

The experience of standing frame use in people with progressive multiple sclerosis

Hendrie W^{1, 2}, Dennett R¹, Jarrett L^{1, 3}, Creanor S⁴, Barton A⁵, Green C⁶, Marsden J¹ and Freeman J¹

Background and Aim

- People with severe multiple sclerosis (MS) often find it difficult to stand independently, spending most of their day sitting down.
- Secondary complications resulting from immobility can be minimised if physical activity is increased.
- This qualitative study ran concurrently with a randomised controlled trial (RCT) evaluating the clinical and cost effectiveness of a home-based, self-managed standing programme using an Oswestry standing-frame in people with severe MS.
- It sought to explore the experiences of using a standing frame from the perspective of both the person with MS and their standing assistant.

Methods

- Participants (people with MS and standing assistants) were purposively selected using a sampling matrix and asked to use a digital audio recorder to diarise their experiences of using a standing frame throughout the 36 weeks of the study.
- They were asked to complete the audio diary, if possible during or after each stand to record reflections on how it felt to stand, changes they were experiencing, and any other comments they wished to make.
- Participants were not given a detailed guide of what to record so as not to direct responses.
- Recordings were transcribed verbatim and data were analysed thematically.

Results

- Twenty participants (twelve people with progressive MS (six female, aged 35 – 71 years) and eight carers (four female)) recorded their experiences.
- Analysis resulted in the emergence of four themes described here and supported by anonymised participant quotes:

“Feeling like the old me”

This theme encompasses the sense of normality gained from standing, and the physical, psychological and social benefits experienced. A key aspect of this was the enjoyment experienced as demonstrated by the following participant quote:

“It’s strange to say but it gives me a different kind of freedom because I don’t have to cling onto everything... Although I am strapped in, I am able to move and it’s really very enjoyable... it really has given me a sense of liberation. I am not completely confined to a wheelchair, I do walk with a rollator, but actually being upright is really most enjoyable.”

Jane, EDSS 7.0

“Noticing a difference”

The variety of changes people reported in their function as well as wide ranging symptoms such as spasms, strength, bladder and bowel function are captured in this theme.

“So, as far as the standing frame is concerned, posture’s improved, upper body movement has improved and I’m in a very good frame of mind.” James, EDSS 6.5

“I don’t have the spasms I used to have by any means. In fact I have really cut down on the Baclofen.... I’ve cut down on a load of my medicines. It’s the best thing ever.”

David, EDSS 8.0

“I have been able to get my jumper on and off without too much ado, so that was quite a big plus point. Especially now the weather is getting a little bit chilly...”

Simon, EDSS 8.0

“I want to do it right”

This theme reflects the value people placed on having guidance and support in establishing a standing programme that worked for them; including the importance of discussing issues such as the expected aches and pains that may be associated with starting an exercise programme.

“We were feeling a bit of, sort of, floundering in it... was he standing up completely straight? Was it alright to be leaning back on the back strap? Anyway, so it was very comforting to have the physiotherapist here, and she said the most important thing is his posture.”

Sophia, standing assistant of Simon, EDSS 8.0

“Today I used the frame for the first time, knees and back a bit sore when standing, but the feeling disappeared when I was back in my chair.”

Joyce, EDSS 7.5

“You have a good day, you have a bad day”

This theme highlights the issues faced by people living with a progressive and fluctuating condition in implementing a self-management programme. Many participants talked about how the unpredictability of their condition affected their ongoing ability to engage in the standing programme, and that this could change on a day-by-day basis.

[week seven] “I’d just describe this as my black dog days. I had very little energy, didn’t feel inclined to do much, it was just hard work the whole time... doing so well over the first few weeks... [three weeks later] I’m finding now, just slowly, that my muscles in my legs are responding a little bit better on a day to day basis while I’m walking around. They feel stronger and I’ve been able to walk a little bit further... [one month later] I’m actually struggling along to do the exercises. I’m not quite sure why this is; I think it may be a mental thing more than a physical thing.”

Justin, EDSS 6.5



Conclusions

- Use of a standing frame at home enabled people to incorporate regular self-managed standing within their lives, an activity many had not achieved for some time.
- Associated with standing were reported wide-ranging physical, psychological and social benefits.
- Provision of guidance and support are important to consider with programmes of this nature.