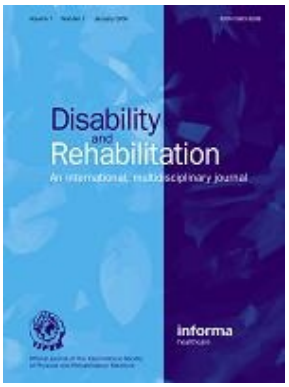
Disability and Rehabilitation



The Impact of Neurological Disability and Sensory Loss on Mindfulness Practice

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Implications for Rehabilitation

- Mindfulness-based practices which focus on the body and sensation are accessible to people with neurological limitations.
- Mindfulness techniques can be extended through the use of visualisation strategies to encourage (non-proprioceptive) awareness of paralysed limbs or areas of the body with sensory loss.
- The language used in mindfulness-based interventions may need adapted by practitioners so that it remains inclusive for people with sensory loss as well as sensory presence.
- Additional care needs to be taken when using body scans during mindfulness as they have the potential to exacerbate psychological distress in people with reduced sensory awareness.

The Impact of Neurological Disability and Sensory Loss on Mindfulness Practice and Body Awareness

Abstract

Objectives: Mindfulness-based approaches are increasingly recommended in the management of medical conditions associated with sensory loss and absence, such as Spinal Cord Injury (SCI), Multiple Sclerosis (MS) and Functional Neurological Disorder (FND). Yet the implications of undertaking practices such as body scanning when living with sensory loss have not been considered. This study aimed to explore the impact of sensory loss on the practice and experience of mindfulness in qualified mindfulness teachers with SCI/FND/MS.

Methods: Eight (5 females, 3 males) mindfulness teachers with SCI/FND/MS, sensory loss and wheelchair use were recruited from mindfulness teacher databases. In-depth, semi-structured interviews were undertaken, lasting between 50 and 93 mins. Interviews were transcribed verbatim and analysed via Interpretative Phenomenological Analysis. Idiographic analyses for descriptive, linguistic and conceptual themes were completed before cross-case analyses.

Results: Analyses resulted in two superordinate themes: (1) Adopting your Body; and (2) Sensation without Loss. These themes reflected the challenge of overcoming initial resistance to areas of the body with sensory disruption, building a relationship with the whole body, such that sensory awareness could be visualised and experienced without proprioception.

Conclusions: Mindfulness offers a unique approach to accepting and working with the body after paralysis or sensory loss. Fundamental to the use of mindfulness with such populations, is the prioritisation of inclusive sensory language and exploring sensory absence as well as sensory presence. The cognitive and emotional outcomes of body scanning may be uniquely elevated in populations with neurophysiological disorders, highlighting the benefits of mindfulness for adaptive and protective self-management.

Keywords: body awareness; disability; spinal cord injury; multiple sclerosis; mindfulness teaching; barriers; mindfulness-based interventions.

Introduction

Mindfulness, a psychological practice primarily focused on guiding attention towards momentary-self-reflection in the present [1], has been implicated as a promising method of self-management in patients with Spinal Cord Injury (SCI) [2]. Through accepting thoughts and feelings without judgement and observing moment-to-moment experiences, it is proposed that these processes minimise cognitive and emotional reactivity to enhance coping, self-control and psychophysiological wellbeing [3]. Within SCI, personal use of Mindfulness has demonstrated the potential to reduce depression and catastrophizing and improve neuropathic pain, pain management, positive attitude and acceptance [2,4,5]. Similarly, people with SCI with high trait mindfulness have been found to have less avoidant coping styles and wellbeing [6]. Group-based mindfulness training in SCI rehabilitation centres resulted in an improved ability to navigate complex environments, develop positive relationships, heighten self-acceptance and increase intrinsic motivation [7]. Such outcomes are attributed to an increased ability to stay in the present moment without rumination or catastrophizing and to observe thoughts and emotions without negative self-judgement [8]. As a consequence, mindfulness has been increasingly integrated in multidisciplinary interventions for patients with changed neurological functioning [9].

Despite the evidence suggesting beneficial outcomes of mindfulness, people with sensory loss often experience barriers to practising mindfulness, which may be both psychological and physiological [4,8]. Psychologically, emotional barriers such as processing difficult feelings of trauma, self-worth, SCI identity or depressive symptomology (often comorbid with SCI), pose challenges to utilising mindfulness in the SCI community ([reference blinded for review]). Physically, there are no formalised recommendations for adaptation of core

mindfulness techniques such as body scanning, mindful movement or yoga-derived movement, limiting their utility in populations living with paralysis/reduced sensation and in wheelchair users. 'Mindful movement' varies within the literature, but may include elements such as mindful walking, small hand movements or yoga-based asanas, combined with mindful observation of personal limits of movement and the bodily and emotional reaction [11]. Additionally, mindfulness typically utilises a sequential body scan in which practitioners direct attention progressively through the body whilst observing the breath, in order to recognise, accept and observe sensation, thoughts and feelings which may arise, without judgement [12]. This technique is considered fundamental to the practice of mindfulness and Mindfulness-based Stress Reduction (MBSR) recommends the routinized practice and regular use of body scans [13]. Collectively, therefore, body awareness, directed focus on sensation and physically working with the body and breath are core tenets of Mindfulness that may need further consideration in terms of adapting them for use in people with neurophysiological disorders.

Whilst the MBSR recommendations to 'observe personal limits' do allow space for individualised adaptation, little research has reviewed or assessed how and why naturalistic, self-developed adaptations are being selected and utilised by wheelchair users or people with motor or sensory loss [see only 10]. No research has looked at specific adaptations made by trained mindfulness teachers with neurological disability. Few MBSR programmes include any form of sensory or functional adaptation within their programmes [14] and as such engagement with and outcomes from mindfulness for SCI/MS/FND may be ameliorated. Due to the difficulty of adapting core mindfulness techniques (such as manualised MBSR), there may be a lack of parity in access to mindfulness programmes

meaning that many individuals with sensory disruption and limited sensory awareness may feel potentially excluded from such courses.

There is an urgent need to develop recommendations for adapting and tailoring mindfulness techniques for people with SCI or sensory loss. In particular, recommendations to better manage the physical, emotional and cognitive challenges experienced as a consequence of changed sensory processing when using body scanning, mindful movement and wheelchairs. To do so, it is necessary to explore how mindfulness is typically experienced by people living with sensory loss who, as highly skilled practitioners, are using mindfulness as a central element in the self-management of their health. This will complement the research by Hearn et al [10] which explored mindfulness practice in lay users without mindfulness training.

The current study is designed, firstly, to improve understanding of the mindfulness practices undertaken by highly trained mindfulness teachers with sensory loss. Secondly, to highlight how such practitioners adapt their practice to encompass and work with sensory loss. Collectively, therefore, this research therefore aimed to explore the way in which living with sensory loss impacts upon the practice of mindfulness.

Method

Design

A qualitative study was undertaken using semi-structured interviews, analysed using Interpretative Phenomenological Analysis.

Participants and Recruitment

Purposive criterion sampling was used to recruit eight Mindfulness Teachers with limited sensory awareness and impaired motor function [15]. Inclusion characteristics were: completion of a formal mindfulness teacher training programme, regular teaching of mindfulness training courses (3 or more times per year), currently (active) personal mindfulness practice and limited sensory awareness as a result of either Spinal Cord Injury, Multiple Sclerosis or Functional Neurological Disorder. Exclusion criteria were: historical Mindfulness Teacher Training without ongoing teaching practice, health conditions which did not entail loss of sensation. All members of a national database of Mindfulness Teachers (Breathworks) were emailed with study invitations. Breathworks provides formal training for Mindfulness Teachers and maintains a registry of accredited mindfulness teachers, many of whom specialise in the delivery of Mindfulness for Health courses (see https://www.breathworks-mindfulness.org.uk). Given the specific nature of the target population, snowball sampling was employed in order to contact other eligible individuals meeting the inclusion criteria, outside of this network [following 16]. A sample size of eight, if accompanied by strong thematic presentation and prevalence, is considered to represent acceptable (strong) sampling quality [17] and was attained in this study.

Eight participants completed an interview (5 females, 3 males). Mean age was 52 years (SD = 9.5 years). Six participants had a Spinal Cord Injury, one had been diagnosed with Multiple Sclerosis and one with Functional Neurological Disorder affecting the spinal cord and lower limbs. All participants were wheelchair users and resident in the UK. All began their use of mindfulness and pursuit of mindfulness training after being diagnosed with their medical condition. Participant characteristics are reported in table 1.

[Insert table 1 about here]

Materials

Demographic Questionnaire

A demographic questionnaire addressing current health status, approximate date of diagnosis of SCI/MS/FND, formal mindfulness training history, teaching commitments and personal mindfulness practice was completed.

Five Facet Mindfulness Questionnaire [FFMQ; 19]

The FFMQ is a 39-item questionnaire assessing five subscales of mindfulness: non-reactivity, observing, acting with awareness, non-judging, describing. The FFMQ has been widely used with student, community and clinical populations and has demonstrated strong internal consistency and reliability [19,20]. Scores were confirmatory only, used to validate expert meditator status: all participants had mindfulness scores on the Five Facet Mindfulness Questionnaire significantly above those shown in clinical populations with participants who are not mindfulness teachers [Mean = 165.6, SD = 12.18; for comparison see 2,18].

Interview Schedule

A 9-item semi-structured interview schedule was developed by [author names blinded], building upon preliminary qualitative research with people with SCI who had used mindfulness (reference blinded for anonymity, 2020). The schedule was reviewed by an accredited mindfulness teacher [author initials blinded] and piloted with a patient representative. The interview schedule is contained in table 2. Interviews lasted between 50 and 93 minutes (Mean 63.5; SD = 16.87). Interviews were conducted between May 2018 and September 2019.

Procedure

Following ethical approval from the University of [blinded for anonymity] ethics committee, information about the research was disseminated to the Mindfulness Teacher distribution lists at Breathworks, with permissions. Participants who responded to the recruitment information were contacted and provided with a copy of the participant information sheet and scheduled for an interview with either the first author (initials blinded; n = 3) or a member of the Trainee Health Psychologist team (n = 5). Before their interview, participants were asked to complete a consent form, giving written, informed consent, to complete a demographics questionnaire and the Five Facet Mindfulness questionnaire (FFMQ), to be returned by email. All interviewers had previously completed advanced training in qualitative research methods and interview techniques as part of accredited postgraduate training programme and further undertook interview training as a research team (2 hours) inclusive of peer-reviewed role-play scenarios based upon the interview schedule to ensure standardisation of interview delivery and fidelity across the study. Transcription quality was additionally audited by the first author. Interviews were semi-structured and guided by the interview schedule (see table 2), with participants given the

opportunity to lead the interview through discussion of the issues most salient to their experiences [21]. After completion of the interviews, participants were thanked for their participation and debriefed. Interview transcripts were returned to each participant for validation and further comment, if desired. Original interview transcripts were not altered, but participants were able to expand any thoughts they felt were unclear and clarify small details in transcription accuracy.

[insert table 2 about here]

Data Analysis, Quality and Rigour

The open-ended, semi-structured interview schedule was used to guide the interviews and also maintain an atmosphere of openness and supportive inquiry within the interview context. Participants were encouraged to make sense of their own experiences by raising topics and examples that were salient to their lives within the context of the interview schedule. The researcher used probes to further consider areas which were participant-generated but in accordance with the research aims [17]. Interviews began with an open-ended exploration of participants' interest in mindfulness in order to promote naturalistic discussion. Interviews were audio-recorded and transcribed verbatim. All identifying information (including places and names) have been changed throughout.

Analyses were undertaken in accordance with recommendations for Interpretative Phenomenological Analysis [21]. To avoid a 'top-down' imposition of theory or thematic content, transcripts were analysed idiographically, maintaining a 'bottom-up' stance and allowing the experience of the participant to be reflected in full. The first author undertook all analyses, with a reflective log kept throughout, to support in 'bracketing-off' assumptions and preconceptions which could bias analyses [21]. Transcripts were individually analysed at

three levels (after initial readings for familiarity): descriptive, linguistic and conceptual. These analytic notes were collated in association with the reflective log, to develop emergent themes for each case. A cross-case analysis was then conducted, maintaining a recursive stance and working closely with the emergent themes and transcripts to develop subordinate and higher-level superordinate themes.

Efforts were made at all points of the research to ensure that the lived experience of participants was fully reflected and that the process of analysis maintained a sense of coherence, rigour and transparency [22]. An independent auditor [initials blinded for review] with significant experience of IPA in clinical research triangulated emergent, clustered, subordinate and superordinate themes, and was fully engaged with the transcripts to validate the representative nature of the themes. Where disagreements occurred in the interpretation of the transcripts or themes, the discussion was presented to the research team for review and the rationale, quotations and transcripts were again considered in full.

Results

Analysis of transcripts resulted in two superordinate themes: 1) Adopting your body; and 2) Sensation without loss. Superordinate and subordinate themes and prevalence of themes within transcripts are shown in table 3.

[insert table 3 about here]

Adopting your body

This superordinate theme described the challenge of resolving and working with both body resistance and body acceptance when employing mindfulness after sensory loss. The desire to avoid focusing attention on the body after paralysis or sensory loss was experienced through cognitive and emotional resistance. To overcome this, mindfulness was deliberately employed as a courageous strategy for befriending the body as an embodied whole, irrespective of the presence or absence of sensation.

Mindful rejection of body resistance

After injury, participants discussed experiencing a period of crisis and emotional fallout which caused a longing for a different reality:

> What's happening for you when you're in that crisis point and you're looking for the lifeline: you want someone to take you and your body is the enemy. You've developed a relationship with your body where you want this fixed. You want it gone and you want to be what you were before. (Jenny)

Jenny specifically referenced her initial desire to return to her old body and the internal conflict she wrestled with as a consequence. Although at the time of crisis she wanted to go back to her pre-injury body, she acknowledged that she needed a lifeline. This tension between the past and future body is a process of overcoming resistance and could be conceptualised as a form of grief and a natural part of the adaptation to injury:

> You go through a grieving vortex. That really difficult patch of getting over [the body] is the last thing I want to do. You're asking me to face my body and I really want you just to take it away from me. That is the hardest thing. (Jenny)

Jenny is referencing that in her mindfulness practice she has to face up to her body. The difficulty inherent in facing the body and the fight to do so is a direct indication of Jenny's choice to work mindfully with the body rather than taking the easier path of avoidance "it's so easy to hate your body, to hate your condition, to be bitter, to be angry and not want to have anything to do with it anymore" (Elise). For Elise, there was a recognition of the difference between the 'easier' negative emotional responses and the potentially alternative path of body acceptance that is required by mindfulness. Within mindfulness practice, this could be manifested as avoidance of areas of the body within meditation:

> I think initially when I was first doing mindfulness, just the fear of going anywhere near around the scar: I was very resistant to it. Having had all the surgery that I've had and the after-effects of it, I really didn't manage very well with that. (Tricia)

Even within mindfulness meditation, resistance was therefore evident in the way in which Tricia was able to engage with her body. Those areas of the body which had experienced surgical intervention felt even more difficult to work through, provoking fear. Mindfulness was not experienced as a rapid solution to body resistance, and in fact, could be a vehicle in which body resistance could continue unless checked:

> I think meditating in a painful body, that's a big ask. The first ten years I basically did that, but I did that in order to escape my body, so I became good at my mind just shooting outside my body and just fantasising. So that was a struggle. And then learning to meditate *with* a painful body, that's been hard and very little instruction. (Jade)

Jade is clear that mindfulness can offer a method of seeking escape from a painful body, but this can manifest as a form of body resistance rather than body acceptance. For Jade, the ability to use mindfulness *with* the body rather than to escape the body, was primary. The magnitude of this challenge was recognised in the transcripts of seven (of eight) participants. This subordinate theme therefore reflects processes of moving through resistance and the deliberate mindful engagement that this requires.

Befriending the body

To move beyond resistance, the strength of the need to befriend and build relationship with the body was strongly represented:

> I think one of the things that was quite important was early on to come into relationship with the paralyzed part of my body because you could often feel, 'well, you can't feel that, well, it's not really you'. But actually, it is. You

> know it is. You need a covenant relationship with your body, the part of the body you don't feel. (Keith)

Keith acknowledged that he had to recognise that despite paralysis, it was his own body and therefore he needed a physical and emotional bond with it that traversed beyond sensory loss: he needed to reconnect with the disconnected aspects of his body. Sarah presented this as unique to Spinal Cord Injury:

> I think the main thing with spinal cord injury in particular, is a sort of a really interesting conundrum… 'cause the foundation of mindfulness is embodiment. You know, coming into the body. And if you've got very disrupted sensations in your body, are you going to sense the absence of parts of your body? Then how do you come into relationship with that? (Sarah)

Embodiment, despite sensory disturbance was consciously acknowledged as an unusual problem that challenged a core tenet of mindfulness. Without true mindful embodiment, Sarah projected a perspective that a full relationship with the body could not be achieved, therefore there was a need to resolve this in full. Resolution of that would enable living well with sensory loss:

> The recognition that actually, this life is good. You can live it well with your pain. Okay, it's not nice, you wouldn't want it. I don't want it in my life: I would rather it wasn't there. But it [mindfulness] is the only thing that has helped me to [pause] encompass the body I now live in and see that this is me, it's part of me and I can go forward with this. (Jenny)

Jenny's of the phrase 'the body I now live in' is particularly insightful, suggesting the significance of the challenge of adopting body post-injury which is experienced as new and different. Mindfulness was the solution to accepting and embracing her body, which enabled her to look again towards a future lived well. To access this future, mindfulness facilitated greater self-compassion:

> I've been able to say to myself 'yeah, you're disabled. It's ok. It's ok.' I can come close to it and not be scared I'm gonna get burned. You know, mindfulness is sort of like giving me more sort of compassion for myself. Much more than I had before. Some compassion. (Pete)

Pete was able to look beyond the stigma of the disabled label and feel warm self-compassion, something fostered to a growing extent by mindfulness. Jenny felt that this was unique to mindfulness:

> Mindfulness is the only thing that enables you to befriend your body again. Everything else seems to be trying to change where you are somehow back to where you were. With a condition that is not fixable, it's coming to terms with that. (Jenny)

In the context of having experienced many different treatment modalities, Jenny felt that mindfulness represented the only approach that enabled self-acceptance of her present body state rather than restoration to a past version of herself. The importance of befriending the body through mindfulness was not considered to be an easy option, nor was the implication for the person working through their sensory loss to be taken lightly: "It's not a distraction technique, you know. I'm saying more and more to people that I think it's the most courageous thing a human being could do. To sit there and face their own body"

(Sarah). In this quote, Sarah demonstrates a recognition of potential criticisms of and stigma about mindfulness, bluntly rejecting these and instead seeing the weight of courage needed to be mindful when living with a chronic health condition, particularly a condition with the potentially catastrophic physical and psychological consequences associated with SCI/MS/FND. In this subordinate theme, therefore, befriending the whole body was seen paramount and mindfulness as uniquely qualified to facilitate this shift in self-awareness and self-compassion.

Sensation without loss

The second superordinate theme addressed the rationale for and adaptations to mindfulness made in response to a body with disrupted sensation, principally through body scanning and visualisation of the body.

Body scan realism

One of the key techniques in mindfulness, the body scan, was presented by all participants as part of their daily and habitual mindfulness practice:

> I usually do a body scan in the morning and that's a habit I've got into from when I was very ill. It is just a straightforward body scan, but it is also just checking in where my body is at, at the time. And that's again a bit about taking responsibility. Just making sure I'm not doing more harm. (Tricia)

Through the body scan, Tricia is undertaking a daily physical check in order to foster a careful preventative awareness of her health status. Pete is using body scanning in a

comparable way: “I do body scans every day […] it’s important for me to lie down for 30 minutes just to let my body totally rest, ok, but by being aware, scanning through, [I] notice any problems I’ve got”. Both Tricia and Pete see the body scan as a method of heightening restful yet active physical awareness which can limit their risk of future difficulties.

The protective nature of the body scan was recognised by all participants, but they also recognised the risk and realism of undertaking a body scan in a body with pain, loss of sensation and paralysis:

> You know if you’re in a guided body scan and then you’re guided to be aware of your legs, but you don’t have much feeling then or you’re aware of a bit of an altered feeling; that’s quite challenging. I think it is one of those things, that kind of crossroads moment where it could have completely put me off, but I thought I just need to make it my own. Actually, for then, with those different sensations going on in my body, the body scan is my safe space to explore them, to be with them and to work with them. (Jade)

Recognising that the body scan could be significantly off-putting to those who do have sensory loss was important to Jade. Yet she personally re-conceptualised this risk as safety in order to work with her changed sensory awareness and as such was able to continue using body scans. The extent of the psychological impact of body scanning, for Robert, was not to be underestimated:

> We were going through the body scan and then it kind of triggered some thoughts or feelings about ‘wow, I can’t move or feel these parts of the body’. So, it took my awareness there in a way which was like a realisation on another level. I mean, obviously I know that I’ve been paralysed; at that

> stage I had been paralysed for a long time. But it was almost like a realisation on another level. I guess it was all the awareness was going to a part of the body where there was this apparent disconnect. (Robert).

Robert found that the body scan triggered a depth of awareness of his paralysis which was unusual for him. Though he was able to work with this and it was not experienced as threatening, the renewed awareness was profound and impactful – reconnecting the disconnected. Managing the risks initiated by body scanning was something discussed by all participants. This risk was recognised as something that could potentially be exacerbated by the use of ill-advised language. Non-inclusive language which is not sensitive to variation in sensory awareness could heighten feelings of loss:

> If it's about absence, then obviously the language of sensation just isn't gonna work for them [people with SCI] 'cause they're gonna think 'well I'm being asked to feel something I can't'. They might even feel really devastated and it might trigger all the feelings of loss that you're being asked to experience something that you can't experience. (Sarah)

Sarah's quotation demonstrates that the risk of body scanning could be significant, precipitating emotional distress and reactivating feelings of the loss of a body without paralysis. To overcome this, she recommends the sensitive use of language:

> One could do it in a way that's multi-purpose. So, you do something like 'now we're going to be aware of our feet. If you have sensations in your feet, what sensations are present? If you haven't got any sensations, how are you aware of the absence of sensations? How is that showing up?' (Sarah)

This body scan technique avoids the requirement that participants in mindfulness must have sensory awareness and instead respects the fact that awareness of sensory absence is equally important. The realism of the body scan therefore represents the importance of this technique as a foundation for protective daily practice, yet the sensitivity with which it must be handled in working with changed sensory awareness.

Working with visualised limbs

This subordinate theme was demonstrated with the greatest strength in those participants with paralysis from Spinal Cord Injury. Despite loss of physical sensation, there was a clear recognition of some form of sensory awareness:

> I've not quite nailed down exactly what's going on, but there is an awareness when one focuses on, say, like the toes or the bottom of the foot and the heel and the arch. It's not like, well obviously I don't have the sensory perception there or the proprioception isn't kind of there. But there is, there is some kind of awareness. There is some kind of perception going on but [it's] not very accurate. It's a bit fuzzy. So, I work with that. (Robert)

Robert recognised that his sensation was disrupted and expressed surprise and curiosity about how he could continue to engage with his lower body. Lack of accuracy in his perception was not a concern, instead he was willing to embrace and accept changed perception. He felt confident that he could still perceive his body below his level of injury and that such perception could be nurtured and worked with. This view was endorsed by Sarah:

> In people with spinal cord injuries, you need to have a heightened relationship with your body because you have to do the thinking for your body. I probably would say see if you can develop awareness of your feet, however it's arising. And it might be in the absence of sensation. So, you're sort of trying to get people to energetically engage with their feet even if they can't feel anything. Because they have got feet and they need to think about their feet if they're not going to get pressure sores and all that sort of thing. (Sarah)

For Sarah, absence of sensation should actually activate a desire for better cognitive engagement with the body in a preventative way. Therefore 'energetic engagement' offers a potential way of working with the paralysed body. This could be through visualisation:

> Sometimes there's like a strange kind of warmth or tingling in paralysed limbs as well. I find that really useful to work with and so it's kind of working with visualisation, but as well, tuning in, taking the mind right into those parts of the body. I find it does have a purpose, does have an effect. So, it's quite useful to really work with that. (Robert)

Visualisation, for Robert, is using the mind to combine his visualised limbs with any subtle physical sensation in the limbs with sensory loss. Keith uses the mindfulness terminology of 'sending awareness' into the body: "In my terminology, I would send awareness down to my feet. So, I thought that's probably a lot healthier to be aware and to take energy into all the different parts of your body". This redirection of awareness and attention are similarly explained as protective by Sarah:

> Because mine's an incomplete injury, I do have awarenesses, sensations in my body. They're altered, but I do have sensations. I think from another point of view, somebody who's got no sensation, they need to be more aware of their body.

By maintaining deliberate body awareness, despite sensation loss, Sarah is thinking and feeling for her body. Keith explains how this can be done in meditation:

> I think a lot of what I'm doing in meditation is not physical. I'll start off with the kind of physical sense of my body, but then it will become almost as if it's not a physical body, it's more a mental body that I'm experiencing. (Keith)

By combining the physical body with mental awareness, then Keith is moving beyond his physical restrictions to experience his body in full through meditation. Working with visualised limbs therefore represents the fusion between actual physical sensation and visualised, mental representations of limbs and sensation in order to fully engage with the body without limits by injury or condition.

Discussion

The results of the current research demonstrated that the experience of working with the body through mindfulness for people with sensory dysfunction presents very specific challenges. These challenges were exemplified in two superordinate themes, *Adopting your body* and *Sensation without loss*. The first superordinate theme encompassed the dynamics surrounding negotiating temptations to resist and avoid focusing on a body which felt separate due to sensory loss, negative symptoms, post-traumatic grief and the desire to

escape from pain and disability during mindful meditation. This was balanced by recognition of the need to befriend the body as a whole, inclusive of those areas of the body with and without sensation. Mindfulness was experienced as being uniquely qualified to facilitate the ability to build a positive and compassionate relationship with the body.

Promoting a move from resisting to befriending the body has been widely shown to be beneficial for SCI [23]. Befriending the body could be considered to be a form of acceptance, in which the changed body is embraced and valued, irrespective of its functional or sensory capacity. Acceptance has been shown to be of foundational importance in maintaining quality of life after SCI [23], protecting against mental ill health and promoting life satisfaction. This extends to acceptance of different physical symptoms associated with traumatic injury or illness: in the context of pain after SCI, acceptance has been shown to improve willingness to engage in physical activity and to reduce pain interference ([24]. In MS, patients with high self-concept integrity and acceptance had the lowest levels of anxiety and depression [25]. By restoring a relationship with the body, self-efficacy may be heightened, depression reduced and protective positive appraisals of disability encouraged [26]. The current research suggests that working with and approaching the body through mindfulness practice may support in the process of encouraging body acceptance and greater self-compassion after sensory loss.

The second superordinate theme considered the practical ways in which mindfulness could be adapted to encourage mindful experience of *Sensation without loss.* This reflected the core mindfulness technique of the body scan, perceived of as a protective and routinized way of fostering physical self-awareness and taking responsibility for observing and

managing fluctuations in physical well-being. Though body scans were recognized as beneficial, the risks inherent in intensifying the depth of bodily awareness were demonstrated in the current study. Directed focus on areas of the body with sensory disruption could be accompanied by emotional distress, feelings of loss and a deepened realisation of paralysis. Yet the absence/reduction of physical sensation was not considered to be a limiting factor in working with the whole body in mindfulness; by using visualisation of limbs, mental representations of the body and 'sending attention' to areas of the body irrespective of paralysis, it was possible to use mindfulness to achieve full embodiment despite the sensory loss.

The experience of psychological distress in response to heightened body awareness has not been addressed in the literature. Research has shown instead that body scans can minimise distress and improve psychosocial wellbeing [12], with mindfulness-based interventions typically increasing distress tolerance [27]. This discrepancy between present findings and wider literature can be explained by the specific experience of sensory loss and paralysis; due to experiencing the significance of such changes in the body and potentially associated traumatic injuries or disease-related decline, body awareness has heightened salience in the current sample. As such, focused attention on the body may (re-)trigger psychological distress, such as is already recognised to be a risk factor for reduced life satisfaction in people with SCI [28], MS [29] and FND [30]. Yet recognition of the protective benefits of the body scan was clear in the current study, with participants who engaged in daily body scans reporting early recognition of somatic symptoms and better management of their functional capacity. Body scans have been found to increase interoceptive awareness [31], decrease risk taking behaviour [32] and reduce PTSD symptoms [33], all protective outcomes that are

highly applicable for people with reduced sensory awareness. The body scan therefore needs to be addressed with sensitivity in mindfulness programmes, with practitioners and participants maintaining an awareness of the potential likelihood of increased focus on the meaning and experience of sensory loss, alongside a recognition of the potential psychophysiological benefits of the body scan. By restoring a sense of connection between the *whole* body and the mind, through mindfulness, the body scan can present a respectful way of encouraging the adaptive and protective process of embodiment despite paralysis.

In the current study, body awareness was not limited by sensory loss. Use of visualisation, mental body representation and imaginal techniques were employed to enhance full body awareness, even in those areas of the body with limited (or no) proprioception. Working with mental representations of the body has been found to improve cognitive processing [34], sensorimotor awareness [35], embodiment and interoception [36]. Doing so can heighten awareness of subtle physical indictors of body feedback (e.g. bladder capacity), and improve sense of personal and extra-personal space perception [37] for people with SCI and neurological disorders. Therefore, the benefits of working with the mental body are clearly evident and mindfulness may be uniquely privileged to enable such processes. By encouraging awareness of the presence or absence of sensation within the body as a whole, mindfulness can promote acceptance of disability and personal identity. These recommendations form helpful suggestions with strong applicability to practitioners and participants in mindfulness.

The current paper has prioritised exploration of the body scan and body awareness. It is noted, however, that other methods of mindfulness practice (for example, mindful

breathing, mindful walking) are likely also to need adaptation for sensory loss and future research should aim to consider adaptive practice more broadly. The nature of the sample within the current research, highly experienced teachers of mindfulness with SCI/MS/FND, may mean that the techniques and adaptations discussed by the participants could be limited to those with significant experience of mindfulness. Further research is needed to consider whether adaptations are accessible and achievable for those without such advanced levels of mindfulness training. It is recognised that variation in sensory loss will be present within the current sample, which may impact upon their experiences and recommendations, however significant efforts were made to manage this through the purposive recruitment of wheelchair users with reported sensory loss in lower limbs: purposive recruitment based on a specific criterion has been recommended for use in IPA [38]. Due to the nature of the interpretative lens, the interpretations offered in the current results may not be the only possible representation of the data [21], however every effort has been made, through idiographic, analytical and reflexive practice, to ensure that the results are representative of the dynamic experiences as revealed by participants.

Conclusions

Mindfulness has significant potential for wider usage in populations living with sensory loss and neurological disabilities. When care is taken to acknowledge and work through the cognitive and emotional challenges associated with using body scanning and meditation after SCI or neurological disruption, mindfulness can promote greater embodiment and body awareness. In particular, the body scan represents a method by which heightened body awareness may (re-)initiate psychological distress'; adequate support needs to be available to manage and work through such cognitive and emotional responses. Where

sensory loss occurs, it is possible to work with this successfully and positively, through using visualisation, mental representation, and awareness of sensory absence as well as presence. The body scan can be re-appropriated to explore presence and absence of sensation, accepting both equally and 'sending awareness' to the paralyzed parts of the body. By prioritising inclusive language that does not focus on sensation at the exclusion of lack of sensation, holistic mindful awareness can be encouraged, such that it can function as a protective and rehabilitative self-management strategy.

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Table 1. Participant Characteristics

Pseudonym	Age	Gender	Diagnosis	Date of Diagnosis	Employment Status	Teaching experience (years)	Daily practice (hours)
Jade	35	F	FND	2012	Part-Time	3	1
Sarah	58	F	SCI (I)	1976	Full-Time	20+	11
Pete	42	M	MS	2010	Part-Time	4	7
Keith	59	M	SCI (C)	1983	Unemployed	20+	3
Robert	55	M	SCI (C)	1984	Part-Time	8	1
Tricia	46	F	SCI (I)	1995	Full-Time	10	3
Elise	59	F	SCI (I)	2009	Retired	20+	10
Jenny	60	F	SCI (C)	1979	Volunteer	5	1

Notes. FND = Functional Neurological Disorder; MS = Multiple Sclerosis; SCI (C) = Complete Spinal Cord Injury; SCI (I) = Incomplete SCI

Table 2. Interview Schedule

1. Can you tell me a little about how you first came across mindfulness?
    a. How has your 'journey' developed since then?
2. Why have you continued to engage in mindfulness?
3. In your experience of SCI/MS/FND what role does mindfulness-based practice play in managing your condition?
4. Can you tell me about how you practice mindfulness?
    a. How often?
    b. Where?
    c. When?
    d. Which techniques?
5. How does your SCI/MS/FND impact upon your personal mindfulness practice?
6. What challenges to mindfulness have you encountered personally?
    a. Physical
    b. Emotional
    c. Prejudice/stigma
    d. Adapting techniques
7. How did you overcome these challenges?
8. Why do you think mindfulness is an effective approach for people with SCI/MS?
9. This research has focused on the barriers and facilitators to mindfulness experienced by people with MS/SCI. Is there anything more that you would like to tell me about?

Table 3. Superordinate and Subordinate themes and prevalence within transcripts

		Participant Pseudonyms							
Superordinate Theme	Subordinate Theme	Jade	Sarah	Pete	Keith	Robert	Tricia	Elise	Jenny
Adopting your body	Mindful rejection of body resistance								
	Befriending the body								
Sensation without loss	Body scan realism								
	Working with visualised limbs								

Key: Grey indicates theme was present in transcript