



CLINICAL - NEUROLOGICAL/ FUNCTIONAL - ASSESSMENT IN POST SPINAL CORD INJURY PATIENTS AND CURRENT ENDEAVORS IN ACHIEVING OF RELATED INTERNATIONAL STANDARDS

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This paper intends to synthesize the complex and rather complicated subject matter of the actual best possible way to approach the comprehensive clinical - neurological/functional assessment in post spinal cord injury (SCI) patients. In this respect, we present the main related steps recommended to be followed by specialists in this field, for daily clinical practice.

Key words: spinal cord injury, American Spinal Injury Association Impairment Scale (AIS)/ Frankel/ International Spinal Cord Association (ISCoS), international SCI data sets and standards.

INTRODUCTION

Spinal cord injury (SCI) usually generates severe and rather permanently impairment or even loss of basic functions, such as: voluntary/ active mobility, sensitivity, micturition and/or defecation control, erection/ ejaculation/ fertility¹⁻⁵. Therefore, SCI are, in most of the cases, devastating, especially as being frequently irreversible. They are usually associated, on long-term or (quasi) continuously, with serious co-morbidities, emerging from: tissue dystrophicity (mainly pressure sores), urinary tract infections (UTI – recurrent/ chronic), metabolic and/or (including related) circulation disturbances of blood pressure⁶, respectively of the venous-lymphatic flow – especially anti-gravitational, in lower limbs⁷.

SCI can be divided into two main types of lesion/ functional damage, *i.e.* complete and incomplete. The effects of SCI essentially depend

on the spine/(al) cord topographic level of injury, too - *i.e.*: paraplegia after thoracic and/or lumbar and tetraplegia, following cervical SCI; from all points of view: generally biological (having also life threatening potential – especially during the acute and sub-acute phases post injury – and functional, including: self care/ autonomy, family relations, work and social activity/ participation), tetraplegia is by far more serious than paraplegia: in fact, is one of the most severe and invalidating sufferings within human pathology – but, this, in principle (see further).

Complete lesion means there is no function/ control below the neurological level of injury: no sensations and no voluntary movement is preserved (including) in the sacral segments S4,5.

Incomplete SCI means there is some functioning below the injury level: such a person may feel parts of the body that cannot be moved, including in the sacral segments S4,5 (type B on the American

Spinal Injury Association Impairment Scale/ Frankel - AIS/ Frankel B) or have preserved some active motility/ functional control, too (AIS C, D)².

Patients/ relatives and professionals are very interested to precisely know how severe is a certain spinal cord (SC) damage and respectively its consequent neurological and functional impairment. This is for good reason, because prognosis – meaning in most of such cases, a life “sentence” for recovery or conversely: severe/ permanent disability – is fearfully expected by post SCI persons and their kin.

At the same time, neurorehabilitation caregivers can not and should not, in any case, avoid establishing an as precise as possible diagnosis – which is also, inevitably, the basis of the aforementioned fearfully awaited prognosis.

Actually, this is the “continuous” motivation/ starting point of a permanent need for improving the standards of SCI neurological diagnosis and scoring.

For instance, as previously announced, regarding the assertion on tetraplegia as being one of the most devastating conditions: but only if it is motor complete; if it is incomplete, for instance Frankel/ AIS D (see further), a tetraplegia is much less severe than a complete (AIS/ Frankel A) paraplegia.

Thus, to correctly establish the threshold between complete and incomplete SCI is crucial and has to be quantitatively objectified in an assessment system/ standards. Such standards must reliably reflect both, the pathological picture of a post SCI patient and the consequent neurological and functional impairment.

Sir Ludwig Guttmann is unanimously considered as the “patriarch” of modern SCI complex/ rehabilitative approach. He began using sport as a vital ingredient in the rehabilitation of spinal cord injured 2nd World War veterans at the Stoke Mandeville hospital, in England.

In 1948 he set up a competition between sports clubs and other hospitals to coincide with the 1948 Olympic Games. Since, the Games have developed becoming Paralympic Games.

The importance of adopting a standardized approach was first identified by Guttmann and Michaelis⁸, in 1969.

The first classification of SCI was developed by Frankel, in 1969⁹. The 1st edition of the International Standards for Neurological and Functional Classification of Spinal Cord Injury, was published in 1982, by the American Spinal Injury Association (ASIA)¹⁰. These standards included the Frankel classification – having adopted

it for describing the severity of injury and of the consequent functional impairment.

They were revised in 1992, when “the sacral sparing” criterion was introduced to differentiate complete vs. incomplete SCI^{11,12}. Earlier versions of the standards defined incomplete lesions by some preservation of motor or sensory function more than 3 levels below the neurologic level, but the sacral sparing was found to be more stable than previous ASIA definition¹¹. Additionally, it was created the ASIA Impairment Scale (AIS), but despite this rather conceptual change of acronym, in literature, the old designation, *i.e.* ASIA, can still be relatively frequently also found. After the first revision, in 1992, “the ASIA standards” were recognized by The International Medical Society of Paraplegia (IMSOP) and became known as the International Standards for Neurological and Functional Classification of Spinal Cord Injury (ISNCSCI-92)³.

Later, the standards were subject to several revisions. The last revision of the ISNCSCI was made in 2002¹³.

“The Standards (and Education – of ASIA’s and ISCoS’s – o.n.) Committee recommended that the numerous items that were revised “should be issued and a serve as a precedent established for a routine published review of the ISNCSCI”. The Standards Committee also noted that, although the 2008 reprint pocket booklet is current, the reference manual should be revised after proposals to modify/ revise the ASIA Impairment Scale (AIS as modified from Frankel) are considered. In addition, the Standards Committee adopted a process for thorough and transparent review of requests to revise the ISNCSCI”¹⁴.

The clinical assessment of a post SCI patient aims, as basic targets, to determine the sensory and motor levels.

The sensory level represents the most caudal segment of the spinal cord with normal sensory function on both sides of the body; it is determined by neurological examination of key sensory points within each of 28 dermatomes on the right and 28 dermatomes on the left side of the body and correspondent limbs.

The motor level is similarly defined, with respect to motor function. It is determined by examining key muscles within each of 10 related myotomes on the right and 10 myotomes on the left side of the body. The skeletal level represents the level of the greatest vertebral damage (found radiographically)^{3,15}.

Patient Name _____
 Examiner Name _____ Date/Time of Exam _____

ASIA AMERICAN SPINAL INJURY ASSOCIATION **STANDARD NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY** **ISCS**

MOTOR
KEY MUSCLES (scoring on reverse side)

C5	<input type="checkbox"/>	<input type="checkbox"/>	Elbow flexors
C6	<input type="checkbox"/>	<input type="checkbox"/>	Wrist extensors
C7	<input type="checkbox"/>	<input type="checkbox"/>	Elbow extensors
C8	<input type="checkbox"/>	<input type="checkbox"/>	Finger flexors (distal phalanx of middle finger)
T1	<input type="checkbox"/>	<input type="checkbox"/>	Finger abductors (little finger)

UPPER LIMB TOTAL (MAXIMUM) + =
 (25) (25) (50)

Comments: _____

L2	<input type="checkbox"/>	<input type="checkbox"/>	Hip flexors
L3	<input type="checkbox"/>	<input type="checkbox"/>	Knee extensors
L4	<input type="checkbox"/>	<input type="checkbox"/>	Ankle dorsiflexors
L5	<input type="checkbox"/>	<input type="checkbox"/>	Long toe extensors
S1	<input type="checkbox"/>	<input type="checkbox"/>	Ankle plantar flexors

Voluntary anal contraction (Yes/No)

LOWER LIMB TOTAL (MAXIMUM) + =
 (25) (25) (50)

SENSORY
KEY SENSORY POINTS

C2	<input type="checkbox"/>	<input type="checkbox"/>	LIGHT TOUCH	<input type="checkbox"/>	<input type="checkbox"/>	PIN PRICK	<input type="checkbox"/>	<input type="checkbox"/>
C3	<input type="checkbox"/>	<input type="checkbox"/>	R	<input type="checkbox"/>	L	R	<input type="checkbox"/>	L
C4	<input type="checkbox"/>	<input type="checkbox"/>						
C5	<input type="checkbox"/>	<input type="checkbox"/>						
C6	<input type="checkbox"/>	<input type="checkbox"/>						
C7	<input type="checkbox"/>	<input type="checkbox"/>						
C8	<input type="checkbox"/>	<input type="checkbox"/>						
T1	<input type="checkbox"/>	<input type="checkbox"/>						
T2	<input type="checkbox"/>	<input type="checkbox"/>						
T3	<input type="checkbox"/>	<input type="checkbox"/>						
T4	<input type="checkbox"/>	<input type="checkbox"/>						
T5	<input type="checkbox"/>	<input type="checkbox"/>						
T6	<input type="checkbox"/>	<input type="checkbox"/>						
T7	<input type="checkbox"/>	<input type="checkbox"/>						
T8	<input type="checkbox"/>	<input type="checkbox"/>						
T9	<input type="checkbox"/>	<input type="checkbox"/>						
T10	<input type="checkbox"/>	<input type="checkbox"/>						
T11	<input type="checkbox"/>	<input type="checkbox"/>						
T12	<input type="checkbox"/>	<input type="checkbox"/>						
L1	<input type="checkbox"/>	<input type="checkbox"/>						
L2	<input type="checkbox"/>	<input type="checkbox"/>						
L3	<input type="checkbox"/>	<input type="checkbox"/>						
L4	<input type="checkbox"/>	<input type="checkbox"/>						
L5	<input type="checkbox"/>	<input type="checkbox"/>						
S1	<input type="checkbox"/>	<input type="checkbox"/>						
S2	<input type="checkbox"/>	<input type="checkbox"/>						
S3	<input type="checkbox"/>	<input type="checkbox"/>						
S4-5	<input type="checkbox"/>	<input type="checkbox"/>						

0 = absent
 1 = impaired
 2 = normal
 NT = not testable

Any anal sensation (Yes/No)

TOTALS: + = + =
 (MAXIMUM) (56) (56) (56) (56)

PIN PRICK SCORE (max: 112) + =
 LIGHT TOUCH SCORE (max: 112) + =

• Key Sensory Points

NEUROLOGICAL LEVEL: The most caudal segment with normal function. **SENSORY** R L **MOTOR** R L

COMPLETE OR INCOMPLETE? **ASIA IMPAIRMENT SCALE**

ZONE OF PARTIAL PRESERVATION: Caudal extent of partially innervated segments. **SENSORY** R L **MOTOR** R L

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Fig. 1. American Spinal Injury Association (ASIA) standards for describing severity of injury and consequent functional deficit [15]

In fact, as the segments at which normal function is (still) found can be different over the body/ limbs, it is strongly advisable to register them at least as a sensory and respectively a motor one on each side (right-sensory, left-sensory, right-motor, left-motor). Additionally, there can be determined a single average /global/ synthetic “level” of each, which is the most caudal (of them) level of the spinal cord with (quasi) normal function (sensory respectively motor)³.

Furthermore, the “single” neurological level is the highest of the both – examined – sensory and motor levels³. Sensory and respectively, motor scores – are actually measuring the magnitude of the correspondent remaining functions and thereby they are indirectly quantifying the neurological impairment. Appreciation of pin prick and of light touch at each of the key points is separately scored on a three-point scale: “0 = absent; 1 = impaired (partial or altered appreciation, including hyperaesthesia); 2 = normal; NT = not testable. In testing for pin appreciation, the inability to distinguish between dull and sharp sensation is graded as 0”³. Hence, for sensory scoring

ISNCSCI admits, totally: maximum 224 points (112 x 2, i.e. light touch maximum 112 and pin prick maximum 112) and for motor scoring ISNCSCI admits, totally: 100 (50 x 2) points.

Specifically, as indicated in³, “the following key points are to be tested bilaterally for sensitivity. Asterisks indicate that the point is at the mid-clavicular line:

- C2 – Occipital protuberance
- C3 – Supraclavicular fossa
- C4 – Top of the acromioclavicular joint
- C5 – Lateral side of the antecubital fossa
- C6 – Thumb
- C7 – Middle finger
- C8 – Little finger
- T1 – Medial (ulnar) side of the antecubital fossa
- T2 – Apex of the axilla
- T3 – Third intercostal space (IS)*
- T4 – Fourth IS (nipple line)*
- T5 – Fifth IS (midway between T4 and T6)*
- T6 – Sixth IS (level of xiphisternum)*
- T7 – Seventh IS (midway between T6 and T8)*

- T8 – Eighth IS (midway between T6 and T10)*
- T9 – Ninth IS (midway between T8 and T10)*
- T10 – Tenth IS (umbilicus)*
- T11 – Eleventh IS (midway between T10 and T12)*
- T12 – Inguinal ligament at mid-point
- L1 – Half the distance between T12 and L2
- L2 – Mid-anterior thigh
- L3 – Medial femoral condyle
- L4 – Medial malleolus
- L5 – Dorsum of the foot at the third metatarsal phalangeal joint
- S1 – Lateral heel
- S2 – Popliteal fossa in the mid-line
- S3 – Ischial tuberosity
- S4 – 5 Perianal area (taken as one level)”

In addition for sacral sensations movements is mandatory as previously emphasized.

As it can be seen in Figure 1, for motor examination there are established (on each side of the body) 10 key muscle points (5 in the upper limbs and 5 in the lower limbs), their force being graded on the six-point, of the Medical Research Council (MRC) – or maybe, in the future, on a newer, modified/ improved – scale¹⁶:

- 0 = total paralysis
- 1 = palpable or visible contraction
- 2 = active movement, full range of motion (ROM) with gravity eliminated
- 3 = active movement, full ROM against gravity
- 4 = active movement, full ROM against moderate resistance
- 5 = normal active movement, full ROM against full resistance
- NT = not testable

As there are also some muscle territories – respectively including with their innervation levels – which’s clinical assessment practically is not available (C1 – C4, T2 – L1 and S2 – S5) it is recommended to consider for them a same level as the correspondent sensory level identified³.

Regarding motor incompleteness (AIS/ Frankel C or D) there must exists either voluntary anal sphincter motility or combined sacral sensations with active muscle control in more than three levels below the motor level on each side of the affected territory.

More specific, if less than half of the key muscles under the cord lesion level have MRC force 3 or more, ASIA/ Frankel considers the SCI as being C and respectively if at least half of the

respective key muscles can be graded with force 3 or better, the SCI should be classified as D.

An important derogative aspect refers to establishing the motor (and if it is the case) even the (global/ synthetic) neurologic level of a SCI: there are, on one hand, several collateral inimical factors frequently associated to the denervation of a muscle/ muscle group (including for the key ones): pain, hypertonicity and positioning, that impair the functional segmental capacities (and this may happen including for a otherwise full innervated muscle/ group of muscles) and on the other hand, it has to be considered that a muscle/ group of muscles is usually innervated from different spinal nerves, i.e. most muscles receive neural commands usually from two myelomers/ nerve roots. Specifically, if the most cephalad muscle/ group of muscles below the level lesion having preserved motor control has at least a MRC graded force of 3, this can be considered as the motor level, although its strength is not 5^{3,17}.

Corollary, to define a cord lesion as incomplete – meaning that at least some sensory functions remained preserved below the lesion level – there must be found sacral sensation, i.e. sensitivity (for light touch and/or pin-prick) in both: anal mucocutaneous junction (S4-5) and anal deep inside.

For considering a cord lesion as motor incomplete there have to be found voluntary contraction of the external anal sphincter upon digital examination.

Conversely, the synthetic/ short (including mnemotechnic) formulation for classifying a SCI as complete is the “N-0-0-0-N sign” (no voluntary anal contraction, no r/l, light touch respectively pin-prick sensitivity and nor any anal sensation)².

For the situation in which some (frequently isolated) dermatomes and myotomes, situated below the lesion level, are found remaining partially innervated (but without, at least sacral sensation conserved), the SCI is considered complete, but with zone(s) of partial preservation (ZPP); such findings must be counted and registered on both sides of the body/ limbs.

In synthesis, for neurological examination/ scoring/ impairment grading (completeness/ incompleteness of SCI), the required/ basic elements of the examination are used to: determine the sensory/ motor/ neurological levels, count the scores to characterize the sensory/ motor deficit, assess, semi-quantitatively, the neurological/ functional impairment grades and objectify the completeness/ incompleteness of the injury.

Likewise for the sensory examination, if a key muscle is not testable, this should be registered as NT.

Several clinical syndromes resulting after SCI:

Central cord syndrome

The lesion, occurring almost exclusively in the cervical region, usually by a hyperextension pathogenic mechanism (*e.g.*: a diving accident and/or in elderly, traumas – including relatively minor – on preexisting spine degenerative alterations) produces: localized (in the dermatome/s, situated nearby the lesion's site) sensitivity alteration for pain and temperature, including with tendon reflex weakness, and possibly – especially if the lesion enlarges – greater motor loss in the upper limbs than in lower ones – therefore also known as “inverse paraplegia”; sacral sparing^{2,17,18}.

Lateral (Brown-Sequard) syndrome

The lesion (*e.g.*: consequent to a stab wound - injury on a lateral side/ hemi-section) produces greater ipsi-lateral (posterior column impairment) proprioceptive, vibration, light touch sensitivity, paresthesias and motor weakness, possible reflex changes, and contralateral loss of sensitivity to touch, pain and temperature^{2,17,18}.

Anterior (ventral) cord syndrome

The lesion, frequently occurring after a hyperflexion injury, produces variable loss of: motor function, urinary continence, sensitivity to pain (but that for touch and vibration is spared) and temperature perception/ regulation; additionally: reflex changes and respectively, preserved proprioception^{2,17,18}.

Posterior (dorsal) cord syndrome

The lesion – more often non traumatic – produces loss of two points discrimination (epicritic sensitivity) and of proprioception, associated with ataxia, paresthesias and possibly urinary incontinence. Sensitivity for pain, and light touch, as well as motor function, remain intact^{2,17,18}.

Transvers/ transection (total) cord syndrome

The lesion – result of a crush, but also possibly secondary to hemorrhagic or infectious, insults – produces complete interruption/ loss of any SC control (sensory, motor – often spastic absolute weakness – and practically total, also autonomic – in terms of efficient functionality) below the lesion level^{2,18}.

Conus medullaris syndrome

The lesion – injury of the distal cord (conus), typically occurring between T11 and L2 – ordinarily results in neurological impairments of: bladder, bowel, sexual and lower limbs functionality (although for the last ones often quite mild/ rather symmetrical), including possibly associated with central motor neuron syndrome. The affected segments may occasionally show preserved reflexes (*e.g.*: bulbo-cavernosus – “Osinski reflex” –, perianal wink/ anocutaneous reflex and respectively – related to micturition); if still absent after the spinal shock has passed, this proves the irreversibility of damage to such neural structures^{2,17}.

Cauda equina syndrome

Injury to the lumbar-sacral (2 or more of its 18) nerve roots within the spinal canal, result in neurological impairments of bladder, bowel, sexual function and/or lower limbs. If there are affected mainly high and/or medium levels (L1-S1), the main symptoms consist in low back pain and somatic sensitive, motor, reflex and/or trophic deficits, whereas insults in the lowest ones (S2-S4) affect the sacral and perineum dermatomes, including with sphincters and/or sexual functions. The prognosis is, in principle, better because being peripheral nerve structures, there is the possibility – although not always certain – of regeneration/ re-innervation^{2,17,18}.

Rapid neurologic assessment

As resulting from the already numerous related emphasized aspects, the clinical neurological and functional examination of a SCI patient is on one hand, difficult and appropriate skills and time allocation demanding, and on the other hand, still subject for further improvements (including the thorough standardization international endeavors to be presented later). Yet – as nevertheless post-SCI patients are both: usually fragile and needing for efficient and, as earlier and precise as possible, treatment approach – a prompt and in the mean time simple, and therefore not excessively time consuming/ patient soliciting method of assessment, has been shown necessary for daily clinical practice. Accordingly, some valuable authors in the field recommend the so called “rapid neurological assessment”, which we consider opportune to quote it as such:

“Determine approximate neurological level. Screen sensation by running a finger or cotton swab for light touch or a pin wheel for pin prick

over the injured legs, trunk and arms. Screen motor power by having the patient (flex – o.n.)/ extend the (thighs – o.n.)/ knee, wiggle the toes, flex the elbow and squeeze your finger.

Determine completeness or incompleteness of injury. Assess the sacral segments, particularly if the injury seems otherwise complete. Perform a digital rectal examination with a gloved finger, for deep pressure sensation, voluntary sphincter contraction and reflex activity (bulbo-cavernosus reflex – Fig. 2 – o.n.). Check pinprick sensation in the peri-anal region and note the presence or absence of the anal wink (anocutaneous – o.n.) reflex.

Perform detailed examination of zone of injury. Conduct a detailed assessment of sensation and strength at the zone of injury. This should include muscles and dermatomes one to two levels above and below the injury level¹⁹.

Regarding the quasi-unanimously claimed in the literature, as being mandatory: the rectal examination; we consider useful some brief comments. Hence, on one hand performing constantly/ in each post-SCI patient the rectal examination as indispensable item of his/her clinical examination may be difficult to be accepted either because of psychological (including for shame and/or mentality, religious) reasons or by possible exaggerated pain perception generating. On the other hand, its necessity for establishing the threshold between SCI complete (AIS/ Frankel A) and incomplete (AIS/ Frankel B) is out of question; moreover, the rectal digital (through a glove finger) examination is highly contributive as well to distinguish a sensitive incomplete from a motor incomplete (AIS/ Frankel C) lesion. And even more, this kind of medical maneuver has a prognostic value, too: S4-S5 sensory (and even better: motor) function being preserved, entails enhanced chances for neurological and functional recovery than missing it.

Considering this antagonical dialectic choice, the current physician has to assume a possibly convenient intermediate solution, which consist in a reasonable compromise, represented by a standardized self-report on the S4-S5 sensitivity/ motor functions.

In this respect, a recent study concludes that post-SCI persons, in generally, can reasonably self-report S4-S5 sensory and motor functions (compared with results from the physical examination at resembling statistical ratios), thus justifying the use of self-report rather than

the rectal digital examination, in some situations²⁰.

Regarding prognostic/ predictivity, the presence/ preservation (in the first - mainly 72 hours but also possibly within the first around 1 month) in post SCI patients, of the pin prick sensation in the lowest sacral area – and better, in a more extended dermatomal region (L2-S1), too – seems to be predictive for a greater chance to regain functional ambulation, in the following 6 months-1 year^{21, 22}.

A reasonable related explanation of this possible property of the pin prick sensation - differing from light touch and proprioception sensitivity – is its neural conveyor's proximity, within the spinal cord, to the spino-thalamic tract, carrying this sensory stimuli to the cortico-spinal bundle/ fascicle – in charge for motor function²². Yet, other authors, in a recent cohort study, include light touch (and not pin prick) among a combination of clinical parameters, with “excellent discrimination distinguishing independent walkers from dependent walkers and non-walkers”²³.

To be also considered – including for further related research – that within the AIS assessment methodology there is not structured differentiation between a normal pin prick perception and sensation of pressure, when testing with a pin/ blunt needle, this being asserted as important, because “75% of patients who felt the pin as pin prick and only 20% of those who felt the <<pin as pressure>> recovered ambulation”²⁴.

Currently the most widely used validated ADL evaluation scale is the Functional Independence Measure (FIM)^{17, 25}.

Considering this, for the post SCI patients – who typically do not have cognitive and/or communication problems – the assessment of the cognitive subtotal score (based on 5 specific assessment items/ parameters, within the FIM) is often a useless endeavor, starting mid nineties there has been progressively developed - at present at its third version – a more specific – “of 94 categories (possible activities to be or not/ partially performed – o.n.) that define 18 individual tasks (items) divided into 3 subscales (areas of function) as follows: self-care (score range, 0–20), respiration and sphincter management (range, 0–40), and mobility (range, 0–40)”¹⁷ – for such patients disability/ independency scale – including currently considered to have each area scored according to its proportional weight in their general activity and to be more sensitive to

changes in their clinical/ functional evolution - the Spinal Cord Independence Measure (SCIM - III). Likewise within the FIM, the basic ranking paradigm assumes that higher scores reflect higher functionality.

After long-term and sustained clinical testing and successive work for its validation, about SCIM III, it has been very recently concluded that “The changes in SCIM III grades and the stability of their relationship with the total SCIM III scores (TSS) throughout rehabilitation, support the validity and the reliability of the classification”²⁶⁻³⁰.

Yet, also very recently, a retrospective, on a consistent cohort (11 685 cases retained) study, found that the value of the (motor) FIM score “for SCI patients at time of their discharge from rehabilitation” has shown to be satisfactory predictive not only regarding (medical) prognostic, but also for demographic and socio-economic and even reinsertion in a paid work outcomes, on short/intermediate and long-term, too (“at 1, 5, 10, 15 and 20 years follow up”).

Thus, it has been also determined that “Improvement in FIM suggests reduced economic burden in SCI patients”³¹.

Other evaluation (with more restricted focuses or less specific) instruments/ tools used, including to approach post SCI patients are:

- the Spinal Cord Index of Function (SIF) – newer and related basically to the assessment of the ability for transfers in non-walking such patients³².

- the Walking Index for Spinal Cord Injury (WISCI - including being revised and submitted to validation in United States and European related populations^{33, 34}.

- the Timed 10-Meter Walk Test – assesses the duration to cover a 10-meter distance of unassisted walk, the time being measured also for intermediate 6 meters – thus enabling for velocity (acceleration/ deceleration) changes performed at a preferred or fastest possible gait speed; the outcome results as the average of 3 related trials; assisted devices can be used but this must be mentioned if it is the case and documented as such³⁵.

- the Six-Minute Walk Test – assesses the distance covered in 6 minutes of gait without assistance, at the fastest possible speed; assisted devices can be used but this must be mentioned if it is the case and documented as such³⁶.

- the AuSpinal test of hand function – is a new seeming quick and reliable, submitted to validation, assessment tool comprising 7 related tasks, that aims to quantify unilateral hand function in tetraplegics³⁷.

- the Jebsen Test of Hand Function – has an original version (1969) with 7 assessment items and some modified ones: Agnew & Maas (Australian, 1982) with 8 items and a most simple one with 3 items (Bovend'Erdt *et al.*, 2004). The original test by by Jebsen, Taylor, Treischmann, Trotter, and Howard comprises the following items: “writing a short sentence (24 letters, 3rd grade reading difficulty), turning over a 3x5 inch card, picking up small common objects, simulated feeding, stacking checkers, picking up large light cans, picking up large heavy cans”. To perform such a test, although the necessary equipment is not completely standardized, the whole scoring methodology is provided as packaged assessment kits to be purchased from related suppliers³⁸.

Main rationale/ aims for developing International Standards and Basic Data Sets in SCI

Although an objective/ quantified assessment, based on unitary, international, largely accepted evaluation standard is a relatively old target – and over time it seemed to be fulfilled – actually the need for better, international standards, based on data/ specific core sets, according to the International Classification of Functioning Disability and Health (ICF-DH)³⁹, appeared in the field, with renewed strength and already specific results.

Accordingly, in the last about 7 years, under the International Spinal Cord Society (ISCoS) auspices, (new) data/ core sets standards, based on the above mentioned World Health Organization (WHO) new concept on human functioning, i.e. the ICF-DH, reached at present, for most of their components, validation. From the mentioned perspective, the principal conceptual novelty, relies on the fact that – as already emphasized – they are based on “core data sets” specific for SCI sub domains.

An added benefit of establishing a standardization approach was to aid collaboration between different - but indispensable necessary - inter-multidisciplinary specialties (Physiatry/ Rehabilitation, Neurology, Neurosurgery, Orthopedics/ Traumatology, Surgery, Intensive Care/ Anesthesiology, Infectious Diseases, Psychiatry, as well as Physio-/Kinesi-therapy, Psychology, Sociology, Assistive Technologies) and respectively between professionals working as health-care providers and/or as academics/ researchers in the respective domains, for using a unitary way of

examining such patients and consequently for being able to exchange reliable related information⁴⁰.

“Comparable assessment parameters sets of neurologic impairment and principal related complications for unitary, appropriate communication/data exchange are meant to improve clinical practice and trials, enabling: implementation development of treatments and standardized data, as basis for facilitate collaborative research within multicenter reliable trials”. Thus leads to increased efficiency of: translation, rendering and application, aiming best SCI patients management, maybe eventually: cure⁴¹.

It is very important data to be collected in an uniform manner and to contain reporting of comparable minimal items. Also essential is the use of a standard format for combining data proceeding from multiple centers/ investigators. In this respect, ISCoS also developed special Core Data Sets for research purposes, in order to standardize the collection of data from SCI patients. These data comprise: age, gender, date of the injury and the clinical status (including ASIA score) at the time of acute admission and final inpatient discharge⁴².

To be mentioned that actually most of the “basic” and “extended” related data sets has been fulfilled by experts of ISCoS, ASIA and other international professional societies – such as The International Society for Physical and Rehabilitation Medicine – and are posted within a special dedicated button (“International SCI Data Sets”) on the ISCoS official website⁴².

Hence, in the final section of this article, there will be (rather, in a brief synthetic overview) reminded these endeavors.

They cover practically all the main areas of physiology and respectively pathology, which a post SCI patient may encounter; in respect to the above mentioned trend for standardization – *i.e.* in order to eventually achieve a unitary, common language and record methodology, and related professional communication – we shall use as for each of the data sets to be presented further, brief representative quotations from the related literature.

Current endeavors towards international standards and basic data sets for neurological (somatic)/ functional classification of SCI

Pain assessment

The International Association for the Study of Pain (IASP) now defines nociceptive pain as the

one “that arises from actual or threatened damage to non-neural tissue and is due to the activation of nociceptors” and neuropathic pain as “caused by a lesion or disease of the somatosensory nervous system”⁴³.

Pain, especially chronic – including disesthesia of neuropathic kind, intricate with subjective sensations generated by spasticity – is rather frequent post SCI and, likewise the SC lesions themselves, has yet rather poor therapeutic options/results.

This may consistently (supplementary) alter such patients’ quality of life (QoL), – especially if the chronic/ neuropathic pains are intensively perceived on long-term – and may also significantly interfere with mental, behavioral and/or physical functioning.

Specific are neuropathic pains but SCI patients may experience also nociceptive ones, mainly related, either to overuse of the upper part of the body/ limbs or to various muscle-skeletal conditions, including below the spinal lesion level.

Accordingly, there have been carried on international efforts in this direction, too, resulting in the issue of the International Spinal Cord Injury Basic Pain Data Set (ISCIBPDS) – endeavor recognized to entail, for better classification results, additional psychometric (for some of its cognitive/ behavioral) components – and respectively, connections to the underlying mechanism of SCI related pain⁴⁴.

Aside the ISCIBDIPS – designed to be administered by a health-care professional – there can be used also, with minor adaptations, a self-report version of this set, with quite seeming results (except, for example, classification of neuropathic versus nociceptive pain, which are not appropriate as self-report items).

Using the self-reported version entails, both introduction of psychometric dimension and, respectively, an important enlargement of the potentially assessed SCI individuals, this version being available for completion - including by electronic interviews - no matter if the respondent is in- or out-patient.

Supporting this assertion, a quite recent published study⁴⁵ objectifies the utility and validity of the self-report version of the ISCIBPDS items for assessing pain in individuals with SCI.

Even more recently, there has been issued the International Spinal Cord Injury Pain (ISCIP) Classification, following the same general purpose frame of bettering – if possible through standardization – the clinical evaluation of SCI patients (more specifically, by a consensus

classification of pain, the post SCI patients may experience).

An international group, of 15 members/ co-authors, worked starting 2009, to deploy the underlying endeavor that resulted in the achievement (based on a literature overview and on each of them practical expertise, active interaction exchange) of a collaborative related research.

Accordingly, it has been produced a synthetic 3 boxes related classification (ISCIP). This is structured on 3 “tiers”⁴⁶: “*pain type*” – with 4 possible framing (nociceptive, neuropathic, other and respectively unknown, pain) –; “*pain subtype*” for nociceptive (musculoskeletal, visceral, other pain); for neuropathic there are also considered 3 framing possibilities (at level, below – SCI pain – and respectively other topographic origin of such kind of sufferance); “*primary pain source and/or pathology (write or type in)*” – enabling, as much precise as possible, to identify the clinical source of the specific, form each patient examined, of the nosological entity responsible for pain. The authors give additionally some suggestive exemplifications: “gleno-humeral arthritis” for musculoskeletal pain, “cholecystitis” for visceral pain, “autonomic dysreflexia headache” for other nociceptive pain; for neuropathic pain: “nerve root compression” - at level SCI pain -, “spinal cord compression” - below level - and “carpal tunnel syndrome”- other neuropathic pain). For other pain within the first tier the authors mention “complex regional pain syndrome type I” and “irritable bowel syndrome”⁴⁶.

The respective classification has been also evaluated concerning its utility and reliability (the second part of the ISCIIP classification) through a methodology based on 75 “clinical vignettes” (encompassing: “brief case histories of hypothetical individuals with SCI pain”), used as support for the interaction and knowledge/ personal clinical experience exchange within “a random sample of members of ASIA and ISCoS. For each vignette these clinicians were asked to classify the pain described.”[46] To be emphasized that for the afore mentioned part 2 of this study, we have been chosen among the solicited professional responders (see the related acknowledgments in⁴⁶).

Spasticity (and spasms) assessment

Spasticity is common in post SCI, especially when the neurologic level is above T10-T11. This major symptom of the upper motor neuron syndrome consists in both, “positive” (stiff muscles and joints, contractures, involuntary movements,

exaggerated cutaneous reflexes, possibly clonus) and “negative” (paresis, weakness, loss of dexterity and early fatigability of voluntary movements) symptoms.

Clinically, it is easily recognizable, but its quantification is a more complex issue and its approach is still perfectible⁴⁷. This is because optimally, there have to be assessed both basic aspects of spasticity: phasic and tonic, on which relies this exaggerated involuntary muscular activity⁴⁸ – due to the pathological enhancement of spinal reflexes, especially the myotatic stretch arch⁴⁹.

The tool most frequently used to assess spasticity, including in SCI, is (still) the modified Ashworth Scale – MAS⁵⁰. This evaluation instrument uses ratings from 0 to 4 to assess resistance to a passive movement, applied throughout the entire range of motion (ROM).

“0 = no increase in muscle tone

1 = slight increase in muscle tone, giving a catch and release, or minimal resistance when the segment is moved into flexion or extension or (or abduction/ adduction - o.n.) at the end of the range of motion (ROM)

1+ = slight increase in muscle tone, giving a catch followed by minimal resistance throughout the remainder (less than half) of the ROM

2 = moderate increase in muscle tone, through most of the ROM, but the segment can easily be moved

3 = severe increase in muscle tone, with passive movement difficult

4 = segmental rigidity (in flexion/ extension, abduction/ adduction), passive movement is not possible”.

Despite its familiarity and fair intra-rate reliability, MAS is more and more criticized in the last years^{47, 51} mainly because its poor inter-rate and inter-session reliability, limiting its validity, especially for assessing lower extremity.

Therefore, there have been proposed – including, radically – the abandon of MAS⁴⁸ and its replacement preferably with a test battery type of approach: clinical and electro-neuro-physiological (even biomechanical/ technological tests – isokinetic dynamometers)^{51, 52}, or an evaluation method similar to that of the Spinal Cord Assessment Tool for Spastic Reflexes (SCATS – a evaluation tool addressing involuntary motor activity, that comprises rating scores, obtained by pinprick and movement stimuli, ranging from 0 to 3 points, for: clonus, flexor spasms – hip, respectively knee – and extensor spasms, where 0 means “no spasm” and 3 refers to “severe spasm”)⁵³.

In addition, more recently, the usefulness of some less evaluated assessment tools is being considered, such as: Wartenberg Pendulum Test (WPT) and/or the psychometric dimension – e.g.: self-rated Visual Analogue Scale of Spasticity (VAS), Penn Spasm Frequency Scale (PSFS) and possibly, evaluation items related to “functional and quality of life aspects”^{54, 55}.

Another scale based on self-reporting is PSFS, which uses a scoring system structured on 2 components:

“1. Spasm Frequency:

0 = No spasm

1 = Mild spasms induced by stimulation

2 = Infrequent full spasms occurring less than once per hour

3 = Spasms occurring more than once per hour

4 = Spasms occurring more than 10 times per hour

2. Spasm Severity:

1 = Mild

2 = Moderate

3 = Severe”[56]

Current endeavors towards international standards and basic data sets for neurological (autonomic) classification of SCI

The sympathetic nerve fibers originate in the spinal cord along with spinal nerves and pass first into the sympathetic chain and then to the tissues and organs that are stimulated by them.

Systematic endeavors to achieve International Standards for assessment of autonomic function following SCI have started at ASIA and ISCoS initiative, about 7 years ago and reached to a preliminary – including conceptual – design, starting 2006^{57, 58}.

Nowadays comprehensive assessment of autonomic function within the International Standards to Document Remaining Autonomic Function After SCI⁵⁹ incorporate: bladder, bowel and sexual functions, and general autonomic function (approached by 4 dedicated subgroups of specialists commissioned by ASIA and ISCoS).

Additionally, the attempts to document and respectively, standardize the evaluation of remaining autonomic function in post SCI patients continued and resulted in the achievement of international classifications, including for cardiovascular, pulmonary, skin and thermoregulation data sets, too.

Following SCI, usually sympathetic activity is decreased in the affected territory. Yet, stimuli below the level of the lesion can generate abnormal

vegetative reactions, such as: profound vasoconstriction, blood pressure increase and/or variations of blood pressure, sometimes abrupt/dangerous. To the above mentioned autonomic dysfunctions, heart dysrhythmias can be added, thus being possible in post SCI conditions – especially acute, sub-acute but also in sub/ (hyper) – chronic ones - the occurrence of some unpleasant/ possibly harmful symptoms: bradycardia/ tachycardia and hypertension/ hypotension (mainly postural/ gravitational). Emblematic for this kind of antagonical deviations from normal cardiovascular parameters is the autonomous dysreflexia entity (for cord lesions above T6) generated under different/ possibly conjugated factors – including originating from below the lesion level). Subjectively, such disturbances may result, most frequently in: dizziness, headache, neck ache, fatigue, flushing and/or sweating above the lesion level. It is mandatory also to document the respiratory capacity in individuals with SCI, even if the autonomic components related to bronchopulmonary control are not easily tested at bedside. Additionally, complete/ partial ventilatory assistance need/ indication has to be documented under clinical/ paraclinical examination. Central/ skin temperature dysregulation (elevation/ decrease) may simply be caused, in such patients, by variations of environmental’s temperature. Therefore, abnormalities of sudomotor function/ thermoregulation (inappropriate responses to various stimuli), such as: – hyperhidrosis – above the injury level -, hypohidrosis - below it are also included within the International standards to document remaining autonomic function after SCI.

The International SCI Cardiovascular Function Basic Data Set encompasses parameters which, in practical application must be assessed in connection with variables within the International SCI Core Data Set “and other relevant autonomic functions data sets (Pulmonary, Skin/ Thermoregulation/Sudomotor and Endocrine/ Metabolic Data Set)”⁵⁷.

It comprises an important amount of registrations - which, in their extended application (see quotation below) may be useful mainly for research purposes, as being very minute, although enabling a desirable completeness image of this central part of human physiology (and of pathology, respectively), which is the cardiovascular apparatus and (dis)function/s. Specifically, this data set regards (presented in a standardized tabular form): “date of data collection, cardiovascular history before the spinal cord lesion to be obtained only once (e.g.: cardiac surgery,

hypo/hypertension, deep vein thrombosis, diabetes, hyperlipidemia, myocardial infarction, stroke, etc.), events related to cardiovascular functions after the spinal cord lesion (e.g.: deep vein thrombosis, pulmonary embolism, etc.), cardiovascular functions after the spinal cord lesion (e.g.: orthostatic hypotension, dependent edema, hypertension, autonomic dysreflexia), medications affecting cardiovascular functions on the day of examination” (and or devices – e.g.: pacemaker, abdominal binder or pressure stockings); “and objective measures of cardiovascular functions (time of examination, position of examination, blood pressure and heart rate)”⁶⁰.

International Spinal Cord Injury Pulmonary Function Basic Data Set – Likewise for the cardiovascular function, the nevertheless important one, represented by respiration – especially in post-SCI tetraplegics who frequently experience, due to respiratory muscle paralysis, important propensity to numerous pulmonary complications, including life threatening - comprises multiple parameters which, although entailing rather time consuming clinical registrations, are still valuable for practice and indispensable for clinical studies.

More precisely, the final version of this data set includes in a standardized tabular form: “questions on the pulmonary conditions diagnosed before spinal cord lesion, if available, to be obtained only once; smoking history; pulmonary complications and conditions after the spinal cord lesion, which may be collected at any time. These data include information on pneumonia, asthma, chronic obstructive pulmonary disease and sleep apnea. Current utilization of ventilator assistance (including mechanical ventilation, diaphragmatic pacing, phrenic nerve stimulation and bi-level positive airway pressure) can be reported, as well as results from pulmonary function testing includes: forced vital capacity, forced expiratory volume in one second and peak expiratory flow”⁶¹.

Current endeavors towards international standards and basic data sets for neurological (autonomic) classification of SCI assessment of the sympathetic level of lesion

Skin reactions – easy to be observed – are very important to identify disturbances emerging, including from autonomic impairment after SCI.

For a long time known and very easy to be reproduced in clinical settings, are the reflex (produced by mechanical percussion with a reflex hammer on the skin, above and below the lesion

level) resulting, in a chronic paraplegic, for instance, in “dermatographia rubra” (spreading flush above) and respectively “dermatographia alba” (a flare below – suggesting sympathetic hypertonia of the vessels in the cord affected territory)^{62, 63}.

This was the main starting point of an endeavor meant to verify the usefulness to establish the sympathetic level of cord lesion, based on the routinely performed bedside Skin axon-reflex vasodilatation (SkARV), quite recently (also) tested by Previnaire *et al.*⁶².

Hence, in patients with complete sympathetic injury, the response below the lesion was either a vasoconstrictor reaction in upper motor neuron type lesions, or total absence of SkARV in lower motor neuron ones. To be noticed a perfect correspondence between complete somatic (AIS/ Frankel A) and complete sympathetic lesions (100% in paraplegic and 94% in tetraplegic patients).

But, in incomplete SCI individuals (ASIA/ Frankel B, D) it has been quite frequently found a complete sympathetic lesion, too. Additionally, in approximately 1/3 of the studied somatic complete patients there has been found a ZPP, extending below the lesion level on sensory denervated dermatomes. Therefore, considering its relatively simplicity, SkARV worth to be clinically used for quick and reliable orienting in establishing the sympathetic level of SCI, especially in complete patients.

International Spinal Cord Injury Skin and Thermoregulation Function Basic Data Set (first draft: 2007)

As well known, the superficial and acral circulation is serving including the thermoregulation function, being at the same time - obviously – part of the cardiovascular apparatus and also being basically under sympathetic nervous control; to say no things about the fact that the compound vessel network is located in the deep skin and subcutaneous tissue. Thereby, it is conceptually and practically appropriate to assess and register in close – including clinical – relationship with both: the circulatory and skin/ subcutaneous functions and conditions, respectively.

The necessity of having always in mind the related whole picture of these structures and functions is strengthened by the reality (objectified including by meta-analytical techniques) that post-SCI patients present strong connections between the severity and topography of lesion and

cardiovascular parameters, especially regarding blood pressure, heart rate – lower for highest injuries – and also between seated and supine positions⁶³. If we add the pressure on the skin and subcutaneous tissue exerted by the body weight when sitting in the wheelchair (prone – if prolonged and without appropriately followed the indications for its timely fragmentation – to appearance of pressure sores), it is completely understandable the great importance and the mandatory syncretic above emphasized approach.

Variables included in the present Data Set are summarized, in a standardized tabular form, as follows: “date of data collection, thermoregulation and history after SCI, including hyperthermia or hypothermia (noninfectious or infectious)”, as well as the “history of hyperhidrosis or hypohidrosis above or below level of lesion. Body temperature and the time of measurement are included. Details regarding the presence of any pressure ulcer – stage, location and size of the ulcer(s) –, date of appearance of the ulcer(s) and whether surgical treatment has been performed are included”. The history of any pressure ulcer during the last 12 months is also noted⁶³.

The International Spinal Cord Injury Endocrine and Metabolic Function Basic Data Set

Regarding endocrine and metabolic function, in 2011 have been published “The final International SCI Endocrine and Metabolic Function Data Set”. According to the “purpose and vision” of the International SCI Data Sets, this standardized focused data collection and reporting aims to approach information on both, previous and after SCI, in the respective physiologic and (if the case – pathologic) domain. Variables included in this data set are presented in a standardized tabular form, as follows: “date perform, endocrine and metabolic conditions registered before spinal cord lesion, collected only once (e.g.: diabetes mellitus, fasting serum lipid values – if available, total/HDL/LDL cholesterol, osteoporosis, thyroid disease), endocrine and metabolic conditions registered after spinal cord lesion (e.g.: diabetes mellitus, lipid disorders, osteoporosis, adrenal/ gonad/ pituitary diseases, etc.), gonad status (gender, respectively pre-pubertal, pubertal, adult – and menopausal, post-menopausal for females), height (or length) and weight within the last year, fasting serum lipid profile within the last year (e.g.: total/HDL/LDL cholesterol: mmol/l \times 39 = mg/dl, triglycerides: mmol/l \times 89 = mg/dl; during anti-lipid therapy: yes/no”⁶⁴.

Current endeavors towards international standards and basic data sets for neurological (autonomic - bladder, bowel and sexual functions) classification of SCI

Regarding bladder, bowel and sexual functions, a frequently morpho/ topographical and related functioning distribution/ approach type is: “supraconal, conal and cauda equine”^{59, 65}. Additionally, supraconal generally causes an overactive/ upper motor neuron pattern of damage, conal results in mixed pathological effects overactive or acontractile states, Cauda equina generally causes acontractile/ lower motor neuron disturbances - all of them, as above emphasized, possibly affecting the urinary bladder, the bowel and/or the sexual functions⁵⁹.

Current endeavours towards international standards and basic data sets for urinary tract (dys-)function in SCI

Concerning this very important matter in post-SCI patients (especially in the past decades, because – as well known – pyelonephritis and consequent renal failure was major cause of death for such patients), the related standardized evaluation endeavours deployed as successive contributions, in progressive steps, mainly represented/ based on valuable contributions (in 2002⁶⁶ and 2006⁶⁷): International SCI Lower Urinary Tract Function Basic Data Set, International SCI Urinary Tract Infection Basic Data Set, International SCI Urodynamic Basic Data Set and International SCI Urinary Tract Imaging Basic Data Set⁴².

International SCI Lower Urinary Tract Function Basic Data Set includes, in a standardized tabular form: “data of data collection, urinary tract impairment unrelated to spinal cord lesion, awareness of the need to empty the bladder, bladder emptying (e.g.: normal voiding/ bladder reflex triggering/ bladder expression; intermittent catheterization; indwelling catheter; sacral anterior root stimulation; non-continent urinary diversion/ ostomy, etc.), average number of voluntary bladder emptying per day during the last week, any involuntary urine leakage within the last 3 months, collecting appliances for urinary incontinence (e.g.: condom, catheter/ sheet; diaper/ pad; ostomy bag etc)”, any drugs for the urinary tract within the last year (e.g.: bladder relaxants; sphincter/ bladder neck relaxants; antibiotics/ antiseptics, etc.), surgical procedures on the urinary tract (e.g.:

supra-pubic catheter insertion – day last performed, bladder stone removal – day last performed, upper urinary tract stone removal – day last performed, botulinum toxin injection – day last performed, artificial sphincter - day last performed, continent catheterizable valves – day last performed etc.)⁴².

International SCI Urinary Tract Infection Basic Data Set comprises in a standardized form (structured on: variable name, description - new onset or increase in symptom, codes and comments - in the presence of a fever one should check for signs of sepsis) as follows: “date of data collection, length of time of onset of new symptom/symptoms (less than 1 day, 1–3 days, ..., more than 3 months), signs and symptoms of urinary tract infection in individuals with spinal cord lesions (e.g.: fever, new onset or increase in incontinence, including leaking around catheter, increased spasticity, malaise, cloudy urine with increased urine odor, pyuria/l eukocyturia, discomfort or pain over the kidney or bladder or during micturition, dysuria, autonomic dysreflexia etc), urine dipstick test for nitrite and leukocyte esterase, culture of urine and sensitivity”⁴².

International SCI Urodynamic Basic Data Set includes in a standardized tabular form: “date performed, bladder sensation during filling cystometry, detrusor function, compliance during filing cystometry (low: <10 ml/ cm H₂O), urethral function during voiding, detrusor leak point pressure (...cm H₂O), maximum detrusor pressure (...cm H₂O), cystometric bladder capacity (... mL), post void residual volume (...mL)”⁴².

International SCI Urinary Tract Imaging Basic Data Set comprises in a standardized tabular form: „date performed, intravenous pyelography/ urography, or CT urography, or ultrasound of the urinary tract (possible findings: stasis/ dilatation in upper urinary tract; kidney stone; stone in the urether; bladder stone; other), X-ray of the urinary tract - kidney urether bladder (e.g.: normal, kidney/ urether/ bladder stone; other), renography (e.g.: Tc-99m dimercaptosuccinic acid – DMSA/ Tc-99m diethylenetriamine pentaacetic acid – DTPA, Tc-99m mercaptoacetyltriglycine – Mag 3 with following findings: normal; stasis/ dilatation in upper urinary tract), clearance (...ml/ min × 1.73 m²), cystogram (findings: normal; bladder stone; vesico-uretheric reflux; bladder diverticulum, etc), voiding cystogram/ micturition cystourogram (MCU)/ videouradynamic (findings: normal, vesico-urethral reflux, bladder neck/ striated urethral sphincter – during voiding; other)”⁶⁸.

Current endeavors towards international standards and basic data sets for bowel (dis)function in SCI

The neurogenic bowel is one of the major pathologic consequences of SCI, occurring in the nervous autonomic functionality.

Main bowel disturbances – including as interference with QoL – are related to digestion/transit (with common symptoms such as discomfort, abdominal pain and/or alteration in stool consistence) and respectively continence, for stool. Such disturbances, especially constipation (but also – more seldom – incontinence) can be found, by various causes, in non-SCI individuals, too. Therefore, the quantification of incontinence, respectively constipation subject matter has been approached before the initiative of ASIA and ISCoS to achieve International SCI related Data Sets^{69,70}.

Thus, the combined SCI Bowel Function Basic and Extended Data Sets has reached to the contemporary comprehensive form, based on some previous important achievements, such as:

Wexner Score: encompasses 5 evaluation items to describe the type of incontinence for: solid, liquid, gas, “wears pad”, lifestyle alteration noted from 0 to 4 points – bigger the number of given points emphasizes greater severity of bowel incontinence matters⁷¹.

St. Marks Score is based on 7 parameters – 4 of them, ranged 0 to 4 points: stool incontinence for solid/ liquid, incontinence for gas, alteration in lifestyle and 3 of them that can be registered with yes or no: “need to wear a pad or plug, taking constipation medicines, lack of ability to defer defecation for 15 minutes”; more points or “yes” answers mean worse symptomatology⁷¹.

Cleveland Constipation Score contains 8 items: “frequency of bowel movements, painful, incomplete evacuation of the stool, abdominal pain, length of time per attempt, needed assistance for defecation, unsuccessful attempts for evacuation per day and duration of constipation, ranging 0 to 4 points – except for assistance to defecation which is 0 to 2 – with a maximum of 30 points; higher scores meaning more severe constipation problems⁷².

Neurogenic Bowel Dysfunction Score consist of a total number of 39 parameters structured in 2 groups: of background kind (e.g.: “age, gender, time since SCI, level and completeness of SCI”) and describing “anal incontinence, constipation, obstructed defecation, and impact on quality of life – QoL” (e.g.: “frequency of bowel movements,

average time for defecation, peri-anal skin problems, How much does fecal incontinence restrict quality of life?").⁷³.

The working group mentioned before⁶⁹ considers that for International Bowel Function Basic Data Set, the most clinically relevant information about neurogenic bowel dysfunction in individuals with SCI is covered by the 12 items listed below: "Date of data collection; Gastrointestinal or anal sphincter dysfunction unrelated to SCI; Surgical procedures on the gastrointestinal tract; Awareness of the need of defecate; Defecation method and bowel care procedures; Average time required for defecation; Frequency of defecation; Frequency of fecal incontinence; Need to wear pad and plug; Medication affecting bowel function/ constipating agents; Oral laxatives; Peri-anal problems"⁶⁹.

Additionally, there are 26 items from the International Bowel Function Extended SCI Data Set that offer more information: "Date of data collection; Duration of constipation; Unsuccessful attempts of defecation; Incomplete rectal emptying after defecation; Abdominal bloating; Abdominal pain/ discomfort; Respiratory discomfort due to a distended abdomen; Perianal pain during defecation; Frequency of flatus incontinence; Frequency of fecal incontinence to liquid stools; Frequency of fecal incontinence to solid stools; Ability to defer defecation for 15 minutes or more; Position for bowel care; Degree of independence during bowel management; Bowel care facilitators; Events and intervals of defecation (time 1): average time from initiation of bowel care to first stool coming out (This variable is an attempt to describe the time spent at bowel care in more detail than just total time spent at defecation); Events and intervals of defecation (time 2): average time during bowel movement that stool comes out (This variable begins when the previous variable stops and documents average time during bowel movement that stool intermittently or continuously comes out with or without assistance); Events and intervals of defecation (time 3): time spent waiting after last stool passes before ending bowel care (This variable begins when the previous variable ends. End of bowel care is defined as end of dressing); Lifestyle alteration due to anal incontinence; Lifestyle alteration due to constipation; Self reported impact on quality of life caused by neurogenic bowel dysfunction; Anal tone; Voluntary contraction of the anal canal; Total Gastrointestinal or Colonic Transit Time; Right Colonic transit Time; Left Colonic Transit Time"⁷⁰.

Each of these items may benefit from a unitary description manner, comprising variable name, description, codes and comments (*e.g.*: for "awareness for the need to defecate" – within the last 4 weeks; description: to document, within the afore mentioned period of any related awareness; codes: normal or direct, indirect for instance abdominal cramping, muscle spasms – abdominal and/or in lower limbs; comments are referring synthetically to practically the majority of symptoms, that may be experienced by post SCI individuals related to digestion and bowel continence: lack of any awareness especially in complete lesions below T6, or respectively with possible autonomic - indirect - manifestation, such as headache, chills and/or sudo-/pilo motricity in cord injuries above T6 or, including in incomplete SCI individuals, different indirect symptoms, all before or during defecation and connected frequently with the reduced ability of bowel to eliminate stools; the exposed array of possible disturbances can be augmented by a most unpleasant manifestation such as fecal incontinence – significantly lowering QoL – and it is also to be noted that the clinical picture may change along the natural history of a post SCI status⁶⁹).

Current endeavors towards international standards and basic data sets for sexual function in SCI

Whereas somatic/ sensitive and motor neurological assessment and classification in SCI has an already long history (over 40 years) and reached to a rather stable evaluation system/ scoring scale in the last about 10 years, systematic research towards Autonomic Standards for Neurologic Classification and Sexual Function Data Sets in SCI has started only around 20 years ago.

This connects with the important and continuous enhancement of people's interest for their QoL, sexual activity being especially in the contemporary world, a more and more important aspect of life. Furthermore, "Sexual function is an important aspect of life and many persons with SCIs report restoration of sexual function would be more important to them than regaining the ability to ambulate".(Alexander M - Sexual Function and Spinal Cord Injury: Documentation and Data Sets⁷⁴.

As sexual function – basically, aside micturition and defecation – is mixed neurologic regulated (*i.e.* autonomic, but with voluntary control component, too), International Standards to Document

Remaining Autonomic Function after SCI⁵⁹ provides thus also a straightforward method to document the SCI impact on general autonomic responses.

Likewise for post SCI neurogenic bladder, the sexual (dis)function consecutive organic impairment has to be reported, including by its anatomic/ topographic origin: supraconal, conal or cauda equina.

Most specific, endeavors regarding international standardization to document sexual and reproductive function have been deployed and fulfilled in the last 5 years^{42, 44, 74, 75, 76}. As natural/ to be expected, concerning sexual function there have been achieved International SCI Female Sexual and Reproductive Function Basic Data Set and respectively International Spinal Cord Injury Male Sexual Function Basic Data Set.

Thus, for female sexual function the related parameters are standardized in a tabular form as follows: “date of data collection, interest in discussing sexual issues, sexual issues unrelated to spinal cord lesion, sexual dysfunction related to spinal cord lesion, psychogenic genital arousal, reflex genital arousal, orgasmic function and menstruation”⁷⁵.

According to the already known paradigm, the instructions for registering encompasses variable name (*e.g.*: “orgasmic function”), description (*e.g.*: for post SCI persons, orgasm means, as well as “a sensation of feeling good” intense and generating satisfaction state; particularly is to be noted possibly related variations in muscle tone), codes (admit the following alternatives: normal, reduced/ altered, absent, unknown) and comments (describe the above mentioned 4 possibilities; *i.e.*: normal – as the absence of alteration in reaching orgasm, reduced/ altered – may be described by the post SCI female either by longer time needed to reach the orgasm or even modified occurring of it, absent – represents the lack of having orgasm although the respective post SCI woman has essayed it)⁷⁵.

Regarding International Spinal Cord Injury Male Sexual Function Basic Data Set, there are standardized in a tabular form, the following: “date of data collection, interest in discussing sexual issues, sexual issues unrelated to spinal cord lesion, sexual dysfunction related to spinal cord lesion, psychogenic erection, reflex erection, ejaculation and orgasmic function”⁷⁶.

The 4 items within the related instructions are (the same): variable name (*e.g.*: ejaculation), description (sperm expulsion); codes (*e.g.*: “normal, reduced/ altered, absent or unknown”) and comments (define the above cited codes; *i.e.*:

normal means antegrad sperm expulsion in similar conditions like before SCI; reduced/ altered means ejaculation still possible, but modified – in volume, aspect, quality; absent is described as lack of external semen emission and unknown refers to impossibility of comparing pre- with post-SCI related states because the respective male hadn’t intercourses before becoming cord lessened)⁷⁶.

Bio-/psycho-socio-economic and QoL outcomes/ characteristics, assessment in post SCI conditions/ states

Many published – including recent – works emphasize the bitter reality of post-SCI persons having a reduced QoL⁷⁷.

This synthetic/ global parameter characterizing contemporary times, especially in the developed countries, as to be expected, has been also subject for ISCoS and ASIA endeavors to develop related International SCI Standards and Data Sets.

Accordingly, it has been fulfilled International SCI Quality of Life Basic Data Set⁷⁸.

It’s compound parameters, standardized in tabular form, are: “date of data collection, general quality of life (overall well-being), rating of physical health, satisfaction with psychological health”⁷⁸. Asside that in an older, larger version [version 1.0 of International SCI Data Sets; QoL Basic Data Set in 44], there are included also, the following items: „disability related QoL, general physical health status, SCI related physical health status, general mood status, SCI related mood status”. The afferent instructions entail the 4 already known parameters: variable name (*e.g.*: „general QoL – overall well-being”); description (refers to the subjectively quantified appreciation of a post SCI person, regarding his/ her general QoL rated on a 0-10 points scale; a bigger number of points means better QoL); codes (explanation that it’s about „numeric self-rating”); comments (speculate on the fact that there isn’t yet a unanimously accepted absolutely comprehensive definition of QoL and so, individual priorities and consequent weighted scoring will be natural to support related inter-individual variability in respect to answers regarding this variable).

It is also well known the World Health Organization (WHO) new paradigm on human functioning: International Classification of Functioning Disability and Health³⁹.

In respect to this global initiative, ISCoS and ASIA deployed the International SCI Activities and Participation Basic Data Set. It encompasses, in a standardized tabular form, the following

parameters, structured such as: “8 items relating to chapters 4 (mobility) and 5 (self-care) of the ICF and 16 items relating to chapters 6 (domestic life), 7 (social interactions and relationships), 8 (major life areas) and 9 (community, social and civic life) of the ICF”⁷⁹.

More precisely, specific items („mobility, dressing, feeding, toileting, paid work, volunteer work, education, household work, spare time activities, spouse relationships, family relationships, friends relationships”) are recorded through performance and experience (e.g.: education – for performance “hours a week” and experience “satisfaction”)⁷⁹.

One of the ICF main conceptual advances is strengthening the integration between biopsychologic and socio-economic compounds of life - and, of course of QoL.

In a recent study⁸⁰, there has been investigated “if individuals with and without SCI differ in biopsychosocial variables according to the International Classification of Functioning, Disability and Health (ICF).”

The results were predictable: “People with SCI reported more health conditions, higher levels of anxiety and depressive symptoms, worse pain and pain interference, lower level of participation and social support, lower self-efficacy, self-esteem and task- and emotion-oriented coping”⁸⁰.

Last but not least, the Editor-in-Chief of the Spinal Cord Journal - JJ Wyndaele - in his monthly Editor's Page, also recently, quotes Krause et al. who showed that a substantial variation in mortality is attributable to employment, above and beyond the effects of previously established demographic, injury, and socio-economic predictors. Although some excess mortality may be the inevitable consequence of SCI, this risk is substantially increased with poor socio-economic characteristics.

Accordingly, Wyndaele summarizes: “Excess mortality risk after spinal cord injuries substantially increases with poor socioeconomic characteristics”⁸¹.

CONCLUSIONS

The impressive efforts and endeavors to continuously improve the SCI approach in its unitary evaluative dimension is both: necessary and commendable and moreover, would hopefully give a substantial input to the long awaited – by the post SCI patients and their kin – cure.

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