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Comfortably Numb? Experiences of People with Stroke and Lower Limb Sensation Deficits - Impact and Solutions.

Abstract

Purpose: To explore personal experiences of loss of foot sensation following stroke in order to inform the focus of clinical assessments and development of a vibrotactile insole.

Methods: Qualitative design with an interpretive phenomenological approach to data collection and analysis. Eight community dwelling adults with stroke (>6 months) and sensory impairment in the feet participated. Data was collected via conversational style interviews which were transcribed and analysed using a thematic framework. Themes were verified with co-researchers and a lay advisory group.

Results: Data formed four themes: Sensory deficits are prevalent and constant, but individual and variable; Sensory deficits have a *direct* impact on balance, gait, mobility and falls; Sensory deficits have consequences for peoples' lives; Footwear is the link between function, the environment and identity. They embraced the concept of discrete vibrotactile insoles, their potential benefits and demonstrated a willingness to try it.

Conclusions: Sensory deficit contributes to effects upon physical function, mobility and activity. Clinical outcome measures need to capture the emotional, psychological and social impacts of sensory deficit. Participants demonstrated a resilience and resourcefulness through adaption in daily living and self-management of footwear. The participants focus on footwear provides the opportunity to develop discrete and non-burdensome vibrotactile insoles for this patient group.

Key words: Foot, mobility, sensory loss, footwear, vibrotactile insoles, stroke

Introduction

The sensory impairments that occur in many people following stroke (1) are known to affect function and reduce the likelihood of regaining independent mobility (2, 3). Feedback from mechanoreceptors in the sole of the foot provides information about pressure distribution and body lean (1, 2). A relationship between reduced lower limb sensation and balance impairment has also been shown (4, 5). Sensation from the feet is, therefore, important for controlling balance and walking. Augmenting these sensory inputs, through vibrotactile or textured insole interventions, has been postulated, and in some cases shown, to improve standing balance for older adults (6) and stroke survivors (7).

However, contrary to best practice recommendations that interventions target specific impairments (8), sensory assessments used in clinical practice take little account of the precise manner in which the impairments affect patients' personal interpretation of their sense of balance, mobility and safe ambulation (3). Further, while 98% of clinicians indicate they treat sensory impairments, fewer than 30% assess these impairments to inform treatment selection (9). The impact of impaired sensation may include the primary sensory deficit, the motor deficit plus compensations for it, real and perceived, and other factors such as the specific environment, choices of footwear design/materials, and the requirements of daily living (e.g. caring for self or others).

Whilst technology such as stimulating insoles may address sensory deficits and their impact on balance (6, 7), adoption of new/any interventions is, in-part, down to patient's willingness to integrate these into their highly personalized daily routines and coping strategies. Before interventions are developed and in order to ensure the adoption of technology, there is a need to understand peoples' daily routines, experiences of living with impairment and the impact it

has on their lives. Indeed, these factors should inform intervention design as much as the clinical presentation of sensory loss and be the focus for patient assessment.

Peoples' experiences of foot and ankle impairments, the consequences of these and their experience of the interventions provided, such as Ankle Foot Orthoses [AFO], and Functional Electrical Stimulation [FES] have been explored previously (10). This previous study showed that the impairments had significant impact on the physical, social and psychological aspects of the participants' lives but that the interventions were limited in their success. This resulted in persistence of their visible impairments, negative physical appearance and low self-esteem. Personal insights clearly have the potential to inform the design and deployment of interventions which promise to improve participation in society and thereby limit social isolation. Interventions that can be housed in footwear, such as vibrotactile or textured insole interventions may reduce the impact of a visible intervention whilst achieving the aim of improved balance, mobility and hence participation and social activities.

Therefore, the aim of this qualitative study was to specifically explore personal accounts and experiences of loss of sensation in the feet and balance following stroke as a pre cursor to informing physical, social and psychological assessments and the design and development of a vibrotactile insole for people with stroke.

Methods

Prior to the commencement of data collection, ethical approval was granted from the University of Salford Research Ethics committee (Reference HSR1617-96).

A qualitative approach to both data collection and analysis was chosen in order to meet the aim of the study, with the underpinning philosophical approach being interpretivistic

phenomenology (11). This approach aims to provide detailed accounts of personal lived experience in its own terms rather than one prescribed by pre-existing theoretical preconceptions.

In line with the smaller sample sizes required for qualitative research, 8 participants with stroke participated (10). A purposive sampling framework was applied in order to achieve maximum variation in terms of age, gender, time since stroke or brain injury and experience of using interventions with the inclusion criteria being:

- people with confirmed diagnosis of brain injury (including haemorrhagic stroke and acquired/traumatic brain injury)
- more than 6 months' post-injury
- Aged over 18
- able to give informed consent and agree to share their experiences, perceptions and opinions

Exclusions:

- those with severe aphasia/communication impairments

All participants were recruited from a community support network known as the Brain and Spinal Injury Centre (BASIC) located in Salford UK.

An advisory group of people with stroke and brain injury worked closely with the research team in order to identify, develop and refine the interview questions (12), which also reflected topics identified within a review of the literature. All the interviews were carried out by a research Physiotherapist (HL) who also had clinical experience of managing people following a stroke.

The interviews were carried out at BASIC in a private room. The ‘conversational’ style interviews were initiated with two opening questions and questions to encourage conversation on the main topic areas (Table 1). A prototype vibrotactile insole was used to demonstrate the type of intervention that could be fitted into footwear.

Table 1 – Opening Questions and Topic Questions

The interviews were digitally recorded and field notes were taken to supplement the data. In order to maintain confidentiality each participant was referred to by a numerical value e.g.: P1 for participant 1. The interviews were transcribed verbatim and then checked against the audio recordings for accuracy. The field notes provided additional data reflecting context for the narrative provided by the patient (e.g. tone of voice, context for the use of language). Post transcription, the data was analysed by the researcher (HL) in an inductive manner and themes created (13). Trustworthiness and credibility of the interpretations of the transcripts was achieved through two of the researchers (HL and AW) agreeing themes and then presented to co-researchers and the advisory group in order to verify them by ensuring that decisions were evaluated and defended.

Results

All 8 participants were independently mobile in the community, 7/8 used a stick. Two were current insole users with another two having past experience of insole use. Ankle foot orthoses/calipers were worn by 3/8, with 2/8 having previous experience of a device. Functional Electrical Stimulation (FES) was used regularly for foot drop by one participant, with another 2/8 having tried it but not adopted its use. The eight participants are fully described in Table 2.

Table 2 - Participant profiles

Four themes emerged from twenty-four sub themes which then informed one global theme (Figure 1)

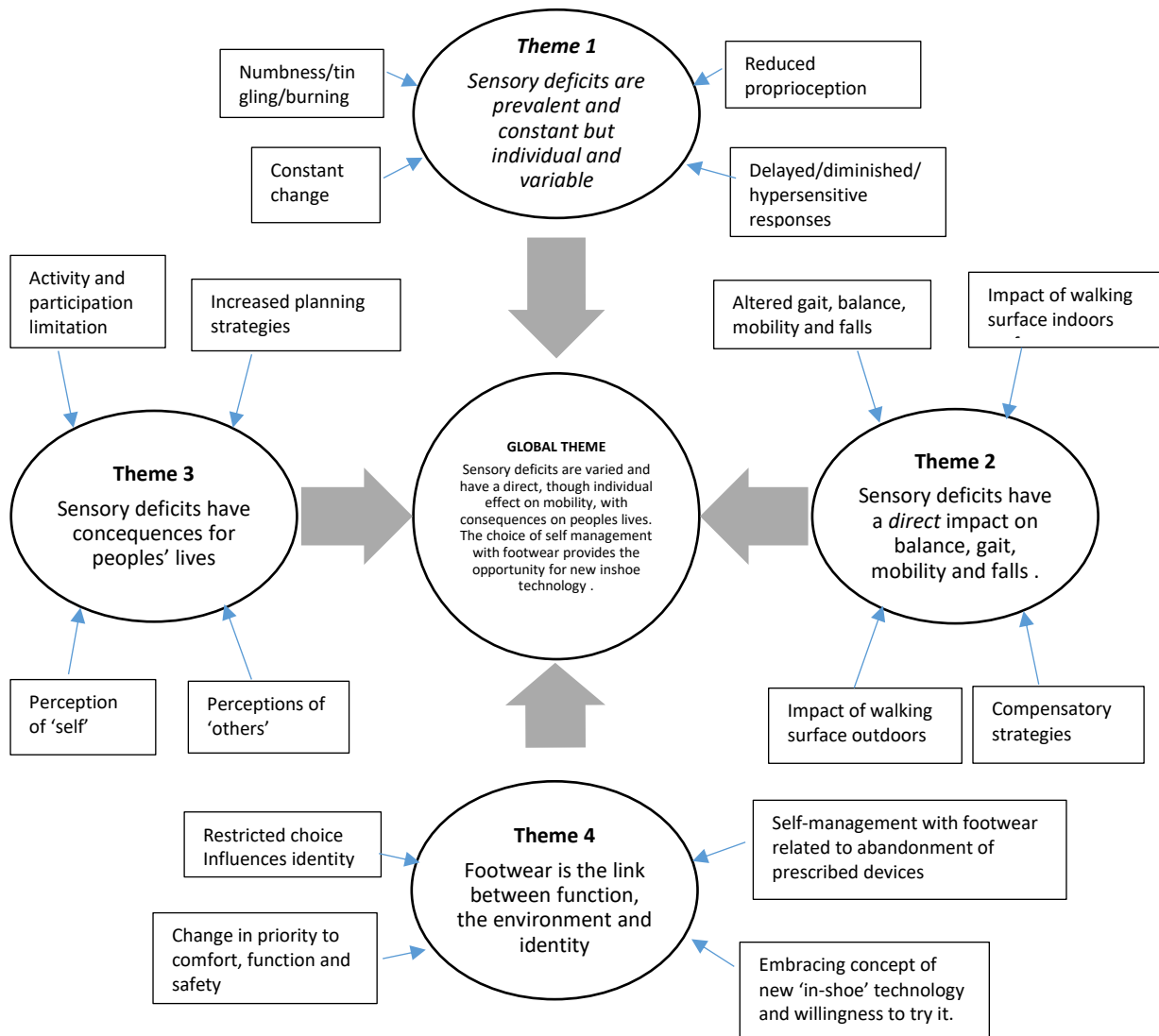


Figure 1. Thematic framework of sub themes, themes and a global theme

The themes and subthemes represented in Figure 1. Verbatim extracts from the transcripts underpin the commentary and represent a good spread of participant views.

Theme 1 – Sensory deficits are prevalent and constant but individual and variable – “It never feels like the other foot” (P1)

All of the participants experienced some sort of sensory deficit, describing it in various ways P7 describes, “...it’s as though you are feeling it from a distance...dulled”, and descriptions such as “...muzziness and fuzziness” (P3), and “a denser feeling” (P1) who also described it as being different to her other foot “...the sensation is completely different” (P1). Participants commented about a broad range of sensory deficits including surface pressure (both light and deep touch), vibration, temperature discrimination and proprioception. An example of this was revealed by P5 who states that her foot has “...a bigger reaction to the temperature”. Further, P7 reported that it can manifest as slower recognition, similarly described as “...delayed...” by P8 and “...reduced by 50%” by P6.

The sensory problems varied greatly including numbness, pins and needles, loss of proprioception and hypersensitivity but were very specific to each individual. Hypersensitivity was described by P5 as “...a very heightened sensation” and by P8 as “...spikes...” in sensation. An example of this is reported by P7:

“...my left foot, the delayed reaction, suddenly it realises there’s something touching it, it can’t work out the difference between a light touch, a heavy touch, something sharp, whether it’s burning or whatever, so it immediately jerks the foot away to be on the safe side, I suppose. A defense mechanism almost.”

Another issue raised by many was reduced proprioception in the foot and ankle. As revealed by P4:

“... I’ve got to really convince myself that the foot’s on the floor and it’s ready to take the weight.”

“Sometimes when my physio asks me to put it in a certain place, I can’t always tell because I can’t feel my foot in that position... without looking at it. If I can’t see where it is, I can’t tell where I am” (P1).

The problem with the positioning of feet can further affect stability and safety, as P6 recalls:

“Sometimes do you look down and it’s over or it’s in a strange position and you think, ‘Oh, didn’t know’ because you’re not getting feedback right”.

The extent of the deficits experienced were many and varied to the extent that being constantly aware of sensations and had become participants’ ‘new normal’. This constant awareness was accepted as part of daily life when living with lower limb sensation deficits yet was met with mixed reactions from participants. P7 reports living with constant sensory issues, *“...it’s all the time. From the time I get up till the time I go to sleep basically”*, and for P3 *“I’ve had pins and needles for four years. And that’s a bit irritating”*. However, some participants welcomed feeling anything as their ‘normal’ has been shifted, as P8 reveals, *“...Oh, I love pins and needles when I do get it, I love it because it’s a normal thing for my feet”*.

Many participants experienced mixed sensory problems with both reduced sensation and hypersensitivity present in the same foot, as described by P6 as *“...the top of my foot is more sensitive to anything... but the sole...It’s less but I do feel it”*. Specific areas can be affected

such as the sole, or toes, and can incorporate more of the lower leg such as the ankle, but is varied and individual across all participants. Half of the participants reported both reduced sensation and hypersensitivity creating a picture of mixed sensation as experienced by P1, *“Sometimes it’s incredibly hypersensitive and other times it’s a kind of, I can’t always feel anything, or feel much”*. Variation was also discussed in relation to different times of day as well as variance from day to day.

Theme 2 – Sensory deficits can have a *direct* impact on balance, gait, mobility and falls -

“I’ll walk for a few yards and then I have to stop, make sure everything’s in the right position and then I’ll start again.” (P1)

Many participants perceived a direct relationship of their sensory deficit with their balance and walking.

“the reaction through my foot has consequences that affects the rest of my body... it’s sort of like a ripple effect up the side of my body.” (P5)

“Balance is the leader, isn’t it? If I’ve got my balance, because I know my foot’s in the right place, walking’s like, it’s like you walking. It’s natural, you don’t think about it, where I’ve got to think about it every time now. But you don’t think about walking.”
(P4)

P1 links the hypersensitivity she experiences to the confounding factors of motor deficits resulting in inversion at the ankle which in turn affects balance and gait. Reduced proprioception and often combined sensation deficits mean that for P1 she *“...can’t always tell ...without looking at it. If I can’t see where it is, I can’t tell where I am.”*

Confidence in their own body is affected;

“...sometimes I’ve got to really convince myself that the foots on the floor and it’s ready to take the weight.” (P4)

Indeed, all participants perceived their sensory deficit and motor deficits to be inextricably linked, interplay and impact on each other. These findings illuminate the sensory deficits and the impact of such as shared by the participants. For P5, crossing the road, where there are raised bumps on the ground is stressful due to her sensory deficits interplay with her motor deficits;

“...I hate it, going across on there because I’m already conscious that I’ve got to carefully cross the road... it has an associated reaction to affect the rest of my leg. So my foot basically then stiffens which then throws me off a little bit so it again pushes me onto my good leg which in turn... so the stress of crossing the road literally comes from those silly little bobbles.”

These participants have lived with their motor and sensory gait issues long enough to develop strategies to progress and are knowledgeable about how they would like to progress with their gait rehabilitation, however this is hindered by reduced proprioception and sensation and hence having reduced feedback to any progress. This was noted by P6:

“...affect(ing) my walking actually because, you know when you don’t realise how much pressure you’re putting on it? I don’t feel the pattern of walking properly”.

The combined issue of hypersensitivity and spasms means for P1 she is aware her base of support is reduced, affecting her balance:

“...my feet are fighting away inside my shoes...It makes me feel unsteady...obviously if they were all splayed out as they should be I’d have more even surface to stand on.”

The impact of sensory deficits on gait and balance in different environments presented various issues in relation to walking surfaces, both indoors and outdoors. Everyday situations such as

walking on different surfaces or a change in surface can have a significant impact. P3 commented on this being “...tricky, any uneven surface I find difficult to negotiate.’

Further, P8 described the direct impact her sensory deficit linked to her motor deficit impacts walking on uneven surfaces for her, “...it (leg) reacts by lifting and that’s what puts me off balance”. Indeed, the sensory and motor deficits interplay to impact on balance and gait, with a level of unpredictability.

“Always particularly careful, yes. Change in surfaces, I mean, you can see it can be as level as can be but if it changes from tarmac to concrete then I’m paying special attention to that...Because I’m not quite sure what’s going to happen.” (P3)

P5 also describes her specific difficulties in relation to the change of flooring textures, “...a bit of laminate flooring before a plush carpet...for me it’s like Everest”.

All but one of the 8 participants reported at least one fall in the last year, though some reported more as P2 describes, also identifying the reason for it,

“There have been three...if I’m moving backwards or if I’m distracted and turn suddenly, I can go over backwards quite easily”.

For some there were serious consequences such as for P1 who “...broke the neck of my femur and my collar bone” and this “knocked my confidence...whereas before I could do everything.”

Due to the need to react and adapt to uneven ground and different surfaces participants discussed their compensatory mechanisms, which include increased effort, concentration and increased visual effort as P7 describes, “...you train yourself, whether you do it consciously or

subconsciously, to scan all the time". P2 draws on previous skills developed as a rugby player, "...if I'm moving forward and I fall, I just roll up again.'

P3's wife revealed her observations of his walking strategy as he "...walks too much with his head down, always looking..." This is a strategy also used by P5, "...I'm looking at...the floor constantly. More visual attention in general just to make sure that I am, you know, I am safe and just be aware".

The balance and mobility issues can have serious consequences though many of the participants develop strategies to compensate or protect against these, incorporating these into their 'new normal', adaptation is key.

"...you adapt your lifestyle, you've got to. Otherwise you're going to be keeling over all the time." (P7)

Theme 3 – Sensory deficits have consequences for peoples' lives – *"So there is definitely a lack of ongoing sensation in this foot which is limiting, very limiting." (P3)*

For all the participants, whilst confounded by motor deficit, the sensory deficits contributed to the post stroke impact on their lives. They revealed about the limitations and restrictions for them:

"It's been really, the sensation in the foot that makes me feel unsteady has really in a way held me back. I've really had to come to terms with actually thinking do you know" (P5)

For P4 he is still participating in activities he enjoys but not in the way he would wish,

"I go to motorcycle rallies and stuff but even so I do these things, once I get there, I'm limited... I can't walk round, for example, I can't walk round a field looking at motorcycles or anything like that".

The physical changes are not understood by others and hence it is clear that personal identity and perception of 'self' is affected. A significant level of planning can go into going out as P3 described that when he does get to go out "...we plan most things fairly carefully, yes". Also P5 revealed the need for planning as a coping strategy, "... I plan because that makes it easier for me to cope with. That's my coping mechanism I think". She also described the extent of her planning when out socially:

"...from the moment I sit down, I clock the best way out...also clocking, 'right, and the toilets are there' so how much water am I going to have to drink because actually it's going to be a bit tricky getting to the loo so I'll just have the one glass of water so I don't need to go...No one ever has absolutely any idea. All that's going on in my thought processes".

This level of planning and detail is in other areas of P5's life, such as when she goes to the supermarket:

"...obviously disabled parking is available right near the door, you might think I'm a complete maniac because I go to the furthest one away, but it's right next to the trolley park so I only have to do a short journey to the trolley park to get myself a trolley and then I'm much more stabilised holding the trolley and walking with the trolley.... But it's the safer option for me".

This demonstrates the extent and unseen impact on everyday lives of persons with a stroke and the level of planning and adaptation that is involved in order to keep some level of independence. Many of the participants talked about how this level of adaptation as their 'new normal' in their life.

Some described creating a life where they avoided certain activities and environments whilst maintaining those where they feel safe such as home, P5 calls this her “bubble”.

“My house, my home, my trainers... my comfort zone...and then I get further out of my bubble. Sometimes I just put a little arm out or my toe. And sometimes I completely get out of my bubble...really go for it! But that’s how I perceive it... I’m in my bubble, making myself safe”.

When asked about the perceptions that others may have, P1 revealed,

“...it’s always amazing how rude people are... people comment and ask you, ‘What’s wrong?’ You know, ‘What have you done?’ Because obviously they notice you’re not walking the same...it just makes me feel really self-conscious. Prior to the haemorrhage, nobody would ever have commented on anything apart from to say something nice about me”.

P1 also comments on how this has happened so often it has been normalized to her and almost creates a change in her own identity and perception of herself.

In addition to problems with gait and balance the participants reported how the sensory deficit, and or combination with motor deficits can directly affect daily life such as impacting on the time taken to do certain tasks. For P1, the hypersensitivity and related spasms in her toes affect her in the task of putting shoes on:

“...my big toe can get spasms...it tends to make me feel unbalanced...When I first put my shoes on, it takes a while for my foot to settle down...about an hour”.

P7 reveals the impact on his bedtime routine,

“...it really makes my leg jump and jitter. So my wife now delays getting into bed till I’ve settled because otherwise I’m, sort of, my leg’s shooting around, making her black and blue”, and P6 the impact on his morning routine,

‘...my toes claw as well...they can take any time for about an hour, ten minutes, 15 minutes. I have to sit on the bed for a bit, you know, before I stand up’.

The gait and balance issues, the impact of the environment and the strategies to prevent falls combined have direct impact on the person in the context of choices in their social world. The burden of increased time to complete tasks, developing strategies to compensate for difficulties in balance and stability have a clear impact on the social lives of these participants.

Theme 4 – Footwear is the link between function, the environment and identity – *“As much as I’d like to wear a pair of killer heels, I know I can’t anymore. Now it’s just a case of comfort. And being safe when I walk.”* (P1)

The participants talked a lot about their footwear and specifically linked this to sensation and gait issues, the importance of it for certain environments and also the negative impact on their identity. All the participants noted restrictions and changes in their footwear choices since their stroke. There was a variety of reasons cited for the footwear choices, it was commonly safety/security and support and with comfort also high on the participants list of requirements.

Where previously they would have worn a range of footwear, five of the eight participants reported wearing predominantly or exclusively trainers as Susan reveals, *“...now I tend to live half the time in trainers anyway...it’s just a case of comfort. And being safe when I walk”.*

Safety is a key criteria when choosing footwear, as P4 describes as,

“...the only thing really that I can walk out in safely” regardless of him describing them as *“...really cheap, horrible things. I’ve got better ones, I’ve decent shoes but every time when I try to walk in the other shoes, my foot gives way, my ankle...So these are the only things at the moment I can manage to walk in”*.

For P5, it is the need to accommodate her Ankle Foot Orthosis (AFO) which restricts her footwear choice in footwear, *“I tend to wear trainers because...they’re more suitable for the splint but if I had the choice I wouldn’t wear these”*.

Some participants choose footwear that they consider to improve function and support. P7 only wears a type of boot as, *“... a, they’re comfortable and b, they support my foot... they support me so I always wear those”*. Also, P8 wears knee high boots in the same style all year round, as they offer her the right amount of support. The boots are worn instead of any Ankle Foot Orthoses or Functional Electrical Stimulation which have been tried and abandoned, so now only footwear provides support and stability by keeping *“... my foot at a 90-degree angle with my leg”*. Hence there was a degree of self-management based on their specific needs as also evidenced by P4 who buys larger footwear to give him a larger base of support:

“These... at least one size bigger. Now because of that they give me a bigger platform to stand on... And that is why some shoes doesn’t support me because they’re narrow”.

The majority of participants reported their footwear choices to be restricted, particularly those wearing AFOs and this in turn has an impact socially and on their identity. Finding the right footwear in shops for their specific needs can be difficult as P4 noted, *“I’ve looked for so many years now, I know the choice is not there”*

Clothing and shoes can be an important part of identity and this loss has had a significant impact on P5 since her stroke,

“Yeah, I feel I’m really, really (restricted) -that’s one of my things is shoes, it was, for me. I have this shoe fetish so that was one of my biggest hits in my life that”.

Footwear is a significant consideration when planning social events. It is directly related to the specific activity and hence choices are made in relation to factors, P5 plans her outfit around her footwear:

“...if you’re going out at night and you think, ‘Oh, what can I wear the night?’ it’s all what shoe are you going to wear? So it’s the shoes that will come first before the outfit comes” and “...I plan my outfit from my footwear”.

The footwear worn for reasons of safety, support and comfort can reduce choice and impact on appearance when it comes to social situations and can cause upset:

‘I did go to a funeral a couple of days ago and I wore something very, very similar to a trainer... I wasn’t a happy bunny...’ P4

Footwear, as the interface between the body and the environment has a significant role in all aspects of mobility. Footwear can be an issue but clearly has the potential to serve as an intervention either in its own right or as an adjunct to other interventions such as insoles. In relation to their thoughts on the vibrotactile insole, all the participants were positive about the vibrotactile insole concept in relation to improved function as *“I’d give it a go at putting this vibrating insole into my shoe and I’d walk on it and I’d give it a, see how it feels, give it a go”* (P7). Also many recognized the benefits of having an intervention that was not visible and may

mean more variety when it comes to footwear choices, as P5 said “*anything that takes up less room in shoes and helps is a bonus*”. The participants made comments about the support insoles could give and the timing of the vibrations during various stages of the gait cycle.

Discussion

This qualitative study is one of the first to focus on personal accounts of living with sensory deficits with the additional aim of finding a solution to the impact of this on activity and participation. Participants revealed what sensory deficits are, how they interact with their motor deficits and impact on stability and balance, how these create social restrictions. Importantly they also revealed about how footwear, as the interface between the body and the physical and visual environment, has a significant role in all of these aspects. These insights are important to inform the design of a vibrotactile insole intervention which aims to achieve the functional improvements, which are meaningful to patients’ lives. Further, these insights contribute to the focus of the clinical assessment which needs to consider how each person functions within the context of their home and social lives.

People with stroke experience sensory and motor deficits and these are inextricably linked. Whilst in a clinical assessment these may be distinctly recorded, they are not in the lived experiences of the individual, who often have a mix both in the nature and location of deficit. These participants tended to talk about their own unique set of issues which can be sensory or a combination of sensory and motor deficits, but rarely were described in such a way as an assessment would be, such as isolating a particular part of sensation. Hence, current sensory assessments are unlikely to capture patient experiences because the vast majority only test one location on the feet (or even only on lower limb not feet) and may be restricted to one mode of sensation such as light touch (3).

While it has long been thought, in clinical and physiological terms, that sensation and balance/mobility are linked (4, 5), often treatments targeted at impairments do not achieve benefits on function, activity or participation (14). Improvements are restricted to uni-dimensional measures of walking e.g. speed and balance e.g. sway in quiet standing but do not translate to activity or participation. One reason for the lack of translation of effect from impairment to activity and participation, may be that treatments have not been designed and delivered based on comprehensive assessment of sensory difficulties (3, 9) including patients' views (either by way of Patient Reported Outcome Measure or capturing the lived experience of patients or both). This work demonstrates the patients' lived experience of sensory and balance difficulties and how they intertwine within the context of their personal and social lives. These descriptions of personal experiences have revealed the issues that might change if the vibrotactile insole concept is successful.

Descriptions of personal experiences in some ways coincide with physiological and biomechanical/behavioral studies (5, 15) showing that deficits of sensation are experienced by patients as being linked with balance and mobility. However, our work goes beyond this and aligns with recent work (10) to reveal the extent of the impact on lives, with altered sensation being dealt with constantly throughout each day, as a 'new normal'. It limits social participation, footwear choices, contributing to unsteadiness and falls and demanding constant vigilance and meticulous planning of the environments in which people can and cannot walk/participate. This indicates that design, evaluation and provision of treatments addressing sensory deficits in the feet could realise better functional outcomes for patients, allowing improved participation and activity.

The range of ways in which the participants in this study describe their sensory deficits differentially over foot and lower limb locations, highlights the need for sensory assessments to include more than one location on the foot and modality of sensory perception; not just light touch thresholds, but also for temperature and pain. These participants' experiences align with findings of previous studies (5) suggesting that cutaneous sensation may be particularly important in adapting walking and balance to the environment (as opposed to during quiet standing/steady state walking over flat and level surfaces- which is how these are often measured in clinic and research (15, 16). Participants revealed a range of delayed, diminished and hypersensitive responses when needing to change their foot placement in response to the environment. Attempts are made to compensate using visual and focused attention or avoidance of the situations altogether. However, both vision and attention are often also affected by brain injury (17). Howe (18) has shown that vision cannot fully compensate for reduced cutaneous sensation in the feet during gait adaptations such as obstacle avoidance. Together, people's lived experiences described here alongside evidence from physiological and biomechanical studies, provides support for the notion that augmenting somatosensation of the feet may improve balance but importantly highlights this may be most effective/meaningful for patients during gait adaptations rather than during quiet standing/steady state walking.

Each participant had their own set of needs that are to be met by their footwear for example stability, support, security, confidence or comfort or a blend of these. For some people, footwear assumes the role of an insole, AFO or FES in assisting with foot drop and inversion, particularly where these devices have been abandoned due to the burden of use (19, 20). By understanding this role of footwear, clinicians and researchers can gain a unique insight into problems experienced and work towards potential solutions. Further, understanding the practical consequences of sensory loss becomes more important when interventions seek to directly compensate for impaired sensation. This is because these interventions will often

involve actions on the part of the patient during each day, outside the clinical setting, and during the daily living tasks which dominate the planning and independence of those affected by stroke. One intervention strategy gaining attention is the use of sensory stimuli to both feet and other parts of the body (21)

Fardon et al (22) presented a detailed representation of patient perceptions of footwear in their daily lives that echoes some of the findings here. For example, a shoe must be physically fit for purpose (e.g. to accommodate an insole), but also socially fit for purpose (e.g. shoes may be required to fit in with others and not stigmatise the wearer). For this reason, if technology such as sensory stimulating insoles are not designed with consideration of the wider physical and social functions of footwear, they may not achieve the desired effects on promoting physical activity, improving participation in society and limiting social isolation. Hence, feet, insoles and footwear are inextricably linked and therefore patients' experiences are integral to development of effective treatments for people with lower limb sensation impairment.

There may have been bias in those participants who came forward, as they may have significant sensory issues and this may not be representative of the wider population. However, the study achieved its goal of exploring the lived experiences of these individuals and gaining a better understanding in order to commence the development of a vibrotactile insole that is based on the needs of the people who will be wearing them.

Conclusion

Sensory deficits of feet are varied after stroke and have a direct, though individual effect on mobility, managed by many predominantly through modification of activity and footwear choices. The bespoke nature of the individual's lived experience could be overlooked by

traditional outcome measures or rating scales. Indeed, there is a need to explore further how these descriptions of patient experiences relate to “objective” measures of sensory function in the foot. Future research, clinical assessment and design of more efficacious treatments should focus on the development of insole interventions that are effective though fulfil the patients need in relation to their emotional, psychological and social needs.

Implications for Rehabilitation

- Sensory deficits are wide ranging and varied and are not distinct from motor deficits though contribute to the overall effect on physical function, mobility and activity.
- The physical effects impact on participants’ lives emotionally, psychologically and socially. Measurement of outcomes need to capture specific activities that are valued by patients.
- The participants have revealed resilience and resourcefulness to create a ‘new normal’ for their lives through adaption and self-management with a focus being on footwear as a solution.
- The participants have revealed the need for insole interventions to be discreet and non-burdensome, welcoming insole technology and contributing to the design and features of such insoles.

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Conflict of interest

The authors declare that there are no conflicts of interest in relation to this study.

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Table 1 – Opening Questions and Topic Questions

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|--|
| <p>Opening questions</p> <ol style="list-style-type: none">1. How have you been affected by your stroke2. What are the problems associated with sensation in your feet and balance? |
| <p>Topic Questions</p> <ol style="list-style-type: none">1. What are the sensory and balance problems that you think are most problematic in your daily life?2. What are your personal experiences of the effects of loss of sensation on balance and the impact of this on your life?3. What are your perspectives and opinions of devices that aim to address balance/mobility issues?4. What is your opinion of this insole in terms of assisting with balance (and walking) problems in order to support your physical activity in your home and community?5. What is your opinion on the type of shoes which could accommodate these insoles in relation to their physical fit?6. What are the restrictions in the type of shoes which would accommodate these insoles in relation to how you perceive yourself?7. What are the restrictions in the type of shoes which would accommodate these insoles in relation to social activities and the views of others? |

Table 2 – Participant Profiles

| Participant | Female/ male | Age (yrs/ months) | Type of stroke (if known) | Time since stroke -months | Walking aid use | Previous experience / use of Insoles | Devices |
|-------------|-----------------|-------------------------|---------------------------------|------------------------------------|--|--|---------------------------------|
| 1 | F | 51yrs 10 months | Stroke | 195 | Stick | Yes but not current | No |
| 2 | M | 85yrs 4months | Stroke - infarct | 48 | Stick outside/ uses furniture inside | Yes but not current | No |
| 3 | M | 73yrs 1 month | Stroke | 45 | Stick outdoors only | No | Caliper,(FES** in the past) |
| 4 | M | 60yrs 4 months | Stroke – hemorrhage | 72 | Tall stick | No | AFO* in past |
| 5 | F | 45yrs 4 months | Stroke – hemorrhage | 197 | Tall Stick | Yes | AFO |
| 6 | M | 45yrs 7months | Stroke – hemorrhage | 35 | Tall Stick outdoors only | No | Inversion Splint |
| 7 | M | 64 yrs 8 months | Stroke – hemorrhage | 36 | None | No | AFO (and FES** in past) |
| 8 | F | 51yrs 10 months | Stroke | 47 | Stick | No | AFO (and FES** in past) |

*AFO ankle foot orthosis

****FES functional electrical stimulation**

References

1. Connell LA, Lincoln NB, Radford KA. Somatosensory impairment after stroke: frequency of different deficits and their recovery. *Clin Rehabil.* 2008;22(8):758-67.
2. Patel AT, Duncan PW, Lai SM, Studenski S. The relation between impairments and functional outcomes poststroke. *Arch Phys Med Rehabil.* 2000;81(10):1357-63.
3. Kessner SS, Bingel U, Thomalla G. Somatosensory deficits after stroke: a scoping review. *Top Stroke Rehabil.* 2016;23(2):136-46.
4. Mildren RL, Yip MC, Lowrey CR, Harpur C, Brown SHM, Bent LR. Ageing reduces light touch and vibrotactile sensitivity on the anterior lower leg and foot dorsum. *Exp Gerontol.* 2017;99:1-6.
5. Rossignol S, Dubuc R, Gossard JP. Dynamic sensorimotor interactions in locomotion. *Physiol Rev.* 2006;86(1):89-154.
6. Aboutorabi A, Arazpour M, Bahramizadeh M, Farahmand F, Fadayevatan R. Effect of vibration on postural control and gait of elderly subjects: a systematic review. *Aging Clin Exp Res.* 2018;30(7):713-26.
7. Sawaki L, Wu CW, Kaelin-Lang A, Cohen LG. Effects of somatosensory stimulation on use-dependent plasticity in chronic stroke. *Stroke.* 2006;37(1):246-7.
8. Kavounoudias A, Roll R, Roll JP. The plantar sole is a 'dynamometric map' for human balance control. *Neuroreport.* 1998;9(14):3247-52.
9. Pumpa LU, Cahill LS, Carey LM. Somatosensory assessment and treatment after stroke: An evidence-practice gap. *Aust Occup Ther J.* 2015;62(2):93-104.
10. Gorst T, Lyddon A, Marsden J, Paton J, Morrison SC, Cramp M, et al. Foot and ankle impairments affect balance and mobility in stroke (FAiMiS): the views and experiences of people with stroke. *Disabil Rehabil.* 2016;38(6):589-96.

11. Smith JA, Larkin MH, Flowers P. Interpretative phenomenological analysis : theory, method and research. Los Angeles ; London: SAGE; 2009.
12. Williamson T, Kenney L, Barker AT, Cooper G, Good T, Healey J, et al. Enhancing public involvement in assistive technology design research. *Disabil Rehabil Assist Technol*. 2015;10(3):258-65.
13. Attride-Stirling, J. Thematic Networks: an analytic tool for qualitative research. *Qualitative Research*. 2001;1(3):385-405.
14. Mehrholz J, Thomas S, Elsner B. Treadmill training and body weight support for walking after stroke. *Cochrane Database Syst Rev*. 2017;8:CD002840.
15. Parsons SL, Mansfield A, Inness EL, Patterson KK. The relationship of plantar cutaneous sensation and standing balance post-stroke. *Top Stroke Rehabil*. 2016;23(5):326-32.
16. Machado Á, Bombach GD, Duysens J, Carpes FP. Differences in foot sensitivity and plantar pressure between young adults and elderly. *Arch Gerontol Geriatr*. 2016;63:67-71.
17. Greenwald BD, Kapoor N, Singh AD. Visual impairments in the first year after traumatic brain injury. *Brain Inj*. 2012;26(11):1338-59.
18. Howe EE, Toth AJ, Bent LR. Online visual cues can compensate for deficits in cutaneous feedback from the dorsal ankle joint for the trailing limb but not the leading limb during obstacle crossing. *Exp Brain Res*. 2018.
19. Prenton S, Hollands KL, Kenney LP. Functional electrical stimulation versus ankle foot orthoses for foot-drop: A meta-analysis of orthotic effects. *J Rehabil Med*. 2016;48(8):646-56.
20. Prenton S, Hollands KL, Kenney LPJ, Onmanee P. Functional electrical stimulation and ankle foot orthoses provide equivalent therapeutic effects on foot drop: A meta-analysis providing direction for future research. *J Rehabil Med*. 2018;50(2):129-39.

21. Cuppone AV, Squeri V, Semprini M, Masia L, Konczak J. Robot-Assisted Proprioceptive Training with Added Vibro-Tactile Feedback Enhances Somatosensory and Motor Performance. *PLoS One*. 2016;11(10):e0164511.
22. Farndon L, Robinson V, Nicholls E, Vernon W. If the shoe fits: development of an on-line tool to aid practitioner/patient discussions about 'healthy footwear'. *J Foot Ankle Res*. 2016;9:17.