

# Indicators of Quality of Care in Individuals With Traumatic Spinal Cord Injury: A Scoping Review

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## Abstract

**Study Design:** Scoping review.

**Objectives:** To identify a practical and reproducible approach to organize Quality of Care Indicators (QoCI) in individuals with traumatic spinal cord injury (TSCI).

**Methods:** A comprehensive literature review was conducted in the Cochrane Central Register of Controlled Trials (CENTRAL) (Date: May 2018), MEDLINE (1946 to May 2018), and EMBASE (1974 to May 2018). Two independent reviewers screened 6092 records and included 262 full texts, among which 60 studies were included for qualitative analysis. We included studies, with no language restriction, containing at least 1 quality of care indicator for individuals with traumatic spinal cord injury. Each potential indicator was evaluated in an online, focused group discussion to define its categorization (healthcare system structure, medical process, and individuals with Traumatic Spinal Cord Injury related outcomes), definition, survey options, and scale.

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**Results:** A total of 87 indicators were identified from 60 studies screened using our eligibility criteria. We defined each indicator. Out of 87 indicators, 37 appraised the healthcare system structure, 30 evaluated medical processes, and 20 included individuals with TSCI related outcomes. The healthcare system structure included the impact of the cost of hospitalization and rehabilitation, as well as staff and patient perception of treatment. The medical processes included targeting physical activities for improvement of health-related outcomes and complications. Changes in motor score, functional independence, and readmission rates were reported as individuals with TSCI-related outcomes indicators.

**Conclusion:** Indicators of quality of care in the management of individuals with TSCI are important for health policy strategists to standardize healthcare assessment, for clinicians to improve care, and for data collection efforts including registries.

### Keywords

quality indicators, health care, spinal cord injuries, Iran, review, quality of health care, registries, health policy

## Introduction

Traumatic spinal cord injury (TSCI) has an annual incidence of 40-80 per million people. About 90% of these cases in underdeveloped countries are caused by external factors such as motor vehicle accidents, falls, or sports-related activities.<sup>1</sup> An individual with TSCI can experience a variety of acute and chronic complications affecting their quality of life. To improve quality of care, healthcare systems have recently attempted to broaden access to care in addition to improving the care delivered. Studies identifying the quality of care for individuals with TSCI are rare and most of them are based on national registries.

To maximize outcomes following TSCI, timely access to a specialized, patient-centered, and evidence-based care is mandatory. A review of the World Health Organization<sup>2</sup> and other national and international databases demonstrate large differences across countries in the TSCI supply-demand relationship.<sup>1</sup> Interestingly, low- and middle-income countries tended to report less availability of all kinds of resources despite greater need.<sup>3</sup> To address this challenge, the WHO and the International Spinal Cord Society (ISCoS), in a collaborative effort to comprehensively map healthcare, social services, and policy requirements, developed evidence-based recommendations to address these needs based on income level.<sup>4</sup> However, we do not have evidence regarding the current adherence of different countries to these recommendations or improvement by different healthcare system interventions. The former is ongoing by the recent Learning Health System-International SCI Survey (LHS-InSCI) initiative,<sup>5</sup> but the latter requires a robust tool to monitor SCI care in different parts of the world.

Well-defined and validated Quality of Care Indicators (QoCI) can help improve TSCI care by establishing parameters that clinicians, healthcare managers and policy-makers can monitor and report. These indicators must be based on evidence and experiences reflecting the standard of care.<sup>6</sup> In the present study, we reviewed the literature to summarize QoCI in individuals with TSCI into 3 groups: 1) healthcare system structure, 2) medical processes, and 3) individuals with traumatic spinal cord injury (TSCI)-related outcomes.

## Method

### Protocol and Registration

Our protocol included the Preferred Reporting Items for Systematic Reviews and Meta-Analysis protocol for scoping reviews.<sup>7,8</sup> The PRISMA chart of this study is also available in Figure 1.

### Eligibility Criteria

We included studies with at least 1 QoC indicator to evaluate patients with TSCI without time and language limitations. We excluded case series with less than 10 cases, as well as animal studies. We excluded studies with new technologic instruments and devices (such as robotic-assistance devices or novel types of wheelchairs), as it was difficult to measure their impact and impractical for worldwide application.

### Data Sources

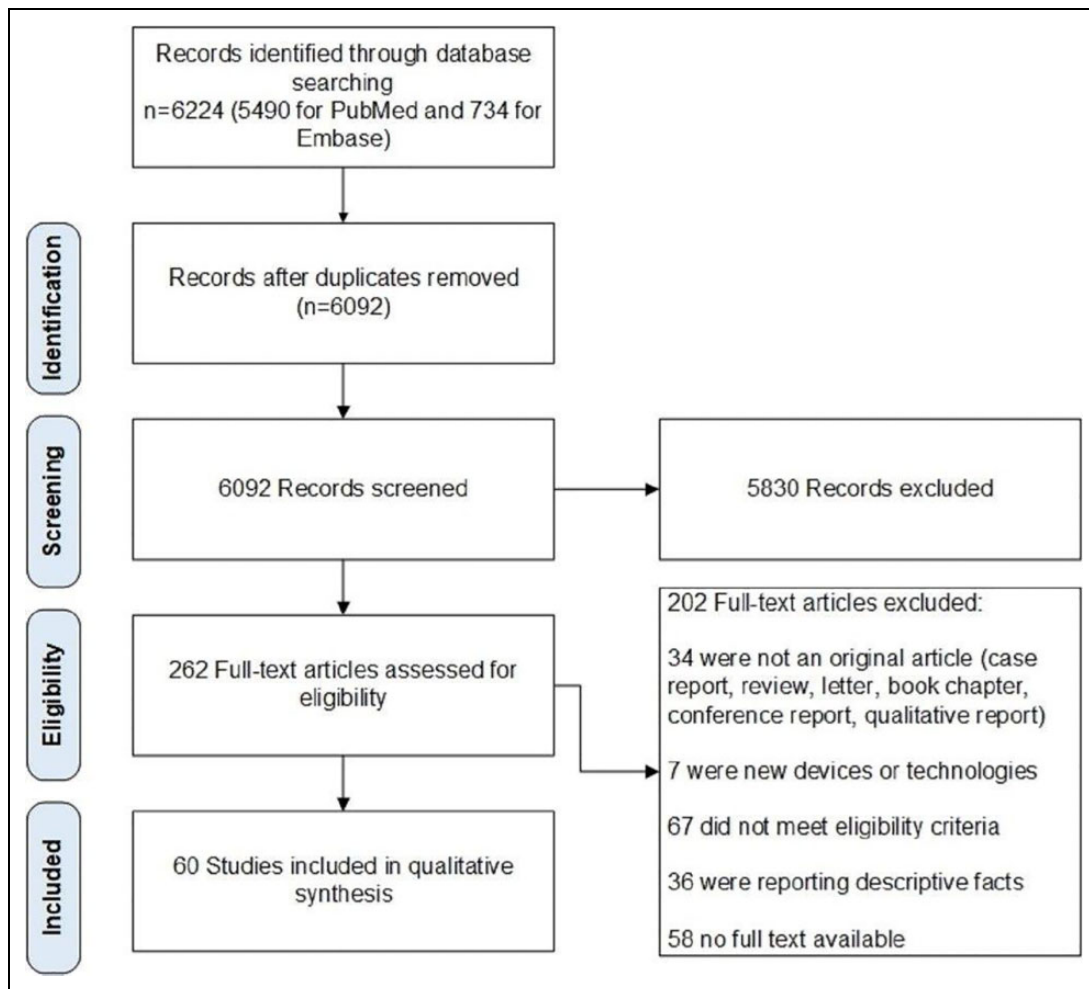
To identify relevant studies, a search was done through the following databases: Cochrane Central Registry of Controlled Trials (CENTRAL) (Date: May 2018), MEDLINE (1946 to May 2018) and EMBASE (1974 to May 2018).

### Selection of Sources of Evidence

In the first phase of screening, 2 authors independently screened related study titles and abstracts. After examining the discrepancies between the 2 teams, the second phase included full text screening of the included studies. The third stage resolved any potential discrepancy regarding the eligibility of studies through discussion and by the decision of a third review author. Then, based on the nature of indicators, we developed 3 categories: healthcare system structure, medical processes, and individuals with TSCI related outcomes. The same categorization was used in another national study.<sup>9</sup>

### Data Charting Process and Data Items

Four review authors independently proceeded with data extraction from included studies and entered the data in standardized



**Figure 1.** Flowchart of studies excluded and included for this study.

data collection forms. Each potential indicator was evaluated in an online, focused group discussion to define its categorization (healthcare system structure, medical process, and individuals with Traumatic Spinal Cord Injury (TSCI) related outcomes), definition, survey options (e.g. types of questionnaire, data registries, etc.), and scale (e.g. percentage, day, hour, dollar, etc.), as well as reproducibility across various healthcare systems.

## Results

The database search resulted in 6092 records. After screening relevant titles and abstracts, 262 records were included for further assessment. Full-text review resulted in 60 studies for evidence synthesis. Out of 60 studies, the main source of data collection of the 2 studies was national data registries. There were 21,574 cases from 60 studies. We identified 87 indicators from 60 studies, among which 37 indicators were associated with healthcare system structure (Table 1).

Healthcare system structure indicators assessed 6 main domains including:

*Cost:* which evaluates 2 classes:

- Medical care cost, including healthcare service, acute hospitalization charge, and rehabilitation care cost.
- Financial ramifications for the patient related to SCI, e.g. loss of income, etc.

*Infrastructure:* which evaluates infrastructure specialized for SCI care, such as number of SCI rehabilitation centers, availability and access to domestic adaptations and outdoor transportation amenities, etc.

*Education:* which evaluates educational programs for physicians, patients, and caregivers.

*Time:* which evaluates 2 main classes including:

- Length of stay in the hospital, ICU, IRCU, rehabilitation unit.
- Time cost for different processes: pre-hospital transfer time, Emergency Department (ED) arrival to first visit, injury to surgery, etc.

*Patient Satisfaction:* which evaluates patient-centered point of view in the SCI care process.

*Others:* not classified into other categories.

The number of indicators for the medical process and individuals with TSCI related outcomes were 30 and 20, respectively.

**Table 1.** Healthcare System Structure Indicators.

No.	INDICATOR	Definition	Survey Option	Scale	Ref
<b>Cost</b>					
1	Median Cost of healthcare services in the year following SCI	Direct medical cost of SCI in the year following SCI	Questionnaire (Patients, Physician, & Caregiver)	Dollar	10
2	Acute hospital charges	Direct medical cost from hospital admission to discharge	Health system records	Dollar	11
3	Rehabilitation care costs	Direct rehabilitation cost in the year following SCI	Questionnaire (Patients, Physician, & Caregiver)	Dollar	12
4	Monitoring and addressing financial issues related to SCI	General financial status of SCI patients based on residence status or ability to quickly obtain up to 1200 US dollars	Swedish Annual Level-of-Living survey	General financial status <sup>A</sup>	13
<b>Infrastructure</b>					
5	Rate of treatment outside health region of residence	Whether the patient who is treated outside of their residential area is treated in a spine/trauma center or a non-trauma center <sup>B</sup>	Questionnaire (Patients, Caregiver, & Health system record)	Percentage	1,14
6	Number of specialized rehabilitation centers	Regional number of private and non-private centers specializing in SCI	Health system records	Private or non-private center	15
7	TSCI surgery volume of the hospital	Hospitals were classified by the number of annual TSCI admissions and TSCI-related surgical procedures	Health system records	Number of admissions	16
8	Frequency of patient with access to domestic adaptations and outdoor transportation amenities	Measure of availability of domestic adaptations <sup>C</sup>	Social system records	Percentage <sup>D</sup>	17
<b>Education</b>					
9	The number of training courses for SCI nurses in managing interpersonal interactions	Weekly meetings with rehabilitation staff to discuss problematic patient interaction	Questionnaire (nurse)	Hours/month	18
10	Number of patient education programs	Discharge appointments with a trained nurse	Questionnaire (patient)	Hours/month	14
11	Number of emergency care providers' education toward patients' quality of life after spinal cord injury (SCI)	Hours of training for paramedics for SCI patient care in emergency cases	Questionnaire (physicians)	Hours/month	19
12	Usage of Coping Inventory of Stressful Situations/patient/year	Response to difficult, stressful, or upsetting situation	Questionnaire (patient)	Five-point Likert-type rating scale	20
<b>Time</b>					
13	Length of hospital stay	Number of days the patient initially was hospitalized after first injury	Health system records	Day	1,14,15,21-23
14	Inpatient rehabilitation length of stay	Number of days stable and unstable patient spent in rehabilitation	Health system records	Day	12,21
15	Median Hours of direct care per patient (for nursing and all health care therapists)	Hours of direct care/per patient for nursing and other health care therapists combined	Health system records	Minute/week	12
16	Mean stay in the ICU	Number of days patient spent in Intensive Care Unit (ICU)	Health system records	Day	1,24
17	Mean stay in the IRCU	Length of stay for patients in the IRCU (Intermediate Respiratory Care Unit)	Health system records	Day	24
18	Median time to visit and treatment	Time SCI patients spent in a clinic waiting for their appointment for a visit or a pre-scheduled procedure	Health system records	Hours/day	10
19	Median Time: injury to surgery	Time from initial injury to the time patient enter the operation room	Health system records	Hours	21,25-27
20	Median time in the trauma emergency department	Time spent to stabilization in the emergency department	Health system records	Minutes	21,28

(continued)

**Table 1.** (continued)

No.	INDICATOR	Definition	Survey Option	Scale	Ref
21	Pre-hospital time (transfer time)	Time spent from scene of trauma to hospital	Health system records	Minutes	28
22	Median time in secondary care center before transfer to a spine center	Time spent in a secondary care center before being transferred to a spine center for treatment	Health system records	Minutes	26,28
23	Median time between onset of SCI and rehabilitation	Median time from initial injury to rehabilitation	Health system records	Days	10,22,29
<b>Patient satisfaction</b>					
24	Patient satisfaction with follow-up care	Items involved quality, continuity, and coordination of care	Questionnaire (patient)	Percentage <sup>E</sup>	30
25	Satisfaction with availability of SCI-related medical care according to region	Patient satisfaction with the availability of SCI-related medical care services within and outside of the region in which they reside	Questionnaire (patient)	Likert scale	10
26	Satisfaction of SCI-related therapy according to region	Satisfaction with care provided by general practitioners, home care professionals available in the region	Questionnaire(patient)	Likert scale	10
27	Satisfaction with care for SCI-related health conditions according to region	Satisfaction with the availability of SCI-related therapy in the region in which individuals reside.	Questionnaire (patient)	Percentage satisfied	10
28	Patient satisfaction with care	Patient experience of hospital stay, rehabilitation, and new life situation	Patient interview	Patient access	31
29	Patient satisfaction with primary care and rehabilitation	Health Care Questionnaire (HCQ): a compilation of 2 published measures: The Primary Care Questionnaire and patient satisfaction with the Health Care Provider Scale (PSHCPS)	Patient interview	Percent	32
<b>Others</b>					
30	Median health care utilization post-discharge	1. Unscheduled emergency department visits within 1 year; 2. Unscheduled hospital readmissions within 1 year are considered as utilization	Health system records	Number of visits	1
31	Number of promotional programs for physical activity/patient/year	Number of promotional programs targeted for encouraging individual with SCI to start a form of physical activity <sup>F</sup>	Questionnaire (patient)	Min./week	33
32	Number of social work and case management services that an individual with traumatic SCI receives during acute inpatient rehabilitation	Social work /case management services for each patient during the acute phase of rehabilitation <sup>G</sup>	Health system records	Hours/week	34
33	Spinal cord injury rehabilitation staff perceptions of individuals with SCI spinal cord -related problems	Study-specific questionnaire containing 45 Spinal Cord Lesion <sup>35</sup> related problems covering 6 problem areas: somatic symptoms, functional limitations, role problems, family-related problems, psychosocial problems, and emotional problems. <sup>H</sup>	Questionnaire (patients & rehabilitation staff)	The response scale had 6 grades, ranging from "not at all" to "very much." Higher scores indicate a higher degree of perceived problems.	36
34	Spinal cord injury rehabilitation staff perceptions of individuals with spinal cord injury coping efforts	Coping activities were assessed by a self-report 47-item questionnaire covering 8 aspects of coping: self-trust, problem focusing, acceptance, fatalism, resignation, protest, minimization, and social trust.	Questionnaire patients & rehabilitation staff	6-step response scale	36
35	Spinal cord Injury rehabilitation staff perceptions of SCI patients' physical and mental well-being	The staff is asked to define their perception of mental and physical well-being and the answers were compared to each other	Questionnaire patients & rehabilitation staff	6-step scale	36

(continued)

**Table 1.** (continued)

No.	INDICATOR	Definition	Survey Option	Scale	Ref
36	Screening and addressing specific prescription misuse	Screening misuse in patients prescribed drugs by checking pharmacy database and adapting it to prescription	Health system records	Yes/No	37
37	Assessment of the health-related quality of life in caregivers (relatives of the patient)	Measuring the quality of life in SCI patients' caregivers	Questionnaire (caregiver)	0-100	38

**Notes:**

A: Residence: condominium vs house, Residence: rent vs own, Financial problems, inability to raise 1200 USD in a short period of time.

B: This refers to the inability of the patient to obtain adequate care within their local geographic region, and is therefore required to visit a specialized SCI center for treatment.

C: Domestic adaptations include (1) ramp to front door; removed thresholds; widening of doors; elevator to upper floor; adapted kitchen, toilet, and bathroom; and an annex to the house; (2) wheelchairs (manual, electrical, or other wheelchairs; and (3) external transport, such as an adapted car.

D: Patients were divided into complete and incomplete tetraplegia and paraplegia, and measured by percent who have access to a ramp to the front door; lowered thresholds; doors; an elevator; an adapted kitchen, toilet, and bathroom; and an annex to the house.

E: Items in this questionnaire were judged as "open for improvement." Patients who believed items could be improved upon were reported as a percentage in each field, and compared between transmurals and traditional follow-up plan.

F: How many hours per week a social worker has spent on a specific problem a patient presented during his acute phase of hospital stay.

G: Staff in a SCI center was asked to answer what challenges a SCI patient face after his injury, the patient was asked the same thing, and the compatibility of the answers is compared.

H: Like case E, the same thing was done this time about coping not the challenges.

**Table 2.** Medical Process Indicators.

No.	Indicator	Definition	Survey Option	Scale	Ref.
<b>Adherence to standard SCI care guideline</b>					
1	CIC (Clean Intermittent Catheterization) education rate)	Caregivers CIC were approached when attending the pediatric urology outpatient clinic of hospital	Questionnaire (patient)	Time of education reported in minutes	39
2	Use of MRI in the diagnostic plan	MRI as an imaging modality in the diagnostic plan for the patients.	Health system records	[+,-]	40
3	Rate of out-of-hospital immobilization of the patients	Practice of spinal immobilization in prehospital and early hospital care for reducing secondary neurological damage to the spinal cord	Health system records/ Questionnaire (patient)	[+,-]	26
4	Rate of administration of methylprednisolone	Early administration of methylprednisolone for isolated traumatic spinal cord injury by hospital data	Health system records	[+,-]	26
5	Consultation rate by orthopedic surgeon or neurosurgeon	Patients in trauma centers consulted by an orthopedic surgeon or a neurosurgeon in the early stages of treatment	Health system records	Hospitalized in a trauma center compared to a non-trauma center	1
6	Implementation rate of physical activity guideline (PAG)	Whether a PAG is followed during patient physical fitness training sessions	Questionnaire (physicians)	Adherence was calculated based on the percentage of a maximum of 32 sessions (2x per week for 16 weeks).	41
7	Adherence rate of physical activity guideline	Rate of adherence to a PAG for physical fitness of individual with TSCI	Questionnaire (patient)	Total number of sessions completed	41
8	The implementation rate of early VTE prophylaxis	Mechanical and chemical modalities for adult venous thromboembolism prophylaxis	Questionnaire (physicians)	Patients are given 5000 units heparin subcutaneously 3 times daily	11
9	Prescription rate of suitable self-care equipment by therapist before discharge	Prescription rate of self-care equipment before discharge and whether it is double-checked (by reviewing clinician progress notes and orders) before patient discharge	Health system records	Yes/No	42

(continued)

**Table 2.** (continued)

No.	Indicator	Definition	Survey Option	Scale	Ref.
<b>Screening of adverse events</b>					
10	Screenings of prescription compliance/patient/year	Screening of patients for medication consumption to find potential adverse reactions affecting hospital stay length.	Questionnaire (patient)	[+,-]	43
11	Pressure ulcer prevention rate	Providing structured and individualized patient education for pressure ulcer prevention; as part of the pan-Canadian SCI Knowledge Mobilization Network	Questionnaire (physicians)	Staff competency, organizational support, and leadership	44
12	Secondary complication rate (after discharge)	Secondary complication rate after discharge from hospital, measured by a questionnaire	Questionnaire (patient)	26 secondary complication (in the article) <sup>a</sup>	45
<b>Patient medical assessment frequency</b>					
13	Prevalence of pressure sore infections	The number and duration of re-admissions to the hospital and rehabilitation center due to pressure sores	Questionnaire (patient)	The prevalence of pressure sores [4-15]	30
14	Number of physical activity assessments/patient/year	Physical activity of patients are self-reported and measured by Leisure Time Physical Activity Questionnaire for People with Spinal Cord Injury (LTPAQ-SCI) in the past 7 days	Questionnaire (patient)	Minutes/week	33
		Number of assessments for Spinal Cord Independence Measure III (SCIM III) score (self-care, respiration and sphincter management, mobility)	Questionnaire (patient)	Score: Self-care subtotal (0-20), Respiration and Sphincter management subtotal (0-40), Mobility subtotal (0-40)	40
		Physical activity of patients who use manual wheelchairs, as measured by Physical Activity Recall Assessment for People with SCI (PARA-SCI) semi-structured interview.	Questionnaire (patient)	Three categories of physical activity: leisure-time physical activity, lifestyle activity, and cumulative activity	46
15	Number of UTI screenings/patient/year	Infection in any parts of urinary tract	Questionnaire (patient)	Number/year	39
16	Number of UTI microorganism susceptibility/patient/year	Urine samples were collected for urine analysis and urine culture performance right after initial interview	Questionnaire (physicians)	Urine culture, colony count, type of organisms and antibiograms	47
17	Number of Screening of modifiable comorbidities/patient/ year	Screening of medical comorbidities	Questionnaire (patient)	[+,-]	43
18	Number of Screening of modifiable hazardous behavior/patient/year	Screening of modifiable hazardous behavior/patient/year: Substance use/withdrawal (Alcohol, drug, withdrawal) This assessed behavior that was gained after TSCI.	Questionnaire (patient)	[+,-]	43
19	Number of Screening of Psychiatric conditions/patient/ year	Screening of psychiatric conditions (post injury)/patient/year by the medical record, questionnaire, interview	Questionnaire (patient)	[+,-]	43
20	Number of screening for depression/patient/year	Screening incidence of depression among SCI patients by Patient Health Questionnaire-9 (PHQ-9) in each year <sup>b</sup>	Questionnaire (patient)	A cutoff of 11 yields optimal sensitivity (1.0) and specificity (.84) for identifying Major Depressive Disorders (MDDs)	48

(continued)

**Table 2.** (continued)

No.	Indicator	Definition	Survey Option	Scale	Ref.
21	Barthel Index (functional score) on admission	Calculating Barthel Index score during hospitalization (The Barthel Index for Activities of Daily Living (ADL) assesses functional independence).	Health system records	Feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair & back), mobility (on level surfaces), stairs	22
22	Median time spent on bowel care per week	Median time in a week spent on bowel care (time documented before and after stoma)	Questionnaire (patient)	Hours	49
23	Number of pain assessments/patient/year	The Numeric Pain Rating Scale (NPRS) used to assess degree of back pain for each patient	Questionnaire (patient)	[0-10]	50
24	Number of fatigue assessments/patient/year	The Profile of Mood States-Brief Form (POMS-Brief) [26] was used to assess affective mood states.	Questionnaire (patient)	[0-120]	50
25	Monitoring program for psychometric performance	WHO Quality of Life-BREF (WHOQOL-BREF) used for monitoring psychometric performance	Questionnaire (patient)	A questionnaire with 100 items	51
26	Number of Psychological assessments/patient/year	Mood and psychopathology were measured by the PAI (Personality Assessment Inventory) during a 2-6 year period.	Questionnaire (Patient)	A 344-item self-reported instrument	52
		SF-36 Mental Health scale (SF-36 MH) used for psychological assessment of patient during 2-6 year period.	Questionnaire (Patient)	The SF-36 consists of eight scaled scores, which are the weighted sums of the questions in their section	54
		Positive Affect and Negative Affect Scale <sup>53</sup>	Questionnaire (Patient)	Likert scale	54
26	Number of Psychological assessments/patient/year	Mood and psychopathology were measured by the PAI (Personality Assessment Inventory) during a 2-6 year period.	Questionnaire (patient)	A 344-item self-reported instrument	52
		SF-36 Mental Health scale (SF-36 MH) used for psychological assessment of patient during 2-6 year period.	Questionnaire (patient)	The SF-36 consists of eight scaled scores, which are the weighted sums of the questions in their section	52
		Positive Affect and Negative Affect Scale <sup>53</sup>	Questionnaire (patient)	Likert scale	54
		Swedish Annual Level-of-Living Survey used for monitoring psychometric performance of the patients.	Questionnaire (patient)	Swedish Annual Level-of-Living Survey	13
<b>Others</b>					
27	Telemedicine usage rate in patients with SCI pre hospital clinical assessment rate of SCI and spine fracture by Emergency Medical Services (EMS)	Using telemedicine to report prehospital clinical data	Questionnaire (physicians & patients)	Patients signs and symptoms collected by EMS providers	55
		Upon arrival at the trauma scene, EMS providers assessed for neck pain/tenderness, altered mental status, history of loss of consciousness, drug/alcohol use, neurologic deficit, and other painful/distracting injury. The results were reported using telemedicine.	Questionnaire (physicians & patients)	Yes/no	56

(continued)



**Table 2.** (continued)

No.	Indicator	Definition	Survey Option	Scale	Ref.
28	Telemedicine usage rate in patients with SCI	Using telemedicine to assess functional status (measured by Functional Independence Measure (FIM) and Spinal Cord Independence Measure II (SCIM II)) 10 days before discharge and 6 months after discharge	Questionnaire (physicians and patients)	Self-care/respiration and sphincter management/mobility (room and toilet)/mobility (indoors and outdoors)	57
		Using telemedicine to find and report complications 6 and 12 months post discharge	Questionnaire (physicians and patients)	Included pressure ulcers, urinary tract infections, problems associated with urinary catheters, pulmonary infections, fever, pain, autonomic dysreflexia, and deep vein thrombosis.	57
		Annual rate of using telemedicine to report patients satisfaction with the care they received <sup>57</sup>	Questionnaire (patients)	Questions were rated on an ordinal scale (0-10)	57
29	Implementation rate of locomotor training program	Patients received standardized locomotor training sessions, as established by Neuro Recovery Network (NRN) protocol, and were evaluated monthly for progress	Questionnaire (physicians)	Model Fit	58
30	Person-Centered Care (PCC) in the rehabilitation program	PCC implementation measured by 4 instruments: the Patient Activation Measure (PAM), the Patient Assessment of Chronic Illness Care (PACIC), the Global Practice Experience measure, and 5 Press-Ganey questions	Questionnaire (patient)	[+,-]	59

**NOTE:**

a: Supplementary information regarding row 20 of this table is here.

Secondary condition includes: 1. Bladder regulation 2. Bowel regulation 3. Pain 4. Spasms 5. Sexuality 6. Pressure scores 7. Dependency 8. Edema 9. Handicap management 10. Increased weight 11. Facilities, equipment, and housing 12. Coping with handicap 13. Daily living activities 14. Excessive sweating 15. Functioning in non-adapted environments 16. Asking for help, being assertive 17. Contractures 18. Breathing/respirator 19. Relationships 20. Household activities 21. Work 22. Leisure-time activities 23. Heterotrophic ossification 24. Low blood pressure 25. Communication 26. Thrombosis.

B: Patient Health Questionnaire (PHQ-9): Consists of 9 questions: 1. Little interest or pleasure in doing things 2. Feeling down, depressed, or helpless 3. Trouble falling or staying asleep, or sleeping too much 4. Feeling tired or having little energy 5. Poor appetite or over eating 6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down 7. Trouble concentrating on things, such as reading the newspaper or watching television 8. 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 9. Thoughts that you would be better off dead, or of hurting yourself.

The healthcare system structure indicators included: the effects of cost of the acute phase hospitalization and rehabilitation, facility costs (including MRI, CT scan, and staff- and patient-perception of treatment). The medical process indicators included physical activity and rehabilitation, complication rates, and overall treatment including every healthcare professional involved in the patient treatment. Furthermore, telemedicine was identified as a new form of care and a potential indicator (Table 2).

Medical process indicators assessed 4 main domains, which are:

- *Adherence to standard SCI care guideline:* Venous Thromboembolism (VTE) prophylaxis, prehospital immobilization, use of MRI, use of steroid, CIC training, etc.

- *Screening of adverse events:* which evaluates 2 main classes:
  - Medical process complications, such as prescription complications
  - SCI complications, such as bed sores
- *Patient medical assessment frequency:* including physical activity, urinary tract infection (UTI) screening, etc.
- *Others:* not classified into other categories.

The third table reports the indicators of individuals with TSCI-related outcomes. Measuring tools such as American Spinal Injury Association (ASIA) score, functional independence Measure (FIM), Oswestry disability index (ODI), Spinal Cord Independence Measure II (SCIM II), Self-efficacy improvement rate by Moorong Self-Efficacy Scale (MSES),

**Table 3.** Individuals With TSCI-Related Outcomes.

No.	Indicator	Definition ± tools for measure	Survey Option	Scale	Ref.
<b>Medical Improvement</b>					
1	Total change in motor score	Motor score measured with ASIA score employing neurological examinations at administration and discharge rehabilitation. Total change from each step is reported.	Patient physical examination	Scored on a 5-point ordinal scale from A (complete injury) to E (Normal sensory and motor function)	<sup>21</sup>
2	Functional Independence Measure (FIM) after discharge or during rehabilitation	FIM after discharge or during rehabilitation <sup>a</sup>	Questionnaire (patient)	18-item of physical, psychological, and social function. Each domain is scored on a Likert-type scale	15,12,60-62
		Oswestry Disability Index for Low Back Pain (ODI) Version 2.0 was reported for each patient after discharge.(ODI Version 2.0 consists of pain Intensity, personal care, lifting, walking, sitting, standing, sleeping, sex life, social life, and traveling)	Questionnaire (patient)	ODI scale	50
		Spinal Cord Independence Measure II (SCIM II) during a 1-year follow-up examination after SCI	Questionnaire (patient)	SCIM II scale	63
		Self-efficacy improvement rate using Moorong Self-Efficacy Scale (MSES) during rehabilitation	Questionnaire (patient)	Seven-point Likert scale for each subscale <sup>b</sup>	20
		Canadian Occupational Performance Measure (COPM) and FIM during rehabilitation	Questionnaire (patient)	COPM: scale of 1-10 and FIM: Likert scale (1-7)	64
	Barthel Index (functional score) used for measuring functional independence after discharge.	Health system records	Feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers (bed to chair and back), mobility (on level surfaces), stairs scoring 0-100	22	
3	Functional Recovery Rate	SCIM II used to measure functional recovery rate	Physical exam	SCIM II	63
4	Motor and sensory recovery rate (before and after surgery)	Motor and sensory function is measured on a scale of A to E before and after surgery. The difference between these 2 scores represent the recovery rate of the patient.	Patient physical examination	Scored on a 5-point ordinal scale from A (complete injury) to E (Normal sensory and motor function)	65
5	Urinary function improvement after surgery	Urinary function of patients based on urinary sensation and frequency of using catheterization.	Questionnaire (patient)	A scale from no urinary sensation, intermittently dependent on catheterization, and completely dependent on catheterization.	65
6	Stoma formation <sup>h</sup>	Colostomy formation in patients with bowel management problems	Health system records	Number of patients	49
<b>Complication Monitoring</b>					
7	Re-admission rate for complications	Number and duration of re-admissions to hospital and rehabilitation center in the first year after discharge.	Questionnaire (patient)	Number of re-admissions and inpatient days	30
8	Discharge efficiency	Number of readmissions in 1 month/ number of discharges	Health system records	Readmission/discharge	14
9	Mortality rate	Number of deaths after spine surgery due to related complications.	Health system records	Number	11
10	Adverse events rate	Spine Adverse Events Severity System (SAVES) <sup>d</sup> used for collecting adverse events reported post-operation such as instrumentation failure, nonunion, and infection.	Questionnaire (physicians)	Yes/No	23

(continued)

**Table 3.** (continued)

No.	Indicator	Definition $\pm$ tools for measure	Survey Option	Scale	Ref.
11	Rate of in-hospital adverse events	Spine adverse events severity system (SAVES) used for reporting adverse events in the hospital setting such as pulmonary thromboembolism and DVT.	Health system records	Adverse events rate	23
Quality of life improvement					
12	Health-related quality of life assessment	SF-36 measures both mental and physical health related quality of life World Health Organization Quality of Life-BREF (WHOQOL-BREF) used to measure health related quality of life. SF12v2 consisting of 2 summary outcomes for physical health and mental health. <sup>e</sup>	Questionnaire (patient) Questionnaire (patient) Questionnaire (patient)	SF-36 Mental and Physical Health sub-scores 100-item questionnaire Summary of eight SF-36 sections	20,23,38,66 67 50
13	Quality of life improvement rate after rehabilitation	WHOQOL-BREF used to measure the improvement in quality of life after rehabilitation.	Questionnaire (patient)	100-item questionnaire	68
Others					
14	Knowing postoperative complication rate	Explaining post-operative complications based on International Classification of Diseases, Ninth Revision (ICD-9) <sup>c</sup> to patients before surgery.	Questionnaire (patient)	Incidence (0-100)	1,11
Psychological Improvement					
15	Social participation after TSCI	Craig Handicap and Assessment-Reporting Technique <sup>69</sup> fused for reporting social participation after TSCI.	Questionnaire (patient)	Score [0-100]	60
16	Frequency of behavioral incident per month	Behavioral or "critical" incidents	clinicians	Number of incidents	12
17	Social integration rate after hospital discharge	The Community Integration Questionnaire <sup>70</sup> used for reporting social integration of patients after their discharge from the hospital. Monitoring and addressing social participation and autonomy by Impact on Participation and Autonomy (IPA)	Questionnaire (patient) Questionnaire (patient)	13-item measure of the lack of handicap 32 item questionnaire	52 20
18	Identifying well-being <sup>§</sup>	The Community Reintegration Outpatient (CROP) Service used to determine patient well-being	Questionnaire (patient)	Patient self-reporting	20
Outcome Assessment Frequency					
19	Number of rehabilitations visits per year	Frequency of contact with caregivers in the last 12 months after discharge to present unmet care.	Health system records	Not at all/1-3 times a year/4-11 times a year/1-3 times a month/1-6 times a week/Daily	45
20	Number of walking ability assessments/patient/year	Lower extremity motor score assessment within the first month and at 3, 6 and 12 months after discharge The Walking Index for Spinal Cord Injury (WISCI II) assessment within the first month and at 3, 6 and 12 months after discharge	Questionnaire (patient) Questionnaire (patient)	0 to 5 for motor grading for each neurological area Level of most severe impairment (0) to least severe impairment (20)	71 72

(continued)

**Table 3.** (continued)

No.	Indicator	Definition ± tools for measure	Survey Option	Scale	Ref.
		6 Minute Walking Test (6MWT) assessment within the first month and at 3, 6 and 12 months after discharge	Questionnaire (patient)	The distance a patient walks in 6 minutes	<sup>72</sup>
		Ten-Meter Walking Test (10MWT) assessment within the first month and at 3, 6 and 12 months after discharge	Questionnaire (patient)	The distance a patient walks in 10 minutes	<sup>72</sup>
		Standardized locomotor training sessions with monthly evaluation for progress	Questionnaire (patient)	Number of screenings for walking ability/ patient/year	<sup>58</sup>

**Note:**

a: A self-administered scale to examine the level of independence in activities of daily living, The Functional Independence Measure (FIM) is an 18-item of physical, psychological and social function. The tool is implemented to evaluate patient level of disability and changed inpatient condition after rehabilitation or medical intervention.

b: The total scale score is obtained by adding the individual item responses. For the factor or subscale scores; "Daily Activities / Instrumental Self-efficacy" (7 items: good health, work, accomplishing things, personal hygiene, persistence in learning things, fulfilling lifestyle, and household participation), "Social Functioning / Interpersonal Self-efficacy." (8 items: maintaining contact, friends, family, relationships, unexpected problems, fulfilling lifestyle, leisure, accomplishing things, household participation).

c: Deep vein thrombosis/pulmonary embolism, pneumonia, pressure ulcer, urinary tract infection, autonomic dysreflexia, bowel complications, renal complications.

d: The SAVES consists of 14 intraoperative and 22 pre- or postoperative adverse events that are common in patients who undergo spinal procedures with an option to record "other" events not already specified.

e: The SF-12 Health Survey (SF-12) is a 12-item questionnaire used to assess generic health outcomes. It contains 12 subsets from SF-36 while covering the same eight domains that SF-36 covers which are physical functioning, role-physical, bodily pain, general health, vitality functioning, social functioning, role-emotional, and mental health.

f: Scale measuring physical independence, cognitive independence, social integration, mobility, occupation, and economic self-sufficiency.

h: The third part of this services identifies and develops a visual roadmap for improving coping, well-being, and overall self-management skills while reintegrating back into the community.

h: Weekly average time of bowel care decreased from 10.3 hours (range 3.5-45) before stoma formation to 1.9 hours (range 0.5-7.75) afterward ( $P = 0.0001$ , paired t-test). At any point, 18 patients reported a stoma gave them more independence and quality of life. 25 patients reported improvement. The effect of colostomy formation is also reported.

Canadian Occupational Performance Measure (COPM), and Barthel Index were used to report functional independence outcomes. Discharge efficiency and readmission rate are also part of outcome measuring tools for individuals with TSCI (Table 3).

Indicators involving individuals with TSCI-related outcomes evaluated 6 main domains:

- *Medical Improvement*: Functional Independence Measure, motor improvement, etc.
- *Complication Monitoring*, e.g. mortality, readmission rate, and discharge efficiency.
- *Quality of Life Improvement*, e.g. health-related quality of life assessment and quality of life improvement rate after rehabilitation.
- *Psychological Improvement*, e.g. social participation after TSCI
- *Outcome Assessment Frequency*: number of rehabilitation visits/year and number of walking ability assessments/patient/year.
- *Other*

## Discussion

In the present study, we summarized important QoCI indicators in individuals with TSCI. In the current literature, the main focus has been on developing QoCI by finding gaps in care

in different phases of the care continuum and designing solutions for the healthcare system, whereas this study focuses on factors affecting the patients care across the TSCI continuum (i.e. from the time of injury through to the community). Examining care in 3 stages is a unique way to report indicators that to our knowledge has not been previously used. We assessed QoCI in terms of access to care and quality of care.

TSCI QoC indicators must cover the TSCI continuum to assist healthcare policymakers, clinicians, and health managers monitor and enhance care. Our study categorized QoC indicators into 3 groups to assist healthcare policymakers with understanding their relevance to care delivery. These groups were healthcare system structure indicators, medical process indicators, and indicators involving individuals with TSCI-related outcomes. Not only were these indicators important for finding gaps in current knowledge, but they also assisted in data collection and designing data registries.<sup>1,73</sup> This study is a scoping review; therefore, the main focus was to identify key concepts of care for individuals with TSCI and provide evidence to inform clinicians, healthcare managers, and policymakers.

## Healthcare System Structure

Cost of care as a healthcare system structure is a challenging indicator to assess accurately. Cost of care has been mentioned as an indicator for QoC, however hospital care is directly affected by hospital length of stay.<sup>12</sup> If cost of in-hospital care

is solely considered as a QoC indicator, many inconsistencies may therefore arise. For instance, certain medications prescribed in the setting of TSCI can be costly compared to other alternatives. In these cases, the incremental cost-effectiveness ratio<sup>74</sup> should be used in cost-effectiveness analysis. This ratio can measure how effective a costly intervention can be in certain patient-specific situations.

The cost of care in this review identified 3 types: acute care costs, cost in the first year following TSCI, and cost of rehabilitation. The effect of costs on the quality of care is not straightforward and there is a need for further research as highlighted by this review. Length of stay is acquainted with better care, including better emotional and social support and also more improvement in FIM, in patients who have suffered from TSCI.<sup>15,22</sup> Shortening the length of stay in acute phase could have positive impact on patient outcome while longer stay in a center specialized for TSCI rehabilitation have been shown to improve FIM of individuals to a greater degree.<sup>12,22</sup> In other words, the patient benefit the most when staying less in the acute phase of hospitalization and spending more time in a center specialized for TSCI rehabilitation. SCI centers have facilities and specialized services for patients who have sustained a TSCI. In the post-traumatic setting, these rehabilitation centers are equipped to manage the patient from arrival to the emergency room until discharge. Education of patients and staff regarding the challenges and concerns of individuals with TSCI is also an indicator that can often be taken for granted. Patient satisfaction with their care is also an indicator measured at multiple phases and has different measures. These QoC measures help us assess the current situation of healthcare systems in responding adequately to TSCI and provide avenues for future improvements in patient outcomes.

### Medical Processes

Medical process indicators mainly focused on screening common postoperative complications such as urinary tract infection, VTE, pressure injuries, and depression. Previous studies reported that urinary tract infections are the most common postoperative complication in patients with TSCI. Clean intermittent catheterization has been proven to reduce the incidence of UTIs and its further complications, such as sepsis in individuals with TSCI.<sup>39</sup> Physical activity and rehabilitation are also considered an essential part of a patient's care. The use of telemedicine for managing complications and subsequent consultation is also reported to have an impact on a patient care. Patient functional score and psychomotor performance have been measured using a variety of different scales and performance scores.<sup>16,34,51,52</sup> VTE prophylaxis at an early stage is an important indicator as well. Evidence-based medicine argues aggressive, early prophylaxis leads to reduced rates of VTE and pulmonary thromboembolism without an increased risk of an epidural hematoma.<sup>11</sup> Early consultation with a neurosurgeon and orthopedic surgeon for spinal cord decompression and spine stabilization was also suggested to increase the quality of care.<sup>1</sup>

### Individuals With TSCI-Related Outcomes

For measuring individuals with TSCI-related outcomes, the indicators mainly focused on the changes in motor score and functional recovery from initial visit to discharge. Characterizing patient well-being was captured through questionnaires and surveys.<sup>20</sup> An interesting indicator is the number of physician visits per year after discharge to evaluate outcome. Readmission after discharge, reoperation rates, and discharge efficiency (measured as the number of visits in the following month after discharge) were also considered as independent indicators.<sup>23,30,45</sup>

### Future Directions

The identification of QoCI in patients with TSCI will help identify pitfalls in clinical data collection and data inclusion in SCI registries. Some of these indicators require resources to monitor over the long term, but the utility in improving future health care delivery outweighs these costs. Globally, developed and developing countries have healthcare systems that significantly differ from one another. Identifying QoCI could help standardize healthcare assessments for each country. Furthermore, these indicators could provide baseline elements for comprehensive QoC questionnaires to compare healthcare systems across the world. In areas where indicators measure similar concepts, a consensus process such as the Delphi method would help establish standards that can be used by all SCI centers.

### Conclusion

This scoping review maps current literature and provides key concepts in the care of individuals with TSCI. These indicators are helpful in improving QoL of individuals with TSCI by providing improved care and enhanced clinical practice. The classification used in this study (healthcare system structure, medical process, and individuals with TSCI related outcomes) models the SCI continuum of care, and may be useful in further data collection efforts.

### Competing Interest

None declared except Alex R Vaccaro (file attached).

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Ethical Approval Number Is 97-02-38-323.


Scoping reviews do not directly access patient data, nor do they intervene in medical treatment course, but rather reviews other studies performed in this field. Hence, the ethical consideration is in the minimal risk category.


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### Supplemental Material

Supplemental material for this article is available online.

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