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Psychological Adjustment after Spinal Cord Injury

Useful strategies for
health professionals



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All recommendations are for patients with SCI as a group. Individual therapeutic decisions must be based on clinical judgment with a detailed knowledge of the individual patient's unique risks and medical history, in conjunction with this resource.

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1. INTRODUCTION

Spinal Cord Injury (SCI) is a catastrophic injury with potential devastating impacts including far-reaching physical, social and psychological consequences. Research on the psychological impact following the sudden onset of SCI has shown that many will develop severe negative emotions in response to the injury which could threaten both psychological and social integration. In the past 10 years substantial attention has been focussed on the dynamics involved in psychological adjustment processes following SCI. Perhaps with some justification, early SCI rehabilitation research concentrated on physical and functional outcomes, and the literature tended to concentrate on medical issues arising in the acute and rehabilitation phases in hospital. However, it is now accepted that a thorough appreciation of the psychological and social factors associated with adjustment is crucial for optimal rehabilitation outcomes following SCI. Factors that will influence psychological adjustment will be multiple, including the effect of institutionalisation, grieving the loss of life before the injury, secondary complications like chronic pain and infections, and restrictions on social and physical mobility. Over the past 15 years or so, research has investigated the psychological and social dynamics associated with SCI adjustment, so that there is now a rich source of information arising from research detailing the short- and long-term psychological and social sequelae and adjustment to SCI.

Summary

- Severe emotional negative reactions following SCI are common which can threaten both psychosocial integration and security, requiring attention to the long-term psychological adjustment of individuals following SCI.
- Successful rehabilitation involves reintegration into the community and adjustment to a very different lifestyle with the re-establishment of satisfying relationships, roles and opportunities to express one's own identity.
- Experiencing a SCI poses a huge challenge and requires adaptation and resilience to cope in order to develop strengths and discover new ways of doing things, not only physically, socially and vocationally, but also emotionally.
- Each person is unique with his or her own individual personality characteristics and coping style, and this needs to be appreciated during rehabilitation.

2. MEETING THE PERSON WITH A SCI FOR THE FIRST TIME

First contact may be made with the individual soon after a SCI or in the early days of hospitalisation. This phase marks the beginning of the healing process. Experiences will be frightening and confusing for the person, highlighting the importance of the first meeting.

Psychological adjustment is influenced by how people are treated during the rehabilitation phase. Working with people in this early phase should initially be gradual and measured, limited to relationship building and gathering information. It is important to provide reassurance, delivered at the level people are able to accept.

Summary

- Emotional recovery following SCI is dependent on experiencing structure and normality in one's daily routine, and therefore it is crucial that this occur as soon as possible in the rehabilitation phase in hospital.
- Daily routines in the rehabilitation unit in the hospital will help to establish some structure.
- A sense of normality is created by interaction with the various health professionals.
- It is essential that support is provided from the beginning and the individual is treated with respect as they begin to rebuild their lives, remembering that the rehabilitation process is both physically and emotionally intrusive.

3. THE PSYCHOLOGY OF PEOPLE WITH SCI

An injury like SCI can happen to anyone in society, although active younger males are over-represented. Research suggests that there is a relationship between psychological dimensions such as personality, behaviour, perceptions with aspects of adjustment after SCI, with factors like optimism, humour, self-efficacy and solution-focussed coping skills predicting better outcomes. Pre-injury education level could also play a role in long-term adjustment.

Younger people have been found to be more accepting of their injury regardless of duration. They tend to be more flexible and open to new directions and experiences, having a greater ability to adapt to new situations. Other research has found a positive relationship between increasing age and risk of depression.

Personality, behavioural and cognitive changes may be apparent for those individuals with SCI who have a co-morbid traumatic brain injury (TBI). Neuropsychological testing has revealed that up to 50% of people with SCI have evidence of some cognitive impairment. Sometimes personality changes can be extreme and may also manifest in behavioural changes. Changes in personality, emotional state and behaviour may include: poor impulsive control, disinhibition, mood swings, aggression, fatigue, depression, agitation, reduced insight, and poor self-monitoring. Changes in cognitive function may include deficits in memory, problem solving and organising, decision making, concentration, initiation and abstract reasoning.

Summary

- Anyone in society is at risk of sustaining a SCI
- There is a relationship between psychological dimensions such as personality and perceptions and adjustment to SCI
- Younger people tend to be more accepting of SCI
- There is a greater risk of depression for older people with SCI
- 40%-50% of people with SCI present with varying degrees and patterns of cognitive impairment due to TBI, which may manifest in personality, behavioural and cognitive changes.

4. PSYCHOLOGICAL SEQUELAE OF SCI: ADJUSTMENT AND COPING

There is nothing predictable about the psychological sequelae of SCI. The response is very much individual and is mediated by both pre-morbid individual characteristics, perceptions of the injury and self-management, medical/secondary complications and external factors like medical factors and drugs. For most people, SCI will be associated with negative emotional reactions, which may not be evident initially. A psychological diagnosis warranting intervention from a clinical psychologist and/or psychiatrist occurs in only 40% of the SCI population as around 60% of adults with SCI cope and adjust well. The majority of people with SCI do not have disabling emotional, behavioural or cognitive symptoms following SCI. Characteristics such as humour, optimism, a robust sense of self-efficacy and an ability to employ problem-solving to deal with difficulties have been identified as common to this latter group. For those who are not adjusting well, the earlier negative symptoms are treated, the greater the likelihood of adaptive emotional recovery occurring.

Spinal cord injury is associated with a variety of emotional reactions, including:

- sadness & crying
- despair & guilt
- fear of losing control
- disbelief & panic
- helplessness & inadequacy
- disorganisation
- confusion
- resentment & bargaining
- loss of interests
- fatigue & lethargy
- loneliness & isolation
- withdrawal.

Psychosocial changes that can accompany SCI:

- Lack of privacy.
- Loss of independence..
- Changes to role/lifestyle.
- Uncertainty regarding the future.
- Sense of helplessness.
- Separation from family and friends.
- Inability to control basic bodily functions.
- Changes in physical health and functional ability.
- Changes in body image.

Other factors that affect psychological adjustment:

- chronic pain
- chronic fatigue
- medication
- isolation
- boredom
- medical complications and body image
- cognitive problems/TBI
- family/Friends/Social Supports.

Pre-injury psychological characteristics such as self-concept, perceptions of control like self-efficacy, and coping styles are considered to be as crucial in determining adjustment to SCI as are external factors like social support, socio-economic status and financial status.

The level and extent of injury or functional impairment have not been found to predict adjustment to the injury. People with tetraplegia have been found to be just as likely as those with paraplegia of achieving healthy adjustment.

5. PSYCHOLOGICAL COMPLICATIONS AND MANAGEMENT

Best evidence shows that adult people with SCI have raised levels of depressive mood and negative psychological states such as anxiety. People with SCI also have increased risk of significantly lowered quality of life. A psychiatric diagnosis can be made in about 40% of people with a recent-onset spinal cord injury. The most common psychiatric diagnoses are: substance abuse disorders, conditions attributable to delirium or brain injury, adjustment disorders (see Appendix C) and depressive disorders.

Post-traumatic stress reactions are common in persons following a major stressful life event like a motor vehicle crash or assault. Symptoms fall into physical, cognitive and emotional domains (see **Appendices A and B**). If not appropriately treated, the symptoms may develop into Post-Traumatic Stress Disorder (see Appendix B). The implication of these findings is that it is crucial that people with SCI receive psychosocial treatments shown to be effective in reducing psychological morbidity and improving quality of life. These treatments should focus on the development of adaptive coping skills that are designed to improve mood states, enhance perceptions of control, increase social engagement capability, improve self-management capacity, improve employability, and increase understanding of the influence of the injury and impairments on crucial areas such as sexuality and physical and mental health.

6. DEPRESSION VERSUS GRIEVING REACTIONS FOLLOWING A SCI

There is frequent mention of individuals suffering from depression in SCI rehabilitation units. This may have been used loosely to describe people having a bad day or to describe someone with Major Depressive Disorder (see **Appendix D**). Clinical impressions have tended to over-estimate psychological disturbance with a consistent bias by staff to over-estimate depressed mood relative to the person's self-report. Findings suggest that those who are least depressed function best during rehabilitation and later after discharge.

Summary

- Major depressive disorder is not a normal and necessary or essential part of the process of adjustment to SCI, but indicates that the person is distressed and not coping adaptively.
- The presence of depression is not related to level or degree of injury, contrary to popular opinion.
- The grieving reaction may appear similar to depression, but unlike depression will dissipate over time as the individual learns to live with his or her injury and impairment.
- Mourning or grieving may also present with physical complaints, preoccupation with a former self-image, feelings of guilt, feelings of anger/irritability and behavioural changes (eg. avoidance of social activity).
- The important distinction between mourning and depression is that people who are experiencing a grief reaction will be focused on loss, such as the paralysis and the accompanying secondary emotional reactions. For example, the individual with SCI would bemoan the high dependence that comes with SCI and consequent altered quality of life. In reactive depression, the focus is self-critical, with feelings such as worthlessness, hopelessness, helplessness, and withdrawal from others.

7. PREDICTORS OF PSYCHOLOGICAL VULNERABILITY AND RESILIENCE FOLLOWING A SCI

There are a number of factors that predict vulnerability to psychiatric morbidity. These include:

- a history of psychiatric disorder (including substance abuse)
- family history of psychiatric disorder
- a history of impulsiveness (which is over-represented in SCI populations)
- a history of family fragmentation
- lack, and especially recent loss, of an intimate relationship.

Please note, injury factors such as the level and severity of the SCI and the extent of related injuries are either only weakly correlated with psychiatric disturbance or not at all. Injury-related variables such as the presence of chronic pain (eg. neuropathic pain) and chronic fatigue are consistently associated with depression.

Just as importantly, there are a number of factors that protect against vulnerability to psychiatric morbidity and thus enhance resilience. These include:

- helpful social support
- a robust perception of self-management and self-control (e.g. self-efficacy)
- an ability to problem solve
- social access and integration
- employment.

8. SUICIDE

Suicide is an extreme behavioural response to the adversity associated with SCI. Death from suicide has been found to occur up to five times as often in the SCI population as in the general population. There has been an alarming increase in suicide amongst this group over the last 20 years. It is most likely to occur within 5-6 years post injury and is responsible for 6-10% of all SCI deaths. Passive suicide is thought to account for additional deaths related to self-neglect, leading to recurrent pressure areas, urinary tract infections and pneumonia.

Suicidal ideation is common, and should be taken seriously. Never assume that because a person has a catastrophic injury like SCI they cannot commit suicide. A referral to an experienced mental health clinician should be made for an assessment and management of suicidal thoughts should be discussed.

Risk factors for suicide

- depression
- anger and aggression
- alcohol and other drug abuse throughout hospitalisation
- pre-morbid psychiatric illness
- prior suicide attempts
- family disintegration
- male gender
- chronic pain and chronic fatigue
- multiple medical problems and frequent hospitalisation.
- social isolation
- schizophrenia
- expressions of hopelessness.

Recommended management

- If any individual expresses suicidal ideation, ensure the person's immediate safety.
- Obtain an urgent psychiatric consultation if the person's immediate safety is at risk.
- Determine the appropriate setting of care.
- Treat underlying problems such as depression, substance abuse, pain, etc.
- Involve family and friends where possible.
- Regular observation of the person is important
- Active listening by staff.
- Encourage expression of feelings and encourage active coping.
- Help with the maintenance of hygiene, nutrition, bowel and bladder programs while the person is in a depressed state.

9. CONCLUSION

While adjustment following SCI is clearly related to multiple factors, latest research has confirmed that psychological and social factors are major contributors to adaptive adjustment. This evidence strongly suggests that for people with SCI to develop optimal resilience and quality of life, the rehabilitation process must incorporate psychosocial processes such as sensitive psychosocial assessment, an emphasis on self-management of the injury, self-management of finances if appropriate, self-management of secondary conditions, develop a problem solving approach, and enhance social and vocational support. Furthermore, resources that enhance adjustment should be increased and made available in the community to encourage increased access after discharge from rehabilitation.

10. SHORT QUIZ

- Adjustment following spinal cord injury is influenced positively by which factors:
 - helpful social support.
 - a robust sense of self-management.
 - the identification of risk factors of poor psychosocial outcomes.
 - all the above.
- Suicide associated with SCI is a risk for:
 - up to 10% of all people with SCI.
 - up to 5% of all people with SCI.
 - up to 20% of all people with SCI.
 - up to 1% of all people with SCI.
- Depressive mood is a risk for what percentage of adults with SCI living in the community:
 - Almost all people with SCI are at risk of developing depressive mood.
 - 20 to 40% of people with SCI are at risk of developing depressive mood.
 - 10-20% of people with SCI are at risk of developing depressive mood.
 - None of the above.
- Evidence suggests the majority of people with SCI:
 - are at risk of suicide or at least, self-harm behaviour.
 - will never return to work at all.
 - become seriously fatigued and anxious.
 - adjust well to the injury and show resilience to the associated impairment.
- Which of the following is not a common secondary condition for adults with SCI:
 - chronic pain.
 - cancer of the stomach.
 - urinary and respiratory infections.
 - sleep disturbance.
- The most desirable management of depressive disorder following SCI is:
 - a rational pharmacological approach.
 - a regular and balanced diet.
 - psychosocial treatments like CBT.
 - a combination of all the above.

Answers: 1: d, 2: a, 3: b, 4: d, 5: b, 6: d

11. APPENDICES

APPENDIX A

Acute Stress Reaction

An Acute Stress Reaction is a transient condition that develops in response to a traumatic event. This diagnosis is appropriate only for symptoms that occur within 1 month of the extreme stressor and resolves within a 4 week period. If symptoms persist for more than 1 month then a diagnosis of Post-Traumatic Stress Disorder may be made.

SYMPTOMS may include a varying mixture of:

- appearing dazed or distracted
- reduced levels of consciousness
- agitation or over-activity
- withdrawal
- anxiety symptoms (e.g. sweating, increased heart rate, flushing)
- narrowing of attention
- disorientation
- depression
- amnesia.

Recommended management

Management strategies will always vary from one individual to the next depending on the individual's particular problem. However, the management of an acute stress reaction generally involves the following:

- Recognise the symptoms and organise a prompt referral to an experienced mental health clinician, such as a clinical psychologist or psychiatrist to determine the severity of the symptoms. Persistent symptoms may require more specialised treatment and a revised diagnosis of Post-Traumatic Stress Disorder and/or Depression.
- Let people know that these are commonly experienced after a traumatic and life threatening event, and a normal reaction to such a stressful situation.

- Encourage the person to talk about what they are experiencing with family and friends. Discussion may help reduce any negative appraisals of his/her reaction during the experience.
- Time: reassure the person that the acute stress reaction is likely to pass in a short period of time.
- Helpful social support will be critical for improving the individual's ability to cope after a trauma has occurred. It may be necessary to identify potential sources of support and facilitate support from others (e.g. partners, family, friends, work colleagues, peer support).

APPENDIX B

Post-Traumatic Stress Disorder (PTSD)

PTSD is characterized by the development of a long lasting anxiety response following a traumatic or catastrophic event. Typically, the individual experiences or witnesses a traumatic event such as actual or threatened death, serious injury to oneself or another person or a threat to the personal integrity of oneself or others. The response involves helplessness, intense fear or horror.

PTSD is often undiagnosed due to failure to appreciate symptoms especially, emotional numbness, a physical/ medical focus, lack of direct questioning by clinician and person trying to avoid or deny feelings.

PTSD usually develops within 3-6 months of the traumatic event (although sometimes later) and involves:

- images, dreams or flashbacks of the traumatic event
- avoidance of cues which act as reminders of the traumatic event
- amnesia about important aspects of the traumatic event
- depressed or irritable mood
- social withdrawal
- concentration and memory difficulties
- nightmares and disturbed sleep
- being easily startled.

Differential diagnosis

PTSD is distinguished from an Acute Stress Disorder by the time frame in which symptoms are experienced. In an adjustment disorder the stressor need not be as severe as in PTSD and individuals do not tend to relive the unpleasant experience/s as they do in PTSD. Depression usually co-occurs with PTSD.

Recommended management

Recognise symptoms and organise a prompt referral to an experienced mental health clinician, such as a clinical psychologist or psychiatrist to determine the severity of the symptoms. PTSD is difficult to treat.

Effective treatment involves a comprehensive approach of medication and learning adaptive skills to cope with and confront systematically the experiences, memories and situations associated with the traumatic event.

APPENDIX C

Adjustment Disorder

Adjustment Disorder is characterised by experiencing distress and emotional disturbance over a period of around six months following the occurrence of a significant life change or stressor. Examples of some such life stressors are: bereavement, divorce, chronic illness, or threat of illness, a natural disaster and retirement, to name a few. The stressor may affect the individual, an entire family, or an entire community.

The symptoms must develop within 3 months after the onset of the stressor(s). The clinical significance of the reaction is indicated either by marked distress, or by significant impairment in social or occupational functioning.

An adjustment disorder should resolve within 6 months of the termination of the stressor. However, the symptoms may persist for a prolonged period (i.e. longer than 6 months if they occur in response to a persistent stressor such as chronic illness).

Adjustment disorders increase the risk of attempted and completed suicides and may complicate the course of illness in individuals who have a general medical condition (e.g. decreased compliance with the recommended medical regime or increased length of hospital stay).

Common symptoms of Adjustment Disorder include:

- depressed mood
- elevated anxiety or worry
- feeling unable to cope with life at present or plan ahead
- insomnia
- stress-related physical symptoms (headaches, abdominal distress, chest pain, and palpitations)
- interference with social functioning or performance of daily activities.

There needs to be strong evidence that the disorder would not have developed in the absence of this stressor or life change. A diagnosis depends on the content and severity of symptoms and on an individual's personality and history.

Recommended Management

- Offer a supportive and confiding relationship.
- Encourage control of negative thoughts.
- Assist and encourage problem-solving.
- Encourage involvement in positive activities.
- Promote health maintenance.
- Provide controlled exposure to reminders of loss.

APPENDIX D

Major Depressive Episodes

Depression is a mood state characterised by significantly and persistently lowered mood and a loss of interest or pleasure in activities that are normally enjoyable. While most people will experience sadness or depressive mood sometime in their lives, Major Depressive Disorder or Episode is distinguished from this by its severity, persistence, duration and the presence of specific symptoms.

Common emotional, behavioural and physical symptoms of Major Depressive Disorder are:

- markedly depressed mood
- loss of interest or enjoyment
- reduced self-esteem and self-confidence
- feelings of guilt and worthlessness
- bleak and pessimistic views of the future
- ideas or acts of self-harm or suicide
- disturbed sleep
- disturbed appetite
- decreased libido
- reduced energy leading to fatigue and diminished activity
- reduced concentration.

Who is at risk of developing Depression?

A personal or family history of depressive illness increases the risk of developing depression during a grief reaction. Premenstrual tension/hormonal factors for women also affects mood and depressive states.

Recommended management

- Referral to an experienced general practitioner, clinical psychologist or psychiatrist for an assessment.
- Individually planned management program.
- Appropriate first-line treatments include a structured psychotherapy such as cognitive-behavioural therapy (CBT) or interpersonal therapy (IPT), and/or trial of antidepressant medication.
- Address issues of stigma, bias against people with mental health issues in rehabilitation settings.

Contacting mental health professionals

Access to clinical psychologists and psychiatrists is often limited requiring the GP to take a critical role in dealing with mental health issues and Community Mental Health Teams.

- For people living within the community, GPs are required to refer individuals to psychiatrists for a psychiatric consultation.
- A psychological consultation can be requested by contacting the clinical psychologist directly. Most rehabilitation units have a consultation-liaison psychiatry service that can be contacted by the rehabilitation consultant or registrar.

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