

The Impact of Supported Standing on Well-Being and Quality of Life

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ABSTRACT

Purpose: To identify the characteristics of people who use standing devices and to explore their degree of device use, experiences with and reasons for standing, and perceived impact of the use of standing devices on well-being and quality of life (QOL). **Method:** Anyone with a current prescription at the time for the study in any of five counties in Sweden ($n = 545$), according to a national register of prescribed devices, was invited to participate in a descriptive survey; the questionnaire was mailed to respondents for self-rating. **Results:** People between 2 and 86 years old were represented among respondents. Standing time decreased with increased age. Respondents who were totally dependent for mobilization or who had received their standing device more than 5 years earlier used their device most frequently. The most common reasons given for standing were to improve circulation and well-being and to reduce stiffness. **Conclusion:** It is important to pay attention to the experiences of standing for this vulnerable group of people, as the use of a standing device has a positive impact on well-being and QOL.

Key Words: disabled persons; postural balance; quality of life; self-help devices.

RÉSUMÉ

Objectif : L'étude visait à déterminer les caractéristiques des personnes qui utilisent des appareils de verticalisation, à explorer leurs expériences de la position debout, le degré d'utilisation des appareils, la raison pour laquelle elles se tiennent debout et l'effet perçu sur le bien-être et la qualité de vie. **Méthode :** Sujets : Toutes les personnes à qui l'on a prescrit des appareils de verticalisation ($n = 545$) dans cinq comtés de la Suède ont été invitées à participer à l'étude. Concept : Sondage descriptif. Procédure : Les répondants ont été recrutés à partir d'un registre national des appareils prescrits. Un questionnaire d'auto-évaluation a été envoyé aux répondants par la poste. **Résultats :** Les répondants au questionnaire sur l'utilisation d'appareils de verticalisation représentaient tous les âges. Le temps passé en position debout diminuait selon l'âge. Les répondants qui étaient totalement dépendants pour l'ambulation ou qui avaient reçu l'appareil il y a plus de cinq ans utilisaient leur appareil le plus souvent. Les sujets se tenaient debout le plus souvent pour améliorer leur circulation, pour contrer les raideurs et pour leur bien-être. **Conclusion :** Il importe d'accorder de l'attention aux expériences de la position debout pour la santé dans ce groupe vulnérable de personnes, car l'utilisation d'appareils de verticalisation a un effet positif sur le bien-être et la qualité de vie.

Prolonged standing has been shown to have beneficial effects on various body functions and structures.¹ In addition, time spent in a standing position can give wheelchair users a sense of confidence and equality through face-to-face contact with the non-disabled community.² Using a standing device can provide opportunities to connect with the outside world, enhance memories from the past, and promote hope for the future.^{3,4} Our study is an attempt to add to existing knowledge about people who use standing devices, and the circumstances and experiences related to their use.

Many studies have shown that standing has measurable effects on different body functions and structures, including bone mineral density, cardiopulmonary function, range of motion, and hypertonicity.¹ For people >18 years old with spinal-cord injuries, the use of standing devices can reduce pressure ulcers, decrease spasticity, facilitate emptying of the bladder, and improve quality of life (QOL).⁵⁻⁷

In addition, standing and other low-intensity activities that interrupt prolonged sedentary time may have beneficial effects on the cardiovascular system, as excessive

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sitting is considered harmful in this area.⁸ The national Swedish guidelines recommend 30 minutes of at least moderate activity every day, but some studies have suggested that this guideline is inappropriate, and that an overall less sedentary lifestyle has important benefits.^{9,10} Studies have reported that energy metabolism is doubled merely by standing instead of sitting,¹¹ which is highly relevant to people who spend many hours a day sitting in a wheelchair.

A standing device should be prescribed to meet a person's individual needs and goals as a part of his or her habilitation or rehabilitation plan.¹² Previously, medical diagnoses were the starting point for prescribing assistive devices, but they do not provide a description of how a person interacts with their environment; thus, the International Classification of Functioning, Disability and Health (ICF)¹³ was developed as a supplementary form of evaluation. According to the ICF, a standing device is an environmental factor, one of several environmental factors that may facilitate or inhibit a person's activity, participation, and body structures and functions.^{13,14} For the purposes of our study, a standing device is defined as any of the following: tilt tables, standing frames, standing frames with rear wheels, standing wheelchairs, and standing shells.

A general review of users' experiences with assistive devices showed that successful integration of the device into their lives requires users to explore (1) the meaning the device holds for them, (2) their expectations of the technology, (3) the expected social costs, and (4) the device's influence on their identity.¹⁵ This review included studies of older adults, people with acquired and congenital disabilities, and people with functional limitations due to progressive diseases.¹⁵ A previous study suggested that people will use their devices more and get more benefit from using them if they encourages users "to flourish rather than to survive."^{16 (p.8)} Another study found that children use assistive devices more often at school than at home;¹⁷ factors in the physical environment, the desired level of independence, and mothers' attitudes also influenced device use.¹⁷

In the present study we included all people with standing devices, regardless of medical diagnosis, in contrast to previous studies that focused on people with specific diagnoses. Our study addresses the use of standing devices from the points of view of people with varying levels of independence and restricted mobility, focusing on the social and personal impacts of using standing devices. The aim of this survey was to identify the characteristics of people using standing devices and to explore their experiences with standing, the degree of use of their standing devices, their reasons for standing, and the perceived impact of the devices on their well-being and QOL.

METHODS

Questionnaire

The questionnaire had four parts. Part 1 asked a series of background questions to determine whether the survey participant responded without assistance (Group 1), received help (Group 2), or had someone else answer on their behalf (Group 3), and to determine each participant's sex, age, diagnosis, movement skills, type of standing device used, time since prescription of the device, and frequency and duration of standing.

In Part 2, participants chose 1 or more of 9 statements to reflect their reasons for using their standing device. Part 3 consisted of 10 statements that respondents rated on a visual analogue scale (VAS) with the anchors *does not match at all* and *fully consistent*. Parts 2 and 3 also provided space for open-ended comments. The statements in Parts 2 and 3 were developed based on recurring themes in the findings of an interview study involving subjects who used standing devices. Before beginning this study, we pilot-tested the statements with users of standing devices and expert physiotherapists, then made modifications in response to participant feedback.

In Part 4 of the survey, respondents rated their perceived health using a vertical VAS thermometer with the 0–100 rating scale from the EuroQol EQ-VAS instrument (0 = worst imaginable health; 100 = best imaginable health).¹⁸

Procedure

During 2010, we sent oral and written information about the study to prescribers and consultants in five counties in Sweden (the four northernmost and one central) who were working with users of assistive devices. Anyone in these five counties with a standing device who could be reached was contacted and invited to participate. Data on the standing devices prescribed for members of this group were collected from SESAM, a Swedish database of prescribed devices. The people who agreed to participate received a questionnaire along with written information about the study by mail. The study was approved by the Regional Ethical Review Board in Umeå. All assistive devices were classified according to the Classification of Technical Aids for Persons with Disabilities (ISO 9999).¹⁹

Data analysis

The data were analyzed with descriptive statistics, including percentages and medians. Since the study was designed as a survey of a sample population of people using standing devices in Sweden, no inferential statistics were calculated.

RESULTS

A total of 545 potential participants were identified; 413 questionnaires were sent, and 319 were returned,

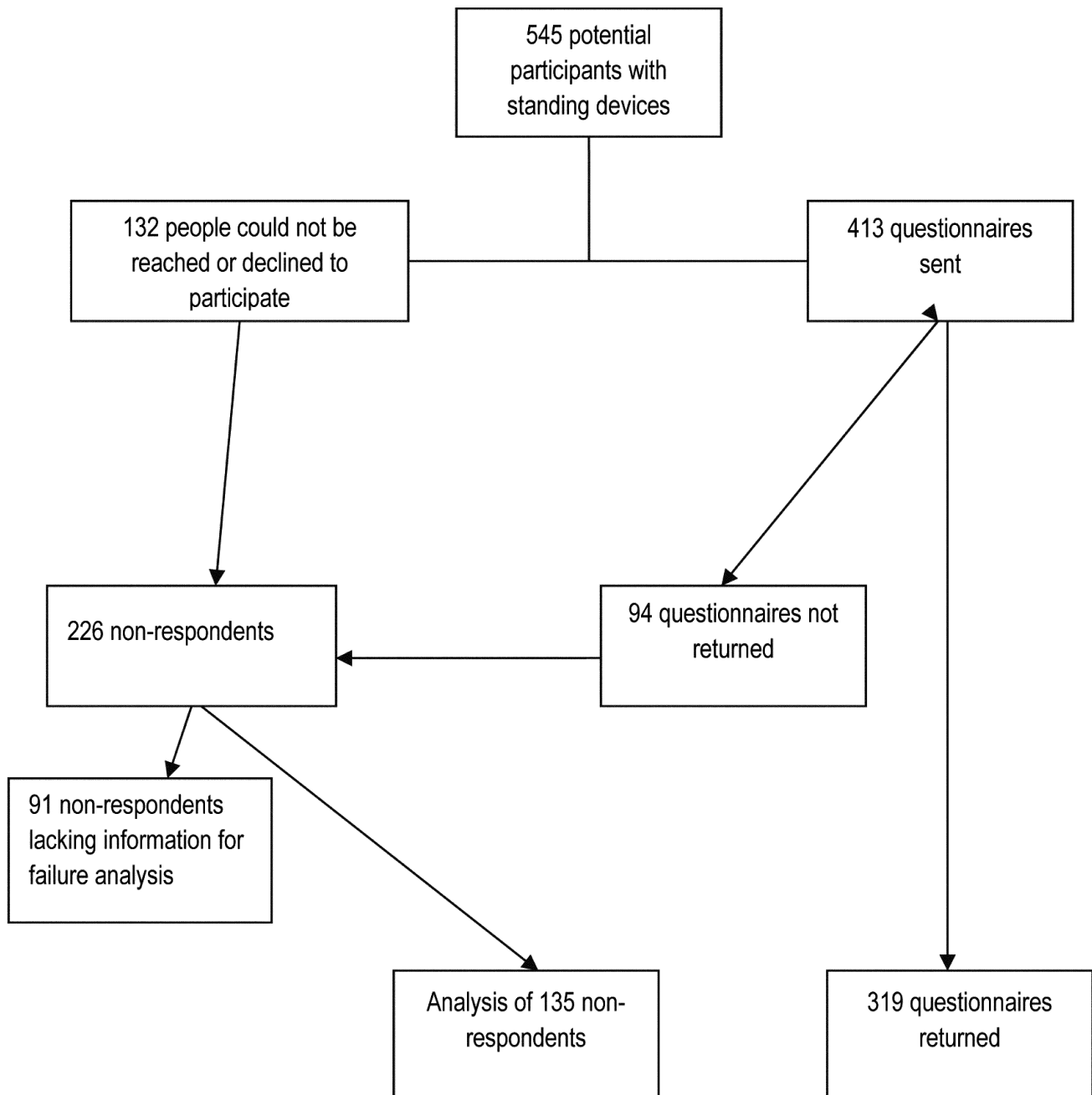


Figure 1 Flow diagram of respondents and non-respondents.

for a response rate of 77%, and 58% coverage of the potential participants (see Figure 1). Respondents were assumed to be representative of all users of standing devices in Sweden, since the process for prescribing standing devices was the same throughout the country.¹²

Analysis of non-respondents

The failure analysis included 135 persons from 3 of the 5 counties, for whom information on sex, age, and type of standing device were retrievable. The only retrievable information about non-respondents from the other two

counties was the number ($n = 91$). This was caused by problems with the inventory management system at assistive device centres and the mailings of the questionnaires at rehabilitation centres. Thus 226 of the 545 potential participants were non-respondents, of which 132 could not be reached or declined to participate and 94 did not respond to the inquiry (see Figure 1).

The sex ratio was equal for respondents and non-respondents. Non-respondents had a mean age of 30 (SD 21.6) years; respondents' mean age was 37 (SD 22.4) years. Tilt tables, standing frames, and standing frames

with rear wheels were equally well represented among the two groups, but people with standing shells and standing wheelchairs were more likely to return their questionnaires. Overall, the difference between respondents and non-respondents regarding the numbers of persons with standing shells and standing wheelchairs was about 10%; we therefore concluded that the non-respondents had not systematically biased the results.

Participant characteristics

The 319 respondents ranged in age from 2–86 years (mean 37 [SD 22.4] years). To a large extent, they received help in completing the questionnaire or were dependent on others to complete it; only 64 (20%) answered without assistance. Medical diagnoses varied, but the majority of respondents (47%) had a congenital disability (e.g., cerebral palsy), with some respondents reporting a combination of diagnoses. Most respondents were adults, but 29% were under the age of 20. The most common means of mobility was by manually operated wheelchair; some were propelled independently, but the majority of respondents needed help. The different types of standing devices were equally distributed, with about 20% of the sample using each type, the exception being standing frames with rear wheels, which were used by only 6% of respondents. The type of standing device varied in relation to age; 80% of children ≤ 2 years of age had standing shells, while none of the children in the two youngest age groups (0–6, 7–12) had a wheelchair with standing function. The majority (62%) of those using standing shells were children up to 12 years old. All types of standing devices were represented in the 13–19 age group. Tilt tables were the most common standing device for people aged 40–64 (36%), followed by standing wheelchairs (31%). Of people aged ≥ 65 , 45% had a wheelchair with standing function and 38% had a standing frame. To cover the child development stages and changes from early childhood to adolescence, we subdivided the younger respondents into smaller age ranges. The growing child needs constant follow up and adjustment of the standing device, whereas adults' needs are more stable. Among users of standing shells, 42% had a congenital disability, while 4% had an acquired disability. Among all participants, 52% had been using a standing device for >5 years, and only 4% had been using such a device for <6 months. Participant characteristics are presented in Table 1.

Extent of use

Almost 39% of respondents reported standing in their devices one or more times per day; 12% used their device once a week or less (see Figure 2 and Table 2). Frequency of standing was connected to the user's age, type of diagnosis, walking ability, mobility function, and device type, but not sex. Overall, those who used standing shells reported a higher frequency of use than those who used other types of standing devices. Around one in five people who had a standing wheelchair (22%) used their

Table 1 Participant Characteristics

Variable	No. (%) of respondents
Who answered the questionnaire	
Respondent (without assistance)	64 (20)
Respondent (with assistance)	106 (33)
Someone else on the respondent's behalf	149 (47)
Age group, y	
0–6	23 (7)
7–12	41 (13)
13–19	29 (9)
20–39	117 (37)
40–64	58 (18)
≥ 65	49 (15)
Missing data	2 (<1)
Sex	
Female	129 (40)
Male	187 (59)
Missing data	3 (1)
Diagnosis	
Congenital disability*	149 (47)
Acquired disability†	138 (43)
Undiagnosed/other‡	32 (10)
Able to walk with or without assistance	
Yes	59 (18)
No	260 (82)
Most common means of mobilization	
Walking	19 (6)
Manual wheelchair	227 (71)
Powered wheelchair	71 (22)
Missing data	2 (1)
Mobility	
Independent	84 (26)
With some help	60 (19)
Totally dependent	175 (55)
Type of standing device	
Standing shell	77 (24)
Standing frame	70 (22)
Standing frame with rear wheels	18 (6)
Tilt table	78 (24)
Standing wheelchair	72 (23)
Other	4 (1)
Time since prescription	
<6 mo	13 (4)
6 mo–2 y	53 (17)
2–5 y	87 (27)
5–10 y	72 (23)
>10 y	93 (29)
Missing data	1 (<1)

*Cerebral palsy, syndromes, multi-disabilities, spina bifida.

† Multiple sclerosis, amyotrophic lateral sclerosis, traumatic brain injury, stroke, virus, tumours.

‡ Persons with no diagnosis or an unusual diagnosis.

device just once a week or less (see Table 2). Eighty per cent of respondents reported that their standing time was either 15–30 minutes or 30–60 minutes. Standing time decreased with increasing age; the proportion of respondents standing for 30–60 minutes decreased from 65% among those ≤ 6 years old to 54% among those aged 7–12, 48% among those aged 12–19, 33% among those aged 20–49, 29% among those aged 50–64, and finally

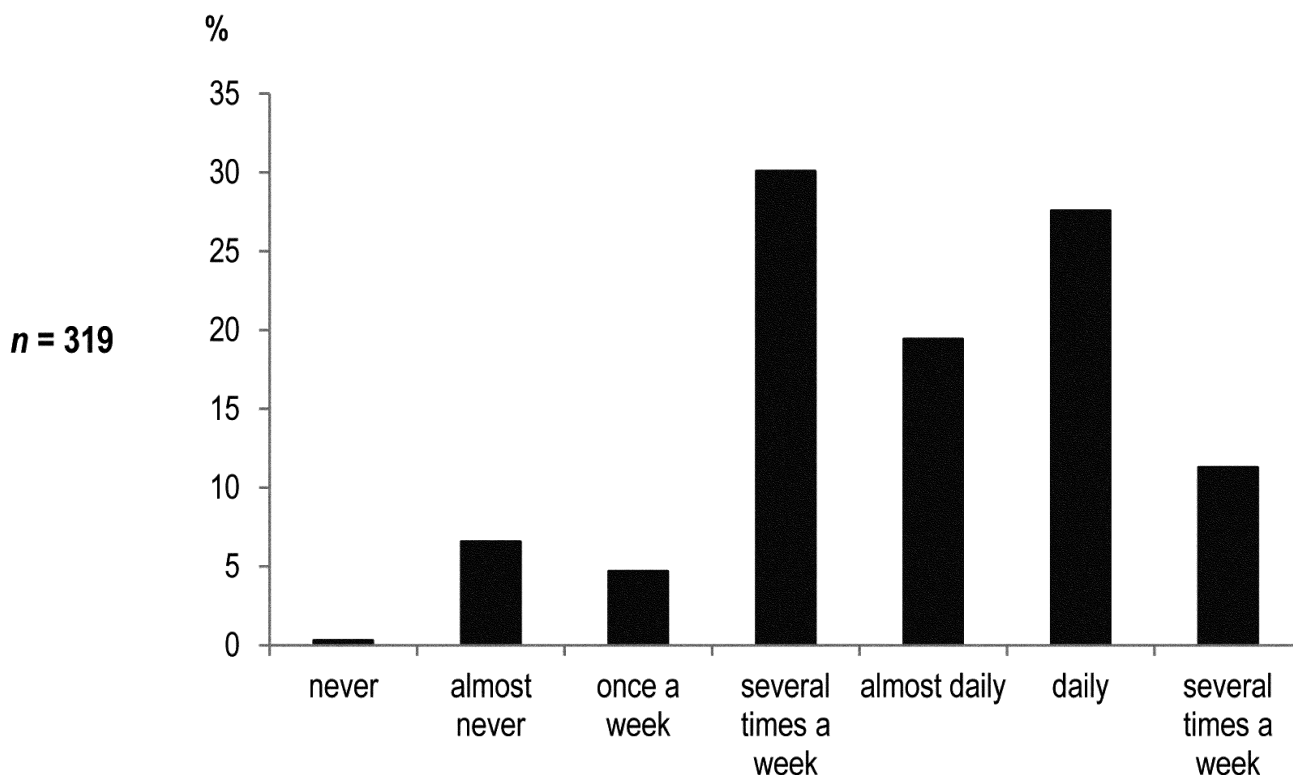


Figure 2 Frequency of standing for people with standing devices.

down to 26% among those aged ≥ 65 years. The most common standing time was 30–60 minutes for people up to age 19 and 15–30 minutes for those 20 and older. The type of standing device did not seem to affect standing time, regardless of respondents' age.

Reasons given for standing

In all, respondents made 1167 selections from the list of statements concerning reasons for standing (see Table 3), for an average of 3–4 statements per respondent. The most frequent reasons given for wanting to stand were (1) to improve circulation (65%), (2) to improve well-being (64%), and (3) to reduce tension and stiffness (59%). Reasons for using the device were similar across the three respondent groups, with the exception of the statements *improve respiration* and *prevent deformities*, both of which were chosen less frequently by respondents who completed the questionnaire without assistance.

A total of 51 people made 59 open-ended comments, stating, for example, that standing makes the digestive system work better ($n = 18$), is a way to exercise their legs and muscles ($n = 15$), or could change their body position and straighten their body ($n = 9$). Other comments that occasionally appeared included “Standing prevents the formation of blood clots”; “Standing relieves the pain in my legs”; “I am standing for psychological, not medical reasons”; and “This is the advice of the physiotherapist.”

Perceived impact on well-being and quality of life

VAS ratings

The VAS ratings shown in Figure 3 indicate the level of agreement between a statement and the respondents' experiences of standing (0 = does not match at all; 10 = fully consistent).

Median response values for the 10 statements relating to the perceived influence of standing ranged from 1/10–9/10. The statements *Standing up gives a pleasant feeling in my body*, *Standing up makes me feel healthier*, and *Standing up increases my quality of life* were rated between 6/10 and 9/10. The use of standing devices contributed positively to respondents' perceived well-being and improved their QOL. The statements *Standing up makes me feel normal*, *Standing up increases my independence in activities*, and *When I am standing I am treated in a different way* received the lowest scores (1/10–2/10), indicating that respondents disagreed with them; the remaining statements received ratings between 3/10 and 5/10.

We observed only small differences among the three participant groups, except on two statements (Figure 3): *When I am standing I am treated in a different way*, which was rated about 1/10 if the respondent was the person doing the rating but 5/10 if someone else did the rating on the user's behalf, and *Standing up increases my independence in activities*, which was rated as fairly

Table 2 Frequency of Standing Related to Age, Gender, Diagnosis, Ambulation, Type of Device, and Time Elapsed Since Receiving the Prescription

Respondent characteristics	% of respondents		
	Almost or ≥1×/d	Several ×/wk	≤1×/wk
Age group			
0–6 y	96	4	0
7–12 y	73	17	10
13–19 y	69	28	3
20–49 y	54	36	10
50–64 y	45	31	24
≥65 y	51	37	12
Sex			
Male	58	32	10
Female	58	29	13
Diagnosis			
Congenital disability*	65	28	7
Acquired disability†	51	34	15
Undiagnosed/other‡	68	14	18
Able to walk with or without assistance			
Yes	68	25	7
No	56	31	13
Need for assistance with ambulation			
Independent	49	30	21
Some help required	57	35	8
Totally dependent	63	29	8
Type of standing device			
Standing shell	80	16	4
Standing frame	54	33	13
Standing frame with rear wheels	67	22	11
Tilt table	45	46	9
Standing wheelchair	50	28	22
Other	75	25	00
Time since prescription			
<6 mo	46	39	15
6 mo–2 y	53	38	9
2–5 y	56	29	15
5–10 y	63	25	12
>10 y	62	29	9

*Cerebral palsy, syndromes, multi-disabilities, spina bifida.

† Multiple sclerosis, amyotrophic lateral sclerosis, traumatic brain injury, stroke, virus, tumours.

‡ Persons with no diagnosis or an unusual diagnosis.

important (6/10) by respondents who completed the questionnaire independently but not important at all for those who completed it with assistance (1/10). It is noteworthy that respondents who completed the questionnaire with assistance gave the lowest ratings for 5 of the 10 statements.

Women's ratings were generally higher than men's, except for the statements *Standing up decreases the risk of getting fractures in my legs* and *Standing up makes it easier for me to breathe*, for which men gave slightly higher ratings than women.

EQ-VAS

Ratings of perceived health determined using the EQ-VAS thermometer indicate that respondents who com-

pleted the questionnaire without assistance and those who had someone else complete the questionnaire on their behalf had a median value of 70/100; for respondents who required assistance to complete the questionnaire, the median rating was 63/100.

DISCUSSION

Regardless of clients' ability to communicate or the severity of their impairments, it is important for professionals to listen to them, as well as their care providers—and, sometimes, to pay attention to what they are *not* saying²⁰—to ensure that the standing devices prescribed corresponds with the clients' real needs.

Extent of use

More than half of respondents used their standing device almost daily or more, and standing time was found to decrease with increasing age. Those who were totally dependent on others for ambulation and those who had received their device more than five years previously used it most often. Among the youngest respondents, 65% reported standing between 30 and 60 minutes each time, whereas only 25% of those aged ≥65 stood for so long. These findings coincides with those of Taylor,²¹ who found that most school-based physiotherapists prescribed 30–45 minutes of standing per day. The reason older people stand for shorter periods may be that their body function does not allow standing for longer periods; it may also be the desire of the user or the ease of achieving a standing position that makes a difference in the extent of use. There is a need for further investigation of disability, aging, and assistive devices through a life-span perspective.²²

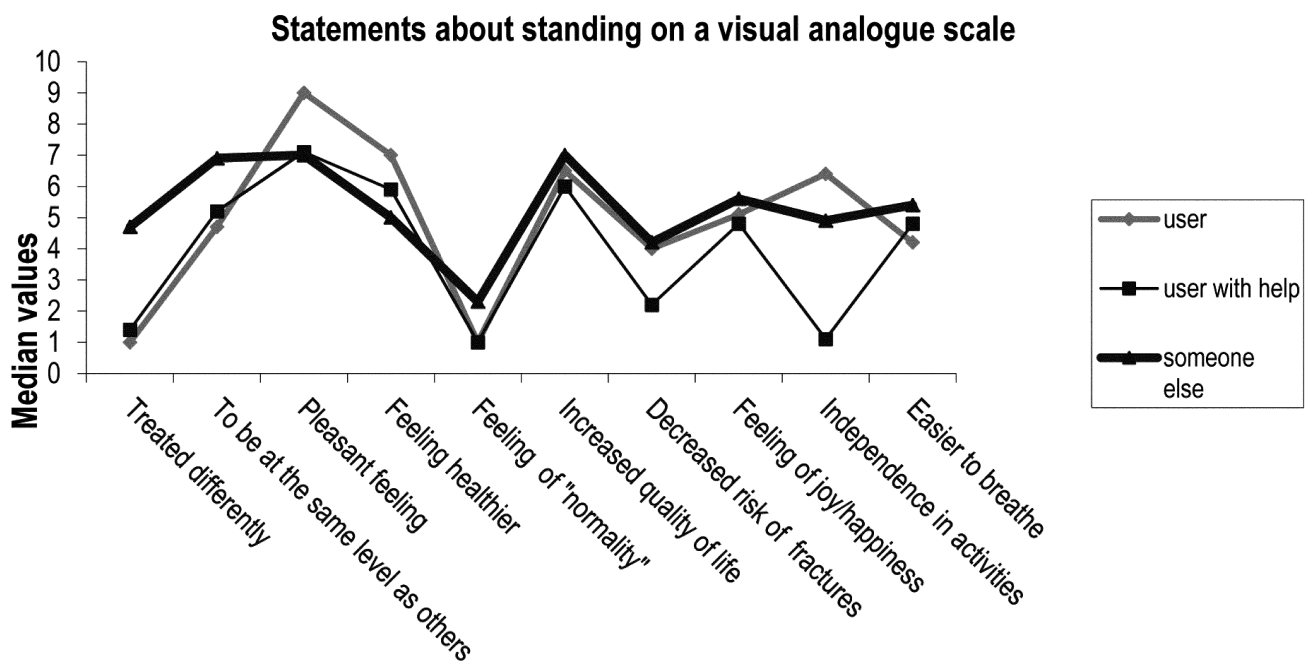
Type of device was connected to frequency of use. Standing shells were used most frequently by respondents with a congenital disability, of whom 62% were ≤12 years old. The first author's experience is that using a standing shell is time-consuming for some parents and children and that the device can be painful, as it needs regular adjustment. For other parents and children, the standing shell is the best standing device available. Huang,¹⁷ has shown that environment is an important influence on the frequency of use of standing devices by children.

Half (50%) of respondents with standing wheelchairs used their device almost every day, or even more frequently, but as many as 22% reported standing infrequently or almost never. One reason for this may be that a wheelchair with a standing function is very heavy, which can hinder manoeuvrability;²³ another could be environmental and contextual challenges.¹⁴ This high level of dissatisfaction and non-use suggests a need to improve the match between people and their assistive devices.^{24,25}

Respondents who were totally dependent on others for mobilization used their standing devices most often. This may be because they have assistance at home, or

Table 3 Reasons for Standing

Reason	No. (%) of respondents			
	All users <i>n</i> = 319	Group 1: Respondent without assistance <i>n</i> = 64	Group 2: Respondent receiving help <i>n</i> = 107	Group 3: Someone else answering on the user's behalf <i>n</i> = 148
Improves circulation	206 (65)	44 (69)	74 (69)	88 (59)
Improves well-being	203 (64)	42 (66)	68 (64)	93 (63)
Reduces tension/stiffness	188 (59)	39 (61)	62 (58)	87 (59)
Prevents deformities	132 (41)	14 (22)	40 (37)	78 (53)
Improves bone density	132 (41)	30 (47)	36 (34)	66 (45)
Improves respiration	99 (31)	10 (16)	36 (34)	53 (36)
Facilitates activities	77 (24)	14 (22)	28 (26)	35 (24)
Reduces risk of developing ulcers	58 (18)	13 (20)	23 (21)	22 (15)
Match the others	19 (6)	5 (8)	8 (7)	6 (4)

**Figure 3** Perceived influence of standing with ratings according to a visual analogue scale.

because standing has the most positive impact on body structure and function, activity, and participation for this group.¹³

Around 60% of respondents who had received their device more than five years previously were using it several times a day, daily, or almost daily. This finding may reflect the fact that, for these people, standing devices were not prescribed with the single aim of correcting or compensating for physical limitations, but also to provide the users' with the experience of a lived body.⁴ According to Scherer and Glueckauf,²⁵ the use of assistive technologies is most effective when the goals and needs of the clients and their care providers are known. It is

also important to consider environmental factors for the user.^{17,25}

Reasons given for standing

Regardless of who completed the questionnaire, standing seemed to give respondents feelings of well-being and positively influenced their circulation and stiffness. These results are consistent with those of other studies.⁵⁻⁷ Less than half of respondents chose *To prevent deformities* or *To improve one's bone strength* as reasons for standing; nevertheless, it is known that for people with spinal cord injuries, standing on a daily basis reduces the risk of fractures.²⁶ One comment that recurred several times

was that standing affects bowel function, an observation supported by several other studies.⁴⁻⁷ Spending several hours every day sitting in a wheelchair is strenuous on the body,²⁷ as noted in an interview-based study where participants mentioned that standing offers them a way to straighten their bodies out.⁴ Interrupting sedentary time with low-intensity activities such as standing appears to have positive effects on health.⁸ When goal-setting is considered in rehabilitation services, patients emphasize activities and participation, whereas professionals report goals that are mainly related to body functions and structures.²⁸ One important factor to consider when prescribing standing devices is that users' functional ability tends to deteriorate over time; continuous follow-up is necessary from a lifetime perspective.^{22,29}

Perceived impact on well-being and quality of life

Use of standing devices was rated positively with regards to perceived well-being and QOL. Ratings for the 10 statements followed a similar pattern across respondent groups, with 2 exceptions: *When I am standing I am treated in a different way* and *Standing up increases my independence in activities*. Differences in ratings for the first of these statements reveal that respondents did not view themselves as positively in a standing position as their care providers did. The second statement was important for respondents who completed the questionnaire without assistance but was indicated as not being important at all for those who required help. The levels of agreement with these statements align with our findings on perceived health, obtained with vertical the VAS thermometer, Equation 5D; this is perhaps because when health is perceived to be poorer, the level of activity a person is able or willing to engage in is lower. When therapists prescribe and evaluate assistive technology, the client's involvement is a prerequisite for enhancing QOL; however, the achievement of a high QOL does not necessarily require the use of such technology.³⁰

Ratings of statements about the perceived influence of standing were generally higher among women than men. This difference is interesting and could be investigated further by researchers focusing on sex-related issues. A recent study found no age- or sex-related differences in general attitudes toward medical technology in general and the use of assistive devices specifically.²⁹

One limitation affecting the generalizability of our findings is that 42% of potential participants did not respond to the survey. We do not know whether these non-respondents used their devices less frequently or were dissatisfied with them. Although respondents and non-respondents were quite similar in age, sex, and type of standing device, a second limitation is that non-respondents had fewer standing wheelchairs and standing shells than respondents. A third limitation is that the questionnaire was designed from a professional perspective, although the questions were developed based on indi-

vidual interviews with people who used standing devices and were intended for use with this group.⁴

CONCLUSION

Participants in this study ranged in age from 2 to 86 years, with varying diagnoses and different types of standing devices. Only one-fifth of respondents were able to complete the questionnaire without assistance, and only one-quarter were able to mobilise independently. The use of standing devices is essential for people with limited mobility, because this may be their only opportunity to alter their body position. For this vulnerable group, physiotherapists should pay attention to the negative effects of sedentary time and promote standing as a means of improving health experiences and QOL.

KEY MESSAGES

What is already known on this topic

Most studies about standing are concerned with people with spinal cord injuries and focus on standing as a way to exercise the body, examining the measurable effects of standing on different body structures and functions.

What this study adds

This study examines the characteristics of users of standing devices and provides data on the types of standing devices used and the degree of use, as well as users' reasons for standing, their experience with standing devices, how their use influences the user, and how important the standing position is to them. This study was intended to illustrate the use of standing devices from the point of view of both autonomous and non-autonomous users.

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