

# **Central Cord Syndrome: Questionnaire Development for Assessment of Long- Term Outcomes**

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## **Abstract**

Central Cord Syndrome (CCS) accounts for nearly 1-in-10 incomplete tetraplegias, and like all spinal cord injuries, is associated with significant physical and psychological dysfunction. Prior research has touched on the negative association of advanced age and more severe neurology at presentation with worse outcomes, although the impact of management approach (surgical versus conservative) remains subject to debate. This study retrospectively identified 64 patients with CSS with a minimum follow-up of 5 years. To further characterise predictive factors of outcome, as well as function, mood and pain following injury, previous explorations of long-term outcomes were considered to devise a self-administered questionnaire for CCS patients.

## Introduction

Central cord syndrome (CCS) is the most prevalent incomplete traumatic cord injury, accounting for around 1 in 10 of all traumatic spinal cord injuries (SCIs) (2, 3). First described in 1887 (5), CCS is clinically characterised by more pronounced weakness in the upper limb compared to the lower limb, as well as neurogenic bladder dysfunction and sensory loss (6). Trauma to the cervical spine is by far the most common cause of CCS. In particular, low-energy trauma or falls are frequently seen, however pre-existing cervical spondylosis and/or stenosis, and acute cervical disc herniation are also observed to precipitate the condition (7). The underlying pathophysiology of CCS relates to the specific mechanism of injury; hyperextension of the cervical spine usually on a background of pre-existing cervical stenosis. Using post-mortem tissue, Schneider et al. first proposed that development of a haematomyelic cavity in the central grey matter preferentially disrupts the more medial fibres of the corticospinal tract (CST), therefore accounting for the relative sparing of lower limb voluntary motor function, compared to the upper limb (6). However this view is likely outdated; more recent neuroanatomical tracer studies in monkeys indicate no somatotopic organisation in the CST (8), which has been corroborated in humans using MRI-based mapping techniques (9). The distribution of symptoms in CCS may instead relate to the preservation of extrapyramidal fibre tracts (10-12).

Given the range of physical and psychological impacts, a multidisciplinary approach is paramount to successful management of CCS. In addition, the impact of management approach on long-term neurological outcome remains unclear. Initial research advocated a conservative approach given a tendency of patients to spontaneously recover neurological function (6), however more contemporary meta-analysis demonstrates no significant difference in neurological outcome between surgical or conservative management (13). Nonetheless, it is paramount to consider the wide heterogeneity of clinical condition when a diagnosis of CCS is made, especially given that conservative management is only a safe option in the absence of spinal instability (14).

Existing literature is limited in terms of minimum follow-up duration and sample size. The longest minimum follow-up of 3 years by Stevenson et al., observed significantly better neurological outcomes in younger patients, although ultimate recovery between surgically or conservatively managed patients was equivocal (15). Dvorak et al. performed a similar cross-sectional study of 114 with mean follow-up of 6 years (minimum: 2 years, maximum 12 years). The effect of advancing age on morbidity and functional outcome was comparable to Stevenson et al., however analysis of

management approach was again inconclusive. These findings reiterate the lack of clarity in optimal management approach, be it early vs delayed surgery, or bias in perusing surgery in those with less potential for recovery at outset than those treated conservatively (16).

The rehabilitation process for SCIs like CCS is complex and often lengthy, relying on several allied healthcare professions. Rehabilitation often occurs in specialist tertiary centres and thus demands significant investment. To optimise patient outcome, as well as remain prudent with funding, it is crucial to accurately assess the efficiency and efficacy of the rehabilitation process with reliable functional outcome measures.

This study aims to extend the current understanding of the long-term outcomes of CCS to a minimum of 5 years post-injury. To do this, a self-administrated questionnaire will be developed. Firstly, the questionnaire will scrutinise the perception of therapies received whilst an inpatient, and subsequently satisfaction with the rehabilitation service provided. Then, physical functional capacity as well as psychological state (i.e., mood) will be explored given the risks of non-recovery and/or deterioration.

# Methods

## ***Patient Identification***

The inclusion criteria for this study required a primary diagnosis of central cord syndrome of traumatic cause during the period December 1<sup>st</sup> 2012 to December 1<sup>st</sup> 2017, confirmed clinically and radiologically. Clinically, this was defined as disproportionately greater weakness in upper limbs compared to lower limb, with sacral sensory sparing (17) ± classically associated features such as neurogenic bladder dysfunction (6). Patients may have evidence of extrinsic compression such as fracture, haematoma, and/or acute disk instability. Eligible patients were identified from the following resources: clinical letters, operative lists, clinical coding lists and Spinal Cord Injury Centre Wales referral list, and clinical imaging records.

Patients were excluded from this study if they had a diagnosis of CCS resulting from an atraumatic cause including but not limited to tumour, spontaneous haematoma, inflammatory and isolated myelopathy. Patients were also excluded if they were under age 18.

## ***Patient Data***

Clinical records yielded a total of 64 patients with a diagnosis of traumatic CCS as diagnosed clinically by the attending physician on presentation, and/or at subsequent assessment during transfer to regional spinal rehabilitation centre. Patient data including demographic information and injury details (date of referral, date of injury, level of injury, management type, discharge date and ASIA grade on admission, discharge, and follow-up) was compiled using Microsoft Excel (Version 16.62 for MacOS). These data are summarised in Table 1.

## ***Outcome Assessment and Questionnaire Design***

To assess the functional outcome following injury, a self-administered questionnaire was designed and posted to living patients fitting the inclusion criteria. To avoid respondent fatigue, conciseness and efficiency of questioning was therefore a primary focus of questionnaire design. The questionnaire firstly explored basic demographic data including ethnicity, education level, current employment status and post-injury employment recovery.

To identify the most appropriate tools to assess functional outcome, existing literature was searched. Tool selection was scrutinised by several academics prior to finalisation to ensure completeness of data.

To explore satisfaction with treatment at the regional Spinal Rehabilitation Centre, patients were then asked which forms of therapy they received (Table 2), which additional therapies they would consider to be beneficial, overall satisfaction with care, as well as their thoughts on the best and worst aspects of their care. Patients were also asked how they thought the spinal rehabilitation service could be improved. A free text entry section was also included to provide opportunity for additional comments.

The questionnaire was piloted on two spinal surgeons and orthopaedic research manager. To optimise structure and comprehensive content, an iterative feedback process was used.

### ***Statistical Analysis***

Patient demographic data and clinical information was compiled with corresponding responses from the questionnaire. This data was then analysed using SPSS (Version 27 for MacOS). Descriptive statistics were performed to explore demographic and clinical data (Table 2).

# Results

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## Long Term Outcomes Following Traumatic Central Cord Syndrome in Wales

Unique patient identifier number: .....  
(If you do not know this then please enter your date of birth)

Thank you for taking the time to answer this questionnaire about your spinal cord injury. The document contains a series of standard assessments that are useful in evaluating your current functional status, the care you received and outcome following your injury.

**Basic demographic information:**

1. How would you best describe your ethnicity?

White	<input checked="" type="checkbox"/>
Black	<input type="checkbox"/>
Asian	<input type="checkbox"/>
Mixed	<input type="checkbox"/>
Other (please state)	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>

2. What is your highest level of education?

GCSE/O-level qualification (left school at 16)	<input checked="" type="checkbox"/>
A-level qualification (left school at 18)	<input type="checkbox"/>
University degree	<input type="checkbox"/>
Other (please state)	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>

3. Are you currently employed?

Yes	<input checked="" type="checkbox"/>
No	<input type="checkbox"/>
Retired	<input type="checkbox"/>
Medically Unfit	<input type="checkbox"/>
Registered Disabled	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>

**Figure 1** – Questionnaire Front Page and Demographics

**15. Bladder management**  
Please think about the way you empty your bladder.

(a) Use of an indwelling catheter

	<input checked="" type="checkbox"/>
Yes → Please go to question 7a	<input type="checkbox"/>
No → Please go to question 6b and 6c	<input type="checkbox"/>

(b) Intermittent catheterization

	<input checked="" type="checkbox"/>
I need total assistance	<input type="checkbox"/>
I do it myself with assistance (self-catheterization)	<input type="checkbox"/>
I do it myself without assistance (self-catheterization)	<input type="checkbox"/>
I do not use it	<input type="checkbox"/>

(c) Use of external drainage instruments (e.g., condom catheter, diapers, sanitary napkins)

	<input checked="" type="checkbox"/>
I need total assistance for using them	<input type="checkbox"/>
I need partial assistance for using them	<input type="checkbox"/>
I do it myself without assistance	<input type="checkbox"/>
I am continent with urine and do not use external drainage instruments	<input type="checkbox"/>

**Figure 2** – Spinal Cord Independent Measure-III (4)

**About Your Pain:**

The following questions relate to any pain you may experience in your neck, back, arms and legs.

27. On a scale of zero to ten, do you experience any pain in your **neck and/or back**?

0	1	2	3	4	5	6	7	8	9	10
No pain				Moderate pain						Worst possible pain

28. On a scale of zero to ten, do you experience any pain in your **arms and/or legs**?

0	1	2	3	4	5	6	7	8	9	10
No pain				Moderate pain						Worst possible pain

**Figure 3** – Visual Analogue Scale for Pain in Neck and/or Back, and Arms and/or Legs

**About Your Feelings:**

29. Over the last two weeks, how often have you been bothered by any of the following problems?

		<input checked="" type="checkbox"/>
Little interest or pleasure in doing things?	Not at all Several days More than half the days Nearly every day	<input type="checkbox"/>
Feeling down, depressed, or hopeless?	Not at all Several days More than half the days Nearly every day	<input type="checkbox"/>
Trouble falling or staying asleep, or sleeping too much?	Not at all Several days More than half the days Nearly every day	<input type="checkbox"/>
Feeling tired or having little energy?	Not at all Several days More than half the days Nearly every day	<input type="checkbox"/>
Poor appetite or overeating?	Not at all Several days More than half the days Nearly every day	<input type="checkbox"/>
Feeling bad about yourself - or that you are a failure or have let yourself or your family down?	Not at all Several days More than half the days Nearly every day	<input type="checkbox"/>
Trouble concentrating on things, such as reading the newspaper or watching television?	Not at all Several days More than half the days Nearly every day	<input type="checkbox"/>
Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?	Not at all Several days More than half the days Nearly every day	<input type="checkbox"/>
Thoughts that you would be better off dead, or of hurting yourself in some way?	Not at all Several days More than half the days Nearly every day	<input type="checkbox"/>

**Figure 4** – Patient Health Questionnaire-9 (1)

<b>Patient Demographics</b>	
Age	68.8 ± 16.5 Min: 26 Max: 105
Age at Injury	63.8 ± 17.9 Min: 19 Max: 105
Sex	
Male	42 (65.6%)
Female	21 (33.3%)
Management	
Conservative	43 (67.2%)
Surgical	20 (31.3%)
Years Since Injury	Min: 4 Max: 9 Range: 4 Mean: 6.1 ± 1.2

**Table 1** – Patient Demographics (n=64). Age presented in years as mean ± SD.

<b>Therapy Type</b>
Bowel management
Chest/breathing management
Driving
Education (of your condition)
Employment advice
Hand therapy
Home adaptations
Home care
Medications/pharmacy
Mobility
Nutrition/dietician input
Occupational therapy
Pain management
Physiotherapy
Psychological support
Skin care management
Social services
Spasm management

**Table 2** – Therapy Types for Evaluation of Rehabilitation Service



## **Discussion**

Several parameters can be used to stratify cases of CCS and therefore inform management, enable prognostication, and assess outcome. Previous research has drawn particular attention to advanced age and worse ASIA Impairment Scale score at time of injury, evolution/plateau of neurology and the development of red-flag symptoms like spasticity (16, 18-21). Indeed, radiological correlates of outcome have also been identified (22), however they will remain beyond the scope of this present study.

### ***Spinal Cord Independence Measure Version III (SCIM)***

Tools to assess functional outcome following SCI are numerous and can focus on various aspects of recovery. According to the International Spinal Cord Society, the SCIM is amongst the most widely used rating scales (23), and found to have superior sensitivity, reliability and validity of global disability compared to other outcome measures such as the Functional Independence Measure (24).

The primary outcome measure for this study was the degree of functional capacity at a minimum of 5 years following injury. As a surrogate for this, SCIM was used to evaluate independence in basic daily activities (4). The SCIM assesses three distinct domains of function: self-care (feeding, grooming, bathing, and dressing) with sub-score range 0-20, respiration and sphincter management with sub-score range 0-40, and lastly mobility with sub-score range 0-40. The total score range for SCIM is therefore 0-100, with a score of 100 indicating full independence of daily activities.

### ***Patient Health Questionnaire-9 (PHQ-9)***

As part of the primary outcomes of this questionnaire, patient psychological mood status was evaluated using the PHQ-9 (1). The PHQ-9 is a screening tool for major depressive disorder used in various healthcare settings. The questionnaire explores the frequency of 9 symptoms over the past 2 weeks. The topics of the questions relate directly to the DSM-IV criteria of major depressive disorder, and thus indicates the severity of depression. The PHQ-9 is designed to be self-administered, and has been demonstrated to have superior sensitivity for depression compared to semi-structured diagnostic interview (25).

Spinal cord injuries, like most chronic health conditions, can predispose to an increased risk of developing psychological comorbidities. Mood disruption, particularly depressive disorders has been found to occur at significantly higher rates in adults following spinal cord injury (29.3% [n = 2,006] vs 9.3% [n = 79,724]) (26). In addition, higher rates of

depression have been associated with the presence of certain demographic, socioeconomic and pathophysiological factors including: female sex, tetraplegia, suicidality, history of suicide attempt, low education level and/or cared for by a family member other than a spouse or parents (27, 28).

At time of writing, no existing research has explored mood at long-term follow-up in patients with CCS.

### ***Pain***

Ongoing pain is a common and significant problem affecting between 70-80% of SCI patients (29) and often presents a greater challenge to manage than any other mobility, continence or sexual dysfunction (30). Pain is also a very important risk factor for the development of psychological comorbidities such as depression (31).

To assess pain, the questionnaire included a Visual Analogue Scale (VAS) both for pain centrally in the neck and/or back, as well as peripherally in the arms and/or legs. The VAS is widely used to assess the severity of various symptoms and is the most used method for assessing pain intensity in SCI cases. Despite this, there is not currently a pain classification system with established evidence of reliability and responsiveness for use in the SCI population (32).

## **Future Work**

To explore the long-term functional outcomes following a diagnosis of CCS, this study successfully designed a self-administered questionnaire. Further work should therefore seek to distribute the questionnaire to the eligible patient group for assessment of their functional outcome. Based on the SCIM, PHQ-9 and VAS for pain, a comprehensive idea of patient function and quality of life can be generated. Then, compiling this alongside existing demographic and clinical data can be performed to explore predictive factors of outcome and survivability.

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