

Quality of Care Checklist in Traumatic Spinal Cord Injuries in Iran

Appendix 1. ~~Quality of Care Checklist in Traumatic Spinal Column and Cord Injuries in Iran~~

Interviewer Information	
1-Full Name	2-Cellphone
3-Center Name	
Phone Interview Information	
1- Interview Date ----/--/--	2-Interview Phase <input type="checkbox"/> After discharge <input type="checkbox"/> Follow-up after one year
3-Contact Type <input type="checkbox"/> Voice <input type="checkbox"/> Video	4-Interviewee <input type="checkbox"/> Patient <input type="checkbox"/> Patient's attendant <input type="checkbox"/> Both
5-Contact result <input type="checkbox"/> The patient was deceased <input type="checkbox"/> Wrong/Changed contact number <input type="checkbox"/> Non-cooperative patient /Patient's attendant <input type="checkbox"/> Successful	5-1: If patient is deceased A: Deceased Date --/--/---- B: Underlying cause of death C: Other causes of death

Part I: Patient Demographic before/ during injury													
1- First Name	2- Last Name												
3-National Identification number (NID)													
<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table>													
3-1-ID or passport number for non-Iranian people													
.....													
4-Sex <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Other	5- Date of Birth --/--/----												
6-Nationality <input type="checkbox"/> Iranian <input type="checkbox"/> Non-Iranian <input type="checkbox"/> Unknown													
7-Marital status <input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Widowed <input type="checkbox"/> Divorced <input type="checkbox"/> Unknown													
8-Education <input type="checkbox"/> Illiterate <input type="checkbox"/> Primary school <input type="checkbox"/> Secondary school <input type="checkbox"/> Diploma <input type="checkbox"/> Associate <input type="checkbox"/> Bachelor <input type="checkbox"/> Master <input type="checkbox"/> Doctoral degree <input type="checkbox"/> PhD, Specialist													
9- Occupation													

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10- Province	11- City
12- Home Address	
13- Residence Contact (with province code)	
14- Cellphone	
15- Work Contact (with province code)	
16- Emergency Contact	
17- Second Emergency Contact	

Part II- Pre-Hospital Information
1-Injury Incident Date and Time --/--/---- -- : --
2- Transport Mode delivering the patient from the scene to the first medical center <input type="checkbox"/> Ambulance (Ground, Air) <input type="checkbox"/> Other transport mode <input type="checkbox"/> Undetermined
3- Ttransfer Facility/Ambulance arrival date and time to the first medical center --/--/---- --:--
4- Pre-hospital measures for immobilization <input type="radio"/> Neck immobilization <input type="radio"/> Spine immobilization <input type="radio"/> Extremities immobilization <input type="radio"/> No-Immobilization <input type="radio"/> No need to Immobilization

Part III- Hospital Information	
A- Admission Information	
1-Name	2- City
3- Date and Time of admission in the triage	
4- Date and time of hospitalization --/--/---- -- : --	
B- Injury Information	
1-Mechanism of Injury: <input type="checkbox"/> Penetrating <input type="checkbox"/> Blunt <input type="checkbox"/> Unknown	
2-Injury severity based on ASIA Impairment scale: <input type="radio"/> A <input type="radio"/> B <input type="radio"/> C <input type="radio"/> D	
3- Injury Type: <input type="radio"/> Complete <input type="radio"/> Incomplete	

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C: Interventions, Services, Measurements	
1- Date and time of spinal decompression --/--/---- --:--	
2-Did the patient receive Prophylaxis Thromboembolisms Treatment (PTE) within the first 72 hours after the injury? <input type="radio"/> Yes <input type="radio"/> No	
3- MRI	
3-1 Date ----/--/--	3-2 Time --:--
3-3 Center Name	
4-CT-scan	
4-1 Date ----/--/--	4-2 Time --:--
4-3 Center Name	
5- ICU Hospitalization Period: ----- days	
D: Complications	
1-Has the patient experienced any fever during the hospitalization period? <input type="radio"/> Yes <input type="radio"/> No	1-1 In case of having fever, the cause should be identified (by an Infectious Disease Specialist) <input type="radio"/> Pneumonia <input type="radio"/> Septicemia <input type="radio"/> Pressure ulcers <input type="radio"/> Surgical wound infection <input type="radio"/> Meningitis <input type="radio"/> UTI <input type="radio"/> Other
2-Does the patient have any other pain rather than the fracture site? <input type="radio"/> Yes <input type="radio"/> No	2-1 If you experience pain, where is the location: ----- 2-2 What is the severity of pain from 0 to 10? ----- 0=no pain, 10= the most severe pain
3-Have the patient experienced any pressure ulcer during the hospitalization period? <input type="radio"/> Yes <input type="radio"/> No	3-1 In case of having pressure ulcer, please complete the pressure ulcer characteristics form for each pressure ulcer. 3-2 Have any of the pressure ulcers undergone an operation? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown If yes, what was the operation date?/...../...
C: Discharge Information	
1-Discharge Date ----/--/--	2-Patient's condition when discharged: <input type="radio"/> Death or severe permanent impairment <input type="radio"/> Leave against medical advice (LAMA) <input type="radio"/> Refer to another center <input type="radio"/> Partial improvement
D- Patient's quality of life (QOL) when discharged Answer to SCQL Questionnaire	

Part IV- Post Hospital Information

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A-Current Patient Demographic		
1-Marrital status <input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Widowed <input type="checkbox"/> Divorced <input type="checkbox"/> Other		
2-Education <input type="checkbox"/> Illiterate <input type="checkbox"/> Primary school <input type="checkbox"/> Secondary school <input type="checkbox"/> Diploma <input type="checkbox"/> Associate <input type="checkbox"/> Bachelor <input type="checkbox"/> Master <input type="checkbox"/> Doctoral degree <input type="checkbox"/> PhD, Specialist		
3- Occupation <input type="checkbox"/> Student <input type="checkbox"/> Disabled / unemployed <input type="checkbox"/> Housewife / Retired <input type="checkbox"/> Employed		3-1-If the person is employed, the job condition: A- <input type="radio"/> New job after the injury <input type="radio"/> Same as before the injury B- Occupation: C- Type <input type="radio"/> Work from home <input type="radio"/> Work from office
4- Residential Province		5- Residential City
6- Residential Address		
7- Home Contact Phone (with area code)	8-Cellphone	9- Work Contact Phone (with area code)
10- Emergency Contact		11-Second Emergency Contact

B. Radiological findings and medical images		
Failure or incomplete decompression <input type="radio"/> Yes <input type="radio"/> No	Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	
Failure or incomplete solid fusion <input type="radio"/> Yes <input type="radio"/> No	Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	
Implant failure/ breakage of the hardware <input type="radio"/> Yes <input type="radio"/> No	Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	
Spine instability <input type="radio"/> Yes <input type="radio"/> No	Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	
Cord hemorrhage <input type="radio"/> Yes <input type="radio"/> No	Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	
Progression of cord edema <input type="radio"/> Yes <input type="radio"/> No	Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	
Transfer lesion to another <input type="radio"/> Yes <input type="radio"/> No	Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	
Syrinx (fluid-filled intramedullary structure expanding above the injured segment with signal is intense to CSF) <input type="radio"/> Yes <input type="radio"/> No	Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	
Cyst <input type="radio"/> Yes <input type="radio"/> No	Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	
Cord atrophy <input type="radio"/> Yes <input type="radio"/> No	Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	
Myelomalacia <input type="radio"/> Yes <input type="radio"/> No	Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	

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	RAY
Cord tethering	<input type="radio"/> Yes <input type="radio"/> No
Diagnosed by <input type="checkbox"/> MRI <input type="checkbox"/> CT-scan <input type="checkbox"/> X-RAY	

C-Complications and Conditions																	
1- Spasticity [1]																	
Does the patient currently experiencing any spasticity? <input type="checkbox"/> No <input type="checkbox"/> Yes If yes , identify the severity of pain according to Modified Ashworth Scale <input type="checkbox"/> 0- No increase in muscle tone <input type="checkbox"/> 1- Slight increase in muscle tone, manifested by a catch and release or by minimal resistance at the end of the range of motion when the affected part(s) is moved in flexion or extension <input type="checkbox"/> 1+ Slight increase in muscle tone, manifested by a catch, followed by minimal resistance throughout the remainder (less than half) of the ROM <input type="checkbox"/> 2 More marked increase in muscle tone through most of the ROM, but affected part(s) easily moved <input type="checkbox"/> 3 Considerable increase in muscle tone, passive movement difficult <input type="checkbox"/> 4 Affected part(s) rigid in flexion or extension																	
2- Autonomic Dysreflexia																	
2-1- Has the patient experienced any of the signs and symptoms listed under the third column resulted from the second column? <input type="checkbox"/> Yes <input type="checkbox"/> No	Description 1- Autonomic dysreflexia means dysfunction of the sympathetic system 2- It may occur in patients with injuries higher than T6 level 3- The most important symptom is an increase in blood pressure by 2 units or (20 mm Hg) 4- Damage is caused by stimulation in the sub-level. The most common cause is an obstruction or urinary retention. 5. Ask the patient whether these symptoms were caused by urinary retention, constipation, burns, tight clothing, or sunken nails?																
<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 20%;">System</th> <th style="width: 30%;">Causes</th> <th style="width: 50%;">Signs</th> </tr> </thead> <tbody> <tr> <td style="vertical-align: top;">Urinary System</td> <td style="vertical-align: top;">-Urinary retention (obstruction/blocked catheter)</td> <td style="vertical-align: top;">-Severe headache -Transient hypertension</td> </tr> <tr> <td style="vertical-align: top;">Gastrointestinal System</td> <td style="vertical-align: top;">-Constipation -Hemorrhoid, Anal fissure -Acute Abdominal Pain -Peptic ulcer, -Gastro esophageal reflux (GERD) -Gallbladder stone</td> <td style="vertical-align: top;">-Hot flash -Goosebumps -Nasal congestion -Anxiety -Palpitation -Shortness of breath</td> </tr> <tr> <td style="vertical-align: top;">Skin</td> <td style="vertical-align: top;">-Ingrown Toenail -Skin burn: contact with heat -Tight clothing -Pressure Ulcer -Sharp force cut/stab -Insect bite</td> <td style="vertical-align: top;">-Diaphoresis above the injury level -Paled and cold skin colour below the injury level -Seizure</td> </tr> <tr> <td style="vertical-align: top;">Reproductive system</td> <td style="vertical-align: top;">-Menstruation -Pregnancy -Intercourse -Infections</td> <td style="vertical-align: top;">-Bradycardia</td> </tr> </tbody> </table>	System	Causes	Signs	Urinary System	-Urinary retention (obstruction/blocked catheter)	-Severe headache -Transient hypertension	Gastrointestinal System	-Constipation -Hemorrhoid, Anal fissure -Acute Abdominal Pain -Peptic ulcer, -Gastro esophageal reflux (GERD) -Gallbladder stone	-Hot flash -Goosebumps -Nasal congestion -Anxiety -Palpitation -Shortness of breath	Skin	-Ingrown Toenail -Skin burn: contact with heat -Tight clothing -Pressure Ulcer -Sharp force cut/stab -Insect bite	-Diaphoresis above the injury level -Paled and cold skin colour below the injury level -Seizure	Reproductive system	-Menstruation -Pregnancy -Intercourse -Infections	-Bradycardia	2-2- How many times has the patient experienced this?----- times	
System	Causes	Signs															
Urinary System	-Urinary retention (obstruction/blocked catheter)	-Severe headache -Transient hypertension															
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Reproductive system	-Menstruation -Pregnancy -Intercourse -Infections	-Bradycardia															
2-3- Complete the following for each autonomic dysreflexia event: - Cause: - The main and important sign:																	

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Respiratory system	-Pulmonary embolism		
Other	-Fracture/ulcer not yet diagnosed (NYD) -Drugs -Muscular spasm -Cold water immersion/exposure (pool, bath)		
3- Pressure Ulcer			
3- Has the patient experienced any pressure ulcer during the past one year? <input type="radio"/> Yes <input type="radio"/> No		3-1 In case of having pressure ulcer, please complete the pressure ulcer characteristics form for each pressure ulcer.	
		3-2 Have any of the pressure ulcers undergone an operation? <input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown If yes, what was the operation date? ----/--/--	

4-Rehospitalization

4-1 Did the patient get re-hospitalized after the acute phase?
 Yes No

If hospitalized, how many times?

5- Pain

5-1 Have the patient experienced any pain currently?
 Yes No

If yes, please complete characteristics of the three most severe pains experienced.

Pain table - characteristics of the three most severe pains experienced [2]

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain Intensity and duration of pain Treatment of pain
Head				Type of pain (check one):
Neck/shoulders throat neck				Nociceptive Musculoskeletal

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shoulder	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	Visceral
Arms/hands	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Other
upper arm	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	Neuropathic
elbow	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
forearm	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
wrist	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
hand/fingers	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
Frontal torso/genitals	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Other
chest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Unknown
abdomen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
pelvis/genitalia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Back	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Intensity and duration of pain:
upper back	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
lower back	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Average pain intensity in the last week:
Buttocks/hips	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	0 = no pain; 10 = pain as bad as you can imagine
buttocks	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	0; 1; 2; 3; 4; 5;
hip	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	6; 7; 8; 9; 10
anus	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	Date of onset: YYYY/MM/DD
Upper leg/thigh	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
Lower legs/feet	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Are you using or receiving any <u>treatment</u> for your pain problem:
knee	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
shin	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
calf	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
ankle	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
foot/toes	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	

Type of pain: This variable documents the type of pain present.

CODES:

- Nociceptive: A: Musculoskeletal, B: Visceral, C: Other
- Neuropathic: A: At-level SCI, B: Below-level SCI, C: Other
- Other
- Unknown

6-Accessibility to facility and modification	
6-1- Does the patient access to wheelchair? <input type="checkbox"/> Yes <input type="checkbox"/> No - If yes, the type of wheelchair: <input type="radio"/> Electrical <input type="radio"/> Regular <input type="radio"/> Others	6-2- Has any home modification been applied? <input type="checkbox"/> Yes <input type="checkbox"/> No - If yes, the type of modification/s: <input type="checkbox"/> Ramp to the main entrance door. <input type="checkbox"/> Remove any elevation <input type="checkbox"/> Expand the doors so that the wheelchair can fit in <input type="checkbox"/> Elevator <input type="checkbox"/> The kitchen has been modified <input type="checkbox"/> Washrooms and bathtubs with safety bar
6-3- Does the patient have any personal vehicle? <input type="checkbox"/> Yes <input type="checkbox"/> No - If yes, has any medication been made? <input type="checkbox"/> Yes <input type="checkbox"/> No	

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7- What is the patients' satisfaction with regards to the quality of your current care from 0-10?

8- How to deal with bladder sphincter problem –Based on SCIM-III Questionnaire

9- How to deal with intestinal sphincter problem –Based on SCIM-III Questionnaire

10- Patient's health condition one year after the injury:

- The patient was deceased
- Wrong/changed contact number
- Non-cooperative of the patient or patient's attendant
- Successful connection

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11 -Quality of life (can be completed by the patient) according to SCQL Questionnaire [3].

To be completed in two times:

1- The day after the discharge (after the first hospitalization)

2- Follow-up, one year after injury

- 1- I am doing fewer social activities with groups of people (SI)
- 2- I get dressed only with someone's help (BCM)
- 3- I am getting around only within one building (M)
- 4- My sexual activity is decreased (SI)
- 5- I am going out less to visit people (SI)
- 6- I do not move into or out of bed or chair by myself but am moved by a person or mechanical aid (BCM)
- 7- I stay home most of the time (M)
- 8- I am staying in bed more (M)
- 9- I am cutting down the length of visits with friends (SI)
- 10- I make difficult moves with help, eg getting into or out of cars, bath tubs (BCM)

1. I look forward with enjoyment to things
2. I can laugh and see the funny side of things
3. I have lost interest in my appearance
4. I feel cheerful
5. I still enjoy the things I used to enjoy
6. I feel as I am slowed down

1. How difficult is it not being able of walk or move freely?
 Very difficult difficult A little difficult not at all difficult
2. How difficult is it being in need of help with many things?
 Very difficult difficult A little difficult not at all difficult
3. How difficult is it not being able to do things when wanted?
 very difficult difficult A little difficult not at all difficult
4. How difficult is it not being able to hide oneself in a crowd?
 Very difficult difficult A little difficult not at all difficult
5. How difficult is it having intestinal problems?
 Very difficult difficult A little difficult not at all difficult
6. How difficult is it having pain?
 Very difficult difficult A little difficult not at all difficult

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12- Functional Independence Status for Daily Life Activities (SCIM-III Questionnaire[4, 5])

To be completed in two times:

- 1- Day after discharge from the hospital (after the first hospitalization)
- 2- Follow-up, one year after the injury

Self Care

1. **Feeding** (cutting, opening containers, pouring, bringing food to mouth, holding cup with fluid)
 0. Needs parenteral, gastrostomy or fully assisted oral feeding
 1. Needs partial assistance for eating and/or drinking, or for wearing adaptive devices
 2. Eats independently; needs adaptive devices or assistance only for cutting food and/or pouring and/or opening containers
 3. Eats and drinks independently; does not require assistance or adaptive devices
 2. **Bathing** (soaping, washing, drying body and head, manipulating water tap)
 - A. Upper body**
 0. Requires total assistance
 1. Requires partial assistance
 2. Washes independently with adaptive devices or in a specific setting (e.g., bars, chair)
 3. Washes independently; does not require adaptive devices or specific setting (not customary for healthy people) (ADSS)
 - B. Lower Body**
 0. Requires total assistance
 1. Requires partial assistance
 2. Washes independently with adaptive devices or in a specific setting (ADSS)
 3. Washes independently; does not require adaptive devices (ADSS) or specific setting
 3. **Dressing** (clothes, shoes, permanent orthoses; dressing, wearing, undressing)
 - A. Upper body**
 0. Requires total assistance
 1. Requires partial assistance with clothes without buttons, zippers or laces (CWOBZL)
 2. Independent with CWOBZL; requires adaptive devices and/or specific settings (ADSS)
 3. Independent with CWOBZL; does not require ADSS; needs assistance or ADSS only for BZL.
 4. Dresses (any clothes) independently; does not require adaptive devices or specific setting
 - B. Lower Body**
 0. Requires total assistance
 1. Requires partial assistance with clothes without buttons, zippers or laces (CWOBZL)
 2. Independent with (CWOBZL); requires adaptive devices and/or specific settings (ADSS)
 3. Independent with (CWOBZL) without ADSS; needs assistance or ADSS only for BZL.
 4. Dresses (any clothes) independently; does not require adaptive devices or specific setting
 4. **Grooming** (washing hands and face, brushing teeth, combing hair, shaving, applying makeup)
 0. Requires total assistance
 1. Requires partial assistance
 2. Grooms independently with adaptive devices
 3. Grooms independently without adaptive devices
- Self-Care Subtotal (0-20)**

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Respiration and Sphincter Management

5. Respiration

0. Requires tracheal tube (TT) and permanent or intermittent assisted ventilation (IAV)
 2. Breathes independently with TT; requires oxygen, much assistance in coughing or TT management
 4. Breathes independently with TT; requires little assistance in coughing or TT management
 6. Breathes independently without TT; requires oxygen, much assistance in coughing, a mask (e.g., peep) or IAV (bipap)
 8. Breathes independently without TT; requires little assistance or stimulation for coughing
 10. Breathes independently without assistance or device

6. Sphincter Management - Bladder

0. Indwelling catheter
 3. Residual urine volume (RUV) > 100cc; no regular catheterization or assisted intermittent catheterization
 6. RUV < 100cc or intermittent self-catheterization; needs assistance for applying drainage instrument
 9. Intermittent self-catheterization; uses external drainage instrument; does not need assistance for applying
 11. Intermittent self-catheterization; continent between catheterizations; does not use external drainage instrument
 13. RUV < 100cc; needs only external urine drainage; no assistance is required for drainage
 15. RUV < 100cc; continent; does not use external drainage instrument

7. Sphincter Management - Bowel

0. Irregular timing or very low frequency (less than once in 3 days) of bowel movements
 5. Regular timing, but requires assistance (e.g., for applying suppository); rare accidents (less than twice a month)
 8. Regular bowel movements, without assistance; rare accidents (less than twice a month)
 10. Regular bowel movements, without assistance; no accidents
8. Use of Toilet (perineal hygiene, adjustment of clothes before/after, use of napkins or diapers)

0. Requires total assistance
 1. Requires partial assistance; does not clean self
 2. Requires partial assistance; cleans self independently
 4. Uses toilet independently in all tasks but needs adaptive devices or special setting (e.g., bars)
 5. Uses toilet independently; does not require adaptive devices or special setting

Respiration and Sphincter Management Subtotal (0-40)

Mobility (room and toilet)

0. Needs assistance in all activities: turning upper body in bed, turning lower body in bed, sitting up in bed, doing push-ups in wheelchair, with or without adaptive devices, but not with electric aids

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2. Performs one of the activities without assistance
4. Performs two or three of the activities without assistance
6. Performs all the bed mobility and pressure release activities independently

9. Transfers: bed-wheelchair (locking wheelchair, lifting footrests, removing and adjusting arm rests, transferring, lifting feet)

0. Requires total assistance
 1. Needs partial assistance and/or supervision, and/or adaptive devices (e.g., sliding board)
 2. Independent (or does not require wheelchair)

11-Transfers: wheelchair-toilet-tub (if uses toilet wheelchair: transfers to and from; if uses regular wheelchair: locking wheelchair, lifting footrests, removing and adjusting armrests, transferring, lifting feet)

0. Requires total assistance
 1. Needs partial assistance and/or supervision, and/or adaptive devices (e.g., grab-bars)
 2. Independent (or does not require wheelchair)

Mobility (indoors and outdoors, on even surface)

12. Mobility Indoors

0. Requires total assistance
 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
 2. Moves independently in manual wheelchair
 3. Requires supervision while walking (with or without devices)
 4. Walks with a walking frame or crutches (swing)
 5. Walks with crutches or two canes (reciprocal walking)
 6. Walks with one cane
 7. Needs leg orthosis only
 8. Walks without walking aids

13. Mobility for Moderate Distances (10-100 meters)

0. Requires total assistance
 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
 2. Moves independently in manual wheelchair
 3. Requires supervision while walking (with or without devices)
 4. Walks with a walking frame or crutches (swing)
 5. Walks with crutches or two canes (reciprocal walking)
 6. Walks with one cane
 7. Needs leg orthosis only
 8. Walks without walking aids

14. Mobility Outdoors (more than 100 meters)

0. Requires total assistance
 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
 2. Moves independently in manual wheelchair
 3. Requires supervision while walking (with or without devices)
 4. Walks with a walking frame or crutches (swing)
 5. Walks with crutches or two canes (reciprocal waking)
 6. Walks with one cane
 7. Needs leg orthosis only

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8. Walks without walking aids

15. Stair Management

0. Unable to ascend or descend stairs

1. Ascends and descends at least 3 steps with support or supervision of another person
2. Ascends and descends at least 3 steps with support of handrail and/or crutch or cane
3. Ascends and descends at least 3 steps without any support or supervision

16. Transfers: wheelchair-car (approaching car, locking wheelchair, removing arm and footrests, transferring to and from car, bringing wheelchair into and out of car)

0. Requires total assistance

1. Needs partial assistance and/or supervision and/or adaptive devices
2. Transfers independent; does not require adaptive devices (or does not require wheelchair)

17. Transfers: ground-wheelchair

0. Requires assistance

1. Transfers independent with or without adaptive devices (or does not require wheelchair)

13- Caregiver burden scale (CBS) [6] Questionnaire (questions to be answered by the main caregiver): one year after the injury

Strain

- 1- Do you find yourself facing purely practical problems in the care of your relative that you think are difficult to solve?
Not at All Seldom Sometimes Often
- 2- Do you think you have to shoulder too much responsibility for your relative's welfare?
Not at All Seldom Sometimes Often
- 3- Do you sometimes feel as if you would like to run away from the entire situations you find yourself in?
Not at All Seldom Sometimes Often
- 4- Do you feel tired and worn out?
Not at All Seldom Sometimes Often
- 5- Do you feel tied down by your relative's problem?
Not at All Seldom Sometimes Often
- 6- Do you find it mentally trying to take care of your relative?
Not at All Seldom Sometimes Often
- 7- Do you think your own health has suffered because you have been taking care of your relative?
Not at All Seldom Sometimes Often
- 8- Do you think you spend so much time with your relative that the time for yourself is insufficient?
Not at All Seldom Sometimes Often

Isolation

- 9- Do you avoid inviting friends and acquaintances home because of your relative's problem?
Not at All Seldom Sometimes Often
- 10- Has your social life; eg with family and friends, been lessened?
Not at All Seldom Sometimes Often
- 11- Has your relative's problem prevented you from doing what you had planned to do in this phase of your life?

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Not at All Seldom Sometimes Often

Disappointment

- 12- Have you a feeling that life has treated you unfairly?
Not at All Seldom Sometimes Often
- 13- Had you expected that life would be different than it is at your age?
Not at All Seldom Sometimes Often
- 14- Do you feel lonely and isolated because of your relative's problem?
Not at All Seldom Sometimes Often
- 15- Do you find it physically trying to take care of your relative?
Not at All Seldom Sometimes Often
- 16- Have you experienced economic sacrifice because you have been taking care of your relative?
Not at All Seldom Sometimes Often

Emotional involvement

- 17- Are you sometimes ashamed of your relative's behavior?
Not at All Seldom Sometimes Often
- 18- Do you ever feel offended and angry with your relative?
Not at All Seldom Sometimes Often
- 19- Do you feel embarrassed by your relative's behavior?
Not at All Seldom Sometimes Often

Environment

- 20- Does the physical environment make it troublesome for you taking care of your relative?
Not at All Seldom Sometimes Often
- 21- Do you worry about not taking care of your relative in the proper way?
Not at All Seldom Sometimes Often
- 22- Is there anything in the neighborhood of your relative's home making it troublesome for you to take care of your relative?
Not at All Seldom Sometimes Often

Scored from 1 to 4 (Not at All, Seldom, Sometimes, Often)

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Pressure Ulcer Characteristics Form [7, 8]

	Date of appearance of the pressure ulcer	Right	Mid-line	Left	Ulcer category (I, II, III, IV, U (Unstageable))[9, 10]	Length - largest opening diameter (mm)	Width - max. dimension perpendicular to the length axis (mm)	Largest undermining (mm)	Largest depth (mm)
Occiput	----/--/--								
Ear	----/--/--								
Scapula	----/--/--								
Elbow	----/--/--								
Ribs	----/--/--								
Spinous process	----/--/--								
Iliac crest	----/--/--								
Sacral	----/--/--								
Ischia tuberosity	----/--/--								
Trochanter	----/--/--								
Genitals	----/--/--								

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Knee	----/--/--								
Malleolus	----/--/--								
Heel	----/--/--								
Foot	----/--/--								
Other location	----/--/--								

Has the ulcer been surgically treated: Yes No Unknown

If yes, date of last surgical intervention: YYYY/MM/DD

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