her get less tired and be able to conserve some of her energy that walking would normally require.

Impact on activities and participation

Ivy feels that her power standing wheelchair really helps her be more independent and interact with her peers. Because her chair was programmed in a sequence that is comfortable for her, she can go easily from sit to stand and it remembers how she wants to stand each time.

There are cooking activities that Ivy enjoys like making her own breakfast and that she can reach farther forward when she is in the standing position. She also is able to do homework while standing at a bench, which she feels like allows her to get a good amount of standing in for her day.

She prefers to stand for 10-15 minutes at a time because she did have one moment where she felt dizzy after standing for 30 minutes. She said that it was a day that was very hot out but feels that 15 minutes is a good amount of time. Ivy's mom stated that when she is doing an enjoyable activity like the time she was singing at a festival, she stood for 30 minutes and had an enjoyable time.

Ivy's family does enjoy going out and about to museums, art galleries, zoos and she states that she has noticed she is able to see better when she uses her power standing wheelchair. Ivy also participates in theater class and she feels that she is able to be more physically expressive in her acting when she stands.

Impact on quality of life

Overall, Ivy says that she has a cool chair which helps her interact with people easier. She has a younger sibling who she likes getting hugs from when she is standing, but in Ivy's words "she's a tricky little sister" so she doesn't always do what Ivy wants. But Ivy got her sister back by taking a toy from her room that was in a place her younger sister couldn't see, but Ivy could when she was standing up in her chair.

Although she is generally quite a confident young lady, there was one moment that make her feel especially good when she had to do a speech trying out to be a captain of her class and she did not need help with managing the microphone. She said that it made her feel recognized and that she had a purpose. She also feels that when she stands, she has equal rights to everyone else.

Ivy's family does have an accessible vehicle with a docking station so that she can stay in her PWC when going out away from the house.

Experienced power standing limitations

Sometimes she is not able to use her PWC where she wants because the environment is not accessible, and they need a manual wheelchair to be able to be lifted up a step. Additionally, Ivy says that going into a standing position feel too slow sometimes when she is trying to talk with her friends. By the time she gets into a standing position her friends have already walked away.

Key areas that are reflected in the systematic review:

Participation, Communication, Functional Reach, Independence, Mental Health, Fatigue

Appendix E: ICF Framework

When matching the right seating and mobility solution to the person who will be using it, there are a multitude of factors that can influence the decision. Factors may include the person's previous experience, the device that fits best with their transportation, or how it improves the ability to complete daily activities with less pain. There is a comprehensive way to include such considerations, which is from the International Classification of Functioning, Disability and Health (ICF) framework[10]. The ICF was developed by the World Health Organization (WHO) to shift discussions from a medical model focused on diagnosis and disability to one highlighting the social model with function as its primary purpose. According to the WHO, ICF creates a standard language to describe health and health-related states.

In "ICF: A Hands-On Approach for Clinicians and Families", the editors state "The ICF framework is a tool to expand our thinking and actions across all dimensions on the field of healthcare providing more rich opportunities to rethink and improve". The ICF framework can be used in many different ways, but the main purpose is as a tool when making decisions around health plans and health policies[10].

This white paper will utilize the terminology of the ICF along with supportive evidence as the structure relates to important areas of a person's everyday life related to body functions and structures, activities, participation, environment, and personal factors.

Figure 26 represents one of the models that is often used when describing the basis of the ICF where the arrows are a visual representation of how health conditions interact and intersect with contextual factors to make up functional outcomes.

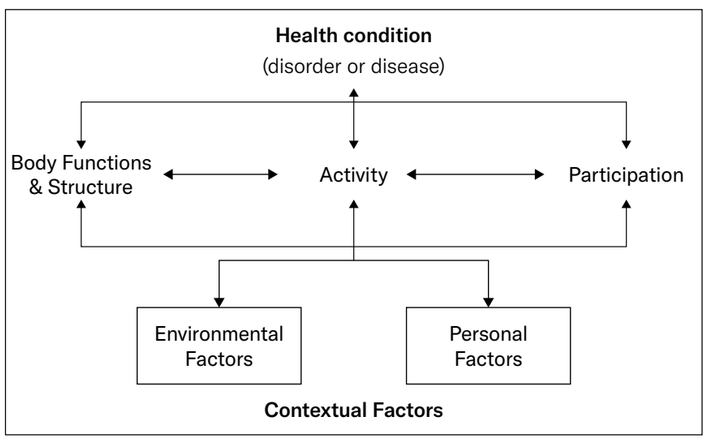


Figure 26. *ICF model from "How to use the ICF: A Practical Manual for using the International Classification of Functioning, Disability and Health (ICF)[10]*

Body Functions & Structures:

Body functions are physiological and psychological processes that occur within the body systems while the structures serve as the "anatomical support". Body functions can include memory and language, sensation and pain, cardiorespiratory functions, neurological and neuromuscular functions of movement as well as integumentary functions of the skin, hair, and nails. Body structures parallel the functions but are related to the actual anatomical body segment. For example, the body function of vision and seeing is followed by the body structures of the musculature, nerves, blood supply for example. Another example as it relates to seating and mobility equipment would be when a person has pain in a body part such as the shoulder or wrist, the sensation of pain is the body function while the body structure would be nervous system, nerve endings, as well as the muscles, ligaments, tendons of the shoulder joint.

Activities:

An activity is anything that is the execution or completion of an action or task. This can vary from basic, everyday required activities such as self-care activities of brushing teeth, combing hair, to mobility related activities such as transferring from the bed to a wheelchair, maintaining body position, or using a wheelchair. An activity is also inclusive of communication, whether verbal or non-verbal, expressive, or receptive.

Participation:

Participation is defined as "involvement in a life situation" which often include the social world around the person such as being a student in a classroom or pursuing a vocation. Participation also often includes community, social and civic life, as well as interpersonal relationships.

Contextual factors:

Environment and internal personal characteristics make up the contextual factors. For environment it is not only the physical environment but the social and attitudinal environment such as social and legal structures. Personal factors are influencers on how a person perceives their disability such as their age, gender, coping style, education, and past experiences.

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