



School of Health and Welfare Professions

Department of Physical Therapy



Spinal cord injuries and peer-counseling:

**The significance of peer-counselor as a member
of a multidisciplinary rehabilitation team
after spinal cord injury**

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Abstract

Spinal cord injury (SCI) can be a sudden and devastating event that changes a person's life forever. Not only does it affect a person's physical function, but also their psychological wellbeing and social life. It is easy to understand that physical interventions alone may not be enough to lead to successful and comprehensive rehabilitation outcomes. In that sense the rehabilitation team should be interdisciplinary and populated not only by physicians, physiotherapists e.tc, but also by psychologists, social workers, peer counselors e.tc. In this thesis it is studied the significance of peer counseling to people who had suffered a SCI. It includes a brief presentation of spinal cord anatomy, the health essentials after the injury and the physiotherapists management, and then discusses the importance of peer counseling in the context of the biopsychosocial model as described in International Classification of Functioning, Disability and Health (ICF). There are numerous studies that support peer counseling as a crucial and positive aspect in a rehabilitation process. Peer support is nowadays recognized as an evidence-based practice and many rehabilitation centers include peer mentoring in their programs. The benefits expand from less inpatient use and fewer problems and needs to greater satisfaction with life and better quality of life. Additionally, peer programs and its benefits are proven to make rehabilitation more cost effective. Nevertheless, more researches should be conducted as organized peer support programs are not always successful. Insufficient funding, lack of staff with skills to coordinate peer mentors, complexity of dealing with numerous types of disabilities, transportation to group meetings, lack of qualified peer mentors, and burnout among peer mentors often leads to failure of the programs.

Results

There are numerous studies that support peer counseling as a crucial and positive aspect in a rehabilitation process.¹ Peer support is nowadays recognized as an evidence-based practice and many rehabilitation centers include peer mentoring in their programs. The benefits expand from less inpatient use and fewer problems and needs to greater satisfaction with life and better quality of life.¹ Additionally, peer programs and its benefits are proven to make rehabilitation more cost effective.²

Method

This thesis was written in the Spring semester of 2016-2017, during my stay at Hochschule 21 university at Buxtehude in Germany, as part of Erasmus exchange programme. My original hypothesis was that since SCI doesn't only concerns a person's physical function, the ideal approach to comprehensive rehabilitation involves equal attention to both psychosocial and physical aspects of care, in the context of the biopsychosocial model as described in International Classification of

Functioning, Disability and Health (ICF). Within this model, peer counseling is of great significance and the peer counselor should be a legitimate member of the rehabilitation team.

I did a 6 month research on papers, researches and websites on spinal cord injuries and peer counseling. My principal sources were high esteemed scientific magazines and internet databases like PubMed (MEDLINE), Cochrane Library (Cochrane Controlled Trials Register) and Physiotherapy Evidence Database (PEDro). Other internet sources came from university's or scientific companies websites. I was particularly helped by an on-line seminar on SCI management held by the International Spinal Cord Society (ISCOS) under the supervision of Lisa A. Harvey.

Finally, this study couldn't be written without the inspiration and in-depth discussions with my supervisor Ms Barbara Zimmermann and the inpatients of Spinal Cord Injuries Rehabilitation Center of University of Patras.

Introduction

What motivated me to write on this topic was on the one hand the many SCI in Greece and on the other hand my interest in disability and how the value code of our society accepts or rejects the disabled body. For the disabled person the moment of the injury and the experience of the rehabilitation center establishes an in-continuity in its identity, in its human subjectivity.³ It establishes a new life, a life *after* the injury, naked of its former meanings. Disability is oftenly considered the main feature of identity, putting aside all the other features of a disabled person in other people eyes. Disability is being presented as an anomaly, as a deviation from the normality of a healthy body and disabled people as medical subjects that within the rehabilitation process should be passive and humble.⁴

Despite the changes that had been imposed by the social model of disability, or the disabled rights movement, we can't oversee that most rehabilitation centers still work in the context of the medical model of disability and that a vast majority of disabled people remain marginalized. My personal experience in the Spinal Cord Injuries Rehabilitation Center of the University of Patras⁵ made it clear (with a small part of the staff excluded).

There are no official records, but people with disabilities are estimated between 700.000 and 1.000.000 in Greece. Especially for people with SCI there are no reliable epidemiological data regarding the incidence, prevalence, and mortality rate.⁶ Most of the times, owing to lack of rehabilitation teams providing health care in the acute SCI stage, initial rehabilitation management is limited to physiotherapy. After the acute phase, usually during the first month after injury, patients are transferred to public or private rehabilitation departments.⁷

During inpatient rehabilitation, persons with SCI and their family members or significant ones receive information and training regarding bladder and bowel management and skills such as transferring, wheelchair skills, and assistance for activities of everyday living. However, information concerning sexual function, fertility issues, and psychological burden is poorly addressed, if addressed at all, as a result of the mentality described above.⁸ In general, Greeks with SCI are not adequately prepared for the transition to live in the community. There are no policies to facilitate housing modifications and return to work. Furthermore, in the current period of economic crisis, even basic issues like assistive devices are not considered priorities. Consequently, individuals with SCI use inappropriate equipment resulting in complications, many of which could have been prevented.⁹

A young person with SCI faces many obstacles to return to school. It is difficult to overcome feelings of low self-esteem, and there is not always organized counseling available, or other preparatory supports. In addition, the lack of teachers trained in the needs of children with SCI, as well as bullying by other students can have a negative impact on their decision to return to school. Finally, exclusion of the educational system is often due to physical environmental barriers. Greece needs to prepare a practical education policy, strategies for making school buildings accessible, as well as to provide educators trained in the needs of children with SCI. The State is making promising steps toward vocational reintegration, but it must be noted that vocational counselors do not participate in the rehabilitation team. As far as employment is concerned, obtaining a job or returning to a preinjury employment is also a challenge. Lack of vocational rehabilitation, counseling and preparation, and inappropriate work adjustments and accommodations exclude people with SCI from most jobs.¹⁰

In general, Greek health care system still faces problems related to lack of trained health staff. Very few of Greek rehabilitation therapists work as members of a rehabilitation team. Most work in their own private offices. Even fewer therapists are specialized in SCI rehabilitation. Although there are well-trained PRM physicians in SCI, the lack of specialized spinal cord units has a negative effect in the quality of care.¹¹ University of Patra's SCI rehabilitation center is the only specialized center in Greece (public or private).

Apart from the need of more specialized rehabilitation centers to be found, there is also the need for these centers to function in a way that promotes interdisciplinary cooperation. To drive it even further, I would say that patient (the rehabilitation subject) should be the protagonists of its own rehabilitation and of its own future.

My hypothesis is that since SCI doesn't only concerns a person's physical function, the ideal approach to comprehensive rehabilitation involves equal attention to both psychosocial and physical aspects of care, in the context of the biopsychosocial model. Within this model, peer counseling is of great significance and the peer counselor should be a legitimit member of the rehabilitation team.

Part I

Spinal cord anatomy

The spinal cord is the most important structure between the body and the brain and together with the brain make up the central nervous system (CNS). It is a long, thin, tubular bundle of nervous tissue and support cells that extends from the foramen magnum, where it is continuous with the medulla, to the level of the first or second lumbar vertebrae.¹² It is a vital link between the brain and the body *and* from the body to the brain. The spinal cord is 40 to 45cm long (around 45cm in men and around 43cm long in women) and has a varying width (ranging from 13mm thick in the cervical and lumbar regions to 6,4mm thick in the thoracic area).¹³

Spinal cord is enclosed within the vertebral column, which, apart from axial stability and movement of the trunk, protects the spinal cord. The spine is organized into four separate sections, each providing unique structural and functional attributes. Starting from the top, there are 7 cervical vertebrae (C1 through C7), 12 thoracic or dorsal vertebrae (T1 through T12), 5 lumbar vertebrae (L1 through L5) and 5 fused sacral vertebrae (the sacrum). Below the sacrum are the 3 to 5 rudimentary vertebrae that make up the coccyx (tailbone).¹⁴

In each vertebra the space created by the posterior aspect of the vertebral body and the neural arch constitutes the spinal canal where spinal cord is located. The different cord regions can be visually distinguished from one another. Two enlargements of the spinal cord can be visualized within the spinal canal: the cervical enlargement, which extends between C3 to T1 and the lumbar enlargements which extends between L1 to S2¹³. As the spinal cord travels downward, it is protected by the bony spinal canal and allows the exit of each individual nerve root from every spinal segment.¹⁴ Two consecutive rows of nerve roots emerge on each of its sides and these nerve roots join distally to form 31 pairs of spinal nerves.¹³

The spinal cord is further protected by three membranes, collectively called the meninges. The meninges are the primary layers of tissue that protect and nourish the spinal cord, within the spinal canal.¹⁴ The outer membrane surrounding the spinal cord is the dura mater. The dura, made of a dense fibrous material, forms the dural sac, which surrounds the spinal cord and cauda equina and terminates at the level of the second sacral vertebra. The dura is separated from the vertebrae by the epidural fat in the epidural space. The next layer is the delicate arachnoid mater which is thin and has web-like filaments connecting to the underlying pia mater. Beneath the arachnoid mater is the subarachnoid space, which is filled with cerebrospinal fluid (CSF). Abbreviated CSF, cerebrospinal fluid bathes the brain and spinal cord as well as the cauda equina, providing protection, nourishment, and a medium

for exchange of nutrients and waste. The innermost membrane surrounding the spinal cord is the vascular pia mater, which is very closely apposed to the spinal cord and supplies it with blood vessels. The pia continues inferiorly from the end of the spinal cord (at the level of the second lumbar vertebra) as the filum terminale internum. The dural sac ends at the level of the second sacral vertebra (S2). Caudal to the end of the dural sac is a specialization of meninges called the coccygeal ligament (or filum terminale externum) that attaches the meninges, and consequently the spinal cord, to the coccyx. The coccygeal ligament is composed of specializations of all three layers of meninges.^{14, 15}

The spinal cord requires its own blood supply to function. The periphery of the spinal cord has the best collateral circulation. This might explain why in incomplete injuries the more peripheral parts of the longitudinal tracts often show the first signs of recovery. The cervical spinal cord has the most abundant blood supply. The more distal (or caudal) spinal cord has less blood flow and is more susceptible to ischemia and infarction of the cord below an injury. The anterior spinal artery is a single, centrally located artery that travels along the anterior portion of spinal cord. It provides blood flow to the anterior two-thirds of the spinal cord. The paired posterior spinal arteries are situated on the posterior surface of the spinal cord, providing blood flow to the posterior third.¹⁴

The spinal cord functions primarily in the transmission of neural signals between the brain and the rest of the body but also contains neural circuits that can independently control numerous reflexes and central pattern generators. The spinal cord has three major functions: as a conduit for motor information (which travels down the spinal cord), as a conduit for sensory information in the reverse direction and finally as a center for coordinating certain reflexes.¹²

Sensory information that flows into the spinal cord to the brain are carried by afferent nerves, while motor signals that flow from the brain to muscles are carried by efferent nerves. Afferent and efferent nerves are further classified as somatic and autonomic (sympathetic and parasympathetic). The somatic afferent nerves carry localizable sensation such as pin prick, light touch and position sense. Somatic efferent nerves control skeletal muscles. Autonomic nerves provide most sensory/motor information to and from organs, blood vessels and other structures that are involuntary and under control from higher structures in the brainstem.¹⁴

The spinal cord is segmentally organized with 31 segments, defined by 31 pairs of nerves exiting the cord. These nerves are divided into 8 cervical, 12 thoracic, 5 lumbar, 5 sacral, and 1 coccygeal nerve. Dorsal and ventral roots enter and leave the vertebral column respectively through intervertebral foramen at the vertebral segments corresponding to the spinal segment.¹³ The ventral root carries the motor signals from the spinal cord to the body (efferent nerves), while the dorsal root relays information from the periphery sensory receptors to the spinal cord (afferent nerves).¹⁴

All spinal nerves, except the first, exit below their corresponding vertebrae. In the cervical segments

there are 7 cervical vertebrae and 8 cervical nerves. C1-C7 nerves exit above their vertebrae whereas the C8 nerve exits below the C7 vertebra (it leaves between the C7 vertebra and the first thoracic vertebra - T1). Therefore, each subsequent nerve leaves the cord below the corresponding vertebra. In the thoracic and upper lumbar regions, the difference between the vertebrae and cord level is three segments. Therefore, the root filaments of spinal cord segments have to travel longer distances to reach the corresponding intervertebral foramen from which the spinal nerves emerge. The lumbosacral roots are known as the cauda equina.¹³

Individual spinal nerves from various root levels merge together in the cervical and lumbosacral regions to form nerve plexuses. In the cervical region the C5 through T1 nerve roots will join together and intermix to form the brachial plexus. Individual peripheral nerves originate from this brachial plexus to innervate the upper extremities. There is a similar arrangement of lumbosacral nerves from L2 through S1 that form the lumbosacral plexus, which innervates the lower extremities and the pelvic organs.¹⁴

Each spinal nerve will innervate a specific sensory segment of skin on the body called a dermatome.¹⁴ Accordingly, a myotome refers to the collection of muscle fibers innervated by the motor axons within each segmental nerve (root).¹⁶ A dermatome is an area of skin supplied by peripheral nerve fibers originating from a single dorsal root ganglion. If a nerve is cut, one loses sensation from that dermatome. Because each segment of the cord innervates a different region of the body, dermatomes can be precisely mapped on the body surface, and loss of sensation in a dermatome can indicate the exact level of spinal cord damage in clinical assessment of injury. It is important to consider that there is some overlap between neighboring dermatomes.¹³

Because sensory information from the body is relayed to the CNS through the dorsal roots, the axons originating from dorsal root ganglion cells are classified as primary sensory afferents, and the dorsal root's neurons are the first order sensory neuron. Most axons in the ventral roots arise from motor neurons in the ventral horn of the spinal cord and innervate skeletal muscle. Others arise from the lateral horn and synapse on autonomic ganglia that innervate visceral organs. The ventral root axons join with the peripheral processes of the dorsal root ganglion cells to form mixed afferent and efferent spinal nerves, which merge to form peripheral nerves. Knowledge of the segmental innervation of the cutaneous area and the muscles is essential to diagnose the site of an injury.¹³

A transverse section of the adult spinal cord shows white matter in the periphery, gray matter inside, and a tiny central canal filled with CSF at its center. Surrounding the canal is a single layer of cells, the ependymal layer. Surrounding the ependymal layer is the gray matter (a region containing cell bodies) shaped like the letter "H" or a "butterfly". The two "wings" of the butterfly are connected across the midline by the dorsal gray commissure and below the white commissure. The shape and

size of the gray matter varies according to spinal cord level. At the lower levels, the ratio between gray matter and white matter is greater than in higher levels, mainly because lower levels contain less ascending and descending nerve fibers.¹³

The gray matter mainly contains the cell bodies of neurons and glia and is divided into four main columns: dorsal horn, intermediate column, lateral horn and ventral horn column. The dorsal horn is found at all spinal cord levels and is comprised of sensory nuclei that receive and process incoming somatosensory information. From there, ascending projections emerge to transmit the sensory information to the midbrain and diencephalon. The intermediate column and the lateral horn comprise autonomic neurons innervating visceral and pelvic organs. The ventral horn comprises motor neurons that innervate skeletal muscle.¹³

Motor neurons that originate in the motor strip in the cerebral cortex and travel down through the brainstem into the spinal cord are referred as upper motor neurons. They synapse with motor neurons in the anterior horn. These motor neuron cell bodies that reside in the anterior horn are referred to as lower motor neurons (α -neurons) and they exit via the spinal nerves to the designated target muscles (as described above). The upper and lower motor neuron connections contribute to the resting (tonic) tone of muscles and clinic reflexes by either inhibition or stimulation mechanisms.¹⁴

Neurons travel through spinal tracts, which are myelinated pathways through the peripheral white matter of spinal cord. The corticospinal tracts are the primary motor tracts, where upper motor neurons originate in the motor cortex and descend down the spinal cord (through the internal capsule and into the brainstem) in the lateral portions of the white matter (after they have crossed over to the opposite side at the level of the medulla).¹⁴ A smaller portion of motor neurons will travel through a similar anterior tract. On the other hand, considering the sensory neurons, there are the dorsal columns, which are white matter tracts that carry information from peripheral receptors in the body to the brain. The primary receptors are vibratory, deep touch, two-point discrimination, proprioception, joint position sense. There are also the spinothalamic tracts that are located anterior and lateral and carry information about pain, temperature, simple tactile sensation.¹⁷

Apart from motor and sensory neurons there are those of the autonomic nervous system (ANS) which innervates the internal organs. The ANS is divided into sympathetic and parasympathetic and most organs are supplied by both these nerves which have opposing efferent and regulatory activities. The parasympathetic nervous control originates in either the brain (cranial nerves III, VII, IX, X) or the sacral spinal cord (S2-S4). The sympathetic nervous control originates in the thoracic and upper lumbar segments of the spinal cord (T1-T12, L1-L2).¹⁴

Spinal cord injuries

The term spinal cord injuries (SCI) is used to refer to neurological damage of the spinal cord. Spinal cord injuries can be caused by trauma to the spinal column (stretching, bruising, applying pressure, severing, laceration, etc.). The most common causes are traffic accidents, falls (including work accidents), sports-related injuries and violence. Motor vehicle crashes are the most common cause of SCI and go up to 50,4% of all the causes of all age groups. Falls are by far the most common cause of SCI in people over 60 years. The average age of injury has increased over the last two decades to an average of 37,6 years old.¹⁸ Spinal cord injury can also be non-traumatic and caused by disease. It affects a vast number of people and is a growing population for admission to inpatient rehabilitation. Nontraumatic SCI includes neoplasms, vascular disease, inflammatory disease, spinal stenosis, spina bifida, Friedreich's ataxia.^{18,19}

In SCI the vertebral bones or intervertebral disks can shatter, causing the spinal cord to be punctured by a sharp fragment of bone. If such an injury occurs the transmission of neural messages between the brain and body is interrupted. The victims will suffer loss of feeling in certain parts of their body and may result in paraplegia, tetraplegia (also known as quadriplegia), or full body paralysis below the site of injury to the spinal cord.²⁰ Epidemiologically, cervical injuries occur more often than thoracic and lumbar injuries. Consequently, people with incomplete tetraplegia made up the highest number (34,5%), followed by complete paraplegia (23,1%), complete tetraplegia (18,4%), and incomplete paraplegia (17,5%).¹⁸

Damage to upper motor neuron axons in the spinal cord results in a characteristic pattern of ipsilateral deficits. These include hyperreflexia, hypertonia and muscle weakness. Lower motor neuronal damage results in its own characteristic pattern of deficits. Rather than an entire side of deficits, there is a pattern relating to the myotome affected by the damage. Additionally, lower motor neurons are characterized by muscle weakness, hypotonia, hyporeflexia and muscle atrophy.²⁰

SCI are classified as either complete or incomplete. In a complete injury there is no voluntary muscle function and no somatic sensation in lowest sacral nerves. In an incomplete injury there is a preservation of sensation in the lowest sacral dermatomes and there may be a significant function below the level of the injury.¹⁶ Either type can result in upper motor neuron paralysis (spastic) or lower motor neuron paralysis (flaccid).¹⁴

Spinal cord syndromes

Central Cord Syndrome → is the most common of the incomplete syndromes and the injury is focused in the central grey matter of the cord. It can occur with hyperextension injury, compression of the cord, a low velocity injury, fractures and dislocations. The injury is focused in the central grey matter of the cord. It results in lower motor neuron weakness (at the level of the injury), upper motor neuron spasticity (below the level of the injury), less severe impact in lower limb function.²¹

Brown-Sequard Syndrome → occurs with a hemisection of the cord, so that the lateral half of the cord is damaged. It results in deficits in motor control, proprioception, vibratory sensation (same side) and pain sensation, temperature sensation (opposite side).²²

Anterior Cord Syndrome → occurs with vascular injury or occlusion and it affects the anterior 2/3 of spinal cord. It results in loss of motor function and loss of pain and temperature sensation. Nevertheless there is a preservation of light touch and joint position sense.²³

Cauda Equina Syndrome → occurs with central disc herniation or lumbar burst fractures. It affects individual nerve roots below the spinal cord itself and results in lower motor neuron flaccid paralysis and partial or complete loss of sensation.²⁵

Conus Medullaris Syndrome → also occurs with disc herniation or lumbar burst fractures. It affects lower spinal cord and/or individual nerve roots. It results in mixed upper and lower motor neurons paralysis, variable sensory loss, anesthesia in the sacral dermatomes, erectile dysfunction, either preserved or areflexic bowel and bladder.²⁵

Motor system impairments

A SCI affects the function of the motor system, the sensory system and the autonomic system, therefore affects sensation, respiration, bladder, bowel and sexual function, temperature regulation, blood pressure, skin integrity. However, the most overt implication of SCI is its effect in the motor system which leads to paralysis.²⁶

A SCI results in either paraplegia or tetraplegia depending on the level that the injury has occurred.

Paraplegia: this term refers to impairment or loss of motor and/or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, secondary to damage of neural elements within the spinal canal. With paraplegia, arm functioning is spared, but, depending on the level of injury, the trunk, legs and pelvic organs may be involved. The term is used in referring to cauda equina and conus medullaris injuries, but not to lumbosacral plexus lesions or injury to peripheral nerves outside the neural canal. *Tetraplegia*: this term refers to impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord due to damage of neural elements within the spinal canal. Tetraplegia results in impairment of function in the arms as well as typically

in the trunk, legs and pelvic organs, i.e. including the four extremities. It does not include brachial plexus lesions or injury to peripheral nerves outside the neural canal.¹⁶

A4 - T1 → tetraplegia

T2 - T10 → high paraplegia

T10 - L1 → low paraplegia

O2 - cauda equina → peripheral type of paraplegia²⁷

The different types of SCI are defined by the *International Standards for Neurological Classification of SCI* which includes a motor and sensory assessment. The results of this assessment are used to determine motor, sensory and neurological levels and classify patient's injury as complete or incomplete.¹⁶ Neurological level is also the strongest predictor of future independence following SCI. It indicates the strength of muscles, which in turn has a large effect on a person's ability to carry out functional tasks. The two areas of the spinal cord most commonly injured are the cervical spine (C1-C7) and the lumbar spine (L1-L5).²⁸

For people with motor complete lesions it is relatively easy to identify the optimal levels of motor function that they will typically attain. However, whether optimal function is reached is highly dependent on environmental and personal factors such as access to equipment and motivation.²⁷ There are some key muscles innervated at each level and these muscles afford people with SCI the opportunity to carry out certain motor tasks.²⁹

C1 - C3 tetraplegia → the key muscle partially innervated at C3 is the diaphragm. Usually, the small amount of diaphragm function at C3 is not enough to breathe spontaneously.³⁰ People with C1 to C3 tetraplegia are ventilator dependent or use diaphragmatic pacing systems. They depend on others for self-care and use a chin-control power wheelchairs for mobility. They also use head, mouth or voice activated technology for independence.³¹

C4 tetraplegia → the key muscles innervated at C4 are the rhomboids and trapezius.³⁰ As a consequence people with C4 tetraplegia have a small amount of shoulder movement. People with C4 tetraplegia depend on others for self-care. They use chin-control, sip and puff or head array power wheelchairs for mobility and they also use head, mouth or voice activated technology for independence. There is one key functional difference between people with C3 tetraplegia and people with C4 tetraplegia. People with C4 tetraplegia have greater innervation of the diaphragm than people with C3 tetraplegia (the diaphragm is fully innervated at C5). As a consequence people with C4 tetraplegia are not dependent on a ventilator.³¹

C5 tetraplegia → the key muscle innervated at C5 is the biceps.³⁰ People with C5 tetraplegia depend on others for self-care. They usually use a hand-control power wheelchair for mobility, but they are able to use a manual wheelchair on flat surfaces and carry out simple hand to mouth activities.³¹

C6 tetraplegia → there is a large difference in functional potential between people that have sustained a C5 and C6 injury. This is due to the innervation of 4 key muscle groups: latissimus dorsi, pectoralis, serratus anterior and wrist extensors.³⁰ Latissimus dorsi has two important roles in people with C6 tetraplegia as it contributes to shoulder depression during lifting and trunk stability in sitting. Pectoralis also has two important roles by producing the momentum required to roll from supine to side lying through horizontal shoulder adduction and enabling weight bearing through the upper limbs and vertical lift of the trunk on the stabilised arms (in combination with latissimus dorsi, serratus anterior and anterior deltoid). The main role of serratus anterior is to provide scapula stability especially during a vertical lift, otherwise the scapula will wing if serratus anterior is paralysed. Innervation of the wrist extensors gives patients the potential for a tenodesis grip. A tenodesis grip is generated by passive tension in the paralysed extrinsic finger and thumb muscles with wrist extension. When the wrist is extended the finger and thumb muscles are passively pulled into flexion. Objects are grasped between the thumb and the index finger or between the fingers and palm of the hand. Consequently, objects are released by passive wrist flexion.³² With these key muscles still innervated people with C6 tetraplegia may carry out self-care tasks with minimal or no assistance such as rolling and transferring independently, they can propel a manual wheelchair (but often use a hand-control power wheelchair), and have the important ability of grasping objects using a tenodesis grip.³¹

C7 tetraplegia → the key muscles innervated at C7 are triceps, wrist flexor and finger extensor muscles.³⁰ People with C7 tetraplegia perform self-care tasks with minimal or no assistance. They can propel a manual wheelchair (but often use a hand-control power wheelchair), roll independently, transfer on bent or straight arms and grasp objects using a tenodesis grip.³¹

C8 tetraplegia → the key muscles innervated at C8 are the finger and thumb flexors.³⁰ People with C8 tetraplegia actively grasp and release objects, carry out self-care tasks with minimal or no assistance, propel a manual wheelchair (but may choose to use a hand control power wheelchair depending on personal and environmental factors). They can also roll and transfer independently.³¹

T1 paraplegia → the key muscle group innervated at T1 is the interossei.³⁰ People with T1 paraplegia have near normal hand function but retain some weakness in the intrinsic and lumbrical muscles. They carry out self-care tasks with no assistance such as propelling a manual wheelchair They roll and transfer independently and they retain extensive trunk paralysis.³¹

T2 to T12 paraplegia → people with thoracic paraplegia have full upper limb movement, varying degrees of trunk paralysis and total paralysis of the legs.³⁰ They carry out self-care tasks with no assistance, propel a manual wheelchair, roll and carry out complex transfers independently. They can even sometimes “walk” limited distances with the assistance of extensive bracing and mobility aids.³¹

Lumbar and sacral paraplegia → people with lumbar and sacral paraplegia have varying degrees of

paralysis of the lower limbs.³⁰ Most can walk with or without aids or orthosis, although some continue to remain wheelchair dependent.³¹ Key muscles innervated at each level are:³⁰

L2: hip flexors

L3: knee extensors

L4: ankle dorsiflexors (knee flexors and hip abductors)

L5: toe extensors (hip extensors)

S1: ankle plantarflexors

ASIA assessment

The *American Spinal Injury Association (ASIA)* indicates 2 key sets of tests required as part of the assessment: *motor* assessment and *sensory* assessment. *Motor* assessment involves testing a 5 key upper limb muscle groups and 5 key lower limb muscle groups, each muscle group representing a myotome. Testing is done with the patient in a supine position and each muscle group is tested using a standard 6 point manual muscle testing scale.

The standard 6 point manual muscle testing scale (Oxford scale) is:³³

0 = no muscle contraction

1 = a flicker of muscle contraction

2 = full range of motion with gravity eliminated

3 = full range of motion against gravity

4 = full range of motion with added resistance

5 = normal strength

NT = not testable (unable to test)

Sensory assessment involves testing a 28 key locations on each side of the body, each location representing a dermatome. Each location is tested separately for light touch and pinprick and each of them are scored on a 0 to 2 scale (Nottingham scale):³⁴

0 = absent (fails to identify the sensation on three occasions)

1 = impaired (identifies the test sensation, but not on all three occasions in each region of the body or feels duller)

2 = normal (correctly identifies the test sensation on all three occasions)

NT = not testable (unable to test)

The results of the motor and sensory assessments are used to determine a left and right motor level and a left and right sensory level. The neurological level is defined as the most caudal level (sensory or motor) with normal function. They are also used to classify patient's SCI as complete or incomplete according to the ASIA Impairment Scale (AIS) where *complete* is considered an injury with no motor

or sensory function in S4-S5 and *incomplete* with some motor or sensory function in S4-S5. Motor and sensory function in S4-S5 is critical to the classification of SCI because it refers to the anus. It is tested by motor, determining whether the patient can voluntarily contract the anal sphincter, and sensory, determining if the patient has light touch or pinprick sensation in the skin around the anus or if the patient can feel pressure applied internally to the wall of the anus.¹⁶

There are 5 AIS classifications:^{16,35}

AIS A – Complete: no sensory or motor function is preserved in the sacral segments S4-S5.

AIS B - Sensory incomplete: sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5, AND no motor function is preserved more than three levels below the motor level on either side of the body.

AIS C - Motor incomplete: motor function is preserved below the neurological level and more than half of key muscle functions below the single neurological level of injury have a muscle grade less than 3 (Grades 0–2).

AIS D - Motor incomplete: motor function is preserved below the neurological level, and at least half (half or more) of key muscle functions below the NLI have a muscle grade >3.

AIS E – Normal: if sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without a SCI does not receive an AIS grade.

The health essentials

As spinal cord is part of the central nervous system an injury in that area has some very unique aftereffects. Even if some of them are mostly coped by doctors through medication, they are essential health topics that a physiotherapist working with people with SCI needs to know and recognize them and some times be able to deal with them.

Autonomic dysreflexia

Autonomic dysreflexia is an acute syndrome of excessive, uncontrolled sympathetic output that can occur in patients who have had an injury to the spinal cord (generally at or above the sixth thoracic neurologic level, because in lesions at or below T6 the brain retains control over enough of the sympathetic nervous system to combat unchecked excitation of the sympathetic nervous system still isolated from the brain). It is caused (in response to a stimulus) by spinal reflex mechanisms that remain intact despite the patient's injury, leading to hypertension.³⁶

These unchecked excitation of the sympathetic nervous system causes extensive vasoconstriction in the large splanchnic blood vessels and a subsequent increase in blood pressure. This is because the

sympathetic nervous system travels between the body and brain by the thoraco-lumbar part of the spinal cord. So, if the spinal cord is damaged in the cervical or high thoracic region, messages can not pass to and from the brain, and without input from the brain the sympathetic nervous system can make an exaggerated and unchecked response to stimuli.³⁷

Autonomic desreflexia is commonly caused by problems with the bladder, bowel or skin. For example, a blocked catheter, constipation, pressure ulcer or tight clothing may cause autonomic desreflexia. Physiotherapy interventions such as stretch and electrical stimulation may also trigger autonomic dysreflexia. Even practice of transfers can cause autonomic dyreflexia because practice of this activity may pull or kink the catheter.³⁷

Signs of autonomic dyreflexia are bradycardia and elevated blood pressure (at least 20-40 mmHg above normal resting systolic level for the individual. It is important to remember that people with paraplegia and tetraplegia may have a low baseline blood pressure). Symptoms include severe headache, profuse sweating, flushing above the level of the injury, nasal congestion, blurred vision, shortness of breath. They have also been reported incidents of hypothermia associated with autonomic dyreflexia as a result of thermoregulatory dysfunction during episodes of autonomic dysreflexia.³⁸ It is more common in patients with complete lesions than in those with incomplete lesions, and the reaction seems to be less severe in the latter group.³⁹ Incomplete injuries involve sparing of the most distal sacral segments of the spinal cord (i.e., preservation of perianal sensation or voluntary contraction of the external anal sphincter).

Whether should a therapist suspects that a patient has autonomic desreflexia he/she should elevate the patient's head and lower the legs, check if blood pressure is elevated, call for medical assistance without leaving the patient's alone, try to identify and alleviate the cause, loosen abdominal binders and remove any compression garments, continue to monitor blood pressure and heart rate. It is important to remember that autonomic dyreflexia is a potentially life-threatening condition because increasing or high blood pressure can cause intracranial haemorrhage, encephalopathy, coronary vasospasm,⁴⁰ convulsions and cardiac arrest.⁴¹

Postural hypotension

Postural (orthostatic) hypotension results from a sudden drop in blood pressure when moving from lying to sitting or from lying/sitting to standing. It is defined by *The Consensus Committee of the American Autonomic Society* and the *American Academy of Neurology* as a decrease in systolic blood pressure of 20mmHg or more, or in diastolic blood pressure of 10mmHg or more, upon the assumption of an upright posture from a supine position, regardless of whether symptoms occur.⁴²

Low blood pressure may cause dizziness and fainting. It is only normal for everyone that after a long

period of lying flat in a bed or sitting in a chair to feel faint when sitting up. In addition, paralysis of the legs removes the capacity of contracting muscles to help move blood from the feet back to the heart. Tetraplegia and high level paraplegia isolates the sympathetic nervous system from the brain, which is the one that helps maintain blood pressure when moving to an upright position.

The drop on blood pressure when sitting up occurs partially due to pooling of blood in the feet and pelvis (as a result of gravity) and partially due to disruption of sympathetic nervous system. However the precise mechanisms responsible for postural hypotension in SCI patients are uncertain, and likely to be multifactorial. In addition the level and severity of spinal cord injury, and the extent to which other systems are affected will play a significant role in the development of postural hypotension.⁴²

The use of compression bandages (such as an abdominal binder) or compression stockings to restrict venous pooling in the splanchnic region and dependent limbs should be encouraged as they can help increase the amount of blood returning to the heart and helps maintain the blood pressure.⁴³

It is also important that the patients will need to sit up in bed prior to sitting out of bed in a wheelchair. This allows their head and body to adjust to the change in position while their legs are still elevated. Sitting up in bed involves incremental changes in position. One suggested protocol is moving into sitting at 30 degree increments every 15 minutes while monitoring blood pressure and symptoms such as dizziness.³⁷

When first sitting up in a wheelchair it is preferable to use a wheelchair with tilt in space, elevating footrests and supportive armrests. Raising the feet and lowering the head helps maintain blood pressure, while supervision and monitoring of blood pressure is required. It also required a gradually increase in sitting time followed by skin checks to ensure that no pressure ulcers are developed.³⁷

Postural hypotension is not only a problem when moving from lying to sitting, as it can also be a occur when moving from lying or sitting to a more vertical position. For example, people with SCI may experience postural hypotension when using a tilt table. In order To minimise postural hypotension when standing a patient on a tilt table for the first time a therapist could elevate the tilt table by small increments, allow time to accommodate to a more upright position and always monitor blood pressure and symptoms carefully throughout the whole process.⁴⁴

Deep vein thrombosis and pulmonary embolus

Deep vein thrombosis (DVT) occurs when a blood clot (thrombus) forms in one or more of the deep veins in your body, usually in your legs. DVT can cause leg pain or swelling, but may occur without any symptoms. DVT can develop if you have certain medical conditions that affect how your blood clots. It can also happen if you don't move for a long time, such as after surgery, following an accident or when you are confined to a hospital or nursing home bed.⁴⁵ DVT is a frequent complication in

patients with acute SCI due to paralysis and bed rest.⁴⁶ They are particularly susceptible to DVT in the first 2 weeks after injury, however prevention is still required beyond this period. As a recent systematic review shows, spinal patients continue to have a significant risk of pulmonary embolus (PE) and DVT after the acute period of their injury. Clinicians are advised to have a low threshold for suspecting venous thromboembolism in the sub-acute phase of SCI and to continue prophylactic anticoagulation therapy for a longer period of time.⁴⁷

It is important that prevention strategies for DVT are commenced immediately after injury. Patients are placed on anticoagulation medication,⁴⁸ fitted with anti-embolism compression stockings and mobilised as soon as possible. External pneumatic compression devices are used in some hospitals. Patients also need to be monitored for signs and symptoms of DVT. The most common signs and symptoms are: low grade fever, local swelling, warmth around the area and discolouration of the skin, localized pain in people with intact sensation.⁴⁹

The dislodgement of a DVT can result in a pulmonary embolus (PE). A PE is a blockage in the pulmonary artery, the blood vessel that carries blood from the heart to the lungs. This blockage is potentially life-threatening because it can prevent blood from reaching your lungs. The symptoms of a pulmonary embolism can sometimes be difficult to recognise because they can vary between individuals. However, the main symptoms include: hypoxia, sweating, haemoptysis, tachycardia, shortness of breath, chest pain and light-headedness.⁵⁰

It is important to remember that PE can be life threatening and result in a cardiac or respiratory arrest. If a patient has signs or symptoms of a PE a medical team needs to be called urgently. Physiotherapy techniques such as mobilisation and manual chest therapy are contraindicated until medical clearance is obtained. Also, passive movements are usually stopped once a DVT is suspected or diagnosed and patients will usually be given anti-coagulant medication. Passive movements can be recommenced within a few days of commencing anti-coagulant medication but as different hospitals and countries have different policies medical directive should be given first.³⁷

Bladder management

SCI can affect the sensory, motor and sympathetic nerves essential for normal bladder function. The sympathetic innervation of the bladder originates in the lower thoracic and upper lumbar spinal cord segments (T10-L2) while the voluntary control of the external sphincter is mediated by α -motor neurons of the ventral horn in the sacral spinal cord segments (S2–S4), which cause the striated muscle fibers of the sphincter to contract.¹⁷ Three implications of disruption to motor, sensory and autonomic pathways for bladder function following SCI are: an inability to feel when the bladder is

full, voluntarily control muscles to void and voluntarily contract muscles to prevent voiding. Even though it is a rare condition a recent review shows that bladder cancer can also be a potentially lethal occurrence in SCI patients.^{51,52}

People with SCI can usually maintain their continence with the assistance of devices and aids. However, for some maintaining continence is an ongoing challenge. Most people with SCI can not void as they did prior to their injury. Instead, they use one of many different options. The appropriate option for a patient depends on the presence or absence of bladder reflexes (for example, complete lesions below the conus have loss of bladder reflexes while those above do not), hand function, patients' preferences or/and other more complex factors.⁵³ It is not uncommon that some patients will be wearing a leg bag for collecting urine. A leg bag may be draining urine from the bladder by its connection to a urodome in men, urethral catheter or a suprapubic catheter. Sometimes, the therapist may need to empty a patient's leg bag for them if it is full. Occasionally a patient's catheter gets twisted in physiotherapy from the exercises and movement and this can block the catheter. This is a possibility that the therapist should be aware of because it can cause autonomic dysreflexia, or force urine back to the kidneys, or even cause bladder incontinence.³⁷

Another common way to manage the bladder is by intermittent self catheterisation. The patient inserts a catheter every 3 to 6 hours to drain the bladder and the catheter is removed once the bladder is drained. The procedure takes 5 to 10 minutes and there are different types of catheters the patients can use.⁵⁴ A physiotherapist should explain to their patients that movement can sometimes trigger bladder reflexes and encourage them to perform catheterisation before physio if feasible.

Bowel management

SCI can affect the sensory, motor and sympathetic nerves essential for normal bowel function. The gastrointestinal tract is controlled by the autonomic nervous system with sympathetic and parasympathetic nerves working in harmony. Nerves from the lower levels of spinal cord control the sphincters. The bowel is primarily innervated through S2-S4, but also receives important sympathetic innervation from T8-T12.⁵⁵

The majority of individuals with spinal cord injury SCI have neurogenic bowel dysfunction including constipation, fecal incontinence and abdominal pain or discomfort.⁵⁶ Bowel symptoms have major effect on the quality of life of individuals with SCI and constipation related symptoms become significantly more severe with time since injury.⁵⁷ Three implications of disruption to motor, sensory and autonomic pathways on bowel function after SCI are: an inability to feel when the bowel is full, voluntarily control muscles to defecate, and voluntarily contract muscles to prevent defecating. A usefull tool is the *The Bowel Function Basic Data Set*, which is applicable to adult individuals with

traumatic or non-traumatic supraconal, conal or cauda equina lesions.⁵⁸ People with SCI can usually manage their continence once a bowel care regime is established. However, for some maintaining continence is an ongoing challenge.⁵⁹

Most people with SCI can not defecate as they did prior to their injury. Instead, they use one or a combination of many different options. These options for managing bowel continence include: rectal medication such as enemas, a good diet with lots of fiber, appropriate amounts of fluids, regular bowel emptying routines, digital stimulation of bowel reflexes,⁶⁰ oral medication such as bowel softeners.⁶¹ The appropriate option for a patient depends on: presence or absence of bowel reflexes (for example, complete lesions below the conus have loss of bowel reflexes while those above do not), hand function, patients' preferences, other more complex factors.

An episode of bowel incontinence may occur if the reflexes of the bowel are still intact. Reflexes will only be intact if the lesion is above the conus. Physiotherapy can sometimes move faecal content into the lower bowel and trigger the reflex. If a therapist is concerned about an episode of bowel incontinence it should be explained that exercises and movement can sometimes trigger bowel reflexes causing an episode of incontinence and therefor reassure patients that if they are incontinent he/she will help them manage it.³⁷

Heterotopic ossification

Heterotopic ossification (HO) is the presence of bone in soft tissue where bone normally does not exist. The acquired form of HO most frequently is seen with either musculoskeletal trauma, spinal cord injury, or central nervous system injury. When it comes to SCI it commonly occurs within the first few months after the injury⁶² and it is less common in children than in adults.⁶³ The clinical signs and symptoms of HO may appear as early as 3 weeks, or as late as 12 weeks after neurogenic and/or traumatic insult and they include: fever, swelling, erythema, pain, an increase in spasticity and decreased range of motion.⁶⁴ It frequently affects shoulders, elbows, hips and knees.⁶³ HO is notoriously difficult to treat as it can sometimes develop into debilitating and unsightly contractures. Medical treatment includes medication, irradiation, and surgical resection.^{63,65}

No causal relationship between heterotopic ossification and physiotherapy has been demonstrated, however aggressive stretch and aggressive passive movements are contraindicated as they have been associated with HO. A proper physiotherapy intervention would be gentle stretch and in some cases splints.³⁷

Pressure ulcers

Pressure ulcers (also known as "bedsores" or "pressure sores") are an injury that breaks down the skin

and underlying tissue. They are caused when an area of skin is placed under pressure. Pressure ulcers can range in severity from patches of discoloured skin to open wounds that expose the underlying bone or muscle. They can develop when a large amount of pressure is applied to an area of skin over a short period of time. They can also occur when less pressure is applied over a longer period of time. The extra pressure disrupts the flow of blood through the skin. Without a blood supply, the affected skin becomes starved of oxygen and nutrients, and begins to break down, leading to an ulcer forming. People with grade four pressure ulcers have a high risk of developing a life-threatening infection. Pressure ulcers tend to affect people with health conditions that make it difficult to move, especially those confined to lying in a bed or sitting for prolonged periods of time, so it is only natural to be a common complication of SCI⁶⁶.

People with SCI are primarily at risk of pressure ulcers due to impaired sensation below the level of lesion, impaired mobility and prolonged lying and sitting. Healthcare professionals use several grading systems to describe the severity of pressure ulcers, but the most common is the 4-grades European Pressure Ulcer Advisory Panel (EPUAP) grading system.⁶⁷ Furthermore, it has been recently developed International Spinal Cord Injury Skin and Thermoregulation Function Basic Data Set.^{66,68} There are many areas at risk of pressure ulcers. When lying in supine the areas most vulnerable are the occiput, scapula, sacrum and heels. In side-lying the areas most vulnerable are the greater trochanter and medial/lateral malleolus. While sitting in a wheelchair a patient is most at risk of developing pressure ulcers over his/hers ischial tuberosities and sacrum. Other areas in contact with the wheelchair such as the heels and scapula also need to be monitored, however these areas are also less at risk than the ischial tuberosities.⁶⁶

There are many strategies that people with SCI can implement to prevent pressure ulcers. People with injuries at C5 and above (as well as some lower level injuries) are unable to lift and lean their body independently to relieve pressure. They would release pressure by tilting their electric wheelchair back (at least 50 degrees using the tilt in space feature). Likewise, a manual wheelchair could be tilted with carer assist, even though manual wheelchairs have been correlated with pressure ulcers.⁶⁹

While in bed it is recommended that turning in bed should be performed at least 3 hourly, and preferably 2 hourly during the acute phase. Another commonly used equipment is an alternating pressure mattress⁷⁰ that helps patients in less regular turning throughout the night in a subacute phase. In some countries leaning techniques are preferred to lift up technique, because lift up technique may put additional strain on the shoulders over many years. The importance of implementing strategies for the prevention of pressure ulcers can not be underestimated. It is far easier to prevent pressure ulcers than it is to treat them.³⁷

Spinal shock

Spinal shock is a long-term depression of spinal reflexes. All reflexes are temporarily lost below the level of injury immediately after SCI. The reflexes eventually return and become hyperactive, appearing in a well defined order, beginning with the Babinski sign, and ending with extensor reflexes.⁷¹ Despite abiding interest by clinicians and physiologists, underlying neuronal mechanisms and clinical significance of spinal shock have remained controversial, until recently. With the exponential growth in new knowledge regarding postinjury spinal cord physiology comes an increased understanding of this complex clinical process. They are normally lost for between 3 days and 3 months. In 2004 was presented a new paradigm for spinal shock consisting of four phases: (1) areflexia/hyporeflexia, (2) initial reflex return, (3) early hyper-reflexia, and (4) late hyper-reflexia.⁷² There is also an associated loss of gastrointestinal function resulting in a paralytic ileus. The main consequence of paralytic ileus is that food can not be digested resulting in abdominal distension and vomiting. This has implications on the respiratory care provided by physiotherapists.

Physiotherapy in SCI

The purpose of physiotherapy for people with SCI is to improve health-related quality of life. This is achieved by treating impairments and improving the ability of people with SCI to carry out activities of daily living. Physiotherapists are only one part of the team assisting people with SCI which includes doctors, nurses, occupational therapists, psychologists, social workers. Physiotherapists are actively involved in all stages of the continuum of care following SCI.⁷³ This continuum of care includes acute management, rehabilitation, outpatient care and care in the home environment.²⁷

Physiotherapy management

The language and framework of the International Classification of Functioning, Disability and Health (ICF) is useful for describing the physiotherapy process.⁷⁴ The ICF defines functioning from the perspective of the body, the individual and society. It is a useful framework for formulating a physiotherapy programme for people with SCI.^{75,76} The process involved in physiotherapy management of people with SCI can be described in 5 steps:⁷⁷

a. Assessing impairments, activity limitations and participation restrictions: important impairments to assess are strength, sensation, joint mobility, skill, respiratory function, cardiovascular fitness, pain

and spasticity. Activity limitations and participation restrictions can be assessed using standardised tools such as the 6 minute walk test⁷⁸ or the Spinal Cord Independence Measure.⁷⁹

b. Setting goals with respect to activity limitations and participation restrictions: physiotherapy goals are based on neurological level, predictions of future independence, patient priorities and environmental factors. Goals are best expressed in terms of activity limitations and participation restrictions, however they can also be set in terms of impairment. They should be specific, measurable, attainable, realistic and time-bound.²⁰

c. Identifying key impairments that are limiting achievement of goals: once goals are defined in terms of activity limitations and participation restrictions it is necessary to identify the key impairments that are preventing the achievement of goals. Some of these impairments are responsive to physiotherapy intervention. Other impairments are either managed by colleagues within the multidisciplinary team or are non-responsive to interventions.²⁰

d. Identifying and administering physiotherapy treatments: six key impairments that commonly impose activity limitations and participation restrictions on people with SCI are: poor strength, poor joint mobility, poor motor skill, poor cardiovascular fitness, poor respiratory function and pain. These impairments are of interest because they respond to physiotherapy treatment.²⁰

e. Measuring the outcome of treatments and re-assesst: outcomes determine whether interventions should continue or change. Similar to the initial assessment they can be measured with respect to impairment, activity limitations or participation restrictions.²⁰ Outcomes can also be measured using tools that articulate patient goals such as the Canadian Occupational Performance Measure (COPM).⁸⁰

Physiotherapy assessment

Assessment is the first step in physiotherapy management of people with SCI, which includes some important components: subjective assessment, assessment of impairments, of activity limitations, of participation restrictions. They are all followed at a later date by a reevaluation of any of the above.²⁷

a. Subjective assessment. A detailed subjective assessment involves several key factors including: patient goals and expectations, history of presenting condition, surgical history and precautions, past medical history and medications, social history, environmental factors.⁸¹

b. Assessment of impairments. Impairments may be identified during assessments of: strength, joint mobility, motor skill, cardiovascular fitness, respiratory function, pain, spasticity and spasm, sensation. Strength can be assessed using manual muscle tests, repetition maximum testing or hand-held myometry.⁸² Joint mobility can be assessed by measuring active or passive joint range of motion. Motor skill can be assessed by observing performance of functional tasks such as bed mobility,

transfers, wheelchair mobility, walking and upper limb activities.⁸³ Cardiovascular fitness can be assessed using standardised fitness assessments.⁸⁴ Respiratory function can be assessed by a comprehensive respiratory examination.⁸⁵ Pain can be assessed by a detailed subjective and objective assessment.⁸⁶ Spasticity and spasm⁸⁷ can be assessed by observation and using measurement tools such as the Modified Ashworth⁸⁸ or Tardieu scale.⁸⁹ Poor or absent sensation can be assessed using the sensory assessment of the International Standards for Neurological Classification of SCI.¹⁶

c. Assessment of activities. Key impairments are associated with activity limitations. Commonly assessed domains include: general mobility, wheelchair mobility, gait, upper limb and hand function. General mobility outcome measures that include items such as bed mobility and transfers are the Functional Independence Measure,⁹⁰ Spinal Cord Independence Measure,⁹¹ Quadriplegic Index of Function⁹² and the Clinical Outcomes Variable Scale.⁹³ Wheelchair mobility outcome measures that assess wheelchair mobility are the Wheelchair Skills Test,⁹⁴ the Wheelchair Circuit⁹⁵ and the Quebec User Evaluation of Satisfaction with Assistive Technology.⁹⁶ Gait outcome measures that assess gait are the 10 metre walk test,⁹⁷ 6 minute walk test,⁹⁸ Walking Index for Spinal Cord Injury⁹⁹ and the Spinal Cord Injury Functional Ambulation Inventory.¹⁰⁰ Upper limb and hand function outcome measures that assess upper limb and hand function are the Sollerman Hand Function Test,¹⁰¹ Jebsen Hand Function Test,¹⁰² Common Object Test,¹⁰³ Tetraplegia Hand Activity Questionnaire,¹⁰⁴ Grasp and Release Test,¹⁰⁵ the Capabilities of Upper Extremity Instrument¹⁰⁶ and the AuSpinal.¹⁰⁷

d. Assessment of participation restrictions. It is most useful to assess the participation domains that the patient is interested in, in a patient-centered assessment. Commonly assessed participation domains include: work, leisure, family, sport.¹⁰⁸

e. Reevaluating. Reevaluating outcomes determines whether interventions should continue or change. Similar to the initial assessment outcomes can be measured with respect to impairments, activity limitations and participation restrictions.²⁰

Physiotherapy interventions

Understanding movement in people with SCI requires an awareness of the optimal levels of motor function that people can expect to attain. It also requires knowledge of the common ways people with different levels of SCI perform motor tasks although there are many acceptable variations.¹⁰⁹ Motor tasks are best described in terms of sub-tasks and these sub-tasks are the critical steps involved in successfully performing motor tasks.²⁰

Bed mobility and transfers → five motor skills that people with C6 tetraplegia and paraplegia have the potential to attain are: rolling, moving from supine to long sitting, unsupported sitting, lifting vertically and transferring.²⁰ Skill training for bed mobility, sitting and transfers is most effective

when it incorporates a large amount of practice, the tasks are practiced in the context in which they will be performed and sub-tasks are practiced if the whole task is too difficult.^{110,111} It is also important that these sub-tasks or tasks are progressively made more difficult with the appropriate instructions given. Demonstrations and manual guidance are also used and never forget that feedback is appropriate.²⁰

Wheelchair mobility → the ability to safely self-operate a wheelchair dramatically increases quality of life and promotes independence for individuals with limited mobility.¹¹² One key factor that determines the type of wheelchair mobility that people with spinal cord injury use is level of injury. People with C1-C4 tetraplegia typically mobilise in a chin-control, sip and puff or head array power wheelchair as they are unable to self propel a manual wheelchair. People with C5 tetraplegia typically, mobilise in a hand-control power wheelchair.¹¹³ Some can propel a manual wheelchair on flat smooth surfaces, however this is not their main form of mobility. People with C6-C8 tetraplegia typically mobilise independently in a manual wheelchair over most surfaces and terrains with varying degrees of skill.²⁰ People with thoracic paraplegia typically mobilise in a manual wheelchair with varying degrees of skill, (they sometimes use power mobility if they are not functional in a manual wheelchair due to impairments such as poor cardiovascular fitness and shoulder pain).¹¹⁴

Gait (standing and walking) → standing and walking are important goals for many people with SCI. The ability to stand and walk is determined by many factors including the strength of key muscles and sensation below the level of injury. People with different levels and types of injury have the potential to acquire different levels of upright mobility.²⁰ All people with SCI can be provided with equipment that allows them to stand. People with complete tetraplegia are able to stand with assistive devices such as a tilt table, standing wheelchair or standing frames (that prevent trunk, hip and knee flexion).¹¹⁵ These methods of standing are also used by people with paraplegia and poor upper limb strength.¹¹⁶ People with paraplegia and good upper limb strength require little or no assistance to get into standing. They are able to stand in a standing frame (that prevents hip and knee flexion). They are also able to stand with knee extension splints in parallel bars or with orthoses.²⁰ What concerns walking, people with complete thoracic paraplegia and lower limb paralysis rarely walk as their primary means of mobility. They are able to ambulate, provided they have good upper limb strength, orthoses and walking aids. People with lumbosacral paraplegia and motor incomplete lesions may have partially paralysed lower limbs and walking is more likely to be realistic.¹¹⁷

Strength → weakness is one of the most important impairments following SCI and a key determinant of motor function. Weakness can be neurally induced or occur in neurally intact muscles. Neurally induced weakness is due to paralysis or partial paralysis. Weakness in neurally intact muscles is due to disuse atrophy or insufficient strength for the demands of novel functional tasks.¹¹⁸ It is important

to assess muscle strength to monitor change and guide treatment. Common ways of assessing strength are: manual muscle testing, repetition maximum testing, hand-held myometers and dynamometers.¹¹⁹ Progressive resistance training is the most common form of strength training. Neurally intact muscles are commonly strengthened using weight programmes or in the context of motor tasks (both are effective provided there is sufficient resistance to induce a training effect). It is more challenging to apply the principles of progressive resistance training to partially paralysed muscles because it is difficult to apply resistance when a muscle is unable to move through full range against gravity. In that case electrical stimulation may also be useful particularly when used in people with weak and very weak muscles where progressive resistance training is difficult.¹²⁰

Spasticity → contractures they are a common complication of spinal cord injury. They are characterised by a reduction in joint range of motion or an increased resistance to passive joint movement both limiting joint mobility. Most importantly contractures prevent performance of motor tasks but they are furthermore undesirable because they can cause: deformities, pain, pressure ulcers and difficulty with activities and hygiene.¹²¹ Contractures can be non-neurally mediated and neurally mediated. Non-neurally mediated contractures are due to structural and biochemical changes in muscles and soft tissue.¹²² They are primarily due to immobility and prolonged sitting or lying with muscles in shortened positions and they also occur secondary to spasticity.¹²³ Neurally mediated contractures are due to spasticity (or involuntary contraction of muscles which is velocity dependent). Stretch, passive movements and positioning in a lengthened position are widely advocated for the treatment and prevention of contractures.¹²⁴

Fitness → poor fitness is a common impairment in people with SCI. Poor fitness can result in activity limitations and participation restrictions because people with SCI may be deconditioned or not fit enough to cope with the demands of moving with paralysis. For example, pushing a wheelchair long distances is physically demanding and requires a high level of fitness. For individuals with SCI, regular exercise training leads to significant improvements in pain, stress, and depression.¹²⁵ Good cardiovascular fitness in those people may enable the performance of everyday activities, decrease the risk factors associated with cardiovascular complications, improve circulation, prevent or treat obesity, improve health and wellbeing, enhance participation and quality of life, promote self esteem. People with spinal cord injury face multiple barriers to physical fitness in functional, psychological, and architectural domains. Identification of these barriers can facilitate the participation of individuals with spinal cord injury in an exercise program, improving long-term health and wellness.¹²⁶ The response of people with SCI to fitness testing and training is influenced by the level and completeness of injury. Key factors that influence exercise response in people with SCI are: loss of supraspinal sympathetic nervous control, use of a small muscle mass to exercise, paralysis of the legs and the

abdomen. SCI also influences peak oxygen uptake, cardiac output and arterio-venous oxygen difference. So, it is important that fitness training is carried out using determined parameters.¹²⁷

Respiratory → impaired respiratory function is common following SCI. Typical respiratory complications following SCI include hypoventilation, atelectasis, secretion retention and pneumonia. Respiratory function of people with SCI is primarily determined by neurological level. Paralysis or partial paralysis of key muscles has a marked impact on respiratory function.¹²⁸ Assessment of respiratory function involves a subjective assessment combined with a thorough physical examination including: observation of the patient and pattern of breathing, respiratory and pulse rate, temperature, auscultation, oxygen saturation with and without oxygen, arterial blood gases, chest X-Ray, effectiveness of cough, spirometry (VC and FEV1). Throughout the course of their lives people with tetraplegia are susceptible to respiratory complications due to impaired lung function as a consequence of respiratory muscle weakness and decreased pulmonary and rib cage compliance.¹²⁹ Physiotherapy interventions aim to remove secretions and increase ventilation. Interventions include assisted cough, percussion and vibration (with or without postural drainage), suctioning, use of a mechanical insufflator/exsufflator, positioning, abdominal binders (assistance with ventilation when in sitting),¹²⁸ deep breathing exercises, incentive spirometry, inspiratory muscle training.¹³⁰

Pain → is a common complication of spinal cord injury. It may result from the initial SCI or develop later on. Pain can affect performance of motor tasks and may impact participation in family life, work, and leisure activities. Pain associated with SCI may be acute or chronic. Around two thirds of persons with SCI suffer from chronic pain. *Acute pain* is an unpleasant sensory experience associated with or warning of damage and it resolves with time. Pain that extends beyond the expected healing time (usually defined as 3 months) is described as *chronic pain*. (Acute pain may become chronic if not well managed at an early stage). Chronic pain is an important problem following spinal cord injury (SCI) and is a major impediment to effective rehabilitation. The reported prevalence of chronic SCI pain is variable but averages 65% with around one third of these people rating their pain as severe.¹³¹ Acute and chronic pain associated with SCI are classified as nociceptive or neuropathic. *Nociceptive pain* can be visceral or musculoskeletal in origin. Pain is usually located in the back or the neck, the shoulders and other joints of the upper limb and is often related to poor posture, poor ergonomics, and/or overuse. *Neuropathic pain* arises as a consequence of a lesion or disease of the nervous system. Neuropathic pain can occur above, at or below the level of injury. Physiotherapy interventions for pain may include: TENS, heat, and cold, soft tissue techniques such as massage, specific strengthening and stretching exercises, graded exercise or activity programmes, hydrotherapy, education on activity pacing, education on posture, education to minimise risk of overuse injuries, retraining of transfers and wheelchair skills, ergonomic review of seating and equipment.¹³²

Part II

Psychological and social impact of SCI

Spinal cord injury (SCI) can be a sudden and devastating event that changes a person's life forever. Not only does SCI affect a person's physical function, but also their psychological wellbeing and social life. It is easy to understand that physical interventions alone may not be enough to lead to successful and comprehensive rehabilitation outcomes.¹³³ With SCI being a condition that, in most cases, leads to life-long disability, affected individuals have extensive needs that, if not addressed appropriately, can create an unbearable burden for the health-care system, the family and the individual. Historically, health care has tended to focus on the physical aspects of disease, but the importance of psychosocial support is increasingly recognised as being important in guidance documents, as is the vital role that non-statutory agencies can play in providing such services.¹³⁴

Prior to World War II persons who sustained a spinal cord injury could expect to survive only weeks. In contemporary times, the lifespan can be measured in decades. So, as lifespans lengthen among people with SCI, there is increasing awareness of issues related to aging with SCI and a growing need to focus resources on understanding how to assess and address lapses in activity levels and community participation in this population.¹³⁵

The ideal approach to comprehensive rehabilitation involves equal attention to both psychosocial *and* physical aspects of care. It has been noted, for example, that hope is a non-physical factor that plays a significant role in both rehabilitation and lives of people who have sustained a SCI.¹³³ Higher levels of hope were also associated with lower levels of depression¹³⁶ and life satisfaction.¹³⁷ In the same context spirituality, religion or non-religion beliefs and philosophies about life and death play an essential role in patient's psychology.¹³⁸

It is also important to point out that in a Spinal Unit environment, working with families is a part of the rehabilitation process. Families may be involved with goal setting, planning for leave and discharge, and assisting with functional activities. Family and friends are often visiting while patients are participating in physiotherapy sessions. Inviting them to observe therapy sessions and even participate may enhance their involvement with the patient's rehabilitation, enabling the patient to feel more supported.^{139,133} It is really crucial to amalgamate spinal cord injury patients in everyday life. Family and friends have to be involved in all rehabilitation programs, because they are the ones who choose the healthcare provider who is specialized in spinal cord injuries. They also provide the emotional support and understand the resources available to the injured person and make the best use of them.¹⁴⁰

The importance of combination of physical *and* psycho-social approach in the rehabilitation process is indicated, apart from many researches and personal experience of many therapists, by the *International Classification of Functioning, Disability and Health (ICF)*. ICF provides a standard language and framework for the description of health and health-related states. Furthermore it offers an international, scientific tool for the paradigm shift from the purely medical model to an integrated biopsychosocial model of human functioning and disability.¹⁴¹

Up until recently two major conceptual models of disability have been proposed. The *medical model* views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. Disability, on this model, calls for medical or other treatment or intervention, to “correct” the problem with the individual. On the other hand the *social model* of disability sees disability as a socially created problem and not at all an attribute of an individual. On the social model, disability demands a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other features of the social environment.¹⁴¹

On their own, neither model is adequate, although both are partially valid. Disability is a complex phenomena that is both a problem at the level of a person's body *and* a complex and primarily social phenomena. Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external. In other words, both medical and social responses are appropriate to the problems associated with disability; we cannot wholly reject either kind of interventio¹⁴¹.

A better model of disability, in short, is one that synthesizes what is true in the medical *and* social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects. This more useful model of disability might be called the *biopsychosocial model*. ICF is based on this model, an integration of medical and social. ICF provides, by this synthesis, a coherent view of different perspectives of health: biological, individual and social. These three levels of human functioning classified by ICF are: functioning at the level of body or body part, the whole person, and the whole person in a social context. Disability therefore involves dysfunctioning at one or more of these same levels: impairments (body function and structure), activity limitations and participation restrictions.¹⁴¹

In order to complete the social model of disability, ICF includes Contextual Factors, in which environmental factors are listed. These factors range from physical factors such as climate and terrain, to social attitudes, institutions, and laws. Interaction with environmental factors is an essential aspect

of the scientific understanding of the phenomena included under the umbrella terms 'functioning and disability'.¹⁴¹

For example, SCI is associated with the three levels of functioning linked to a health condition in the following order:

health condition → spinal cord injury

impairment → paralysis

activity limitation → incapable of using public transportation

participation restriction → lack of accommodations in public transportation leads to no participation in social activities

Although activity and participation represent critical outcomes for persons with SCI existing measurement tools in this population have significant limitations. Investigators are encouraged to become aware of the flaws in available measures in order to make informed decisions for specific projects. A number of measures are available that can serve as indices of activity, participation, and influential factors until the next generation of instruments is developed and disseminated. Such measurement tools that focus on social and emotional measures and can be applied in SCI patients are:

- CHART - Craig Handicap Assessment and Reporting Technique (a 32-item questionnaire scored in domains physical independence, cognitive independence, mobility, occupation, social integration and economic self-sufficiency)
- LIFE-H - Assessment of Life Habits (77 to 240-item measure of activities and participation providing 12 subscales: nutrition, fitness, personal care, communication, housing, mobility, responsibility, interpersonal, community, education, employment, and recreation)
- IPA - Impact on Participation and Autonomy (a 32-item questionnaire assessing participation and restrictions - subscales include social relations, self-care, mobility, leisure, family role, work and education)
- PARA-SCI - Physical Activity Recall Assessment of People with Spinal Cord Injury (interview tool about activities in the 3 previous days, yielding activity scores for cumulative, leisure time and lifestyle)
- LiSat – Life Satisfaction Questionnaire (9-item measure of life satisfaction in domains global, vocational, financial, leisure, friends, sexual, activities of daily living, family life, and partnership)
- BDI - Beck Depression Inventory (21-item measure of depressive symptoms)
- CES-D - Centers for Epidemiologic Studies-Depression (20-item measure of depressive symptoms)
- FIM - Functional Independence Measure (18-item scale quantifies activity limitations by assessing performance in self-care, sphincter control, transfers, locomotion, communication, and social cognition)
- CPI - Community Participation Indicators (measure integrating objective and subjective definitions of participation)
- FABS/M - Facilitators and Barriers Survey/Mobility (133-item measure of personal and community facilitators and barriers to participation)

- CHEC - Community Health Environment Checklis (63-item measure of physical barriers to participation in environment)
- PARTS/M – Participation Survey/Mobility (measure of community participation)
- SCI-QOL - Spinal Cord Injury Quality of Life (covers multiple domains of functioning: depression, grief, resilience, anxiety, positive psychological, stigma, self-esteem, role performance, role satisfaction, independence, bowel, bladder, respiratory, pain, skin breakdown, sexual, and satisfaction with sexual functioning)
- SCI-CAT - Spinal Cord Injury Computerized Adaptive Testing (assesses multiple domains of functioning: mobility, wheelchair mobility, walking, upper limb, and communication)

The biopsychosocial model of ICF is being supported by many researches, case studies and systematic reviews. For example, in an 2009 article, Japanese researchers came to the conclusion that depression severity and inflammation were associated with each other and appeared to have independent effects on perceived pain (in patients with Rheumatoid Arthritis). Therefore, a clinical approach that takes into account both the body and the mind could have benefits and could enable optimal pain control.¹⁴² The use of a biopsychosocial model in rehabilitation doesn't simply mean that body and mind/soul should be taken under consideration separately. Body, mind and social context are being in a dialectic bond with each other. You simply can not regard one without regarding at the same time the other. In that sense it is quite different than a Christian approach which criticizes the fact that human existence is identified with the biological body, only to defend an immortal soul and afterlife.¹⁴³ In that context body and soul are part of two different ontological levels and in fact the spiritual is superior to the somatic one.

Apart from the person itself, interpersonal interactions and relationships are so important in a person's life that the World Health Organization has recognized their importance as a domain of human functioning, by including it as a chapter in the ICF.¹⁴⁴ In the case of SCI, the most obvious consequence which may restrict an individual's capacity to participate socially is a mobility impairment which can be exacerbated by aspects of the natural and built environment.¹⁴⁵ There are, however, other hidden sequelae, such as bladder, bowel, and sexual dysfunction, and secondary health conditions, such as persistent pain and pressure injury, which can have a negative impact upon social participation including relationship formation and preservation.¹⁴⁶

While relationships may be negatively affected by the presence of disability, healthy, robust relationships have the capacity to positively impact individuals' perceptions of health and quality of life in the presence of disability.¹⁴⁷ For example, positive spousal relationships have been associated with reduction in functional limitations and depressive symptoms for people with vision impairments¹⁴⁸ and less disability for women coping with persistent pain.¹⁴⁸ Similarly, partner support

has been shown to have a positive effect on self-esteem and well-being for people with multiple sclerosis, particularly when they reciprocate the support.¹⁴⁹ Especially for people with SCI, the quality of relationships with family and friends has been identified as contributing to resilience and adaptability,¹⁵⁰ as social support in general has been linked to positive psychological outcomes.¹⁵¹ In this context, creating rehabilitation environments which encourage and support social interaction between the person with SCI and family and friends as well as the broader community is vital. This might be achieved through creation of shared social spaces, time for social interaction, and flexibility of rehabilitation programming. Importantly, rehabilitation space needs to provide a sense of welcome to these significant others.¹⁵²

In order for the biopsychosocial model to be adopted in the last couple of decades, a lot had to be done. From the early 1960's, along with other political and social movements, the *disability rights movement* emerged. As described in UC Berkeley's website on the Disability Rights and Independent Living Movement:¹⁵³

The disability rights movement asserts that people with disabilities are human beings with inalienable rights and that these rights can only be secured through collective political action. It arises out of the realization that, as historian Paul Longmore has written, "whatever the social setting and whatever the disability, people with disabilities share a common experience of social oppression"[...] People with disabilities throughout history have been defined as objects of shame, fear, pity, or ridicule. They have been incarcerated, sometimes for life, in state institutions and nursing homes. Social prejudice kept disabled children out of the public schools, and sanctioned discrimination against disabled adults in employment, housing, and public accommodations. This prejudice has been exacerbated for people of color, women, and for members of ethnic and sexual minorities. Although groups and individuals have since the nineteenth century advocated for an end to this oppression, large scale, cross-disability rights activism, encouraged by the examples of the African-American civil rights and women's rights movements, did not begin until the late 1960s [...] The independent living movement has been an important part of this broader movement for disability rights. It is based on the premise that people with even the most severe disabilities should have the choice of living in the community. This can be accomplished through the creation of personal assistance services allowing an individual to manage his or her personal care, to keep a home, to have a job, go to school, worship, and otherwise participate in the life of the community. The independent living movement also advocates for the removal of architectural and transportation barriers that prevent people with disabilities from sharing fully in all aspects of our society.¹⁵⁴

Peer Counseling

Among other changes in rehabilitation philosophy and practices, dictated by the biopsychosocial model, was the adoption of alternative and more broad minded approaches. One of them was the creation of Centers of Independent Living,¹⁵⁵ based on the premise that disabled people should

reintegrate in society. Within the Centers of Independent Living the peer support programs flourished, making them a cornerstone of the independent living movement.¹⁵⁶ Apart from these centers (mainly located in USA), peer support programs started to expand. For instance, in 1976 in Sweden started the Active Rehabilitation (AR), a community peer-based approach on rehabilitation. As a key component of the approach, AR training camps provide intensive, goal-oriented, intentional, group-based, customised training and peer-support opportunities in a community environment for individuals with spinal cord injury.¹⁵⁷

Peer support is based on the philosophy that the person who can be most effective in providing support is the one who has shared similar experiences.¹⁵⁸ The term “peer-counseling” was originally taken from the name of counseling and support activities by AA (Alcoholic Anonymous), a self-help group of alcoholic patients,¹⁵⁹ but soon expanded in a range of other conditions, including traumatic brain injury, HIV, cancer, kidney disease and burns.¹⁶⁰

A booklet from Washington's National Rehabilitation Hospital informs its patients that:

The word “peer” simply means someone who is similar to you, be it in age, gender, race, education, or disability. “Mentoring” simply means serving as a trusted counselor or teacher. When we talk about spinal cord injury (SCI) peer mentors we mean other people who have an SCI and have faced some of the same experiences and challenges that you may face. Peer mentors have learned from their own experiences. They are also knowledgeable about resources and living with SCI, so peer mentors can be helpful in many ways [...] While peer mentors are not a replacement for the health care professionals that you usually work with, they can be a valuable resource in many ways [...] Sure, your doctors, nurses, and therapists have explained to you how the SCI affects your life. Most likely, you have also received plenty of brochures and booklets, and perhaps watched some videos about SCI. However, you probably have plenty of unanswered questions, and new questions will also come to mind periodically. Therefore, it's important to find someone with experience who can tell you about the realities of day to day living with an SCI. Based on their training and personal experience, peer mentors can provide you with this type of information.¹⁶¹

Support provided by peers (peer-counseling) is a *holistic psycho-social rehabilitation approach*. A person with spinal injury becomes a counselor, and has counseling with other persons with spinal cord injury. Peer support and contact with others who have a SCI can be extremely important in helping a person adjust to the injury. Peer support is generally most helpful and accepted when people share similar problems and issues.¹⁶² Peer-based programmes have an important role in the process of re-adjusting in the community as they improve the patients's re-entry into the community and quality of life after spinal cord injury.¹⁶³

Shortly after their injury, some people with SCI may feel angry, frustrated, anxious, or depressed, or respond to their injuries in other ways. Peer mentors are good listeners and can provide emotional support when need it. After all, they understand what a person with SCI is going through because they've been there themselves. Peer mentors can talk about their own experiences during the first

weeks or months after their injury, how they learned to confront their feelings and how they dealt with their emotions after their injury.¹⁶⁴

During the first weeks and months after your injury, people with SCI confront changes in their body that can impact their life and may sometimes lead to serious, life-threatening problems. To prevent problems, they need to learn how to stay healthy and detect signs of complications such as urinary tract infection, autonomic dysreflexia, and pressure sores, among others. Peer mentors can also talk about what they've learned that has helped them to avoid problems and can advise about when and where to get help. They can show how they do things and what they do to prevent medical complications. For example, a peer mentor might show how to transfer safely from bed or a chair to wheelchair, how to ensure that clothes don't put too much pressure on areas of your body that are prone to pressure sores, how to avoid dehydration, and how to do self-catheterizations.¹⁶⁴

Furthermore, relatives of people with SCI are important beneficiaries of the service; perhaps in the early stages more so than the injured person themselves. We shouldn't forget that just as people with an SCI need a listening ear, so too do their relatives, particularly during a period of adjustment that is bewildering and frightening. For relatives, as for the injured person, it was the fact that the peer counselor had himself been through the experience of having an SCI that was particularly helpful.¹⁶⁰ It's been reported that being part of a group of individuals with similar functional level and goals allowed people with SCI to share knowledge, skills and experiences. Observing peer-mentors and other participants demonstrate skills was an important learning process.² Discussing and negotiating was the two other processes that were identified.¹⁶³ These processes were often used to transfer knowledge, to develop a positive mindset and to strengthen the sense of belonging to the group. Participants also valued the practical advice on such topics as bowel and bladder management, care of the skin, information on housing and sources of financial support, and about devices and appliances to support independent living with an SCI.¹⁶⁰

Verbal persuasion was more effective as it came from the sources that were considered credible, that is, peer mentors, as compared with non-disabled instructors. Participants felt that they had the opportunity to use their own language freely, which was different to that used by health professionals. This was seen as a way to reclaim their identity.¹⁶³ Participants acknowledged that getting together with others who were in a similar situation and faced similar issues was empowering. The sense of safety, support and collegiality facilitated the relatedness of the participant with peers. In such a learning environment, seeing others dealing with fears, motivated participants to push their own boundaries. Participants commented that instead of being given the solutions to their problems, they had to learn how to solve problems.^{2,165}

Peer mentors were described as a living example of what the participants could achieve and a resource for how to achieve it. At the same time, sharing openly their own limitations made participants feel comfortable with the idea of not being able to manage everything. Therefore, peer mentors were credible both for what they could and could not achieve. Peer mentors undertook their role either because they had a sense of duty to help those in need, or because they had similar personal experiences in the past, or lastly, because they benefitted personally through that role. In any case, attributes that were described as unique to peer mentors, as these could not be offered by a non-disabled health professional.^{2,163} Furthermore, peer mentors were shown to sometimes act as a critical corrective to instructions provided by rehabilitation professionals and their ability to empathise was a vital quality not easily found in other non-disabled health professional.¹⁶⁰

In many cases people with SCI had not realised their full potential, as they did not know what was possible to achieve, particularly in relation to major life areas, such as living independently without a personal assistant, being able to travel, socialise effectively and get a partner.¹⁶⁶ These potentials only became apparent to them during the programme through observing and interacting with peers. Others reported not knowing that it was possible to perform so many activities and live an active life after injury. This holistic psycho-social rehabilitation approach contributed into developing a can-do culture. This positive mentality and the availability of the peer mentors' and the other participants' living example motivated individuals to accomplish their own goals. This in turn led to higher perceived self-efficacy and self-confidence.¹⁶³

Changes occurring at cognitive, affective and behavioural levels during a peer counseling program led to realisation of needs and opportunities, which in turn led to more self-determined actions. Patients reported improvements in wheelchair skills, community access, being more socially active, being able to enjoy activities that they always liked, achieving higher self-confidence and independence.² Overall, participation in a peer counseling programme was a transformational experience for many participants and a transition point for achieving higher level of functioning, well-being and identity rebuilding.¹⁶³

Peer counseling creates a unique learning environment, different to other settings or programmes, such as inpatient rehabilitation, therapeutic recreation, leisure activity programmes, wheelchair sports, support groups, etc. Especially in the case of community peer-based programmes, gathering of many people with a SCI became a transformational experience for those attending making them an effective form of participatory learning.¹⁶³ As a researcher puts it "gathering has a power".¹⁶⁷ Through the prevalent of a can-do attitude in the peer counseling programmes, participants developed a high level of perceived efficacy in performing tasks that were important for them. This is important given that higher level of self-efficacy has been reported to improve resilience and to reduce the risk for

depressed mood in people with SCI after discharge.¹⁶⁸ After all, self-efficacy beliefs are an important aspect of human motivation and behaviour and influence the actions that can affect one's life.¹⁶⁹

(Community) peer-based programmes create an environment that helps participants feel safe, overcome their fears, encouraged them to try activities and led them to push their own boundaries. It is important to say that it was the flexibility of the programme that facilitated participants to pick and choose the right tools for themselves, and thus to customise the intervention to their personal needs. Peer mentors understand the needs of participants and respect their feelings primarily because of their common lived experience of disability. In this way, participants feel valued and accepted. Furthermore, by using a language that is built on their common experiences, participants feel understood.¹⁶³

Furthermore, the peer mentors' role was characterised as motivational being an important source of social influence that can impact theoretically relevant motivational determinants of behaviour such as self-efficacy, perceptions of competence and self-determination. The availability of peer mentors with different characteristics and socio-cultural backgrounds suited participants with differing needs and learning styles.⁸⁴

During the chronic phase of SCI, there are factors that facilitate (that is, self-efficacy, motivation, access to learning resources in an appropriate learning environment, access to peers) and factors that hinder (for example, fear, lack of knowledge, isolation, lack of basic skills, depression) the achievement of outcomes. Community peer-based programmes endorsed the facilitating factors and minimised the hindering factors through a plethora of learning processes. Participants achieved positive outcomes in significant life areas, such as independent living, employment, leisure and social life.¹⁶³

In well-functioning systems of care, community peer-based programmes fill an important service gap in long-term SCI management. It may be possible that these programmes fill even bigger service gaps in countries with less well-functioning systems,¹⁶³ where funds and personnel are fewer. This whole procedure is facilitated by the fact that health-care professionals are generally positive about the service, and find it a useful addition to the therapeutic team, providing a holistic, humanistic element to care. They regard the peer mentor as an invaluable member of the therapeutic team, providing a dimension to care which health professionals cannot offer, by being able to focus on patients' and carers' emotional and psychological needs rather than clinical imperatives, and by being willing to share their own experiences.¹⁶⁰

Building a peer program

Volunteer mentor (peer) program greatly increases available services in rehabilitation centers and/or independent living centers and has proven to be highly beneficial for mentors and mentees.

Approaches to peer support vary considerably from country to country and center to center, from all volunteer peer support mentors, to qualified non-professional mentors, to professional mentors that work in group sessions, one-on-one meetings or a mixture of both.¹⁷⁰

A functional definition of an “organized peer support program” is the one that:

Recruits, trains, assigns, and supervises a group of individuals with disabilities whose role it is specifically to provide either one-on-one or group support to other individuals with disabilities. This may include individuals who are paid or volunteers, excluding full or part-time staff who are hired to fill basic positions within their centers, who also have a disability.¹⁷¹

Peer support provides a mutual, one-to-one relationship between more experienced and less experienced individuals for the purpose of personal and professional development.¹⁷² Peer mentors themselves are people with disabilities who are already living independently, are fully integrated into their community and have a desire to help others do the same. Not everyone has the qualities to be a peer mentor. A good mentor displays empathy, listens and communicates well and is direct, sincere, ethical, and trustworthy. In addition, a mentor needs to be skilled and experienced with at least a fair knowledge of disability rights and issues. Peer mentors should also be competent, flexible, authentic, nurturing, approachable and conscientious.¹⁷³

It is very important that people with SCI are at ease and comfortable with their peer mentor. Several additional criteria, including injury level, age, sex, interests and hobbies, and geographic area, may be considered. Some individuals may feel less comfortable with a peer mentor of the opposite sex, others think they would benefit more if they had someone with an injury similar to theirs, while for others common interests and activities are the driving force. It is important for the peer mentor to be reliable, dependable, trustworthy, knowledgeable, resourceful, and active.¹⁶⁴

The idea behind peer support is that people with disabilities have the life experience and knowledge to best assist others in learning to become more independent in their communities. The wants and needs of people with disabilities are best understood by other individuals with disabilities, who also easily understand how best to fulfill those needs. Peers serve as role models and facilitators to help others lead meaningful lives and achieve desired levels of independence.¹⁷⁴

Before the existence of peer support and CILs, people with disabilities did not usually have a person to talk with or an agency to turn to that could effectively and knowledgably help resolve housing, personal assistance, financial or other difficulties that have a very significant impact on psychological and physical well-being. Peer mentors became increasingly involved with CILs over the years,

especially in the areas of information and referral, skills training, emotional support, problem identification, goal setting, action planning, and goal attainment.¹⁷⁵

The psychosocial functions of effective mentors include counseling, friendship, role modeling, acceptance, and confirmation.¹⁷⁶ Peer support can foster personal growth and provide relevant information that can not be obtained in any other manner. Peer mentors often provide information about local support systems and the "ins and outs" of dealing with them. Peer support can provide an avenue for dealing with personal and complex issues.¹⁷⁷ Peer support is effective in reaching, teaching, and supporting people with a variety of disabilities. Peers can reach people that may be unwilling to engage with and trust professionals. Peer mentors provide living proof of success and hope for individuals with mental illness that recovery is possible.¹⁷⁸

People with spinal cord injuries may receive moral support and advice such as how to prevent pressure sores and urinary tract infections. They also can learn how to positively adjust to and live with their disabilities, resulting in higher self-expectations, self-confidence, and self-esteem.¹⁷⁹ A two year study examining the reintegration and quality of life for adults with spinal cord injuries found that social support and peer mentoring were invaluable.¹⁸⁰ Another study focusing on individuals with traumatic brain injury reports that peer support programs have been found to be an effective intervention which maximizes adjustment, provides potent stress-buffering influences and increases an individual's sense of empowerment and self-efficacy.¹⁸¹

It is important to emphasize on the fact that providing peer support may be a powerful growth experience for both parties. Peer support can help a person gain a sense of self-determination, rekindle ambition, and provide real-life solutions based on their experiences. Peer support provides a dynamic nurturing process in a non-competitive environment that promotes independence and self-actualization.¹⁸²

On the other hand providing peer support may foster pride, fulfillment, and continuity in the mentor.¹⁷² Peer mentoring provides an opportunity for individuals with disabilities to give back to their communities, gain a sense of purpose and a greater sense of identity.¹⁸³ The peer mentor has the opportunity to reach out to others, meet new people and participate in a worthwhile experience. The mentor may also learn or enhance a different set of skills, such as teaching, which may be a vehicle for career development. One peer mentor stated that it helped her gain self-confidence and the ability to stand up for herself.

Experience shows that these programs really work. That happens because it is important for people with disabilities to have a positive identity, which peer mentors can foster. Individuals with disabilities may often hear of the things that they can not do from professionals and family members, resulting

in low self-esteem. A relationship with an experienced person with a similar or even different disability is very helpful in forming a stronger, more positive identity.¹⁸⁴

Individuals with similar disabilities are more likely to understand and provide targeted assistance to each other than individuals who do not have this shared experience.¹⁸⁵ Peer support for people with comparable life experiences is very important for resolving and moving through difficult situations. Peers may provide an influential demonstration of how they analyzed problems and developed successful coping strategies.¹⁸⁶ Peer support increases experiential learning because mentors share their experience, successes, and mistakes. Peer support provides encouragement and guides personal growth and development. Mentees value the peer support relationship and report that it helps them better understand the rehabilitation process, learn about community resources, share common experiences, and feel a sense of acceptance and connectedness.^{172,183}

Peer support provides a sense of safety in the context of an open, mutually responsible, non-judgmental and trusting relationship. Peer support provides an almost instantaneous level of shared understanding that is not usually there with most family members and friends. It can provide creative and practical solutions that are not easily found in books or from other sources. Above all peer support provides empathy, friendship, and a morale booster.¹⁸⁴

Even though counseling traditionally relies on verbal interaction, peer support usually involves more than conversation. It includes other learning through the observation of another person with a disability solving their own problems, which contributes to self-confidence. Peer mentors can provide knowledge from personal experience, friendship, emotional support, identity, meaningful roles and a sense of belonging.

Finally, peer support also benefits the organization and community. The general public may form more positive images of and increase interaction with persons with disabilities who are living independently. The community also benefits by increased inclusion and participation of people with all kinds of disabilities in recreational, political, vocational, social, educational, and faith-based activities.

Discussion

There are numerous studies that support peer counseling as a crucial and positive aspect in a rehabilitation process.¹ Peer support is nowadays recognized as an evidence-based practice and many rehabilitation centers include peer mentoring in their programs. The benefits expand from less inpatient use and fewer problems and needs to greater satisfaction with life and better quality of life.¹ Additionally, peer programs and its benefits are proven to make rehabilitation more cost effective.²

However, organized peer support programs are not always successful. Insufficient funding, lack of staff with skills to coordinate peer mentors, complexity of dealing with numerous types of disabilities, transportation to group meetings, lack of qualified peer mentors, and burnout among peer mentors often leads to failure of the programs. A lack of consumer progress or apathy, a sense of disconnection with the Center of Independent Living (or the Rehabilitation Center) and feeling overwhelmed by paperwork may lead to peer mentor burnout and discouragement.¹⁸⁴

Research shows challenges like role confusion and staff resistance¹ acting like an obstacle to peer counseling programs. Non-peer staff and other stakeholders often have concerns about employing peer support providers. Their attitudes are a key determinant in the success or failure of involving peer support providers within a health care organization. It seems that it is not yet a common place that rehabilitation is not only a process that involves medical professions, but (should) include other professional groups as well, e.g. social workers and pedagogues. It must be underlined that the ultimate goal of rehabilitation is independence and participation in society. Though restoring lost function is important, it is not enough. Rehabilitation professionals must also ensure that patients are enabled to be involved in important life situations, enable participation and independence.²

In this point emerges another big issue. What is called “participation in society” or “reintegration” is not as innocent as it sounds. “Society” or “community” are themselves a field of controversies and difficult situations to cope with. A net of competitive relations which often creates places of social exile and objectification, specially for mentally ill or disabled people. We must address the fact that “community” is not always a place of freedom and opportunities that the disabled person will meet after its exit from the rehabilitation center. It's a place of big inconsistencies between its needs and reality, filled with places and opportunities prohibited to disabled people. Disabled people have to face a society dominated by the culture of normality, which considers them as an anomaly. Exiting the rehabilitation center is not the end but the start of a series of everyday problems that reveal the issue of disabled people rights. Their new life is proved to be filled with contradictions and discriminations.¹⁸⁷

In that sense, social skills provided to disabled persons are only one step. The other is for the society itself to change and to be ready to accept disability. This can be done with public initiatives that challenge negative attitudes towards disability, large campaign of information (especially in schools), e.tc. This is important to take place in a state like Greece, where education and social awareness considering disability are rather poor.

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