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## Improving current understanding of cognitive impairment in spinal cord injury: The patient perspective

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**Context:** Emerging research suggests that individuals with a spinal cord injury (SCI) may be at a higher risk of developing cognitive impairment. Early detection of cognitive impairment is essential to improving quality of life and tailored rehabilitation. However, the true incidence of cognitive impairment in this group is unclear, largely due to the difficulty in administering cognitive assessment tools which often have elements that are dependent on hand function *e.g.* drawing and writing.

**Design:** We conducted three semi-structured focus groups with a total of 9 participants with the aim of gaining a better understanding of patient perspectives on subjective cognitive difficulties following their SCI.

**Setting:** Online focus groups.

**Participants:** 9 participants who have sustained a spinal cord injury.

**Interventions:** Focus groups were transcribed verbatim and analyzed using reflexive thematic analysis.

**Outcome Measures:** Transcript were coded to identify patterns which were analyzed using reflexive thematic analysis to produce five overarching themes.

**Results:** People with SCI reported various levels of cognitive difficulties following their injury, and shared strategies that they have implemented to cope with these challenges. All participants expressed a lack of information or assessments on cognitive impairments, highlighting that the focus of their care has predominantly been about the physical aspects of their SCI. Additionally, they observed a difference in the approach to SCI management across different centers within the UK.

**Conclusion:** Patients with a SCI report cognitive issues following their injury but there is a lack of information or testing by healthcare professionals. Patients advocated for a more consistent and standardized approach, particularly since cognitive impairment can increase care needs and reduce engagement with rehabilitation.

### KEYWORDS




Spinal cord injury; Cognitive impairment; SCI and cognition; MOCA; MMSE

## Introduction

Spinal cord injury (SCI) can be a debilitating neurological condition with a rising prevalence, particularly amongst the elderly population (1,2). It is commonly associated with physical impairments such as loss of motor or sensory function. However, emerging research shows that people with a SCI may be up to 13 times more likely to develop cognitive impairment than those without a SCI (3). Furthermore, people with SCI are up to twice as likely to develop early-onset Alzheimer's disease (4).

Individuals with a SCI have multiple risk factors for developing cognitive impairment including traumatic brain injury sustained at the time of the injury, neuroinflammation, medications used in the management of SCI, and psychiatric disorders that may develop post injury (5).

Early detection of cognitive impairment enables both the patient and their healthcare providers to plan for their future. By identifying cognitive impairment early, patients may implement lifestyle changes focusing

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on modifiable risk factors for dementia, such as smoking, alcohol use, and obesity (6). Furthermore, clinicians working with people with SCI could address cardiovascular disease, social isolation, and mood disturbances, all of which are also risk factors for developing dementia and worsening cognitive dysfunction (6). Finally, disease modifying therapies for Alzheimer's disease are more likely to have a greater impact earlier in the disease process (7), further emphasizing the importance of early detection of cognitive impairment in SCI due to the higher risk of developing Alzheimer's disease.

When cognitive impairment is suspected, various psychometric tests are used to support a diagnosis, such as the Montreal Cognitive Assessment (MoCA), the Mini-Mental State Examination (MMSE) and the Clock Drawing Test (CDT). However, a major limitation of these tests is that they all rely on intact hand function, making them less suitable for patients with a SCI, particularly those with a higher cord injury where hand function is impaired. There is also limited description often in national guidelines on which assessment tool is the best to use and when.

We previously explored the clinicians perspective on the development of cognitive impairment following a SCI (8). When questioning SCI clinicians there was an appreciation that people with SCI develop cognitive impairment, but a lack of national guidelines, knowing which cognitive test to use, and cognitive tests not always being appropriate were barriers to fully understanding cognitive impairment post SCI.

As there was a lack of consensus amongst clinicians regarding the prevalence and optimal management of cognitive impairment following SCI we felt it was important to understand if a similar perspective existed in people living with SCI. We also wanted to know what initial challenges come with cognitive difficulties in those with SCI. This study aims to examine the lived experience of people with a SCI who report subjective cognitive difficulties. Through reflexive thematic analysis (9,10), we explore participants' perceived challenges, the types of information or assessments they have received, and their views on how SCI centers and healthcare professionals currently address, and can better address, cognitive difficulties in this group. Exploring participants' subjective experience through an interpretivist lens allowed for a more nuanced and context-sensitive interpretation of the challenges faced by people with a SCI.

## **Methodology**

### **Participants**

Nine participants were recruited from local clinical contacts and online (Facebook) peer support groups to participate in one of three focus groups conducted between July 2024 and January 2025. Participants were included if they had a spinal cord injury and self-identified as experiencing cognitive difficulties. No strict exclusion criteria were applied, in line with our use of reflexive thematic analysis and focus on obtaining a broad range of subjective experiences. All participants were White British English language speakers. To ensure diverse perspectives, participants were not selected based on other factors *e.g.* age, socio-economic background, severity of injury, or time since injury.

Participants in our study were aged between 35 and 67 (average age 53) and had sustained their injuries between 1 and 45 years ago (average time since injury of 19.8 years). 7 participants had sustained a higher spinal cord injury (C3-C7) with 2 participants sustaining a lower spinal cord injury (T4-T5 and L1-L5).

Participants who agreed were contacted by the author (HP) and given further information on the study aims and objectives. Written informed consent was obtained from all participants.

### **Data collection**

We followed the COREQ checklist (11) to ensure transparency (see Appendix 2). The research team included both medical doctors and experienced qualitative researchers. The lead interviewer (HP) was a male doctor trained by a researcher with experience in reflexive thematic analysis. HP had no prior relationship to participants.

Three semi-structured focus groups were conducted online with at least 2 members of the research team. Each focus group lasted around 1 h. The focus groups were led by the author (HP) using a semi-structured interview guide which was developed collaboratively by the research team based on the study aims,

knowledge of literature, and clinical context. Questions focussed on participants experience of symptoms of subjective cognitive deficits including adaptations, information and assessments from healthcare professionals, and how services can be improved (see Appendix 1). As part of the discussion, we showed participants a short video of an online automated cognitive screening tool called CognoSpeak (video <https://vimeo.com/839101519>).

Sessions were audio-recorded and transcribed verbatim. Field notes were taken by the facilitators to capture non-verbal cues and contextual information.

### **Data analysis**

Transcripts were derived from audio recordings verbatim. An organic and recursive coding process was conducted by the lead interviewer (HP). An inductive, thematic analysis (10) was used to identify patterns and generate (initial) themes from the data. These themes were iteratively developed and organized into five overarching categories, whilst acknowledging and reflecting upon the researcher's role in the analysis process. Themes were developed directly from the data without the use of a predefined theoretical framework. The term "subjective cognitive difficulties" was used when referring to participants self-reported symptoms, to differentiate between "cognitive impairment" which has been objectively measured through formal testing.

We did not aim for data saturation and instead applied the principle of information power to guide sample adequacy, as this is more consistent with our reflexive thematic approach.

### **Patient and public involvement**

This study was conducted to collect information from those with lived experience of SCI. The study adhered to ethical guidelines ensuring all participants provided informed consent, confidentiality, and allowing participants to withdraw from the session or study at any point. Ethical approval was gained through the University of Sheffield Ethics committee, reference 046972 and approved on 11/07/2022.

### **Results and analysis**

Through reflexive thematic analysis 5 overarching themes were identified, which explored participants experiences with symptoms, adapting their lives, current support, and suggestions on how to develop services.

### **Cognitive issues following spinal cord injury**

Cognitive issues following a SCI are frequently underappreciated and can significantly impact daily life.

People say that I have problems remembering things, that I forget things. [P1]

I would not remember specific dates and that we were due to be doing stuff. [P2]

These impairments seen following a SCI may be due to biological factors related to their injury, secondary complications such as poor sleep, or as a result of the medications used to manage the complications of a SCI, which may have adverse cognitive effects (5,12).

Furthermore, the intense rehabilitation and subsequent lifestyle adaptations required following a SCI is a source of an additional cognitive burden which may hinder cognitive processes.

Having that added pressure whenever you want to do anything, and having to worry, even after so long, about bathrooms and access and everything else that most people wouldn't have to even consider when planning a journey can sometimes be taxing. [P3]

But so much of that is probably down to the fact that I've got so many things to deal with on my plate at the same time. [P4]

The cognitive load associated with living with a SCI might significantly impact working memory performance. Working memory has a limited capacity (13), and individuals with a SCI must continuously adapt and acquire new skills. However, the cumulative cognitive load resulting from their injury may impair this learning process.

### ***Adapting to living with a spinal cord injury***

Participants with a SCI often develop adaptive techniques to cope with the cognitive effects of their injury.

Having an iPad now really helps a lot, especially being able to use voice recognition for emails to myself, reminders, and memoir notes. [P2]

These strategies allow the individual to regain control over their cognitive challenges and reclaim a sense of agency. However, despite using these strategies to cope with their cognitive difficulties, they are a further source of cognitive burden.

I find it exhausting having to write everything down and plan everything on paper. [P5]

This theme highlights the contrasting experiences in adapting to life following a SCI and the complex interplay between remaining resilient in compensating for cognitive difficulties with the additional cognitive demand it produces. Difficulties in adapting to and coping with the effects of a SCI can increase the likelihood of developing maladaptive behaviors such as non-adherence to therapy or substance misuse and emphasizes the importance of individualized rehabilitation and coping strategies (14).

### ***A lack of information about cognitive impairments following a spinal cord injury***

Many individuals expressed that they were unaware of the potential cognitive impairments associated with their SCI. This can lead to a sense of helplessness as individuals may struggle with cognitive changes without an understanding of their cause or significance.

There was never at any point during the rehabilitation phase or subsequently as an outpatient, any input on memory, thinking problems, emotional problems, or counselling. It has purely been about practical coping with either medical issues or activities of daily living. [P2]

Participants reflected that the absence of a diagnosis prevents them from identifying with a specific group, limiting their access to support groups, such as those available for Alzheimer's disease. This contributes to feelings of uncertainty and social isolation. Support groups play a crucial role in enhancing the well-being of individuals with chronic conditions including offering emotional support and a sense of community. Participation in these groups can improve psychological wellbeing, reduce feelings of isolation, and enhance coping strategies through peer learning (15,16).

### ***The need for a national standardized tool***

The need for a national standardized approach resonated powerfully within the group and emerged as a recurring theme in the discussions.

I really strongly would support the development of a national strategy. There's quite a lot of areas where there are different processes and approaches from different spinal cord injury centres. [P6]

Participants acknowledged, through peer support groups, that people receive different care depending on the area that they are based in and their local healthcare system. This is identified by the Spinal Injuries Association in a recent publication "A Call For Action" which highlights regional variabilities in quality and provision of healthcare, including a lack of agreed standards and pathways of care (17). Reassuringly, participants who are still actively involved in peer support groups reflected that SCI care has improved significantly within the last 10 years. However, there remains significant variation in rehabilitation pathways depending on geography and socio-economic background.

### **The utility of an online screening tool**

We demonstrated an example of an online tool called CognoSpeak, which uses a talking head “digital doctor” to analyze distinct speech patterns that may indicate cognitive impairment or dementia (18,19).

All participants expressed interest in using such an online platform, particularly since it can help to break down barriers to assessment.

I think it's a great tool if it relies on speech rather than body language which can be a problem with tetraplegics. [P4]

I like the idea of doing it at home or in the waiting room before an appointment as there's so much to cover during the appointment. [P7]

Participants particularly appreciated the idea of completing the assessment prior to their clinic as they recognized the time constraints of outpatient clinic appointments. However, some participants did report that the computer-generated clinician in the tool could be “unnerving” or an “uncanny valley” and therefore it is vital to recognize that while technology can enhance accessibility, it requires careful consideration of user-friendliness.

### **Discussion**

The impact of cognitive impairments in SCI can create significant challenges to both rehabilitation and quality of life. Cognitive impairments following a SCI are complex and likely to be influenced by a myriad of factors including the biological, pharmacological, and psychological sequelae of the injury. Most participants in our focus groups described a degree of subjective cognitive difficulties following their injury. They also described reliance on external memory aids to adapt for cognitive impairments following their injury. However, these pose an additional cognitive demand and highlights the importance of tailored rehabilitation strategies and support systems designed to minimize cognitive load.

Participants reported a lack of information by healthcare providers on possible cognitive impairments following their injury and discussion in the focus groups indicates a disconnect between the individual's experience of cognitive difficulties and acknowledgement or recognition by healthcare professionals. We have previously highlighted that many SCI centers across the UK do not routinely screen for cognitive impairments, despite noting a higher incidence of cognitive impairment in this group (8).

Individuals with a SCI highlight a difference in care provided across SCI centers in the UK. From a cognitive health perspective, this is consistent with findings from our survey of SCI clinicians which indicated that not all SCI centers in the UK screen for cognitive impairments, many do not have neuropsychology services, and the waiting time for review in a memory service ranges from 1 month to 18 months (8). This highlights the pressing need for a more standardized approach, as failure to properly assess cognitive function can lead to missed opportunities for early intervention and tailored support.

Clinicians report barriers to screening for cognitive impairment in this group, including a lack of time and a lack of a standardized tool (8). This is also reflected in SCI research, where there is no consensus on the most appropriate tool to use (20). Participants in our study reported difficulties in understanding their cognitive symptoms, reflecting broader issues around access to information and services. This aligns with literature on health disparities in the SCI population, particularly around access to services and technology (21). These are often compounded by fragmented healthcare (22) and mobility or transportation barriers that may limit access to health services (23). The use of digital health interventions including telemedicine has expanded significantly since the COVID-19 pandemic (24,25), particularly given high patient satisfaction rates (26). Furthermore, current pressures to reduce waiting times have led to calls for the development and increased utilization of technology that can assist clinicians in delivering out-patient care (27). The potential implementation of an digital screening tool for cognitive impairments presents an innovative avenue for overcoming current barriers. Several studies have demonstrated digital cognitive assessment tools, that have been validated against standard tools, to screen for cognitive impairment and Alzheimer's disease (28,29). For example, the Cambridge Neuropsychological Test Automated Battery (CANTAB) tool is widely used and has shown to be highly sensitive in differentiating both mild cognitive impairment and Alzheimer's disease from healthy controls (30–32). CogState, another widely used tool in research and clinical practice has shown to be sensitive in detecting mild cognitive impairment (33) and Alzheimer's disease related

cognitive impairment with high test-retest probability (34). However, all of the currently available tools rely on intact hand function to complete, and may not be suitable for all patients with a SCI, particularly those with higher cord injuries. CognoSpeak, a tool which uses Automatic Speech Recognition to analyze linguistic measures seen in the speech and language of patients with cognitive impairment, has previously been tested as a brief cognitive assessment to screen for dementia in people with a stroke (19,35). At present there is limited data on use in SCI populations. We showed a video demonstrating CognoSpeak to participants in the focus groups, who generally responded positively. Given that this tool does not rely on intact hand function, it may be a more suitable alternative to currently available tools. Whilst digital tools provide an opportunity to reduce health disparities in this group, it is important to consider that digital tools may present challenges for some individuals, given the aging SCI population, in particular, those with reduced comfort with technology or limited digital literacy (36,37).

Although our study provides valuable insight into the experience of subjective cognitive difficulties in individuals with a SCI, there are several limitations highlighting the need for further research. Our study involved a modest sample size of three focus groups with a total of nine participants. However, these focus groups included a diverse group of people with varying ages and levels of injury and the data we collected gave us good information power (38). However, in future studies we would aim to recruit more individuals to obtain a broader perspective. The demographics of individuals were all White British and English Language speakers and this homogeneity sample likely reflects access patterns of support groups. Individuals were primarily recruited through either local peer support groups or an online peer support group through Facebook, with literature suggesting that individuals with chronic diseases who access peer support groups through Facebook are primarily White middle aged or older adults (39). The homogeneity, particularly with regards to race, language, and cultural backgrounds, may limit the transferability of our findings to more diverse populations. In future focus groups we would want to consider the way in which we recruit individuals and the language abilities of people, as those from other ethnic groups have not been represented.

Our work so far shows that both clinicians and patients report cognitive deficits following a spinal cord injury. Currently available tools to screen for cognitive impairments are not always suitable. Furthermore, there is a lack of research on the best tool to use, with variation in both assessments and care received across different SCI centers in the UK. Future work should look to develop a more standardized assessment tool that is suitable for this patient group and easy for clinicians to administer. The aim would be to standardize cognitive testing and ensure timely assessment to improve patient care. Consideration also needs to be given to automated cognitive assessment tools that can be performed without the use of a limb.

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## Appendix 1

### Interview guide for focus groups

1. Have you noticed problems with remembering things or working things out after your injury?
2. Have you received any information about memory or thinking problems following your injury from your healthcare team?
3. Have you had any assessments / tests on your memory or thinking skills following your injury?
4. How long after your injury did you have any of these assessments?
5. Have you received / are you receiving any help or resources specifically for memory or thinking problems following your injury?
6. If we developed a national strategy, it may help to make things fairer – what do you think? How could we make this fairer?
7. What do you think about the idea of a digital test of memory and thinking skills?
8. Are there any specific areas of care that you feel we could do better?

## Appendix 2

COREQ checklist – consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist.

Item No	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>		
Personal Characteristics		
1. Interviewer/ facilitator	Which author/s conducted the interview or focus group?	3
2. Credentials	What were the researcher's credentials? <i>e.g.</i> PhD, MD	3
3. Occupation	What was their occupation at the time of the study?	3
4. Sex	Was the researcher male or female?	3
5. Experience and training	What experience or training did the researcher have?	3
<b>Relationship with participants</b>		
6. Relationship established	Was a relationship established prior to study commencement?	3
7. Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g.</i> personal goals, reasons for doing the research?	3
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g.</i> Bias, assumptions, reasons and interests in the research topic	2–3
<b>Domain 2: study design</b>		
<b>Theoretical framework</b>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g.</i> grounded theory, discourse analysis, ethnography, phenomenology, content analysis	3
<b>Participant selection</b>		
10. Sampling	How were participants selected? <i>e.g.</i> purposive, convenience, consecutive, snowball	3

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Item No	Guide Questions/Description	Reported on Page No.
11. Method of approach	How were participants approached? <i>e.g.</i> face-to-face, telephone, mail, email	3
12. Sample size	How many participants were in the study?	3
13. Non-participation Setting	How many people refused to participate or dropped out? Reasons?	N/A
14. Setting of data collection	Where was the data collected? <i>e.g.</i> home, clinic, workplace	N/A
15. Presence of nonparticipants	Was anyone else present besides the participants and researchers?	3
16. Description of sample	What are the important characteristics of the sample? <i>e.g.</i> demographic data, date	3
<b>Data collection</b>		
17. Interview guide	Were questions, prompts, and guides provided by the authors? Was it pilot tested?	3
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	3
20. Field notes	Were field notes made during and/or after the interview or focus group?	3
21. Duration	What was the duration of the interviews or focus group?	3
22. Data saturation	Was data saturation discussed?	3
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
<b>Domain 3: analysis and findings</b>		
<b>Data analysis</b>		
24. Number of data coders	How many data coders coded the data?	3
25. Description of the coding tree	Did the authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	3
27. Software	What software, if applicable, was used to manage the data?	N/A
28. Participant checking	Did participants provide feedback on the findings?	N/A
<b>Reporting</b>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? <i>e.g.</i> participant number	4–6
30. Data and findings consistent	Was there consistency between the data presented and the findings?	8
31. Clarity of major themes	Were major themes clearly presented in the findings?	4–6
32. Clarity of minor themes	Is there a description of diverse cases or a discussion of minor themes?	N/A

Developed from: Ref. (11).