

The meaning of fabric orthoses to long-term users with multiple sclerosis: an Interpretative Phenomenological Analysis.

SNOWDON, Nicola, BOOTH, Susan, MCLEAN, Sionnadh <<http://orcid.org/0000-0002-9307-8565>>, WHEAT, Jonathan <<http://orcid.org/0000-0002-1107-6452>> and PIERCY, Hilary <<http://orcid.org/0000-0002-7663-8858>>

Available from Sheffield Hallam University Research Archive (SHURA) at:
<http://shura.shu.ac.uk/27742/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

SNOWDON, Nicola, BOOTH, Susan, MCLEAN, Sionnadh, WHEAT, Jonathan and PIERCY, Hilary (2021). The meaning of fabric orthoses to long-term users with multiple sclerosis: an Interpretative Phenomenological Analysis. *Prosthetics and Orthotics International*.

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

The meaning of fabric orthoses to long-term users with multiple sclerosis: an Interpretative Phenomenological Analysis.

Nicola Snowdon^{a*} (ORCID ID 0000 0003 1516 7009), Susan Booth^b, Sionnadh McLean^a,
Jon Wheat^c, Hilary Piercy^d

^aDepartment of Allied Health Professions, College of Health, Wellbeing and Life Sciences, Sheffield Hallam University, Sheffield, UK; ^b Bolton Foundation NHS Trust, Bolton, UK; ^cAcademy of Sport and Physical Activity, College of Health, Wellbeing and Life Sciences, Sheffield Hallam University, Sheffield, UK; ^dDepartment of Nursing and Midwifery, College of Health, Wellbeing and Life Sciences, Sheffield Hallam University, Sheffield, UK.

Address for correspondence: Nicky Snowdon, Senior Lecturer in Physiotherapy, Collegiate Crescent Campus, Sheffield Hallam University, S10 2BP, United Kingdom. E-mail: n.snowdon@shu.ac.uk.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Department of Allied Health Professions at Sheffield Hallam University.

Declaration of Conflicting Interests

The authors declare that there is no conflict of interest.

Acknowledgements

We are grateful to DM Orthotics Ltd and the MS Society UK for assisting with recruitment.

Abstract

Background

Fabric orthoses are elasticated garments designed to provide support to the musculoskeletal system. They may benefit people with multiple sclerosis, however, in this population, their acceptability is largely unexplored.

Objectives

This study aimed to explore the meaning that fabric orthoses hold for people with multiple sclerosis and factors influencing acceptability.

Study design

Qualitative methodology, using an Interpretative Phenomenological Analysis to explore the meaning ascribed to lived experience.

Methods

Four people with multiple sclerosis were interviewed in face-to-face semi-structured interviews. Two used upper limb orthotic sleeves for involuntary movement control, one used orthotic shorts and one a soft ankle brace. Three participants had fabric orthoses they no longer used. Themes were validated by peer review.

Findings

Two themes were identified. “Giving back control” describes how perceived physical benefits, such as decreased involuntary movement and improved stability, led to important benefits for autonomy and self-image. Orthoses were not worn longer-term where self-image was not improved. “Learning to live with an orthosis” captures the way in which participants learnt from experience over months or years about how to maximise effectiveness and overcome disadvantages. Acceptability was determined specific to the contexts in which the orthoses were used, with the social appropriateness of appearance and the demands of the tasks being important considerations.

Conclusion

Fabric orthoses can be acceptable to people with multiple sclerosis. Professionals should be mindful of the active learning process that users engage in, as they learn about the pros and cons of orthotic use. Further research into effectiveness is justified.

Word count: 250 words.

Background

Multiple sclerosis (MS) is a chronic, progressive neurological disease and is a leading cause of non-traumatic disability in young adults.¹ MS is characterised by uncertainty in longer-term prognosis and day-to-day variability.² This feeling of unpredictability is exacerbated by problems with sensory feedback, movement control and pain.³

Fabric orthoses are elasticated garments, designed to support parts of the body through compression and reinforced panels. Originally developed for use in children with cerebral palsy,⁴ a variety of fabric orthoses have been used with adults with stroke^{5,6}, MS^{6,7}, acquired brain injury⁶, spinal cord injury⁶ and degenerative cerebellar ataxia⁸. Fabric orthoses are theorised to function as a flexible exoskeleton that might improve stability, proprioceptive awareness and posture, without the loss of movement and sensory feedback that might occur with inelastic supports.^{5,9}

A limited body of evidence has examined the value of fabric orthoses for people with MS.¹⁰ Two previous studies included PwMS, both were mixed methods feasibility studies.^{6,7} Miller et al. investigated an upper limb orthotic sleeve compared to a placebo sleeve in PwMS and reported improvements in tremor (n = 21).⁷ Stone investigated orthotic socks and gloves as adjuncts to Botulinum Toxin in people with focal spasticity resulting from various pathologies, including one person with MS (n = 25).⁶ Their findings suggested that the fabric orthoses might enable greater goal

achievement than a thermoplastic splint.⁶ A further qualitative study interviewed practitioners familiar with fabric orthoses. In their experience, PwMS presenting with weakness, incoordination and poor sensation respond positively to fabric orthoses.¹¹

In order to be effective, fabric orthoses must be used and this depends on their acceptability to the user.¹² Acceptability is defined as “a multi-faceted construct that reflects the extent to which people delivering or receiving an intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses” (p1).¹² Miller et al and Stone captured experience of usage at the end of their trials, which lasted 9 and 12 weeks respectively.^{6,7} They reported perceived physical and psychosocial benefits, such as improved control, function and confidence, alongside some challenges with donning and doffing and with tailoring the fit of the garment.^{6,7} These offer valuable insights into short-term usage. However, MS is a long-term, progressive condition and orthotic devices are intended to be used long-term. Detailed insights into what it is like to live with an orthosis over several months or even years and what determines either continuation or discontinuation of usage are important and have not been explored previously in PwMS. This study addressed that gap in knowledge. Its aim was to determine the meaning that a fabric orthosis might hold for PwMS and to explore the factors that determine long-term acceptability.

Methods

The study was approved in October 2015 by the Research Ethics Committee of the Faculty of Health and Wellbeing, Sheffield Hallam University (Ref: 2015-6/HWB-HSC-5).

Study design

This qualitative study utilised an Interpretative Phenomenological Analysis (IPA). This approach seeks to determine meaning ascribed to experiences, which may help understand the motivations behind actions.^{13,14} The researcher aims to see an experience as the participant sees it, attempting to understand how they make sense of such experiences. A key feature of IPA is the double hermeneutic, the attempt to find meaning in the meaning that participants themselves attach to their experiences.

Sampling, recruitment and participants

Sample sizes in IPA studies are typically between three and six participants.¹³ This reflects the study aims, which are exploratory in nature, rather than aiming to create or test theory.

Participants needed to meet the following inclusion criteria: (1) confirmed diagnosis of MS, (2) have used a fabric orthosis regularly, for at least the preceding two months and (3) remembered their initial experiences with the orthosis. A fabric orthosis was defined as an orthosis (an externally applied device used to modify the structural or

functional characteristics of the neuromuscular system)¹⁵ manufactured from elasticated cloth fabrics. According to this definition, those using a custom-made device and those using an off-the-shelf product that they identified as a fabric orthosis were eligible to participate.

Participants were recruited through two routes. Firstly, through a UK manufacturer of fabric orthoses who sent invitation letters and an information sheet to all those clients they knew to have MS and fabric orthosis experience. Secondly, through the MS Society UK, who advertised the study on their webpage and provided a link to the information sheet. Six potential participants contacted the first author who answered their questions and ascertained eligibility (see Figure 1). Four participants were eligible and willing to be interviewed. They were recruited to the study by the first author, a neurological physiotherapist. As part of the process, she made it clear that she had no experience of fabric orthoses and no connection with the orthotic company. Written informed consent was obtained immediately prior to each interview.

Recruitment was stopped after eight months because no further responses to the recruitment strategy were forthcoming. The concept of data saturation was not used to guide sample size because this is not commonly applied in IPA, being considered inconsistent with the exploratory, idiographic aims of the methodology.^{16,17}

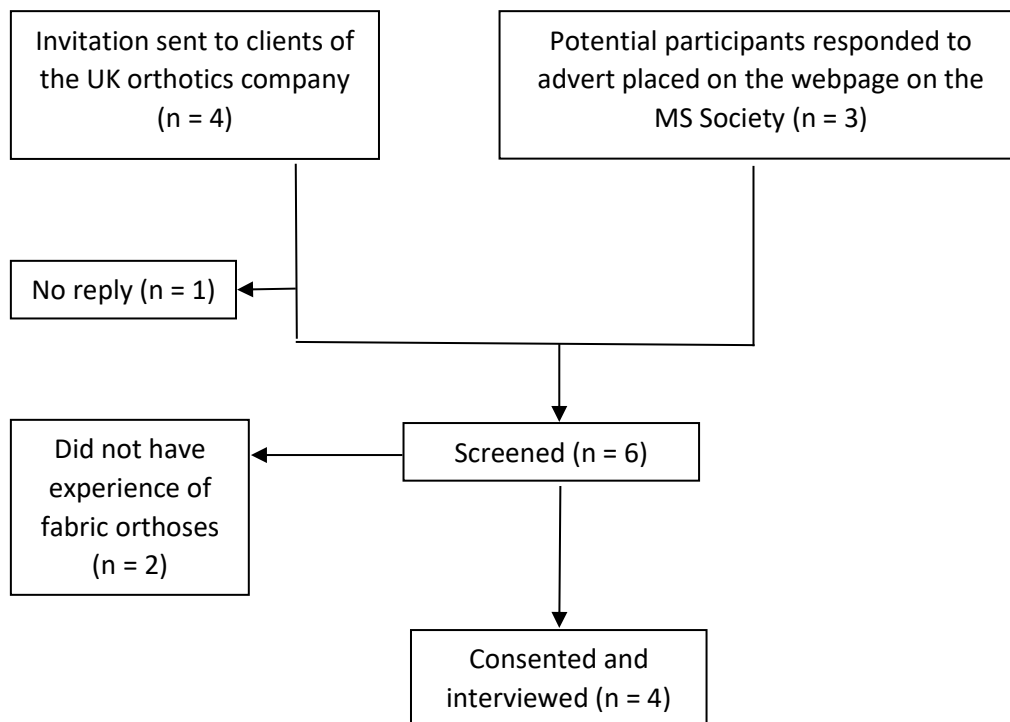


Figure 1: Flow chart showing recruitment process

Data collection

Data were generated using face-to-face semi-structured interviews, conducted by the first author. Interviews took place in a location of the participants' choice; three in participants' homes and one in a quiet café. Interviews were directed by a topic guide, designed by the first author, using guidelines for a phenomenological study.¹⁸ The interview initially covered the context in which the orthosis was provided and used. Later, it moved onto the deeper meaning of the orthosis, using open questions and responsive follow-up questions that encouraged participants to describe how they felt

with and without their orthoses at different times and in different contexts. Interviews lasted between 40 and 80 minutes (mean duration 55 minutes). Interviews were transcribed verbatim, from an audio recording, by the first author. In keeping with the principles of IPA, the first and third authors reviewed the topic guide after the first interview. They confirmed that it was effective in drawing out experiences and emotions relevant to the study aims and no changes were required.

Data analysis

Data were analysed as suggested by Smith et al.¹⁴ The first author read the transcripts repeatedly and annotated with exploratory comments, which were: (1) descriptive, taking the content at face value; (2) linguistic, exploring the potential significance of the words used and (3) conceptual, the possible meanings revealed by the participants. Exploratory comments were merged into emergent themes for each participant until these themes appeared to encapsulate the meaning of the orthosis and the factors perceived to be important to acceptability for that individual. Emergent themes were reviewed and approved by a co-author (HP), an experienced qualitative researcher. Emergent themes were compared across the four participants to identify superordinate themes.¹⁴ Following several iterations, superordinate themes were agreed that included the greatest number of emergent themes, mapped closely to the study aims and data and best expressed the commonalities across the participants' stories.

Trustworthiness and reflexivity

Trustworthiness is particularly important in IPA because this method encourages researchers to find their own interpretations of their participants' stories.¹⁹ In this study, trustworthiness was assured throughout data generation and analysis via four main strategies: (1) reflexivity, (2) prolonged engagement with the data, (3) a thorough analytical process and (4) an independent peer review of the data analysis.

Reflexivity was facilitated with a reflective journal, recording assumptions before and during data collection and analysis, and in-depth consideration of the impact of the interviewer on the data. Prolonged engagement with the data was achieved via transcription and extensive annotation. The second author conducted the independent analysis. She added her own exploratory comments to the raw transcripts and identified emergent themes, before comparing these to the emergent and superordinate themes agreed by the first and fifth author. The second author was satisfied that an IPA approach had been systematically applied and that data were accurately represented by the final themes.

Findings

A description of the participants and their orthoses is provided in Table 1. Two participants regularly used custom-made upper limb orthotic sleeves for control of involuntary movements. Two used off-the-shelf products to control voluntary

movement: one used a soft Neoprene ankle brace and one used compression cycling shorts. In addition to the fabric orthoses used regularly, three participants had experience of other fabric orthoses that they no longer used. Although unexpected, this enabled an important exploration of acceptability and meaning.

Two superordinate themes explained the meaning of a fabric orthosis for PwMS. These were "giving back control" and "learning to live with an orthosis". "Giving back control" included four subordinate themes: (1) the impact of MS, (2) reclaiming my body, (3) regaining autonomy and (4) maintaining my self-image. "Learning to live with an orthosis" included subordinate themes describing four stages through which participants adjusted to orthotic use: (1) initial experiences, (2) getting to know my orthosis, (3) compromising and adapting and (4) establishing routines.

Table 1: Participant characteristics and experiences of orthoses

Pseudonym	Age	Age MS symptoms started	Overview of presentation	Overview of functional ability	Fabric orthosis currently worn	Perceived effect of orthosis	Length of time orthosis has been used for	Where and when orthosis worn	Fabric orthoses trialled but not regularly worn
Sarah	32	14	Relapsing-remitting MS; poor balance; distal weakness left lower limb; poor dexterity, weakness, involuntary movement in upper limbs, worse on left.	Independent with daily living, walking independently, working full-time.	Upper limb sleeve - axilla to tips of fingers on left (non-dominant) arm.	Decreased severity of tremor.	18 years	All day, every day, at home and in the workplace.	Upper limb sleeve, axilla to wrist on right arm, provided for tremor control, 9 years before interview.
Rebecca	25	22	Relapsing-remitting MS, dystonia in right upper limb, poor proximal control.	Independent with daily living, walking independently with walking stick, able to run, working full-time.	Upper limb sleeve - axilla to tips of fingers, right (dominant) arm.	Decreased severity of dystonia.	2 years	When exercising at the gym.	Orthotic shorts and a shoulder support provided for poor proximal control at the same time as upper limb sleeve, 2 years before interview.
Marion	53	41	Primary progressive MS, ataxic right upper limb, weakness in trunk, left upper and lower limb.	Full-time wheelchair user, did not work, independent in transfers.	Off-the-shelf Neoprene soft ankle brace.	Prevented inversion of ankle during transfers.	1 year	Every few days, when left leg felt particularly weak.	Upper limb sleeve elbow to tips of fingers, provided for ataxia in right arm, 18 months before interview.
David	46	36	Relapsing-remitting MS, walking slow and unsteady, spasticity in both legs, weakness in right leg.	Independent with daily living, walking independently. seeking employment.	Off-the-shelf, mountain bike undergarment compression shorts.	Stabilised hips and improved control of walking.	1 year	All day, every day, at home and in the workplace.	Shorts manufactured by a UK orthotics company, trialled for hip stability, 1 year before interview.

Giving back control

The impact of MS

Participants explained how MS had affected them, physically and emotionally, to provide context for their orthotic use. Important aspects were a feeling of dissociation of one's body from oneself, a sense of distrust of their body and a feeling of loss of bodily control.

Dissociation of their body from themselves was evident for Sarah, Rebecca and Marion. Sarah and Rebecca used language such as "the left arm" and "the toes" as though they were talking about a separate entity. Rebecca talked about "eliminating the arm altogether" and exclaimed: "Forget about the arm, it's useless." Marion referred to her legs as "props".

The sense of distrust and loss of bodily control came across for all participants. They talked about how their bodies let them down and that they were unable to predict how their body might behave. David described falling down the stairs because his foot would seem to be secure when it was not: "thinking that everything's fine but not realising that I am stepping onto the edge". Marion suggested that her body was deliberately trying to deceive her: "I've just grown to accept that your muscles tell you lies with multiple sclerosis." Loss of control was particular evident for Sarah and Rebecca because of their involuntary movement. Sarah described the jerky tremor in

her left arm as "crazy", "wild", "random" and "literally uncontrollable". She described that the tremor "sparks" from her forearm and "spreads" throughout her arm, resulting in movement that was tiring, off-putting and embarrassing. Rebecca had dystonia in her right arm, which worsened with movement. She described her movement as "crazy", triggering in her right arm, before spreading to her trunk and "not being able to control what was going on".

Reclaiming my body

For all participants, there was a sense that orthoses gave them back control, making their bodies feel more part of them. Marion explained that her fabric ankle orthosis decreased her clonus, "stops that ankle from turning over" and "helps you to be conscious of where your foot is". Both Rebecca and Sarah felt that their upper limb sleeves decreased the amplitude **and spread** of their involuntary movements. Rebecca explained: "[the dystonia] tends to get triggered from my right side, so if that's controlled, the rest of the body seems to be OK". She summed up the effect of her upper limb sleeve by saying: "It just makes me feel like I am more in control." Similarly, Sarah described that her orthosis prevented the spread of her tremor: "If I didn't have my splint on, a tremor in my fingers would set off a tremor in my arm, which would set off a tremor higher up in my arm." Sarah felt the sleeve made the tremor "slower" so

that she could “overrule it” and know that her arm would remain relatively motionless by her side.

David had difficulty walking, with weakness and tightness in his legs and “problems with stability” around his pelvis and hips. He usually walked with a stick and would trip when his weaker foot caught the ground. Reflecting upon how his shorts improved his sense of stability, he reported:

"It was quite remarkable, the difference in my walking. It was a lot more even. I was a lot stronger in the mid-section. ... With the orthotic shorts, the limp more or less disappeared. I could feel that I wasn't wavering when I was walking, which was a big improvement, a huge improvement for me." (David)

Regaining autonomy

David, Sarah and Marion felt their orthoses improved their independence. David wore his shorts every day because he felt he needed them to walk and that they benefitted his posture, his ability to stand for long periods and to exercise: “If I don’t wear the shorts, my walking is absolutely the worst that it can be. Whether I am at the physio doing exercises or at work just doing things... I wear them all the time, because I know they make a difference, all of the time.”

For Sarah, tremor significantly influenced her function. Without the orthotic sleeve, she explained that she “wouldn’t be able to drive to go to work and I wouldn’t be able to use a keyboard”. Sarah wore her orthosis every day, all day and felt dependent upon it, explaining: “It’s very stressful knowing that I have one glove that I am hanging on to and if the zip breaks on it, then that’s me out.”

Marion related the improvement in control of her ankle posture to improved functional ability. Without support, her ankle inverted, leaving her unable to bear weight. She explained: “it’s so frustrating, when you’re there, trying to transfer and your ankle’s letting you down.”

Maintaining self-image

David, Sarah and Rebecca talked at length about the importance of how they appeared to others. For David, the appearance of his walking was extremely important and his shorts had a positive influence on his self-image. He believed the appearance of his walking had an impact on people’s perceptions of him, particularly considering that many of his colleagues were unaware of his diagnosis and that David’s work role was an important aspect of his identity. He explained: “I can’t take the risk at work of not wearing them. Without them on, it would just be horrendous. It definitely has an impact on people’s perceptions of you... I know because I can see their reactions. And... that just makes me feel even worse.”

For Sarah and Rebecca, how they appeared to others was an important part of living with involuntary movement. Sarah started with MS as a child, aged 14, and constantly strived to prevent others from seeing her tremor. She described that she “wanted to just be normal and fit in” and explained that the calming effect of her orthosis on her tremor improved her confidence and self-image: “[the orthosis] gave me a lot of confidence to go out to do things and more drive for the future really.” Rebecca was similarly self-conscious, explaining that when her arm was at its most severe she tried to stay out of public view: “My arm will be in a state that it's not going to be seen.”

Rebecca’s decisions around whether to wear or not wear her orthoses seemed strongly linked to appearance. She would wear her orthotic sleeve only at the gym when her dystonia was exacerbated and where close-fitting clothing was commonly worn by others. However, she disliked the appearance of her rarely-worn shorts and shoulder wrap, explaining “You've got to try and hide them” and describing the shorts as “high-waisted” and “not elegant”. She worried that her shoulder wrap was visible beneath her clothing and that wearing extra layers caused her to perspire visibly. Both of her rarely worn orthoses had, on balance, a negative influence on her self-image.

Sarah had adjusted over time to wearing a visible orthosis, describing that when she was younger, she chose clothes that concealed it. More recently, she was less self-conscious, describing her orthosis as “part of me”. Nevertheless, when tremor began

in her right arm, she did not want a second orthosis. Partly, a second orthosis felt like confirmation of her deterioration but she also expressed concern around how others might view her:

“When it was talked about having a second garment on my right arm, the big thing for me was that I didn't want to be seen with two.” (Sarah)

Learning to live with an orthosis

The participants' stories gave the sense of a journey travelled with the orthosis, during which participants were actively engaged in a learning process. This second superordinate theme is structured around that journey and is informed by experiences with both the orthoses that they used and those they no longer used.

Initial experiences

Sarah, Rebecca and David described their initial experiences with fabric orthoses as experiments. Sarah explained: "It was almost a bit of an experimental thing on me. It was like, 'let's try it.'" In Sarah and Rebecca's accounts, use of "we" and "us" implied collaborative experimentation with their healthcare professionals. Rebecca's phrase "we were just playing around", makes Rebecca and her therapist's experimentation appear random, as though they were trying anything.

For all the orthoses used in the longer-term, there was some change to movement when the orthoses were first worn. The language of “experimentation” implies that neither participants nor their therapists were expecting a positive effect. This is supported by David’s description of his physiotherapist’s response: “(My physio) made independent observations of her own and said ‘wow’ these really do seem to make a difference.”

Marion’s first experience of her, now unused, orthotic upper limb sleeve contrasted with this sense of collaborative experimentation. She was given her sleeve in a research study and her language indicates that she had not been actively involved in this. She used phrases including “they suggested”, “they wanted to try the sleeve” and “they were hoping for me to have a steadier arm”. There were no indications of collaborative problem solving and, indeed, Marion explained that her unsteadiness was not really problematic for her. She could overcome the unsteadiness of her right arm, by holding her right arm with her left: “If I am doing that, I am quite steady”.

Sarah and Rebecca used their orthoses to control involuntary movement and both described an initial period of adjustment to the sensation of wearing the orthosis. For example, Sarah explained that “It is going to feel like an alien thing on your body but you have to be quite patient with it” and Rebecca reported that “the first time they put it on... it took a while to settle”.

Getting to know my orthosis

Following their initial experiences, participants continued to learn about how and why their orthoses might work and how best to achieve positive effects. For example, participants commented on the importance of a tight fit, relating this to the orthoses' ability to provide support and control. Sarah explained that as her splint loosened with age, she could "tell the difference. I start to lose certain abilities". Similarly, Rebecca explained that she had lost weight since her orthoses were first fitted so that: "They are not as tight as they used to be, so they don't do as much as they should". Marion described experimenting with the fit of her ankle support as "just getting to know it" so that it was "tight enough to do its job".

Sarah and Rebecca described orthoses as replacements for physiotherapy. Sarah had experienced her physiotherapist inhibiting her tremor by holding the point in her arm where the tremor originated. She said her orthotic sleeve felt as though "someone had got hold of my arm". She had joked with her physiotherapist about taking her everywhere to inhibit the tremor and felt that the orthotic sleeve had enabled this. Rebecca described her recovery from an earlier relapse and how a physiotherapist would hold her as she walked, improving her confidence and providing feedback through their hands. She felt her orthotic shorts provided a similar feeling, suggesting

“you are getting that kind of feedback constantly” and “you’re able to continue doing stuff because of that”.

David’s experience differed from the other participants, in that having trialled shorts manufactured by an orthotics company in a physiotherapy session, he recognised similarities between these and the compression cycling shorts he used to wear when mountain biking. His mountain biking shorts became his regular orthosis. He explained that his shorts worked by providing “greater support to the core” and that this reduced the cognitive effort of walking:

“What I find particularly draining as it were is that I have two things to think about at once. Number 1, picking my feet up and moving forwards without tripping over myself but number 2 is the wobbliness as well and taking care of that wobbliness actually is a lot more than it seems because suddenly I don’t have to worry about one thing, I can just concentrate on the other”. (David)

Compromising and adapting

Sarah, Rebecca and Marion explained disadvantages to orthotic use, particularly in comparing the orthoses they no longer used and the orthoses they still use. They appeared to be compromising, weighing up the advantages of orthotic use against the

disadvantages. Where they continued wearing their orthosis, they explained how they had adapted either the orthosis or their activities to minimise the disadvantages.

Sarah's upper limb sleeve was tighter than recommended by her orthotics provider. She felt this was necessary for the sleeve to be effective but it caused disadvantages such as fatigue, soreness and pins and needles. She stressed that she accepted these risks and that the fact that she coped with these difficulties indicated how important the orthosis was to her. She explained: "I make that choice to wear it all day."

The upper limb sleeves experienced by Sarah, Rebecca and Marion all had integral gloves and this caused difficulties with hygiene. Sarah described wearing a rubber glove over the orthosis whilst cooking, to keep it clean. Marion explained that being unable to wash her hand easily was the main reason she stopped wearing her upper limb sleeve. She had tried wearing her sleeve "on and off for several months" but explained that she stopped wearing it because of the problems with hygiene, considered alongside her perception that it was ineffective: "Every time I went to the loo, I would take it off and I did get to the point where I didn't put it on. I didn't put it on and it didn't really do what it was supposed to do anyway."

In most of the interviews, participants had decided what they would continue to use and what they would not. However, after two years of experience, Rebecca still seemed uncertain about whether she should use her orthotic shorts. Alongside the

aforementioned issues with appearance, she found the shorts uncomfortable. Even though she was certain that they were beneficial for her, she explained that she preferred to manage without them.

"I walk quite badly without my stick. When I am at my worse, my legs just kind of turn in and I kind of walk a bit weird. The shorts can kind of counteract that... I should probably wear them more often, they would probably help... but I just battle on and get through it." (Rebecca)

The feeling of adapting the orthosis to get the most out of it, whilst minimising the disadvantages appeared important. Sarah described a lot of "toing and froing" when she was younger, trying to get the fit and the design of her sleeve correct. Marion was able to adapt her ankle support herself, to "play around to make sure it wasn't too tight". Marion described ideas for adapting her now unused upper limb sleeve, including redesigning the glove to make it easier to remove "if it maybe went over one finger" and to stabilise higher up her arm to where she perceived her instability was worse: "If it did include the elbow, it may have given me a little bit more reach". However, she had been unable to explore these adaptations with the orthotics provider.

Establishing routines

This theme captures the routines involved in using an orthosis and the routine of discontinued use. Routines of orthotic use included basic practical strategies, such as ensuring the orthosis was ready for use, washing, drying and storing the orthosis. For example, Rebecca's sleeve belonged in her gym bag and was washed after every gym session so that she never went to exercise without it. Sarah wore her orthotic sleeves all day, every day, therefore kept two sleeves so that one could be drying whilst she wore the other. Marion did not wear her ankle support every day, but she still described a routine. She would exercise her legs in bed, first thing in the morning, to decide whether to wear the orthotic or not: "it helps me to gauge what I am going to be able to do. I can sort of say 'Oh that feels weak today' and then I'll put it on straight away."

Sarah probably faced the greatest challenges in using her orthosis because it seemed far tighter than those used by other participants. She had established an extensive repertoire of coping strategies. These included her choice of clothing and her habit of always keeping talcum powder in her holiday bag, to enable the orthosis to be fitted in a hot climate. She conveyed a sense of pride in her ability, describing herself as "a bit of a pro". Her sleeves needed replacement every six months and this itself had become

a routine. Coping with the challenges of orthotic use contributed positively to her self-image.

"Whenever anybody measures them, I am quite good at knowing whether that fits or not... [I say] you are talking to someone with experience and I need it that tight."

(Sarah)

Where an orthosis was felt to have a negative influence on self-image, such as Sarah's second upper limb sleeve and Rebecca's shorts and shoulder wrap; or where the balance between the pros and cons weighed against orthotic use, a routine of disuse became established. Rebecca still kept her shorts and her shoulder wrap but explained that they "look pretty new, if I am honest". Marion's upper limb sleeve was located immediately prior to her interview but only after an extensive search of cupboards and drawers.

Discussion

This study provides the first perspective on long-term acceptability and use of fabric orthoses by PwMS. The findings show how fabric orthoses support PwMS in their daily lives, particularly with respect to their autonomy and self-image, as well as how they learnt about the positives and negatives of orthotic use in a range of activities and contexts. Some findings are similar to those found in previous research. For example,

Miller et al and Stone also found that benefits are both physical and psychosocial and that fabric orthoses could enable a sense of improved control.^{6,7}

The current study provides several new insights into the experience of using a fabric orthosis. Our findings show that fabric orthoses were used in the longer term when the physical benefits led to a positive influence on self-image. That positive influence came from the fact that the fabric orthoses enabled study participants to occupy social positions, at work, at leisure and within their homes, that they did not feel they could occupy without their orthoses. Where fabric orthoses were perceived to have a negative influence on self-image, they were no longer used. “Assistive devices”, a term applied to any device used to maintain or improve an individual’s function and independence, including walking aids and orthotic devices and devices that assist feeding, washing or dressing²⁰ have similarly been found to have a positive effect on self-image.^{21,22} However, the visibility of assistive devices is commonly reported by those with MS as having a negative influence on self-image because of their stigmatising effect, which leads to disuse.^{23,24} These negative influences will not apply to orthotic devices that are largely invisible, resulting in a more favourable balance of influence. Fabric orthoses may be particularly helpful, therefore, for those with MS, because it is the balance of influence on self-image that largely determines acceptability and long-term use.

The Sekhon et al definition of acceptability suggests that users will either consider an intervention to be appropriate or not.¹² Our findings, which offer a long-term perspective on acceptability, indicate that this binary distinction is overly simplistic. Rather, the decisions around the continued use of a fabric orthosis are complex and made over several months or years. The appropriateness of an orthosis may be activity or context specific. It may depend upon factors such as the suitability of their appearance in a specific social context, the requirement for hygiene where the orthosis covers the hand and other task-specific demands.

Our findings indicate that the initial period of adjustment to wearing an orthosis described in previous fabric orthosis studies^{6,7} is, in fact, a more drawn-out active learning process. Our participants formed their own ideas about how their orthoses worked; they learned from their own experience about how to maximise effectiveness and how to overcome the disadvantages. To our knowledge, this active learning process has only been identified before in one previous study. In that study, Functional Electrical Stimulation (FES) was used as an orthotic device for foot drop in PwMS and the researchers investigated experiences after 12 months of use.²⁵ The specific technological skills and understanding associated with electrode placement may explain the prolonged learning process associated with FES. This does not apply to fabric orthoses but, nevertheless, the process of experiential learning appears similar

and equally important. An appreciation of this active learning process is important for practitioners, in order that it can feed into consultations and improve collaborative decision making. It may be that this learning process is common across other devices and this merits further investigation.

Strengths and limitations

Given the range of custom-made and off-the-shelf orthoses used by study participants to address a range of physical impairments, the findings reflect commonalities across devices. Consequently, their applicability to specific orthoses may be limited. The initial experiences of usage described by participants were quite distant memories for some. Their recall and the meaning ascribed to these experiences will have been influenced by the passage of time. Recruitment via an orthotics company may have introduced some selection bias but this was offset by also recruiting through the MS Society. The overall study design was oriented towards those with a positive outlook on fabric orthoses which may have produced unbalanced accounts. This was mitigated by the interview approach and the unforeseen opportunity to capture experiences of little-used orthoses and routes to discontinued usage. Finally, the small sample size and the methodology chosen limit the diversity of experiences captured.

Conclusion

This study found that the key meaning ascribed to a fabric orthosis by long-term users is that of regaining control over one's autonomy and self-image. This was crucial for acceptability in that, if benefits to self-image were perceived, then users learnt from their own experience about how to maximise the benefits and overcome the challenges of orthotic use. The balance between the positive and negative effects of an orthosis is determined on an individual level and is heavily influenced by context and the demands of specific activities. Findings indicate that professionals might maximise acceptability through good collaborative practice and by acknowledging the importance of self-image. Further research into the effectiveness of fabric orthoses in MS is warranted. Such studies should include assessment of psychosocial effects and may benefit from a follow-up assessment at six months to one year after provision.

Word count = 5261 words

References

1. Browne V, Chandraratna J, Angood J, et al. Atlas of Multiple Sclerosis 2013: A growing global problem with widespread inequity. *Neurology* 2014; 83:1022–1024.
2. Dennison L, McCloy Smith E, Bradbury K, et al. How do people with multiple sclerosis experience prognostic uncertainty and prognosis communication? A qualitative study. *PLoS One* 2016; 11.
3. Vickers M. Life and work with multiple sclerosis (MS): The role of unseen experiential phenomena on unreliable bodies and uncertain lives. *Illn Crises Loss* 2009; 17:7–21.
4. Nicholson J, Morton R, Attfield S, et al. Assessment of upper-limb function and movement in children with cerebral palsy wearing Lycra garments. *Dev Med Child Neurol* 2001; 43:384–391.
5. Watson M, Crosby P and Matthews M. An evaluation of the effects of a dynamic Lycra® orthosis on arm function in a late stage patient with acquired brain injury. *Brain Inj* 2007; 21:753–761.
6. Stone K. *Dynamic Elastomeric Fabric Orthoses (DEFO) and physiotherapy after Botulinum Toxin (BT) in adults with focal spasticity: a feasibility study using mixed methods*. PhD thesis, University of Essex, UK, 2014.
7. Miller L, van Wijk F, Lamont L, et al. Sensory dynamic orthoses in mild to moderate upper limb tremor in multiple sclerosis: a mixed methods feasibility study. *Clin Rehabil* 2016; 30:1060–1073.
8. Serrao M, Casali C, Ranavolo A, et al. Use of dynamic movement orthoses to improve gait stability and trunk control in ataxic patients. *Eur J Phys Rehabil Med* 2017; 53:735–743.
9. Matthews M, Blandford S, Marsden J, et al. The use of dynamic elastomeric fabric orthosis suits as an orthotic intervention in the management of children with neuropathic onset scoliosis: A retrospective audit of routine clinical case notes. *Scoliosis Spinal Disord* 2016; 11: 14–24.
10. Snowdon N, Sier D, Potia T, et al. Compression garments and fabric orthoses for rehabilitation and function: a systematic mapping review. *Int J Ther Rehabil* 2018; 25:655–664.
11. Hassan A and Snowdon N. Clinicians' perceptions and experiences in using Lycra garments with patients with neurological disorders. *Int J Ther Rehabil* 2015; 22: S7 – S7.

12. Sekhon M, Cartwright M and Francis J. Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. *BMC Health Serv Res* 2017; 17:88.
13. Finlay L. *Phenomenology for therapists: researching the lived world*. Chichester: Wiley-Blackwell, 2011.
14. Smith J, Larkin M and Flowers P. *Interpretative phenomenological analysis: theory, method and research*. London: SAGE, 2009.
15. Ponton FT. Orthotics. In: Goodwill CJ, Chamberlain MA and Evans C, (eds) *Rehabilitation of the physically disabled adult*. Cheltenham: Stanley Thornes, 1997.
16. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 2018; 52: 1893–1907.
17. Manen M, Higgins I and Riet P. A conversation with Max van Manen on phenomenology in its original sense. *Nurs Health Sci* 2016; 18: 4–7.
18. Bevan M. A method of phenomenological interviewing. *Qual Health Res* 2014; 24: 136-144.
19. Rodham K, Fox F and Doran N. Exploring analytical trustworthiness and the process of reaching consensus in interpretative phenomenological analysis: lost in transcription. *Int J Soc Res Methodol* 2015; 18: 59–71.
20. World Health Organisation. *International classification of functioning, disability and health (ICF)*. Geneva: World Health Organisation, 2002.
21. Copolillo A, Collins C, Randall N, et al. The impact of experience and heuristics on everyday decisions to use mobility devices: the need for control in nine African-American older adults. *Phys Occup Ther Geriatr* 2001; 20: 57–74.
22. Pape T, Kim J and Weiner B. The shaping of individual meanings assigned to assistive technology: a review of personal factors. *Disabil Rehabil* 2002; 24: 5–20.
23. Ploughman M, Godwin M, Stefanelli M, et al. The path to self-management: A qualitative study involving older people with multiple sclerosis. *Physiother Can* 2012; 64:6–17.
24. Squires L, Williams N and Morrison V. Matching and accepting assistive technology in multiple sclerosis: A focus group study with people with multiple sclerosis, carers and occupational therapists. *J Health Psychol* 2019; 24:480-494.

25. Renfrew L, Flowers P, Lord A, et al. An exploration of the experiences and utility of functional electrical stimulation for foot drop in people with multiple sclerosis. *Disabil Rehabil* 2020; 42: 510 - 518.