



# ‘Trying to bring attention to your body when you’re not sure where it is’: An interpretative phenomenological analysis of drivers and barriers to mindfulness for people with spinal cord injury

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**Objectives.** Work is beginning to explore the impact of mindfulness in managing the physical and psychological health of people with spinal cord injury (SCI). However, no previous work has sought to understand what drives people with such conditions to try mindfulness, and what barriers are experienced in accessing mindfulness.

**Design.** An exploratory, qualitative, interview design, utilizing interpretative phenomenological analysis.

**Methods.** Semi-structured interviews were conducted with 11 people with SCI who had experience of mindfulness since sustaining their injury. Verbatim transcripts were analysed using IPA to understand the lived experience of mindfulness post-SCI.

**Results.** Analysis suggested that managing physical and mental health, and viewing mindfulness as proactive and protective were key drivers for exploring mindfulness. However, multiple barriers to accessing opportunities and developing capability impeded engagement. These included the focus on areas of the body that participants had reduced sensation in, physical environments that could not be navigated in a wheelchair, social stigma surrounding the use of mindfulness, and a sense of obligation and risk of failure implied by perceived requirements for engagement.

**Conclusions.** The results demonstrate the need for specific interventions to accommodate the reduced sensory and physical function experienced by people with neurological conditions and to enhance sense of control and autonomy. In addition, recommendations include minimizing the stigma surrounding mindfulness, and the potentially demotivating impact of the perception of ‘failing’ to engage.

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## Statement of contribution

### **What is already known on this subject?**

- The physical and psychological consequences following neurological injury, including pain, social isolation, anxiety, and depressive symptoms, can complicate care needs and management.
- Mindfulness-based interventions demonstrate positive outcomes for people with spinal cord injury. However, these studies focus on efficacy rather than lived experiences, which can provide valuable insight into drivers and barriers to engagement in psychological management strategies.
- Evidence suggests that people with neurological conditions such as spinal cord injury want better access to psychological interventions that are tailored to their needs. However, there are few studies considering how standard mindfulness exercises are experienced.

### **What does this study add?**

- Acute injury and condition exacerbations, as well as reducing reliance on pharmacological treatment, served as key motivators of help-seeking, whilst perceived benefits served to reinforce engagement.
- Physically disabling environments prevented access to mindfulness courses, whilst stigma towards mindfulness, and the sense of 'failure' to engage served as barriers to help-seeking.
- As participants continually engaged in mindfulness exercises, habits were formed, thus building self-efficacy.
- Language in mindfulness exercises for the general population was a commonly cited barrier, given that this did not accommodate the physical and sensory losses associated with spinal cord injury, and could induce distress.

Neurological damage occurs through damage to the central or peripheral nervous system, for example, through traumatic injury. Spinal cord injury (SCI) can lead to partial or complete loss of motor and/or sensory function below the level of injury (American Spinal Injury Association [ASIA], 2015). Secondary physical and psychological consequences that may arise after neurological injury include increased risk of depression and anxiety, which are experienced in around 22.2% of people with SCI (Williams & Murray, 2015) and acute and chronic pain (Ullrich *et al.*, 2013). These complexities inevitably complicate self-management, and psychological interventions may be ideally placed to aid such management. Qualitative evidence suggests that people with SCI seek improved access to psychological interventions that are tailored to their specific needs (Hearn, Cotter, Fine & Finlay, 2015), making them an important and desirable support mechanism.

Studies of interventions such as cognitive behavioural therapy (CBT) demonstrate mixed evidence, with some initiating improvements in depression for people with SCI (Ullrich *et al.*, 2013), whilst others report no change (Norrbrink Budh, Kowalski, & Lundeborg, 2006). More recently, research is beginning to explore acceptance and mindfulness-based interventions (MBIs), which aim to promote non-judgemental, present-moment awareness to, and acceptance of, internal experiences (such as physical sensations, thoughts, and emotions; Kabat-Zinn, 1990). Research with people with multiple sclerosis has demonstrated benefit for promoting mental health and quality of life (Simpson *et al.*, 2014; Simpson *et al.*, 2019) and relieving fatigue, with inconsistent results for pain (Simpson *et al.*, 2020). A recent review of mindfulness-based interventions for people with SCI, however, concluded that further evidence is required to demonstrate efficacy of such interventions and explore their suitability for people with neurological conditions (Hearn & Cross, 2020).

There remains a dearth of evidence in this area, and that which does exist focuses on intervention efficacy (e.g., Curtis *et al.*, 2017; Hearn & Finlay, 2018), suggesting that internet-delivered MBIs can improve anxiety and pain unpleasantness (Hearn & Finlay, 2018), and is associated with improved mood in people with SCI (Skinner, Robertson, Allison, Dunlop, & Bucks, 2010). However, the understanding that can be obtained from personal experiential stories of people with neurological conditions such as SCI has been neglected, despite such investigations adding depth to literature. For example, people living with pain describe how initially engaging in MBIs can be difficult, particularly with regard to the time commitment required (Day *et al.*, 2019), demonstrating a need to explore personal motivation, perceived barriers, acceptability, and accessibility of mindfulness. The specific motor and sensory deficits uniquely associated with neurological conditions such as SCI may compound experiences of mindfulness, particularly given that widely used MBIs were developed for people without neurological conditions. Such exercises include practical exercises such as ‘mindful walking’ that would not be appropriate for wheelchair users. Thus, personal experiences of people with SCI are valuable in understanding the appropriateness of such interventions for this group.

Phenomenological approaches allow participants to discuss their experiences in their own terms and context, allowing for exploration of in-depth understandings, whilst remaining aware and open to previously unanticipated issues. Interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009) utilizes phenomenology and interpretation to understand ‘what personal and social experiences mean to the people who experience them’ (Shaw, 2010, p. 178). IPA can illuminate existing quantitative literature through analysis of accounts of those living and engaging with the phenomenon of study, making it an appropriate methodology to study the experience of mindfulness after neurological injury.

This study, therefore, aimed to obtain a rich understanding of the experiences people with SCI have in engaging in mindfulness post-injury. Specifically, this study aimed to:

- Explore factors motivating participation in MBIs and modalities used to practise mindfulness.
- Examine any benefits arising from engagement in mindfulness.
- Identify barriers that prevent/reduce engagement in mindfulness.

## **Methods**

### **Design**

An exploratory, qualitative design, utilizing IPA to analyse data obtained using semi-structured interviews with a small, homogeneous sample of people with experience of mindfulness since sustaining their SCI.

### **Participants**

Participants were self-selecting, in a purposeful sample, such that they had experiential knowledge of mindfulness since their SCI (Smith & Osborn, 2003). Inclusion criteria included: living with SCI for at least 1 year (considering adjustment to injury), experience of mindfulness through formally taught courses or personal exploration, over 18 years of age (no upper limit), sufficient understanding of English, given the nature of the methodology.

The sample ( $N = 11$ ) consisted of seven females and four males. Ages ranged from 22 to 65 years ( $M = 42.5$ ). Level of injury ranged from C6 to L5 (levels of spinal nerves, C1 being the highest, located in the cervical spine, through thoracic and lumbar levels, to S5 being the lowest, located in the sacrum; higher levels of injury are associated with increased physical impairment). Demographic information is provided in Table 1. Pseudonyms are provided to preserve anonymity.

### **Procedure**

Advertisements for the study were shared via social media and SCI charity websites. Those interested in participating were directed to contact the researcher, who provided them with the participant information sheet, which provided further detail of the study, including potential risks and benefits of participation, confidentiality, ethical review information, and offered the opportunity to ask questions. Participants had at least 24 hr to consider the study, after which times and dates of interviews were arranged. Informed consent was obtained prior to interviews, and demographic questionnaires, in which ten standard demographic variables, were completed: gender, age, employment status, ethnicity, marital status, cause of injury, time since injury, level of injury, completeness of injury, and ASIA impairment level. All participants opted to do their interviews via phone for ease and due to geographical location. The systematic approach of IPA described by Smith *et al.* (2009) was used, with data collected using an open-ended, semi-structured interview schedule (Table 2), which was developed to remain open and exploratory (Smith, 1996). The interview schedule was only referred to where areas had not been covered by the participant. Participants led interviews and were encouraged to discuss their experiences in terms of what was important to them. Minimal probes were used to gather further detail. After the interview, a debrief was provided to remind participants of the purpose of the study, dissemination of results, and their right to anonymity. Details of the research team were provided for questions or concerns. An independent contact point was detailed should participants want to discuss anything further. Interviews lasted between 36–58 min, were audio-recorded on an encrypted device and transcribed verbatim, including major dialogue expressions such as pauses and laughter.

### **Ethical considerations**

The study was granted full ethical approval by The University of Derby and was designed with full consideration of The British Psychological Society Code of Ethics and Conduct (2018). Participants were fully informed of the research prior to consenting and were offered ample time and opportunity to consider the study and raise questions or concerns. They were reminded of their rights to withdraw without giving a reason. Interviews were conducted at a time and date of the participant's choice to maximize accessibility.

Participants were given a verbal debrief after interviews, and a written debrief was provided in a follow-up email. After transcription, audio recordings were erased securely. Participant identifiable information and corresponding transcribed data files were stored separately on an encrypted, password-protected computer. Identifying features (e.g., locations) were replaced with descriptive information. Participants were given pseudonyms to retain anonymity and to 'bring the participant to life' during the analysis (Smith *et al.*, 2009). A key identifying which pseudonyms corresponded with each participant was stored securely and separately from transcriptions.

Table 1. Participant demographics (N = 11)

Participant <sup>a</sup>	Gender	Age	Employment status	Ethnicity	Marital status	Cause of injury	Time since injury (years, months)	Level of injury	ASIA impairment	Experience of mindfulness	Time practising/ exploring mindfulness
Alison	F	30	Part-time	British	Single	Fall	8y, 1m	T3/T4	ASIA A	Apps	4 years
Rachel	F	43	Unemployed	British	Single	Sporting injury	14y	L4/L5	ASIA A	Face-to-face course, apps, CDs	9 years
Stuart	M	46	Retired	British	Married	Fall	12y, 5m	T11	ASIA B	Reading	2 years
Anya	F	34	Part-time	British	Single	RTA <sup>b</sup>	12y, 7m	C6	ASIA A	Face-to-face course	4 years
Tony	M	34	Retired	British	Single	Fall	3y, 5m	T9	ASIA A	One app	3 years
Joanne	F	65	Retired	British	Divorced	RTA	42y	T10	ASIA A	One app	1 year
Aoife	F	22	Full-time	Irish	Single	RTA	3y, 5m	C6/C7	Unknown	Apps	7 years
Suzie	F	44	Part-time	British	Single	RTA	9y, 6m	L2/3	ASIA D	Face-to-face course	7 years
Thomas	M	58	Unemployed	British	Single	Sporting injury	6y	T4	ASIA A	Element of psychological therapy, app	4.5 years
Stephen	M	34	Part-time	British	Single	RTA	2y	T4	ASIA A	Books, one app	1.5 years
Erin	F	57	Retired	British	Divorced	Traumatic accident	7y	T11/12	ASIA A	One app, classes (not full course)	28 years

<sup>a</sup>All names changed to preserve anonymity; <sup>b</sup>Road Traffic Accident.

**Table 2.** Interview schedule

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1. Tell me about how you came to begin to explore mindfulness.
    - a. What motivated you to try mindfulness? (e.g., symptoms, recommendations)
    - b. Have you completed any mindfulness courses? Which ones, and when?
  2. What do you use to support your mindfulness practice?
    - a. e.g. YouTube, apps, books, websites
  3. How do you integrate mindfulness into your daily life (e.g., mindful eating), if at all?
    - a. Do you use cues/reminders to practice? Can you tell me about these cues?
  4. What benefits do you experience as a result of practising mindfulness?
    - a. e.g. Mental/physical health/symptoms
    - b. e.g. Social relationships
  5. What barriers do you experience that prevent or reduce your engagement in mindfulness? (e.g., tiredness, discomfort, accessible language, lack of sensation)
    - a. How do you respond to those barriers, if at all? (e.g., accommodating physical limitations, adapting mindfulness to suit your needs)
  6. Do you talk about your mindfulness practice with anyone?
    - a. If so, who?
    - b. Why?
    - c. What does this sharing add to your experience?
  7. How/why do you think mindfulness does/does not work for you?
  8. Is there anything else you would like to add to the discussion which you feel we have not already covered?
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### **Analytical strategy**

To gain familiarity with content, interviews were read at least once prior to conducting IPA. Each transcript was re-read, with linguistic, descriptive, and conceptual notes recorded to aid the development of emergent themes. Super-ordinate themes were abstracted through interrogation of emergent themes, with connections based on psychological concepts and abstractions. A table of super-ordinate themes was developed, with corresponding sub-ordinate themes and representative quotes highlighted. Each account was fully analysed ideographically before moving to the next.

Analysis was conducted iteratively, constantly moving between part (e.g., sub-ordinate themes) and whole (e.g., super-ordinate themes), and data were regularly revisited to ensure grounding of themes in the data (Smith *et al.*, 2009). Patterns across cases were then established through cross-case analysis, with convergences and divergences across individual experiences identified. A master table was generated, including super-ordinate themes and their corresponding sub-ordinate themes. Super-ordinate themes present across half of the sample are presented here, as recommended by Smith *et al.* (2009).

### **Quality checks**

The interpretative nature of IPA suggests that interpretation of data may differ across researchers, according to subjective contexts. To remain transparent in the analysis, a reflective diary was utilized to 'bracket off' prejudgements. Rigour, quality, and validity of the themes were verified with an independent auditor with experience of IPA and SCI research. The auditor reviewed the super-ordinate and sub-ordinate themes and quotes representing each theme. Interpretations of the data were discussed, leading to enhanced

**Table 3.** Super-ordinate themes and corresponding sub-ordinate themes

Broken bodies, calm minds	Inequalities in access to SCI-appropriate opportunities	Transitioning from obligation to identification
Motivation to manage trauma	Focus on inaccessible bodily sensations	Obligation intensifying risk of failure
Psychological benefits maintaining motivation	Disabling environments driving technology reliance Stigmatizing attitudes driving selective disclosure	Nurturing the new normal

understandings. Any disagreements were resolved through discussion and reworking of themes. Prevalence across the sample, and the richness of data aided prioritization of themes, which are considered credible and meaningful, although it is acknowledged that the interpretations presented here are not the only interpretations of the data (Smith *et al.*, 2009).

## Results

Participants discussed various drivers, outcomes, and barriers they experienced in terms of obtaining opportunities to practise and learn about mindfulness. Three super-ordinate themes were identified: (1) 'Broken Bodies, Calm Minds', (2) 'Inequalities in Access to SCI-Appropriate Opportunities', and (3) 'Transitioning from Obligation to Identification'. Super-ordinate themes and corresponding sub-ordinate themes are presented in Table 3.

### ***Super-ordinate theme one: Broken bodies, calm minds***

Representing core motivations for exploring mindfulness as a strategy to cope with the physical and psychological sequelae of SCI, this theme identifies the hierarchy of priorities in participants' health management, starting at acute management of their 'broken' bodies and progressing to maintenance.

#### *Sub-ordinate theme one: Motivation to manage trauma*

Participants' reasons for turning to mindfulness centred on acute but often serious deteriorations in physical or psychological health. For Suzie, pain and reliance on a cocktail of medications triggered her exploration of alternatives:

I had an incomplete SCI, but I was smashed to pieces in my accident. I got run over by a car . . . all my ribs were broken. I had a head injury, my hip was broken, my pelvis was broken, and my back was broken . . .<sup>1</sup> I had localised pain, but all that localised pain was everywhere . . . I was taking oxycontin, and tramadol, and oromorph, and paracetamol and all [emphasis] these other drugs, and I just thought 'I can't do this for the rest of my life' and so I was exploring other ways to [.]<sup>2</sup> address the pain. Suzie

<sup>1</sup> Indicates where text has been removed to improve fluency.

<sup>2</sup> Indicates a pause in speech, with one full stop representing 1 s.

Suzie's repetition of the word 'broken' and emphasis in describing having pain everywhere illustrates the extent of her injuries and pain, and the unlikelihood that medication could appropriately manage it. She described no desire to rely on pharmacology, stressing 'all' to indicate her aversion to the regime, highlighting her perception of the biomedical approach to physical health as inappropriate, along with her motivation to seek alternatives.

Rachel experienced low mood and was reliant on antidepressants, but sought another way to manage her health:

After my injury, I [. . .] went through a very low patch for a few years. I got very depressed. . . . I was put on antidepressants, and then after a few years I felt like I needed, something [emphasis] . . . I found . . . a mindfulness course, so I went along to that and [. . .] I don't know, I, the whole way that I was thinking about my injury and my life, sort of totally changed. Rachel

Rachel emphasized her need for an alternative to reduce her reliance on pharmacological intervention, her emphasis on 'something' underscoring the perceived dominance of the biomedical approach. Her exploration of alternatives led her to a mindfulness course, her attendance at which enabled her to better manage her health. Rachel describes cognitively reframing her injury and life in general, leading to enhanced motivation to practise.

This story was common across all participants, with physical and mental health a priority for people with SCI, highlighting the nature of mindfulness as sought out to address what pharmacological and more common psychological interventions may be less able to. This theme underscores the perception of mindfulness as having 'stronger' effects than other interventions in managing health.

#### *Sub-ordinate theme two: Psychological benefits maintaining motivation*

Despite physical health acting as the initial motivator for help-seeking, psychological benefits experienced maintained motivation to continue to practise. The large majority of participants focused on reduced anxiety and stress, and improved mood:

Just the act of meditation . . . the act of thinking about things differently, really helped my mood . . . it just helped me to [. . .] not have my disability as my main focus. Rachel

Mindfulness was beneficial in supporting Rachel in terms of improving her mood, reducing emotional reactivity, supporting her in seeing life in a manner less clouded by pervasive and ruminative thinking. Mindfulness also triggered cognitive reframing of her injury, with mindfulness undermining the dominance of her disability and improving her confidence.

However, one participant, Suzie, discussed how she had tried mindfulness but experienced no benefit:

I threw myself into it for a couple of months and it just . . . didn't work for me . . . it didn't help my pain . . . I felt a little bit jilted honestly, so [*laughter*]. Suzie

Suzie highlights her expectations of mindfulness as something that could aid pain management but was left feeling deflated after seeing no improvement, despite active and



enthusiastic engagement having ‘thrown herself into it’. Her feeling of being jilted reflects an impeded belief in mindfulness as an effective intervention, with her laughter echoing disappointment, hampered motivation, and a sense of lost hope.

Despite health deterioration being the main motivator for seeking alternative support, benefits experienced as a result of mindfulness were enough to maintain engagement. This highlighted how the experiential element of mindfulness practice enhanced motivation to maintain consistent practice. However, where expectations for improvement of specific symptoms were not met, motivation was hindered, demonstrating the need to manage expectations and manage the potential impact of unmet expectations on well-being.

***Super-ordinate theme two: Inequalities in access to SCI-appropriate opportunities***

After discussing motivations for engagement, discussion centred on the barriers (linguistic, environmental, and stigmatizing) that prevented full engagement with mindfulness practices. Such barriers were experienced when practising alone at home, and when attempting to access opportunities in community settings.

*Sub-ordinate theme one: Focus on inaccessible bodily sensations*

A key barrier was the language used within mindfulness, and the lack of adapted/accessible meditations accommodating for neurological injury. When practising a body scan, and asked to focus on her feet, Aoife experienced stress and frustration:

I was quite stressed one time and went on one of the apps that I’d never used before . . . and of course, the first thing it asked me to do was focus on my feet [*laughter*] and I was like ‘I don’t know where my feet are!’ so um, I found that kind of thing somewhat difficult because you’re obviously trying to bring attention to your body when you’re not entirely sure where it is.  
Aoife

Aoife’s laughter and acknowledgement ‘of course’ underscores the irony that she should seek stress relief and not have the neurological consequences of her SCI accommodated within the language of the meditation, with the body scan requesting focus on an area of the body that Aoife cannot sense. As a result, this could act as a barrier to engagement in mindfulness, particularly where it induces distress. In contrast, Anya’s experience was that bringing attention to areas with reduced sensation improved her relationship with her body:

What I really struggled with when I started to meditate was um, people saying ‘relax your head, relax your shoulders’, and then when you get down past my level of injury and I’d go ‘what am I supposed to do with that?’ . . . the language around the body was a barrier to start with and it took me some thinking around it to overcome it um [. . .] and to start with I was just like ‘well this is a load of rubbish, because I can’t do that’ . . . with practice I’ve realised that just because I can’t feel those parts of my body doesn’t mean that I can’t do it. I think it’s made me more aware that I do have a connection with those parts of my body still, rather than them just not really [. . .] existing just because I can’t feel them. Anya

Anya demonstrated initial scepticism towards mindfulness and the language that forced her to confront a psychological disconnect, pairing her loss of sensation with a sense of her body ceasing to exist. Anya emphasized her frustration and resignation that

mindfulness would offer her no benefit, referring to the exercise as ‘a load of rubbish’. Despite this, perseverance in the practice aided psychological progression towards enhancing her bodily awareness, and her sense of connection with her body.

When encountering language deemed inappropriate, participants described strategies to overcome this:

I mean, none [of the *mindfulness exercises*] actually are geared up for people who are wheelchair users with mobility issues . . . I don’t have any sensation, but I am able to imagine the different parts of my body very easily . . . I can’t physically feel my calf being tense or whatever it might be, but I can imagine that and visualise it quite easily. Alison

Alison acknowledged that no exercises have been specifically developed to accommodate SCI, but she could use visualization to overcome this, and doing so is not necessarily a burden. Despite the lack of accommodating language and the additional work required to alter the practice, her adaptations enabled her to experience the benefits of mindfulness. This emphasizes the need to reduce such burden on people with SCI and accommodate their needs such that they can fully engage with the mindfulness itself, as opposed to focusing on adapting it.

This theme highlights that generic mindfulness practices do not wholly accommodate the needs of people with neurological injury, and may emphasize an individual’s limitations, thus posing a barrier to engagement. This may be particularly prominent in the early stages of injury, when people are still adapting to functional losses.

#### *Sub-ordinate theme two: Disabling environments driving technology reliance*

In addition to linguistic barriers, non-wheelchair friendly environments acted as a barrier to opportunities:

I’m living in Ireland . . . so um, there’s just not much accessibility. So, like any of the groups and events that would be related to mindfulness aren’t accessible. Aoife

The experience of physical barriers and environmental inaccessibility was common across participants, highlighting a lack of control and autonomy over what participants could and could not do. This deprived participants of opportunities to access something that could hold potential for this group of people. In response to such physical barriers, participants described resignation to using technology:

I’m more or less house bound, and I can’t often go out to classes or anything because when I do, I struggle to get to them. Um [ . . . ] so the apps are probably the only thing I could do. I can’t think of any other way of doing it. Joanne

Joanne discussed having no option but to rely on apps (e.g., Headspace) to overcome environmental barriers surrounding her SCI and wheelchair use, emphasizing disappointment and resignation in not having ‘any other way of doing it’. Despite this, this underscores the additional options available to people unable to access face-to-face courses, which can offer control and autonomy until physical/environmental access is improved. However, such alternative options do not provide users with the supportive group setting in which mindfulness courses are situated, nor the guidance of a trained teacher, which can support course participants in enhancing their mindful awareness.

Environmental barriers were frequently cited as impeding opportunities to learn about and practise mindfulness. This emphasizes the importance of the environments selected for mindfulness classes to be inclusive, suggesting that further consideration is required to accommodate people with physical disabilities.

*Sub-ordinate theme three: Stigmatizing attitudes driving selective disclosure*

The third barrier to engagement reflected concerns surrounding being stigmatized leading to a hesitancy towards open discussion. As such, participants experienced a selective disclosure, altering behaviour and discussion according to the responses of others:

It very much depends who I'm talking to and how they respond to what I'm saying, but I tend to be a lot more guarded when I'm talking about it with people that I don't know or people who I know don't have any experience of it. Anya

Anya described being 'guarded', indicating her hesitation and reservations discussing her experiences with others. The openness of others was used as an indicator of the level of judgement she might be subject to, with Anya actively evaluating social responses to guide her disclosure and protect her psychological well-being and identity. Stuart also discussed similarly stigmatizing attitudes:

There are people who think it's codswallop and it's rubbish and . . . that new-age kind of thinking. Again, going back to some of the forums I've been on [. . .] you know, there's people that sound like they're beyond help, in terms of what they've had to live with for a long time . . . and their automatic response is to shut me down. You know 'Don't be daft. How can mindfulness help me when medication can't?'. Stuart

Stuart's attempts to help others by recommending a potentially useful intervention were frequently met with scepticism and rejection. His repeated use of negative descriptors ('codswallop', 'rubbish') suggests that he saw others place little value on mindfulness, viewing it as 'unconventional' and lacking in evidence, and his surprise surrounding this is echoed in his expectation that the people 'beyond help' would be open to such a suggestion. The value placed on pharmacological management demonstrates the dominance of the biomedical narrative and need for further integration of psychosocial interventions. Erin also acknowledged the need for psychological readiness:

It would be good for people, I am absolutely certain, but they've got to be open to it haven't they? But that is the difficulty; if people could be open to it. Without it sounding too wacky, people just think 'bleurgh', you know? Yeah, they just think you're a bit mad. Erin

Despite Erin's belief in the power of mindfulness ('absolutely certain') to facilitate positive change for people with SCI, she acknowledged the resignation of trying to help others without them being ready to engage. She indicated prejudgements she has been met with in response to her discussion of a perhaps more unconventional method of managing stress, her use of 'bleurgh' indicating a sense of disapproval and aversion presented by others in response to her suggestions, which may have implications for her social support.

The sense of disapproval and attitudinal challenges prevented discussion about mindfulness. Despite this, most participants spoke of it as something not necessarily overwhelming. However, such views could have negative implications, with those describing such negative experiences potentially experiencing isolation, and reducing their access to a tool to aid stress management. This theme underscores the importance of education surrounding SCI and mindfulness techniques.

***Super-ordinate theme three: Transitioning from obligation to identification***

Despite the multiple challenges discussed, participants' experiences were of a transitional nature that were not necessarily impeded by such barriers. Those who had learnt about mindfulness through courses/classes experienced a sense of responsibility to commit and adhere to instructions provided. As time progressed, their practice became habitual; mindfulness became a proactive coping strategy.

*Sub-ordinate theme one: Obligation intensifying risk of failure*

Participants who attended formal, face-to-face classes often reported a sense of obligation to practise:

I feel like a course puts pressure on you to have to do it, and when you don't you beat yourself up, but when you just pick and choose and dip in and out [ . . . ] I like that, then I'm not beating myself up for not doing it. Alison

Alison's perceptions of the demands of a mindfulness course induce unnecessary pressure, which she felt would set her up for 'failure', and that failure to engage would result in punishing responses from others/herself. This could lead to demotivation and further psychological difficulties if the perception of failure persists. Instead, Alison adapted her engagement in mindfulness to her personal preferences, which also meant that she did not berate herself for not following prescribed guidelines. This was echoed by Aoife:

I think courses are difficult for people, because it makes it into a competition with themselves. Um, so say a three-week course, um, if they end up not doing a day they will feel like they've failed and they're no good at it, when it's not actually something to be good at. Aoife

Courses were perceived to foster pressure to adhere to course requirements, and feelings of being encouraged to strive and establish superiority over their past selves. Aoife emphasizes the nature of mindfulness as not something to strive to be 'good at', demonstrating the contrast between the values of mindfulness and the sense of achievement and failure potentially fostered by courses.

Arising from the sense of obligation that a course might unintentionally promote, feelings of failure could be induced where attendees are not able to commit to regular practice, arising from culturally based attitudes that striving and achieving is positive. This could lead to dissociation from the values of mindfulness, reduced motivation in those feeling they are not 'good enough', and reduced engagement in a potentially meaningful practice.

*Sub-ordinate theme two: Nurturing the new normal*

As participants gained experience in mindfulness techniques, engagement transitioned from obligation to proactive, habitual engagement. Erin reinforced the view of mindfulness as a tool to be integrated into one's life, used as a proactive and protective tool:

It's just sort of, part of me now . . . for quite a long time I used to say 'It's like a friend, you've got to practice it. You can't just pick it up when you want it'. I think it's part of me now. Erin

Erin's reflection on the reactive use of mindfulness draws comparison of nurturing the skill of mindfulness as one would nurture a friendship, rather than 'picking it up' when needed and dropping it when not, which would have implications for any friendship, and in the context of mindfulness practice, well-being. Having nurtured her practice, mindfulness became part of Erin's identity, which may play a role in her sustained practice. Rachel's experience also shifted from obligation towards her sense of mindfulness being a natural part of life:

I think I needed to think more about making sure I [.] had time for it, before, back in the beginning, and . . . I'd look back at yesterday and think 'oh, I didn't do it'. But now I think, I don't need to kind of schedule it in as before, it's just natural now. Rachel

Rachel's mindfulness practice was perceived as a proactive lifestyle choice. Her reflection echoes the sense of effort required to make time for mindfulness before it became an integrated part of her life, with little planning required. This echoes her high internal motivation and self-efficacy, reinforcing that mindfulness was used as a proactive and protective mechanism to prevent health deteriorations, rather than in response to crises.

This theme underscores how mindfulness can become habitual, with the sense of pressure initially experienced as a potential target for altering guidance within courses/classes, to build self-efficacy, and avoid feelings of failure and demotivation.

## Discussion

The current study aimed to obtain a rich understanding of experiences of mindfulness post-SCI. Three themes were developed: (1) 'Broken Bodies, Calm Minds', (2) 'Inequalities in Access to SCI-Appropriate Opportunities', and (3) 'Transitioning from Obligation to Identification'. These encompass factors pertaining to participants' capabilities, opportunities, and motivations to engage in mindfulness, representing barriers that reduce/prevent engagement. Some elements relate to barriers for people practising mindfulness such as the time commitment (Day *et al.*, 2014; Day & Thorne, 2017), yet these results highlight considerations required to accommodate people with neurological conditions. Whilst accounts demonstrated convergence in themes, the contextual and subjective nature of experience at the individual level was highlighted, signifying that mindfulness should be adapted to unique needs and preferences to maximize psychosocial function.

The key driver of help-seeking was management of acute health crises, and resistance to medical management (a theme echoed in previous research with this group; Hearn, Cotter, Fine, & Finlay, 2015). This can be related to Ryan and Deci's (2000) self-determination theory, with health deterioration an extrinsic motivator to seek help to avoid further negative health consequences, rather than seeking the experiential aspect of

mindfulness. The progressive experience of psychological benefits is representative of a large body of literature suggesting that engagement in mindfulness can improve symptoms of depression (Hofmann *et al.*, 2010) and undermine ruminative thinking (Gu *et al.*, 2015), both of which were discussed by participants in this study. However, in line with previous evidence (e.g., Hilton *et al.*, 2017) and a previous trial of an MBI (Hearn & Finlay, 2018), one participant reported that mindfulness did not improve her experience of pain, suggesting that reductions in pain may not be an appropriate motivation for using mindfulness.

Barriers to engagement were identified that could impede autonomy and control over one's health. The language used within generic mindfulness practices was not deemed appropriate for people with neurological injury, given the associated sensory and motor deficits. This impeded participants' abilities to develop capability in the practice, particularly in the early stages where people felt disconnected from their bodies as they adjusted their 'new' bodies. This novel finding stemmed from participants' lived experiences of the 'standard' mindfulness meditations available, with only two previous studies examining mindfulness for people post-stroke (Garrett *et al.*, 2011; Merriman *et al.*, 2015) demonstrating similar challenges. This emphasizes the need for further research in this area to accommodate neurological conditions, given the variable sensory and motor function post-injury, such that participants can fully immerse themselves in the practice without having to adapt them to their SCI.

Difficulty navigating physical environments in a wheelchair prevented access to courses. This could lead to feelings of incompetence and may, over time, induce a sense of helplessness and reduce future participation (Yau, Mckercher, & Packer, 2004). Addressing physical and environmental barriers and other psychosocial challenges will help ensure that people with physical disabilities are empowered to engage in supportive practices. In contrast, accessing mindfulness via apps and CDs augmented capability, allowing participants to achieve similar results without navigating potentially complex environments. Indeed, technology-delivered MBIs demonstrated improvements in stress and depression in a recent review (Fish, Brimson, & Lynch, 2016) and may improve access to mindfulness (Baumel, Muench, Edan, & Kane, 2019). However, apps may not provide detailed information and supportive networks that face-to-face courses do (Birtwell *et al.*, 2019), which may contribute to disappointment experienced in those unable to access face-to-face support. Whilst apps may be suitable for introducing mindfulness, enhancing accessibility of face-to-face courses and developing apps geared towards people with neurological conditions may provide greater benefit.

The final barrier surrounded stigmatizing attitudes, which led to protective behaviours such as selective disclosure. This is noteworthy given that most people had not attended a formal course that may have introduced participants to a supportive network with which to discuss mindfulness, in line with previous research (Birtwell *et al.*, 2019). Lack of understanding of mindfulness and its benefits was cited as a common reason for judgemental reactions, with participants being met with perceptions of mindfulness as 'unconventional' and a 'quick fix' that was considered ineffective. Selective disclosure has not been demonstrated in previous literature pertaining to mindfulness but is exhibited in people with long-term conditions like depression and is associated with treatment non-adherence and poorer health outcomes (Sirey *et al.*, 2001). Drawing parallels, participants in the present study used selective disclosure as a protective mechanism, which could implicate similar behaviours and outcomes for those practising mindfulness who are met with critical perceptions, highlighting a need for supportive and educational interventions to mitigate this.

Mindfulness courses were often perceived negatively, with a sense of obligation to adhere to instructions driving extrinsic motivation. However, perceiving oneself as 'failing' can induce aversive psychological tension such as guilt (Whatley *et al.*, 1999), which could demotivate engagement in mindfulness. However, initial engagement led to experiences of efficacy and psychological 'rewards' that may strengthen the intention-behaviour relationship (Langer & Moldoveanu, 2000), particularly if individuals are supported by others and appropriate content (Birtwell *et al.*, 2019), as was acknowledged by participants in the present study. Habitual practice was reflected by many participants, which is consistently identified as a predictor of behaviour (Hagger *et al.*, 2002); those who form habits are better placed to subsequently act on opportunities to practise mindfulness, where such opportunities (e.g., piques in stress) activate stored cue-behaviour associations (Michie, Stralen, & West, 2011). This demonstrates the value of forming habitual mindfulness practice, and the need for further research in this area, which can enhance intrinsic motivation, sense of autonomy over one's health.

### **Clinical implications**

The present study indicates that motivation to engage in mindfulness is present, often arising from a drive to manage health. Motivation can be hindered by the lack of specific considerations to accommodate functional and sensory deficits after neurological injury. As such, specifically tailored exercises that maximize capability and opportunities to practise mindfulness, such as guided exercises that provide options for where and how to focus attention on areas of the body with less sensory function, are desirable. Through maximizing opportunities for people with SCI to engage in mindfulness, actual engagement is more likely (Michie *et al.*, 2011), as is habit formation (Lally & Gardner, 2013).

MBIs may be appropriate for people with SCI, when modified to SCI-specific needs. Considerations surrounding developing modified exercises should focus on inclusive language that accommodates reduced sensory function, physical accessibility of face-to-face courses, and training mindfulness teachers to minimize the sense of pressure experienced within courses (as demonstrated in the present study). To address this, whilst making clear that home practice is important, participants could be reassured that they can adapt their home practice to suit their personal schedule, an appropriate consideration for people with SCI, where activities of daily living may be somewhat time-consuming. Developing mindfulness practice as habitual and complementary to everyday life, and fitting this in where appropriate at the individual level (rather than advocating 30 min per day, e.g.), would help to maximize engagement.

### **Limitations and future research**

The interpretative nature of IPA means that causality cannot be determined (e.g., the relationship between mindfulness and the psychological benefits described). Longitudinal interviewing would better aid the understanding of benefits experienced and the integration of mindfulness into daily life over time. The self-selecting sample likely led to the recruitment of individuals with positive experiences who may have been compelled to participate. The results, therefore, may not be representative of those who had not experienced benefits of mindfulness. However, purposive sampling meant that overlapping and diverging experiences were illuminated and demonstrates the challenges for those with SCI in sourcing appropriate psychological support. The themes identified are

under-represented within the literature and warrant further study to maximize outcomes for people with SCI.

### **Conclusions**

This study demonstrates the various motivations, benefits experienced, and challenges faced when seeking to engage in mindfulness post-neurological injury. The novel findings indicate key issues that require further development to maximize health outcomes, including examining the role of language in accommodating neurological deficits within mindfulness practices, and focusing on habit formation as a way to integrate practice into daily life.

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### **Author contribution**

Jasmine Heath Hearn (Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Writing – original draft; Writing – review & editing)  
Katherine Anne Finlay (Conceptualization; Formal analysis; Writing – review & editing)  
David Sheffield (Conceptualization; Methodology; Supervision; Writing – review & editing).

### **Conflicts of interest**

All authors declare no conflict of interest.

### **Data availability statement**

Research data are not shared.

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