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'I just want someone to rub some life into them!': the lived experience of impaired

sensation in the feet related to multiple sclerosis

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Background: Impaired sensation in the feet is a commonly reported symptom experienced

by people with multiple sclerosis. Aim: To explore the lived experiences of people living with

multiple sclerosis-related impaired sensation in their feet. Method: Five open, unstructured

interviews were analysed using a descriptive phenomenological method developed by

Amedeo Giorgi. Findings: The essential structure of the research phenomenon consists of

six key constituents: sense of heightened awareness of body sensation; sense of changed

relationship to the feet; sense of changed participation in daily life; sense of the self with

multiple sclerosis; sense of the meaning of interaction with others; and sense of being with

impaired sensation. **Conclusions:** Findings imply that the experience of impaired sensation

in the feet related to multiple sclerosis is a complex, lived-through phenomenon, interrelated

to other aspects experienced with the condition. Clinicians are encouraged to consider

implications of the phenomenon during encounters with people with multiple sclerosis, being

well-placed to provide meaningful support.

Key Words: multiple sclerosis; impaired sensation; lived experience; descriptive

phenomenology; feet

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Multiple sclerosis (MS) is a chronic, demyelinating, neurological condition, which is estimated to affect more than 100 000 people in the UK (MS Trust, 2019). The signs and symptoms related to MS vary depending upon the size and location of the demyelination in the nervous system (Perkin and Wolinsky, 2006). Common symptoms include visual problems, spasticity, muscle weakness, incoordination, poor balance and impaired sensations; while this list is not exhaustive, it incorporates many of the impairments seen in clinical practice.

Individuals with MS describe a range of sensory experiences, (MS Trust, 2018), yet the prevalence of sensory symptoms in this population is poorly understood. A survey conducted by the MS Society (2017) of participants involved in the UK MS register trial (n=15 500) reported that 60% of respondents experienced altered sensation, 58% experienced pins and needles, and 55% reported sensory loss.

Intact sensation in the feet has an important role as part of the intricate interaction of both the motor and sensory systems to achieve balance, postural control and normal gait patterns (Horak, 2006). Disruption in any of these systems due to injury or pathology may result in related postural instabilities, and many quantitative studies have, therefore, attempted to quantify the role of the somatosensory system and sensation of the feet.

Studies have explored the effects of reduced vibration sense at the ankle (Thournie and Mevellec, 2002; Citaker et al, 2011; Uszynski et al, 2015), proprioceptive impairments (Soyuer et al, 2006) and slowed somatosensory conduction (Cameron and Lord, 2010). Each of these studies demonstrated related impairments in balance or gait. In practice, the functional implications of impaired sensation are further related to impairments in the ability to walk unaided or drive.

While the available quantitative studies can provide insight into the 'objective' reality and generalisable effects of impaired sensation in the feet, the lived bodily experience of the symptom may be varied between individuals (van der Meide et al, 2018). This suggests that

more qualitative research is required to understand the complex phenomenon in a more holistic manner.

To the best of the authors' knowledge, there are no published qualitative or particularly phenomenological studies specifically exploring impaired sensation in the feet as experienced by people with MS. There are, however, several qualitative studies that have tangentially uncovered insights into impaired sensation. For example, a study exploring falls self-efficacy (Peterson et al, 2010) revealed participants living with MS highlighted the significance of impaired sensation as a symptom. Furthermore, in studies exploring the lived experience of disability (Toombs, 1995), perceptions of the self (Mozo-Dutton et al, 2012), the phenomenology of the body with MS (van der Meide et al, 2018) and the perspectives of older adults related to MS (Finlayson and van Denend, 2002) participants highlighted the relationships to their body and its sensations, raising significant issues and important questions regarding the experiences of the body in MS.

The aim of this study is to explore how impaired sensation in the feet is experienced by individuals with MS, from a phenomenological descriptive perspective. The findings will provide a more in-depth understanding of how the phenomenon of interest is present to people with MS in their everyday life, adding subjective and contextual knowledge to the available quantitative data.

Ethical approval was granted by the Health and Social Science, Science and Engineering Research Ethics and Governance Committee of the University of Brighton. Further successful permissions were sought through the Integrated Research Application System (IRAS project ID 196522) and the host NHS trust.

Methods

To uncover the essential features of impaired sensation in the feet related to MS as a livedthrough experience, the study utilised the descriptive phenomenological approach (Giorgi, 2009). This approach, founded in Husserlian phenomenological philosophy, required a key shift in the researchers' attitudes, using the principles of epoché (an ancient Greek term typically translated as 'suspension of judgement'). This practice, also known as phenomenological reduction and bracketing, is often criticised due to the misinterpretation that the researcher must 'forget' any prior knowledge of the phenomenon (Englander, 2016). However, it is more of a self-critical process, requiring the researcher to remain naïve and open to the phenomenon by acknowledging any prior knowledge, experience or assumptions to avoid affecting the descriptions of the participants (Giorgi, 2008).

Participants

To ensure the research phenomenon was explored in-depth, the research participants were purposively recruited. Each participant was required to be an adult (over 18 years of age), have a confirmed diagnosis of MS and have self-reported experiences of impaired sensation in their feet. After stakeholder consultation, it was decided that for richness of description, the symptoms should be active, or have been experienced within the preceding 6 months of the interview. Participant characteristics at the time of the interviews can be seen in Table 1.

Table 1. Participant characteristics at the time of the interviews

Participant	Characteristics
	P1 is a widowed woman, 53 years of age. She has had a
Participant 1 (P1)	diagnosis of MS for 32 years, which is secondary progressive
	(SPMS) in nature. She lives with her two daughters in a house and
	is retired from her occupation as a beauty therapist. P1 is mobile
	with a walking aid (a four-wheeled frame) and able to drive an
	automatic car. P1's mother, deceased at the time of the interview,
	had also had a diagnosis of MS.
	P2 is a married woman, 61 years of age. She has had a
Participant 2 (P2)	diagnosis of MS for 3 years and describes it as progressive in
	nature. P2 lives with her husband in a house and is retired from her
	occupational role in business administration. P2 can drive a left-
	footed automatic car and is mobile with walking aids (either sticks or
	a four-wheeled frame).
	P3 is a married woman, 65 years of age. She has had a
Participant 3 (P3)	diagnosis of MS for 26.5 years, identifies as having SPMS, and is
	treated with disease-modifying therapies (DMTs). P3 lives in a
	house with her husband and is mobile with a walking aid (a walking
	stick). She is retired from her roles as a PE teacher and
	subsequently employed in administration.
	P4 is a married male, 62 years of age. He has had a
Participant 4 (P4)	confirmed diagnosis of MS for 18 years, which is SPMS. P4 lives in
	a house with his wife and is retired from his role as a consultant
	surgeon. He is mobile, using walking aids (walking sticks)
	intermittently, and is unable to drive.
	P5 is a married male, 61 years of age. He has had a
Participant 5 (P5)	diagnosis of relapsing remitting MS (RRMS) for 5 years. P5 lives in
	a first floor flat with his wife and continues to work as a support
	worker in a residential home. He uses walking aids occasionally and
	can drive a manual car.

Data collection

Open, in-depth, face-to-face interviews were conducted with participants in their own home by the first author (CC). Before the interview, each participant was informed of their right to 5

withdraw without explanation, and written consent was obtained. A single opening question focusing the participants toward their experiences of the phenomenon was used, followed where necessary with neutrally probing questions (see Box 1). The interviews (lasting approximately 47 to 85 minutes) were audio recorded and transcribed verbatim by the same researcher-interviewer (CC).

Box 1: Interview format

Opening question:

Please can you describe your experiences of the impaired sensation in your feet as concretely and in as much detail as possible?

Follow-up questions:

Can you tell me in more detail what you meant by that?

Can you describe a concrete situation where this occurred?

Can you tell me more about this situation?

What were your thoughts/actions in that situation?

Closing question:

Thank you for your time. Is there anything else you would like to say about impaired sensation in your feet before I stop the recording?

Data analysis

The data, in the form of concrete descriptions, were analysed using the descriptive phenomenological method proposed by Giorgi (2009) and based on Husserlian phenomenological principles. The steps of the analysis can be seen in Table 2. During the analysis, each step was discussed in the research team (between the first and the second author), while assuming phenomenological descriptive attitudes.

Table 2. Steps of descriptive phenomenological analysis

Step 1	A phenomenological descriptive attitude was adopted while reading each
	transcript to gain a sense of the whole
Step 2	Each transcript was systematically delineated into smaller meaning units by
	demarcating the data when there was a shift in the meaning of the narrative
Step 3	Each meaning unit was rewritten, retaining the language of the participant, but
	using the third person. This step prevented the researcher identifying with the
	participant, reducing the risk of projecting onto the data (Giorgi, 2006)
Step 4	With the use of imaginative variation, the researcher transformed the meaning
	units, using disciplinary language, into expressions more revelatory of the
	experience of impaired sensation in the feet. The act of imaginative variation,
	based on Husserlian principles, involves removing the individuality from the
	concrete descriptions provided by the participants, to reveal essential aspects
	of the experience under investigation (Moran and Cohen, 2012)
Step 5	In the final step of the method (see Giorgi, 2009), the general structure was
	used as a guide for a deeper understanding of the data and the dynamics
	among the key constituents comprising the structure. As a result, one table
	and a diagram were formed to present an overview of the constituents of the
	general structure and their empirical variations

Findings

The outcome of the phenomenological analysis of the raw data from five participants is the essential, unifying structure of the lived-through experience of impaired sensation in the feet related to MS. The structure, seen in Box 2, incorporates the meaningful, most prevalent

expressions of impaired sensation in the feet, drawn from the participants' descriptions, into a single paragraph to give a sense of the whole experience.

Box 2: Essential structure

Impaired sensation in the feet related to MS can be experienced pre- and/or post diagnosis and varies in intensity, duration, laterality and type. At whatever time impaired sensation in the feet is experienced by the participant (P), a heightened awareness of altered bodily sensations occurs, and P becomes aware of a change in their relationship to the feet. This occurs both at rest and in movement, and P acknowledges thoughts and sensations of the feet and other areas of the body that previously went unnoticed. The experienced change affects participation in daily life, manifested in an increased awareness of risk, increased concentration when moving around and a sense of a loss of freedom to act and move spontaneously. The experienced change is positively and/or negatively related to a sense of living through the diagnosis and other symptoms associated with MS, as well as interaction with other people. At some point, there is a sense of becoming familiar with impaired sensation, which relates to the adoption of a new mindset of accepting change and assistance (sometimes reluctantly) in order to get on with life, and regarding impaired sensation in the feet as the new normal.

Six key constituents, in the sense of the most invariant meanings, were identified to be present in each description provided and, therefore, were considered essential for the given phenomenon to present itself. The constituents are: sense of heightened awareness of sensation in the body; sense of the self with MS; sense of changed relationship with the feet; sense of changed participation in daily life; sense of the meaning of interactions with others; and the sense of being with impaired sensation.

Although these constituents will be discussed separately, in line with descriptive phenomenological philosophical principles, they must be understood as part of the whole experience of impaired sensation in the feet related to MS. *Figure 1* depicts the meaningful relationships between the six key constituents. Despite being presented in this way for easier understanding, there is no hierarchy, or 'direct' or 'indirect' relationships, hence the lack of arrows. Further, it must not be read as an attempt to explain or create a universal theory (aiming for generalisation from a sample to a population) relating to the lived-through experiences offered by the participants; however, a sense of how the unifying key constituents are meaningfully and dynamically interrelated can be represented by this diagram.

As presented in the structure, once one experiences impaired sensation, there is a heightened awareness of the changed and previously unnoticed bodily sensations, which changes one's relationship with the lived body and the feet. There is a sense that having a diagnosis of MS, which may precede or follow the experience of impaired sensation, is related to how these constituents are lived. There also appeared to be a dynamic relationship between the sense of the meaning of interactions with others, heightened bodily awareness and changed relationship to the feet, all of which were closely interrelated to the experienced change in one's participation in daily life. There was a sense that interactions with other people may either positively or negatively contribute to how this change was experienced. Moreover, the constituents forming the structure are dynamically interrelated with what appeared to be a sense of impaired sensation becoming the everyday normal. This constituent was present in all descriptions; however, it was more fluid as to when it became present for an individual.

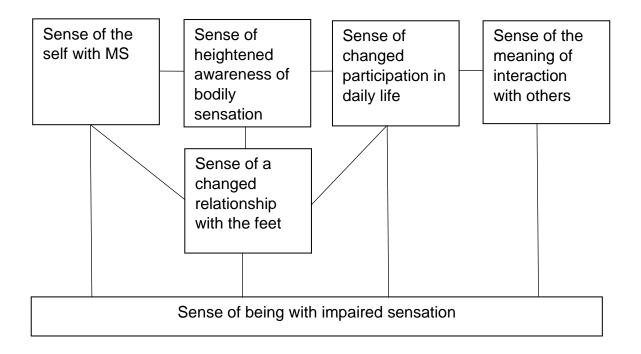


Figure 1. Diagram demonstrating the interrelatedness of the six key constituents within the essential structure of impaired sensation in the feet related to MS

Sense of heightened awareness of bodily sensation

Within the raw data, despite being focused around participants' experiences of impaired sensation in their feet, a sense of heightened awareness of bodily sensations was strongly and explicitly present throughout the lived-through experiences of all participants. These included awareness of changes in the sensation of the skin, both at rest and during movement, changes in perception of temperature and a notion of 'normal' areas of sensation in the body (where the sensation had not changed) by comparison. In addition, all participants, although expressing it in different ways, described how they became more attentive to their bodily sensations, which they previously took for granted.

Participants provided varied accounts of how they experienced impaired sensation: some pre- and post-diagnosis, some unilaterally and bilaterally. Despite the variation, all the participants provided rich descriptions that evoked a strong sense of the disruption to their

body:

- '... if you touch a joint of meat, you get that [pounds hands together] ... it's like dead meat ... that's what it feels like.' [P2]
- '...sort of like an out of body sensation really it was almost as if they weren't mine, you know like nothing to do with me ... I just want someone to rub some life into them. They feel dead to me.' [P3]
- '... when I move my toes ... it feels as though I've got crisp packets folded up between my toes ... I've got the crackling and the sensation, I can even hear the sound of it happening, even though I know I'm making that up ...' [P5]

Sense of a changed relationship with the feet

From the raw data, the sense of increased awareness of the sensation in the feet appeared in relation to a change in the participants' relationship to their feet. This sense of the belonging of the feet was described by P1, who recalled:

'I tend not to have socks or shoes on, just 'cause I feel that I'm touching the ground.'

P2, however, stated she could no longer walk barefooted:

'I don't tend to wander about in bare feet like I used to ... it doesn't feel as safe as having a pair of socks on or a pair of shoes for some unknown reason I don't know why.'

Similarly, because of the impaired sensation, P4 was particularly risk aware, describing a new routine of caring for and checking his feet, as he stated he was concerned he would not sense an injury if it occurred. From a different perspective, P5 instead described a change in the awareness of the role his toes played in balance.

P1, P2 and P3 all described a sense of an enforced change to the type of footwear they could wear, more or less explicitly related to acknowledgement of the impaired sensation. P2 and P3 further discussed their emotions related to this change, and had not been able to bring themselves to throw away pairs of heeled shoes they could no longer wear:

'I can't tell if I've got a shoe on or not ...' [P3]

'I resent the fact that I can only wear lace ups really because that is annoying, because I like shoes as well and I like to look decent about my feet.' [P2]

Sense of the self with MS

For participants, when describing their experiences of impaired sensation in the feet, there was a sense of the significance of their experiences of being diagnosed, and subsequently living with, MS. There was variation in the data regarding when the impaired sensation in the feet had first been acknowledged by participants, with some experiencing the impaired sensation before they were diagnosed. There was, however, an appreciation that, following the diagnosis, it was accepted that the phenomenon was related to MS and it was, therefore, not likely to disappear:

'... I developed 4 limb paresthesia ... I had an MRI scan and that really confirmed that I had MS.' [P4]

"... It's the feet that don't let you forget that you've got MS." [P5]

There was a strong overall sense that the diagnosis of MS was inextricably linked to the participants' everyday experience of the research phenomenon. All participants further described other symptoms and aspects of life related to their MS being interwoven into their

experiences. Fatigue was the most experienced and mpst interrelated symptom with impaired sensation among participants:

'... I get really tired and the sensation goes bleurgh ...' [P2]

'I don't know if that is the MS in my legs or whether it is just lack of sensation and I can't feel what my feet are doing ... I know when I am tired I drag my leg and I have to really think about picking my feet up.' [P3]

Disruption to the lived body was interrelated to the disruption of the self; there was a significant sense of loss of previous roles and identities (occupational, social and domestic/personal). For example, participants described the perceived loss of their role within the family:

'It's much easier doing it for other people then doing it for yourself basically and losing the ability to do it for others is hard ...' [P1]

Disruption was also associated with hobbies and interests, especially the cessation of participation in sport and previous leisure activities:

'I played my sport to enjoy it ... because it is tiring me, and I am not playing brilliantly, I'd rather not do it ...' [P3]

'I'll stagger in here and my wife tells me off for going out into the garden at all, but I'm not going to stop going out in the garden...' [P4]

Participants also reported changes in job roles:

'I did live-in care for a friend with cerebral palsy, but I didn't have any impairment then, I was doing things like, erm, manual handling for him ... I was actually getting his wheelchair on and off buses and trains ... I was physically able and capable then, so really this deterioration I put down entirely to MS ... you know the fact that I have to think twice before I kneel down for example.' [P5]

Sense of changed participation in Daily Life

There was a strong sense from participants that life had to be planned and activities paced due to the impaired sensation and other symptoms of MS. When describing concrete situations of impaired sensation in the feet, all participants addressed their need for increased concentration when moving around to maintain their balance. All but one of the participants further described a situation in which they had fallen. P1 and P2, for example, relating a loss of sensation in the feet to the fall:

'... my feeling went in my feet, I didn't know, that I couldn't feel ... I actually went over, so that was another instance of not having any feeling in the foot.' [P1]

'I turned quickly and lost, well, the sensation in this right side wasn't as good as I thought it was, I just spun round in the bedroom and I went klonk straight onto the floor.' [P2]

For some participants, there seemed to be an element of frustration present in the experiences related to the perceived reduction in mobility and loss of autonomy. Participants also described a sense of perseverance and striving to achieve more, despite the difficulties encountered:

"... it's a bit like being on a leash really, it's just pulling you back all of the time from doing what you want to do because you know the sensation is rubbish." [P2]

Sense of the meaning of interaction with others

Within the data, the experience of impaired sensation in the feet for all participants was meaningfully related to interactions with other people, such as members of the family, health professionals and other people, including other people with MS.

When describing their interactions with other people with MS, P2 and P4 compared themselves to this group, describing that, at the time of the interviews, they may be in better circumstances in some cases:

'I'm much better off than many people with MS.' [P4]

Further, P1 compared her own experiences to those of her mother, who had MS. P5 was reassured that other people with MS also had impaired sensation, which validated his own experience of symptoms:

'I thought I had quite a poetical description of it and then I discovered that just about everybody [with MS] says "oh well it's like standing on pebbles" and I thought oh fair enough ...' [P5]

P3 interacted with other people with MS and described how it surprised her that they experienced symptoms that she did not and vice versa, including those related to experiences of impaired sensation in the feet. P1 stated that she had only been made aware that other people experienced impaired sensation in their feet through joining an online forum, which had opened lines of communication and awareness about the phenomenon.

Within the participant descriptions, there was a sense of concern about interactions with other people who may not have knowledge or understanding of their condition:

'If I am playing [golf] with somebody, it's embarrassing for them to have to watch me and it's embarrassing for me to spoil their game.' [P3]

'... I don't like to be thought of as the silly old lady with the sticks.' [P2]

Participant experiences included descriptions of interactions with family members, both in a positive and negative sense. Generally, the participants of this study expressed feelings of satisfaction with the help and support from their family members. However, they also described examples of frustration and concern:

'... so, if they [daughters] weren't around then I wouldn't be able to have a bath on my own, I wouldn't trust myself.' [P1]

'My wife's very frustrated by the fact that you [I] can't do a lot of walking ...' [P4]

Although participants also described their interactions with health professionals both positively and negatively, they addressed the overall significance of the encounters:

- '...well I always feel better if I have spoken to a health professional.' [P2]
- '...it reassured me that ... they would be able to understand me if they were treating the condition [impaired sensation].' [P5]

A sense of being with impaired sensation

The participants described the positive development of a mindset of accepting adaptations, such as the use of walking aids or swapping to automatic cars, to continue living their lives, despite the changes they were experiencing. The participants, for example, described moments when seemingly 'impaired' sensations became their 'normal' and/or they could not recall noticing sensation before it became impaired:

'... I think you just get used to it, I think it's like if you break an arm you just adapt don't you, it doesn't make you unable to do things.' [P3]

'I just regard it as the normal ...' [P4]

Discussion

The main outcome of this descriptive phenomenological study has been to uncover the essential structure of the lived experience of impaired sensation in the feet related to MS, formed by six key constituents. Both the structure and the constituents provide a deeper understanding of the lived phenomenon of impaired sensation in the feet related to MS in a phenomenological descriptive sense. As they are 'general' in their applicability to others living through this phenomenon in similar situations/contexts (in that they transcend the individual accounts in which they were given), they will be discussed considering other published evidence.

Although the interviews directed participants towards impaired sensations of the feet specifically, the findings of this study revealed that participants experienced an increased conscious awareness of the lived body as a whole. A similar theme was revealed in a phenomenological exploration of the mindful body in MS by van der Meide et al (2018). They described the narrowed focus and constant alertness to bodily sensation described by the participants as 'corporeal contraction'. Furthermore, like the participants in our study, the participants in van der Meide et al's (2018) experienced similar sensations of bodily uncertainty and, in the context of the overall experience and at an undefined point in time, participants experienced these changed bodily sensations becoming their 'normal'. These findings further resonate with a transitional sense of 'being' portrayed in a study by Strickland et al (2016). Their conceptual framework presented the concept of a 'liminal' self, whereby people with MS change their biographical narrative to incorporate the disruption to the lived body. Similar to our findings, the expressed phenomenological meanings, which

emerged in Finlayson's (2003) study, included a sense of the changed relationship to the body and to the self, and the adaptations participants made to live with these changes. These themes raise important issues to be considered when clinicians have therapeutic encounters with people with MS, as the body can be seen as the fundamental in which individuals access the world. The sense of 'being' with impaired sensation in the feet in this study, however, implies that individuals may learn to adapt to impairments and continue to access their world in new ways, with and/or without the assistance of others. This is an important point for clinicians to consider: in order to provide true patient-centred care, encounters need to be dialogical and supportive of individual choice.

Carel (2016) articulates that a progressive deterioration in the abilities of the lived body, in the context of an illness or disease, can seem to gradually erode an individual's sense of freedom. In this study, the existential loss of perceived freedom participants described was related to a deterioration in their mobility, and particularly related to their experiences of falls. All but one of the participants in this study specifically related a concrete experience of falling to changes in the sensation of their feet. This is not a surprising result, as it has been previously reported that falls are prevalent in the MS population (Coote et al, 2013; Nilsagård et al, 2015). Although participants recalled falls and discussed an increased awareness of risk, they considered this in the context of continuing to get on with their lives. In line with this, impaired sensation and increased vigilance have previously been highlighted as an important factor when considering self-efficacy and risk of falling in MS (Peterson et al, 2010). In consideration of these findings, it is acknowledged that awareness of impaired sensation in the feet, and previous experiences of falling, may be meaningfully related to an individual's ability to mobilise. In the current study, for example, all participants described changes in their ability to walk, which they related to impaired sensation in the feet. This included using walking aids and not being able to walk as well or as far, which they experienced frustration about. Some of these frustrations were particularly related to the perception of others when individuals were mobilising or using aids in public. Clinicians

should consider exploring these concerns if issues of compliance with suggested aids arise in practice.

Furthermore, participants in our study further expressed a sense of mourning related to the loss of mobility, comparing their mobility at the time of the interview to their previous abilities. These findings suggest that health professionals and researchers may want to consider and explore, in more depth, the potential functional and emotional implications of impaired sensation in the feet in people with MS.

Gaining information regarding the prevalence of impaired sensation in the feet in the MS population may be beneficial for policymakers and funding bodies and could be gathered using a large database, such as the UK MS register. The impaired sensation experience, in this study, was positively and negatively related to the participants' perceptions of the role of others people, including health professionals. Therefore, the experiences and practices of those who encounter the phenomenon in clinical practice should also be explored. The significance of conducting further research, from both qualitative and quantitative perspectives, regarding MS-related impaired sensation in the feet or more generally could help to improve how we address the phenomenon in practice.

Limitations

The inclusion of only five participants and the contextual nature of the knowledge attained in this study—for example, the lack of ethnic diversity and close geographical proximity of the participants—could be seen as limitations. However, it is important to consider that in-depth, discovery-based research, such as this descriptive phenomenological study, does not aim to uncover the individualised experience or generalise from a sample to a population. The structure of the phenomenon is an eidetic generalisation in the sense that the findings of the study transcend the individual participants. Nevertheless, the chosen empirical research perspective, the characteristics of the lived situations and the type of the phenomenon being studied all place constraints on generalisation.

Conclusion

The findings of the study imply that impaired sensation in the feet, as experienced in relation to MS, is a complex phenomenon that is closely and inextricably interrelated to other perceived symptoms and aspects of life associated with the condition. The findings may

confirm clinicians' experiences, but it is hoped they provide deeper insights to expand understanding of how the phenomenon is lived, and, by increasing awareness of this, may help to improve meaningful person-centred practice. Clinicians are, therefore, encouraged to consider the significance of the phenomenon and its individually varying implications, as well as their own role in providing advice and support when encountering people with MS.

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Key points:

- Impaired sensation is experienced by people with MS on a varying basis
- It is a complex phenomenon, closely interrelated to other symptoms and aspects of MS, such as fatigue
- Health professionals should investigate the presence of the phenomenon, as people with MS may consider impaired sensation as normal and, therefore, fail to report it
- Health professionals should consider the significance of impaired sensation in the feet when assessing balance, mobility and falls risk related to MS

Reflective questions:

- A large proportion of people with MS experience impaired sensation. When first meeting a person with MS, how might you approach and discuss impaired sensation?
- The participants' descriptions of impaired sensation in the feet encompassed a range
 of experiences. If an individual reported impaired sensation, consider what probing
 questions you may ask to explore this and how you might examine their sensation
 'objectively' and 'subjectively'.
- The participants within the study described some implications of impaired sensation in the feet. What might some of the functional implications of impaired sensation be, and how might you be able to support somebody with impaired sensation?

References:

- Cameron MH, Lord S. Postural Control in Multiple Sclerosis: Implications for Fall Prevention. Curr Neurol Neurosci Rep. 2010;10:407–412. https://doi.org/10.1007/s11910-010-0128-0
- Citaker S, Gunduz AG, Guclu MB et al. Relationship between foot sensation and standing balance in patients with multiple sclerosis. Gait Posture. 2011;34(2):275–278.

 https://doi.org/10.1016/j.gaitpost.2011.05.015
- Carel H. Phenomenology of Illness. London: Oxford University Press; 2016
- Coote S, Hogan N, Franklin S. Falls in people with multiple sclerosis who use a walking aid:

 Prevalence, factors, and effect of strength and balance interventions. Arch Phys Med Rehabil.

 2013;94(4):616–621. https://doi.org/10.1016/j.apmr.2012.10.020
- Englander M. The phenomenological method in qualitative psychology and psychiatry. Int J Qual Stud Health Wellbeing. 2016;11:1–11. https://dx.doi.org/10.3402%2Fqhw.v11.30682
- Finlayson ML, van Denend T. Experiencing the loss of mobility: perspectives of older adults with MS. Disabil Rehabil. 2003;25(20):1168–1180. https://doi.org/10.1080/09638280310001596180
- Giorgi A. The Descriptive Phenomenological Approach in Psychology: A Modified Husserlian Approach. Pittsburgh: Duquesne University Press; 2009
- Giorgi A. Concerning a Serious Misunderstanding of the Essence of the Phenomenological Method in Psychology. J Phenomenol Psychol.2008;39(1):33–58.

 https://doi.org/10.1163/156916208X311610
- Horak FB. Postural orientation and equilibrium: what do we need to know about neural control of balance to prevent falls? Age Ageing. 2006;35(S2):ii7–ii11. https://doi.org/10.1093/ageing/afl077
- Moran D, Cohen J. The Husserl Dictionary. Oxford: Bloomsbury Academic; 2012

Mozo-Dutton L, Simpson J, Boot J. MS and me: exploring the impact of multiple sclerosis on perceptions of the self. Disabil Rehabil. 2012;34(14);1208–1217.

https://doi.org/10.3109/09638288.2011.638032

MS Society. The invisible symptoms of MS. Res Matters Winter. 2017; 012:4–5.

MS Trust. Altered sensations. 2018. www.mstrust.org.uk/a-z/altered-sensations (accessed 7 December 2020)

MS Trust. MS: the facts. 2019. www.mstrust.org.uk/about-ms/what-ms/ms-facts (accessed 7 December 2020)

Nilsagård Y, Gunn H, Freeman J et al. Falls in people with MS – an individual meta-analysis from studies from Australia, Sweden, United Kingdom and the United States. Mult Scler. 2015;21(1):92–100. https://doi.org/10.1177/1352458514538884

Perkin GD, Wolinsky JS. Fast Facts: Multiple Sclerosis. 2nd Ed. Oxford: Oxford Health Press; 2006. https://dx.doi.org/10.1136%2Fjnnp.2006.088823

Peterson EW, Kielhofner G, Tham K et al. Falls Self-Efficacy Among Adults with Multiple Sclerosis:

A Phenomenological Study. OTJR. 2010;30(4):148–157. https://doi.org/10.3928%2F15394492-20091123-02

Soyuer F, Mirza M, Erkorkmaz U. Balance performance in three forms of multiple sclerosis. Neurol Res. 2006;28:555–562. https://doi.org/10.1179/016164105x49373

Strickland K, Worth A, Kennedy C. The liminal self in people with multiple sclerosis: an interpretative phenomenological exploration of being diagnosed. J Clin Nurs. 2016;26:1714–1724. https://doi.org/10.1111/jocn.13593

Thoumie P, Mevellec E. Relation between walking speed and muscle strength is affected by somatosensory loss in multiple sclerosis. J Neurol Neurosurg Psychiatry. 2002;73(3):313–315. https://dx.doi.org/10.1136%2Fjnnp.73.3.313 Toombs K. The lived experience of disability. Human Stud. 1995;18:9–23.

https://dx.doi.org/10.1007/BF01322837

Uszynski M, Purtill H, Coote S. Relationship between foot vibration threshold and walking and balance functions in people with multiple sclerosis (pwms). Gait Posture 2015;41(1):228–232. https://doi.org/10.1016/j.gaitpost.2014.10.010

van der Meide H, Teunissen T, Collard P, Visse M, Visser LH. The Mindful Body: A Phenomenology of the Body With Multiple Sclerosis. Qualitative Health Research 2018; 28(14): 2239–2249. https://doi.org/10.1177/1049732318796831