

## A Clinical Perspective on the Need for Psychosocial Care Guidelines in Spinal Cord Injury Rehabilitation

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### Abstract

**Objective:** Spinal cord injury (SCI) is a catastrophic physical injury presenting substantial obstacles to adjustment in the long-term, often being associated with additional challenges, including traumatic brain injury, frequent hospitalization, substance abuse, co-morbid psychiatric conditions, chronic pain and fatigue, social discrimination and poor employment prospects.

**Methods:** In an effort to improve rehabilitation and outcomes for people with SCI in the state of NSW, Australia, psychosocial guidelines have been developed to provide direction for enhanced service delivery, staff training and care processes. A major goal was to ensure persons with SCI would receive comprehensive psychosocial care, arguably leading to improved quality of life and functionality in daily living. It is believed that implementation of psychosocial recommendations into care settings will improve decision-making concerning assessment, treatment, referral and living arrangements by rehabilitation health professionals (such as physicians, psychologists, social workers, occupational and physical therapists, rehabilitation counselors and nurses). A secondary goal was to provide guidelines that would promote improved understanding of the psychosocial needs of people with SCI in legislators, policy-makers and other stakeholders within the health and social care environments.

**Conclusion:** This paper provides details of the developed guidelines, discussing implications for their application in rehabilitation practice within the hospital inpatient setting, as well as the significance for research directions into psychosocial aspects of SCI rehabilitation.

**Keywords:** Spinal cord injury; Psychosocial; Rehabilitation; Pain; Depression; Quality of life

### Introduction

While the efficacy and nature of medical aspects of spinal cord injury (SCI) rehabilitation have been subject to systematic study and refinement resulting in highly developed approaches [1], psychosocial aspects have historically been less commonly investigated and applied, and arguably, are less developed in comparison. Furthermore, given the increased longevity of people with SCI [2], negative psychosocial outcomes have become more apparent, increasing the need for research on improving psychosocial status following SCI [3-17]. This state of affairs has arguably resulted in a deficit in best treatment implementation for psychosocial management in SCI rehabilitation, with the consequence that clinicians are often unsure of how to help someone when, say, they present with problems like sadness, suicidal ideation, aggressive and challenging behavior, or alcohol dependence. This is the case in Australia, if not in many SCI units worldwide. Psychosocial management is certainly required when specific problems are examined, for instance, high occurrence of psychological morbidity [18-31]. Rates of depression are estimated to range between 20 to 40% of the adult SCI population, almost 10 times the rates of

depressive mood in the able-bodied [4,8,28]. Incapacitating severe chronic fatigue and pain can be experienced by at least 50% of adults with SCI [7,12,13,22,23], unemployment is prevalent in the majority of adults with SCI [14,15,21], and suicide rates can be more than twice the rate in the able-bodied population [20].

The methodology of selecting psychosocial guidelines has been provided in detail elsewhere [15]. The process began with numerous discussions with stakeholders and a forum being held with a wide selection of health professionals from SCI Units, staff from specialized clinics and hospitals, in conjunction with an interchange with an international expert who visited Australia for this purpose (Professor Paul Kennedy from Oxford, UK). Following this quite extensive process over a period of two years or so, the goal of improving the psychosocial care of people with SCI was promoted through the development of a Statewide Committee, with principles and guidelines [15] developed following an extensive systematic literature review process. Search engines employed included Medline and PsychInfo, and the review was conducted by the authors. Keywords used in the systematic review included terms such as "spinal cord injury" and "psychosocial", and these were combined with more specific terms such as "depression", "anxiety", "employment", "alcohol abuse", "chronic pain", and so on, to generate relevant research papers.

Consistent findings from the systematic review that could influence psychosocial guideline recommendations were then provided to a multi-professional group in the form of a systematic review document that detailed the findings and the available evidence. The group was selected on the basis of their expertise in the area, and the group was composed of prominent health professionals, including a rehabilitation physician, research and clinical psychologists, a psychiatrist, a neuropsychologist, a social worker, a specialist rehabilitation nurse, an occupational therapist, as well as stakeholders such as a person with SCI. This group then met to discuss guideline recommendations in the light of the findings of the systematic review, so as to gain consensus on best evidence clinical practice in SCI psychosocial rehabilitation. Where best evidence was not available from the literature on specific areas of psychosocial rehabilitation, guideline recommendations were based on consensus by the expert group.

Table 1 presents factors that influence adjustment to SCI, providing a background to the psychosocial guidelines, and Table 2 presents principles we believe require consideration when developing psychosocial guidelines for SCI rehabilitation. Of all the principles listed underpinning the guidelines and related recommendations, the acknowledgement that psychosocial care should be regarded as the core business of all those involved in SCI care, including medical and nursing staff, physiotherapists, occupational therapists and other allied health professionals is foremost. The material in these tables demonstrate the complex nature of SCI and its management [3,4].

It is hoped that this discussion will promote improved appreciation of the psychosocial needs of people with SCI, as well as serve to advocate for people with SCI, amongst relevant stakeholders and lead to better client-focused care provision.

Factor	Influence on adjustment
Effective communication	Effective communication improves patient outcomes by establishing rapport, trust and encouraging disclosure [16,17]
Institutionalization and dehumanization	SCI rehabilitation requires very long hospitalization stays, resulting in increased dependency, reduced privacy, confusion, and reduced self-responsibility [18]
Pre-morbid influences	Factors operating prior to the onset of the SCI will influence adjustment, such as a tendency to substance abuse, a complex personality profile, or other physical disabilities/ diseases [4,19,20]
Social, family and sexual influences	SCI is associated with significant changes to sexual, social and family relationships and has the potential to disrupt functional equilibrium [3]
Employment and social access	Financial concerns, home modification requirements, transportation difficulties and reduced rates of employment are challenges to adaptive adjustment [11,21]
Comorbid and secondary conditions	Conditions such as traumatic brain injury (TBI), recurrent infections, chronic pain and mental health disorders have the capacity to influence adjustment negatively [6,7,11,12,22-24]
Coping styles and perceptions	Attributions (eg. self-efficacy) and coping styles can enhance or become a barrier to adjustment [9,13,22,26]
Mood states	Elevated negative mood states will impede adjustment and possibly result in higher risks of attempted suicide [4-8,25,27,28]

**Table 1:** Factors influencing adjustment following a SCI.

The Biopsychosocial Model should guide SCI rehabilitation, as it integrates biological, psychological and social dimensions of physical and mental health outcomes, and it has been successfully applied previously to SCI care [29,30].
Adjustment is a continuing non-linear cyclical process and can therefore be unpredictable and complex [31,32].
An overarching goal of SCI rehabilitation is to establish optimal independence for each individual person [33,34].
Psychosocial care should be regarded as the core business of all those involved in SCI care, and that adjustment should not be the sole responsibility of the person with SCI, but a combined effort of family, friends, the rehabilitation team, work, and so on [31,32].
Peer involvement and support should be standard feature in rehabilitation, that is, encouraging the use of peers as role models and mentors, as well as for sources of support [33,35].
A tiered approach to provision of services is necessary, that is, training in self-management strategies should be regarded as a core requirement for effective rehabilitation. However, more intensive and specialist interventions, as well as case management/more assertive approaches, may be required for complex cases and those at risk of poor outcomes.
Individuals with SCI should have uncomplicated access to mainstream specialized psychosocial services, such as treatment for substance abuse, chronic pain or traumatic brain injury, as well as mental health disorders.
Enhancement of relevant skills of staff working in mainstream areas is therefore required, including health professionals working in private practice and in rural and remote areas.

**Table 2:** Psychosocial principles guiding rehabilitation practice.

## Psychosocial Guidelines

Based upon the review of the evidence concerning psychosocial care of people with SCI, and the discussions undertaken with local and international experts, the steering group agreed on a range of recommendations, with the key aspects of the guidance to improve psychosocial care in people with SCI summarized below under various headings. While these guidelines are specifically applied to the inpatient rehabilitation phase, it is important to state that psychosocial support and management should begin during the acute/admission phase of SCI management, and furthermore, psychosocial support should continue in the community, for instance, providing assistance with social re-integration, employment and injecting resources into family members and caregivers [32-34].

## General Guidelines

Psychosocial rehabilitation should begin immediately after admission, depending on the person's medical condition and cognitive status, with every attempt made during inpatient, as well as subsequent outpatient rehabilitation to promote a supportive/healing environment. This includes respecting privacy and making the person aware of their rights and responsibilities, as well as treatment options with information about their diagnosis and prognosis. It also involves promoting active engagement of the person with SCI in their rehabilitation using strategies to enhance self-efficacy and appropriate perception of control. This principle may be reflected both in the physical environment of inpatient services (such as providing access to areas to practice skills out of usual therapy hours) and in the rehabilitation process (such as promoting the client's active participation and decision-making in the treatment and discharge planning process). To facilitate this, the following are recommended:

A health professional key-worker should be designated and allocated to each new person with SCI admitted to the inpatient rehabilitation program. The key-worker was a qualified health professional working in the SCI Unit, and could be any member of the SCI team such as a psychologist, social worker, occupational therapist, physiotherapist, or rehabilitation nurse. The key-worker's role was informed by professional ethics, and each professional was accountable to the team and to their patient. The key-worker's role is to ensure that a psychosocial needs assessment has been conducted and that assessment outcomes are considered when implementing treatment. The key-worker role is only active while the person with SCI is resident in the SCI Unit. Where co-morbidities are present (such as psychiatric disorder), it is desirable that the selected key-worker should have skills in the management of the co-morbidity. The key-worker concept has been used with success with inpatients with SCI in the National SCI Centre, Stoke Mandeville Hospital in the United Kingdom [33].

Rehabilitation team members should employ effective communication skills based upon empathy and active listening when interacting with the person with SCI and their family.

The treating team should receive training so that they are sensitive to signs and symptoms of distress, as well as the concerns of the patient and their family, and maintain an awareness of what constitutes an appropriate response to clinically significant symptoms such as elevated anxiety/panic, negative mood states as pessimism and persistent sadness, post-traumatic stress reactions, alcohol abuse behavior, signs of traumatic brain injury, pre-morbid psychopathology, suicidal ideation, and so on.

The treating team should be sufficiently skilled so that they can conduct brief psychosocial interventions appropriate to their role, and/or provide timely and appropriate referral.

## Recommendations Concerning Psychosocial Assessment

A comprehensive systematic assessment should be conducted covering aspects of psychosocial function. The first needs assessment should be conducted within five days of the person with SCI being admitted to rehabilitation and should be repeated just before discharge and after 6 and 12 months of living in the community. Wherever possible, assessment tools used should have acceptable scientific validation and reliability [15]. Assessment should include: pre-morbid details, including occurrence of prior psychopathology and substance abuse; presence of mental disorders (via a structured or semi-structured mental disorder diagnostic interview), mental health screens and psychological status (eg. post-traumatic reaction, negative mood, anxiety, anger, fatigue and confusion, perceptions of control or self-efficacy, resilience, and quality of life); neuropsychological status, a brief personality test; and an interview assessing social factors such as ethnic, cultural and spiritual factors; sexual concerns, vocational and educational status, social support and family networks, financial status; housing and living arrangements, leisure interests, and family expectations of rehabilitation. An abridged assessment should be repeated just before discharge and 6-12 months after living in the community. Given the length of assessments, it is recommended that assessment be performed in 2 or 3 stages, so the client does not become fatigued.

Younger people with SCI being transferred from pediatric to adult services should also receive a comprehensive psychosocial needs assessment at that point. Particular care should be taken to assess the need for further rehabilitation input in those areas that may not have been systematically addressed at the time of initial injury, such as sexuality. To support these recommendations, all staff should have training to develop skills for basic psychosocial assessment to screen for psychological distress.

## Recommendations on the Planning for Psychosocial Aspects of Rehabilitation

A multidisciplinary psychosocial treatment plan, based upon the initial needs assessment, should be developed to cover all stages of the adjustment process, including inpatient rehabilitation, integration into the community, and outpatient rehabilitation. The plan should contain information concerning the treatment such as presenting needs, the individual and family goals and expectations and any anticipated risks or barriers to successful outcome. It is recommended that:

Psychosocial rehabilitation goals be composed of specific steps (eg. steps for learning activities that strengthen physical, social, interpersonal and psychological skills), and

Rehabilitation goals be open to revision, as significant changes in an individual's condition occur.

## **Recommendations for the Provision of Psychosocial Interventions during Rehabilitation**

It is recommended that all people admitted to rehabilitation as an inpatient receive comprehensive evidence-based psychosocial treatment consisting of cognitive behavior therapies (CBT) and related psychological components. CBT treatment should be tailored to the needs of the person and effectiveness assessed at the termination of the treatment for each participant. If treatment has not resulted in demonstrable improvement, the person with SCI may need to be referred to specialized interventions. For instance, for persons with high levels of pain, referral to a specialized pain management program or those with a history of substance abuse, referral to a specialized substance abuse prevention program may be required.

### **Self-Management Community Based Program**

It is recommended that all persons with SCI receive a specialized evidence-based self-management program designed to improve their self-care and mental health in the long-term. The SCI needs assessment plan should provide ongoing community re-integration services and social support through community referrals, including community mental health programs; driver education training; educational programs; financial assistance services; home health services; home modification services; independent living centers; recreation programs; sexuality and couple counseling; SCI associations; transportation services; and vocational rehabilitation services.

### **Support for Health Professional Staff in the Provision of Psychosocial Rehabilitation**

Staff will need to receive additional training in order to be adequately resourced and skilled to undertake the recommended tasks and roles; for example, concerning psychological and iatrogenic reactions in the acute stage of catastrophic injury, managing difficult behaviors and coping styles including aggression; motivational interviewing and developing effective communication techniques. In addition, it is recommended that rehabilitation staff attend regular team debriefing sessions.

### **Provision of Support for Caregivers and Significant Others**

It is recommended that caregivers and family receive support that will enhance their capacity to deal with the pressures and strains of caring for a person with SCI. Support should include full awareness of government and non-government organizational support systems, peer support services, advocacy, accommodation programs and mental health assistance resources.

### **Specialized Psychosocial Rehabilitation**

It is recommended that where a SCI person has been diagnosed with a severe psychological disorder (such as post-traumatic stress disorder or bipolar disorder), they be referred to specialized services. Collaboration between the rehabilitation treating team, primary care services and the relevant providers of the specialized psychosocial care should be encouraged to ensure that the SCI person's needs are met appropriately.

## **Discussion**

Psychosocial care should be regarded as core business for all front-line staff that are involved in SCI care, including medical and nursing staff, physiotherapists, occupational therapists and other allied health professionals, and not just the domain of those in the team with specialized training in managing psychosocial and mental health disorders. The Guide incorporates a number of models [29-37] that have the capacity to improve the psychosocial rehabilitation of people with SCI. In particular, the clinical recommendations were influenced by the premises of the Biopsychosocial Model [29], acknowledging that people with SCI, in addition to the physical challenges, have experienced psychological and social changes requiring substantial adjustment. The Guide also recognized the value of other models in shaping SCI psychosocial rehabilitation, such as the Stress Appraisal Model [36], which suggests that adjustment and coping depend upon a person's stress and health status, believed to be a product of how people perceive their ability to cope with life stressors, and the Transtheoretical Readiness to Change Model [37], proposing that the ability to change depends upon the person's psychological readiness to change.

The Guide also discussed the important contribution to psychosocial rehabilitation of several service design models. These included peer support models that encourage the use of peers as role models, mentors and for sources of support [35]. Best evidence research into self-help and consumer initiatives consistently shows that participation by consumers is associated with reduced hospitalization, reduced use of other services, increased knowledge, information and coping skills, increased self-esteem, confidence, sense of well-being and of being in control, and stronger social networks and supports [34]. An additional service model included the Stoke Mandeville Key-worker Goal Planning Model [33], which places emphasis on the importance of comprehensive assessment and analysis of the SCI person's needs, including a broad range of activities of daily living and psychosocial status, followed by specific goal planning. Breaking down goals into small practical and achievable steps with active patient involvement is central to this approach. The model contends that the role of a designated key-worker is crucial to the effectiveness of rehabilitation provision and improvement of outcomes in people with SCI.

The outlined recommendations concerning the psychosocial care of people with SCI are currently being implemented in the SCI units and outreach services in Sydney, NSW, Australia, with the goal of improving and standardizing care. Regular review of implementation is being conducted by an ongoing steering committee made up of stake holders and health professionals. There are, however, some implications and challenges that need to be considered in relation to scope of practice, selection of staff and continuing professional development for existing staff in order that staff in SCI rehabilitation services would be able to implement these recommendations. A tiered approach to provision of services is required. The demands placed upon the individual following acquisition of a SCI means that training in general self-management strategies is regarded as a core requirement for effective rehabilitation. However, it is recognized that there are also those who are clearly at risk of a poor outcome and so may need more intensive intervention, or who may be experiencing co-morbid psychological disorders that require specialist treatment.

Further investigation is required into what constitutes sensitive routine psychosocial assessment during the inpatient phase (acute and rehabilitation phases, and after discharge) that can be used to predict



rehabilitation outcomes. Screening assessments must also be economical in terms of time and cost. An additional challenge involves the development of the psychosocial treatment programs recommended in the Guide with demonstration of their efficacy (in terms of improving adjustment outcomes). The intervention has been recommended to be multilayered in the sense that while all inpatients with SCI will receive a CBT program, different CBT programs will be recommended for people with SCI who present with various psychosocial risks. For instance, people with SCI who have been assessed as having a low risk of co-morbidities (such as major depressive disorder, cognitive deficits, substance dependency, and so on) will receive low intensity CBT intervention. However, inpatients with SCI assessed as at increased risk will receive specialized CBT packages designed to address the identified risk.

Finally, it is difficult enough to provide well integrated biopsychosocial care within an inpatient rehabilitation setting, but this becomes far more challenging after discharge into community. Individuals with SCI should be able to access mainstream psychosocial services, particularly where these are highly specialized (such as drug and alcohol, pain management, mental health and traumatic brain injury services). However, there are many physical and environmental barriers to the use of such services, as well as the lack of knowledge and skills of those professionals within such services in relation to SCI. This highlights that in the future for continuity of care and the ongoing provision of psychosocial support of individuals with SCI for adjustment and their families an important strategy for implementing the recommendations in the Guide will be to focus on how to support existing services in increasing access for those with SCI and staff in acquiring appropriate knowledge and skills. This will need to include providing support to individual psychosocial health professionals working in general services or in private practice in rural and remote areas to enhance access to interventions that would otherwise be inaccessible.

Dissemination of these guidelines has been achieved through publication of the recommendations and guidelines [15] which are freely available at: <http://www.aci.health.nsw.gov.au/networks/spinal-cord-injury/resources>. Further dissemination is occurring through seminars, conferences and publication of papers. It is hoped that this paper will provide the basis for further discussion and be a catalyst for collaboration amongst SCI rehabilitation providers in relation to service design and delivery of psychosocial rehabilitation for people with SCI, ultimately leading to improved outcomes of care with a greater chance of individuals experiencing good quality of life after SCI. Acknowledgments

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