



SPINAL CORD INJURY: REDEFINING LIFE AFTER LOSS

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SPINAL CORD/DISORDERS UNIT

WHAT IS A SPINAL CORD INJURY?

AN INJURY THAT CAUSES PERMANENT OR PARTIAL DAMAGE TO THE AREA OF THE SPINAL CORD THAT IS AFFECTED. IT IS A LIFE-CHANGING INJURY THAT RESULTS IN MULTIPLE LOSSES OVER THE LIFESPAN.



DEMOGRAPHICS

- 1.2 million Americans live with SCI-related paralysis
- Over 17,000 new traumatic spinal cord injuries each year in US
- Predominately Males (81%)
- Average age at time of injury is 42 years old
- Single (51.3%); Married (32.9%); Divorced (9.5%)
- Non-hispanic White (63.3%); Non-hispanic Black (21.7%); Hispanic (11.1%); Native American(0.7%); Asian (2.1%); Other (1.1%)
- Employed (58.3%); Students (15%); 13% employed 1 year post-injury

CAUSES OF SPINAL CORD INJURIES

- Traumatic – resulting from a MVA, Falls, Acts of Violence, Sports, Surgical complications, and Other (i.e. diving)
- Non-Traumatic – Spinal Tumors or Diseases (i.e. Malignant Spinal Cord Compression; Multiple Sclerosis; Guillain-Barre; Amyotrophic Lateral Sclerosis; Spinal Stenosis; Arthritis, etc.)

NEUROLOGICAL LEVELS OF SCI

- Incomplete – individual has sensory and/or motor function below level of lesion; causes partial damage to the spinal cord (66.7%)
- Complete – no motor or sensory functions found below the lesion; causes permanent damage to the area of the spinal cord that is affected (32.9%)
- Normal - no functional impairment (0.4%)

AMERICAN SPINAL INJURY ASSOCIATION (ASIA) IMPAIRMENT SCALE

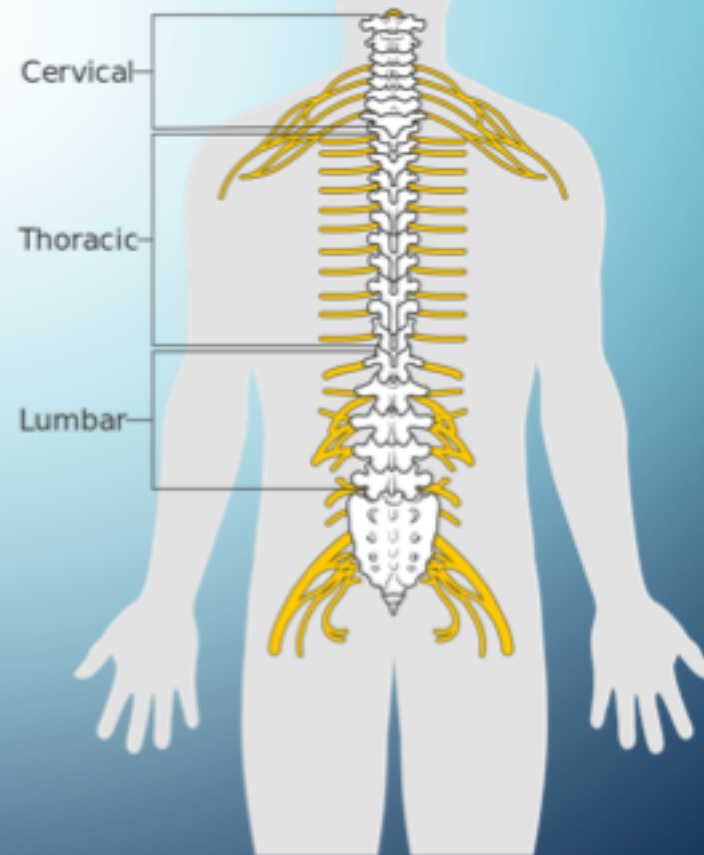
- Grade A = Complete; no sensory or motor function is preserved in sacral segments (S1-S5)
- Grade B = Sensory incomplete; sensory but no motor function is preserved below the neurological level and includes the sacral segments
- Grade C = Motor incomplete; motor function is preserved at the most caudal sacral segments for voluntary anal contraction OR the patient meets the criteria for sensory incomplete status

AMERICAN SPINAL INJURY ASSOCIATION (ASIA) IMPAIRMENT SCALE

- Grade D = *Motor Incomplete*; preserves at least half of key muscle functions below the single neurological level of injury
- Grade E = *Normal*; sensation and motor function are graded as normal in all segments, and the patient had prior deficits.
- The ASIA score can change over time.

THE SPINAL CORD

- 8 cervical segments (C1-C8)
- 12 thoracic segments (T1-T12)
- 5 lumbar segments (L1-L5)
- 5 sacral segments (S1-S5)



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LEVELS OF SPINAL CORD INJURIES

- Cervical Spinal Cord Injuries – the head and neck region above the shoulders are affected, as well as areas below level of lesion
- Thoracic Spinal Cord Injuries- the upper chest, mid-back, and abdominal muscles are affected and below
- Lumbar Spinal Cord Injuries – the hips and legs are affected
- Sacral Spinal Cord Injuries- the hips, back of the thighs, buttocks and pelvic organs are affected

TYPES OF SCI

- *Paraplegia* – paralysis starting in the thoracic (T1-T12), lumbar (L1-L5) or sacral (S1-S5) area; retain functioning of arms and hands; (incomplete = 20.9% / complete = 19.7%)
- *Tetraplegia* – damage in the cervical area (C1-C8); paralysis of arms and hands (incomplete = 45.8% / complete = 13.2%)

MOST PREVALENT CONSEQUENCES OF SCI

- Motor level – mobility is decreased
- Sensory level – i.e. sensitivity of the skin is decreased
- Autonomic level – activity and functions of the inner organs are controlled involuntarily (person does not consciously control these functions); bladder, bowel, cardiovascular activities, respiration, sexual functions, etc.)
- Recurring Pressure Sores
- Chronic pain

LIFE EXPECTANCY

- Before 1960, life expectancy was low
- At present, almost the same level as persons without SCI; 40 years post-injury
- With the exception of Malignant Spinal Cord Compression

SPINAL CORD COMPRESSION

- Complication of metastatic, malignant disease
- Depending on type of cancer, as many as 40% have spine lesions
- Recognized as an oncological emergency
- Most present with normal neurologic examinations
- If sudden loss of ambulation, >10% chance of regaining function

CHALLENGES FACED

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- Persons with SCI face extraordinary challenges beyond adapting to physical limitations
- Functional limitations
- Restrictions in physical and psychosocial environment
- Uncertain prognosis (in non-traumatic injuries)
- Financial Stressors

AVERAGE YEARLY EXPENSES FIRST YEAR &

MULTIPLE LOSSES

SUBSEQUENT YEAR

- High Tetraplegia (C1-C4) - \$ 1,079,412 / \$ 187,443
- Low Tetraplegia (C5-C8) - \$ 779,969 / \$ 114,988
- Paraplegia - \$ 526,066 / \$ 69,688

MULTIPLE LOSSES

- Loss of mobility (paralysis of legs, arms and/or hands, and internal organs)
- Loss of function (unable to feed self; unable to urinate; unable to climb stairs)
- Loss of independence
- Loss of profession/vocation

GRIEVING THE LOSSES IN SCI

- Loss of income
- Loss of home (must be adaptive)
- Potential loss of significant others
- Loss of identity

FACTORS AFFECTING THE GRIEF PROCESS

- Controversy about the applicability of grief and bereavement to understanding the reaction to catastrophic losses such as SCI
- Models of grief cannot be fully applied to SCI-related loss of physical capacity, social or occupational role function, and life goals
- With exception of spinal cord compressions due to malignant tumors, person is grieving loss of the body, not loss of life.

KEY SYMPTOMS OF PATHOLOGICAL GRIEF

- Context of the loss
- Suddenness
- Unexpectedness
- Violence (assault, gunshot wound, etc)
- Combat experience
- Normal, complicated or prolonged grief vs pathological grief

GRIEVING THE LOSSES IN SCI

- Yearning for what was
- Difficulty accepting the loss
- Emotional numbness
- Avoidance of reminders
- Confusion about one's role in life

ROLE OF DENIAL AND HOPE IN TREATMENT

- Rather than experiencing “the Stage theory” of grief to achieve positive adjustment, persons with SCI are thought to oscillate between a focus on loss and a focus on restoration in daily activities
- View Resilience as a modal response (Bonanno, et al.)

BREAKING THE NEWS IN SCI

- May be used as a verbal disavowal of prognosis
- Harmful when patient acts on erroneous beliefs
- Family members asking not to tell patient of negative prognosis
- Explore hope with patient
- NEVER take away the patient's hope for the future

WHO SHOULD DELIVER BAD NEWS IN SCI & WHERE

- Help patients understand their prognosis
- Foster hope for their future
- Failure to deliver bad news in a clear manner interferes with process of coping and reduces subjective well-being

FACTORS TO CONSIDER IN DISCUSSING BAD NEWS

- Senior (most experienced) physician involved in the case
- Must deliver information in a sensitive manner and competent manner
- Take into account patient's personality, culture, education, age, etc.
- Ideally takes place in a private and quiet setting
- Ask patient if they wish to have a relative or friend present
- Physician may ask psychologist or social worker to be present, or assigned to follow up at a later time; may also ask for interpreter

TIMING OF DELIVERING BAD NEWS: WHEN?

- Advanced Preparation
- Build a Therapeutic Environment
- Communicate well/clearly
- Deal with Patient and Family Reactions
- Encourage and Validate Emotions

• Upon admission to rehab setting - determine whether or not the patient and/or

BENEFITS OF EFFECTIVELY DELIVERING BAD NEWS

- Gratitude

- open admission to team setting, determine whether or not the patient and/or family have raised questions to staff regarding prognosis
- Major differences between team and patient goals
- Prognosis should be discussed before patient/family invited to a team conference

ADVERSE CONSEQUENCES OF INEFFECTIVELY DELIVERING BAD NEWS

- Depression and/or Anxiety from uncertainty

- Peace of mind
- Positive attitude
- Reduced anxiety
- Better adjustment
- Improved compliance with treatment
- Better long-term relationship with provider

ROLE OF HOPE IN RECOVERY

- Distrust and/or Resentment towards provider
- Poor compliance with treatment
- Reduces subjective well-being
- Reduces patient's process of coping

- Setting realistic goals

ROLE OF HOPE IN RECOVERY

- Belief in oneself and ability to handle one's future
- Patients who participate in their own care have a greater sense of hope
- Promoting a sense of control by informing the patient about developments in treatment/rehabilitation
- Making resources available (i.e. about SCI/disease; spirituality; adaptive equipments)
- Awareness of own feelings

TREATMENT INTERVENTIONS

- Relationship with family, friends, caregivers
- Flexibility of patient and rehab team to adapt to changes and evolving circumstances
- Being future/goal-oriented; acknowledgement that there is a future

- Help patient restore hope

TREATMENT INTERVENTIONS (CONT.)

- Making meaning of losses
- Finding meaning has been associated with positive adaptation to injury
- Balance between holding onto pre-injury goals and adaptation to life after injury
- Assess person's subjective experience of losses (SCI-QOL Grief and Loss item bank)
- Construct and reconstruct narratives/life stories
- Allow person to grieve "the death of the body"



- Acknowledge added complication of lifelong disability
- Continuity of care (Community Reintegration)
- Encourage acceptance and resilience
- Provide an open narrative environment



ADJUSTMENT TO SCI IS A PROCESS, NOT AN END POINT, WHERE
LOSS CAN BE TRANSFORMED INTO NEW BEGINNINGS



TIME FOR QUESTIONS...MAYBE?

