

# **PSYCHOSOCIAL GUIDELINES IN SPINAL CORD INJURY REHABILITATION**



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(ASCoN)

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# **ASIAN SPINAL CORD NETWORK ASCoN**

## **PSYCHOSOCIAL GUIDELINES IN SPINAL CORD INJURY REHABILITATION**

**2015**

### **Preface**

Individuals with spinal cord injury (SCI) experience drastic changes in almost every aspect of their lives. These include disruptions in the physical, psychological and social domains. Moreover, a positive adjustment to SCI often requires enormous behavioural change and attention to self-care activities. The person with a SCI has to learn and maintain skin checks, pressure releases, vigilance to urinary tract infections, respiratory illnesses, exercise, dietary modifications and ongoing stress management. Attention to these matters is much more difficult and complicated than one might initially assume; and is influenced by multiple behavioural and psychosocial variables.

In many cases, the psychosocial needs of an individual with SCI can be as devastating as the physical changes themselves. In other cases, the psychosocial needs of the individual and family can be so overwhelming that rehabilitation cannot proceed. Yet, in many countries, psychosocial issues tend to be overlooked and neglected both during rehabilitation and after discharge. This leads to issues such as apathy, depression, suicide, poor self-care and feelings of hopelessness. As a result, successful community living and a positive quality of life become non-existent.

## Background

For the past several years, addressing these psychosocial issues has been an increasing priority of the Asian Spinal Cord Network (ASCoN). In this regard, there has been a growing interest among ASCoN countries, to develop guidelines or standards of care for psychosocial services for people with SCI. Once developed, it is anticipated that psychosocial services could be implemented in regions, where such services currently do not exist or are provided sporadically.

This ongoing recognition of the importance of psychosocial services in SCI rehabilitation has evolved gradually over a period of time. As rehabilitation services have improved, the emphasis in SCI rehabilitation has slowly shifted from survival to quality of life. Our experience with people who have a SCI has demonstrated the growing importance of quality of life and community integration, especially as people live longer with SCI and are more active with their families and in their communities.

To meet the growing need for education on psychosocial issues, ASCoN and other organisations have included psychosocial presentations at their annual meetings, conducted workshops at ASCoN member SCI Centres and provided consultations and involvement on psychosocial issues from regional and international resource people. These efforts have been met with enthusiasm and a growing realisation that people with SCI can lead productive and fulfilling lives.

In addition, during 2007 ASCoN developed and published the Guiding Principles for Management of Spinal Cord Injuries. These principles provide an overview of SCI care based on the experience of various experts in the Asian region. In 2009, ASCoN expanded their resources and published a spinal cord injury prevention guide in an attempt to raise awareness as to the common causes of injury.

The development of the current “Psychosocial Guidelines in SCI Rehabilitation” are consistent with the ASCoN commitment to develop more detailed guidelines for each specific aspect of SCI management. These guidelines are intended to be shared among facilities and to serve as a resource for newly developed services.

In October 2009, this growing interest in psychosocial functioning after SCI culminated in a successful 5-day ASCoN sponsored peer counsellor workshop at the Indian Spinal Injuries Centre in New Delhi, India. Peer counsellors, psychologists, psychiatrists and SCI consumers from various countries in the ASCoN region participated in educational presentations, role playing and clinical counselling exercises. The outcome of this workshop was designed to increase the knowledge and clinical skill set of people providing psychosocial services to individuals with SCI and their families. Evaluations of the programme were extremely positive and strengthened the network of collegial relationships among psychosocial providers in the region.

At the conclusion of the 2009 workshop, the workshop participants and faculty developed an initial draft of psychosocial guiding principles. This initial draft, completed in 2009 and 2010, serves as the foundation for the present version of these psychosocial guidelines. Members of the original 2009 workshop are acknowledged for their many contributions in developing this document and in beginning this process.

In addressing the need for psychosocial services, the UNCRPD establishes the human rights of people with disabilities to the highest attainable standards of health and provision of rehabilitation. The International Perspectives on SCI (IPSCI), a collaborative publication of the World Health Organisation, (WHO) and the International Spinal Cord Society, (ISCoS) highlights that during the post-injury period, individuals with SCI and their family members will often experience grief and a range of emotions including denial, sadness, fear, frustration or anger as they begin the process of adjustment.

In developing these psychosocial guidelines, ASCoN endorses the fact that people with SCI have the right for full and effective participation in society and equality of opportunity, as stated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Thus, it is our belief that the ideal approach to comprehensive rehabilitation includes equal attention to both the psychosocial and the physical aspects of care. Although this concept of psychosocial care for people with SCI and their families is gaining momentum and recognition, the various SCI centres throughout Asia have different approaches in accomplishing this goal. Resources tend to be scarce and services are limited.

ASCoN advocates that ideally a SCI Centre should include a complete mental health rehabilitation team that utilizes the services of a psychiatrist, psychologist, social worker and peer counsellor. In most cases however SCI centres may have only one or other of these professionals who may work on a part time basis with multiple responsibilities. In addition, some programmes may use peer counsellors with little or no training or supervision who volunteer from local consumer organisations or who live close to the SCI centre.

While we recognise that various centres may have limited financial resources, lack of qualified personnel, or other priorities during rehabilitation, ASCoN does endorse the concept that the psychosocial needs of the individual with SCI are central to a full and productive life after discharge.

ASCoN further advocates that certain minimum educational and personal criteria are important for all people who provide psychosocial services to people with SCI. As such, it is our belief that providers of psychosocial services should undergo a comprehensive curriculum of training and should follow professional standards and ethics. They should also have opportunities to network, exchange ideas and receive ongoing education. It is the goal of this document to address these issues and to develop consensus regarding the importance of psychosocial services.

## **Psychosocial Responses to Spinal Cord Injury**

Statistically, the average age for SCI to occur is between 16 and 30 years of age, with the majority (male to female ratio 4:1) of injuries happening to men. This is an important time for emotional growth and psychosocial development for young people. Psychologically, these years are characterised by separations and independence from family, graduation from school and early career decisions. Intimacy in relationships and productivity in work are the major developmental goals to be accomplished. This is also a time in which alcohol or substance abuse may occur along with defiance of authority and acting out behaviours.

Adjustment to the injury is a process that proceeds gradually over an extended period of time. It is not linear in nature and is unique for each individual. For most people, the psychosocial adjustment to SCI is an overwhelming

process that involves all of the human emotions and coping mechanisms of the individual. It typically begins at the time of injury and extends throughout the individual's life, demanding new adjustments as the individual progresses and faces new experiences. Over time, the person with SCI begins to perceive the injury less of a threat and more as a challenge to be overcome.

Rehabilitation is a time in which both physical and psychological growth is important. Following discharge, it is essential that the person who has sustained a SCI has the psychological skills to actively participate socially and vocationally in the community and in society. This includes the ability to maintain health and to direct care givers as needed in order to reduce the possibility of secondary complications. Self-management is an important asset to be mastered early in the rehabilitation process.

Psychologists, social workers, counsellors and other team members such as occupational therapists assist people with SCI by providing counselling, education, and problem solving. They also facilitate positive coping skills and teach methods to manage anxiety. In addition to improving mental health, a peer counsellor can serve as a role model by demonstrating mobility, involvement in sports, and a positive attitude.

## **Individual Differences and Common Reactions to the Injury**

As mentioned previously, each person or family may have unique and individual adjustments to injury. It is not unusual and typical of most people to have a wide range of emotions. These emotional responses often include depression, anger, anxiety and hopelessness. However, depression may not always be present early after injury. For some people, the full impact of their injury is not apparent until they return to the community.

Once in the community, many people with SCI experience new problems that they did not anticipate while in the rehabilitation centre. These might include difficulties with accessibility, discrimination, reactions to the wheelchair by strangers, financial hardships and isolation in the home. Each new challenge often brings an emotional response. Within a short period of time, these responses can become overwhelming. Ultimately however, most people do cope and manage the injury quite well.

While it is important to stress that every person reacts to circumstances in different ways, the psychosocial provider must be able to recognise if the individual's reaction is extreme or potentially harmful. In this regard, it is important that the counsellor has the capacity to both recognise potentially harmful psychological responses and the skills to make referrals to other mental health professionals when needed.

In some cases, people with SCI may feel uncomfortable sharing their emotions with someone in a counselling position. The individual with SCI may see this as a sign of weakness or believe that painful emotions should remain within the family. In many cases, emotional distress may be difficult to evaluate without a complete history from the patient and a comprehensive assessment. Although the emotional reaction may be unique for each individual, psychosocial providers should be vigilant to some of the more common reactions to injury.

These may include:

- Unnecessary dependency on others
- Social Isolation
- Negative body image or shame
- Feelings of worthlessness
- Low self esteem
- Anger and aggression
- Shame and embarrassment
- Feelings of helplessness and hopelessness
- High levels of stress
- Self-Blame
- Depression
- Post-traumatic stress disorder
- Suicidal thinking or lack of desire to live
- Apathy and not caring about life
- Inability to provide self-care and follow medical advice
- Marital and relationship conflict
- Lack of motivation for vocational or educational pursuits
- Feeling trapped in the family surroundings

## **Environmental and Social Issues**

Although the individual's psychosocial adjustment is important for quality of life, we also realise that the environment plays an important role in defining the level of disability. Discrimination against people with disabilities, inaccessibility and negativity, often increases the level of impairment experienced by the person with SCI. This concept, well understood in countries such as Vietnam, is called the "social approach" to disability.

The "social or biopsychosocial approach" understands that disability does not only result from the physical limitation of a person but is determined by the interaction between a person's functioning and their social and physical environment. In many cases, discrimination, fear and inaccessibility further intensify a disability. These negative views of disability tend to focus on issues of dependency and deficit, rather than on a more positive model in which disability is seen as an opportunity for growth and well-being.

Rather than viewing disability in a negative light, a modern approach to disability views people with disability as autonomous individuals, with the right to make their own decisions and choose their own path in life. With this perspective, physical, sensory, cognitive, and psychological impairments only become disabling in an environment that fails to recognise individual differences.

It is our belief that it is the responsibility of all rehabilitation professionals to reduce impairment by creating a better social environment that respects the dignity, human rights and needs of all. Advocating on behalf of people with disabilities is important in removing environmental barriers and negative social attitudes so that people with disabilities can contribute equally in society.

## **The Role of Psychosocial Providers**

### **Psychiatrists**

Although various psychosocial providers are all concerned with the emotional well-being of the individual with SCI and their family, each provider has different responsibilities and completes their task in a slightly different manner. Psychiatrists, for example, tend to evaluate the individual's need for

psychotropic medication depending on the range and severity of psychiatric symptoms and their classification. Typically not all spinal cord injury rehabilitation centres have a psychiatrist on staff. However, each centre should have access to a psychiatrist if needed.

Referrals to a psychiatrist will typically involve patients who have a significant depressive disorder, psychotic symptoms, certain personality disorders or patients who have expressed suicidal thinking or are at risk of suicidal behaviour. When the person with SCI expresses suicidal ideation, a psychiatric consultation should be considered. Furthermore, when the patient articulates any specific suicidal plan or details, this is a cause for concern and immediate referral. Other indications for referral may include excessive worry about prognosis, frequent tearfulness and lack of interest in rehabilitation.

A spinal cord injury is bound to impact the patient's life in many ways. The emotional impact can be significant. This can easily lead to psychiatric disorder such as depression, anxiety, post traumatic stress disorder and a poor quality of life. The prevalence of a psychiatric problem in patients with SCI is quite high in the initial stage of an injury but with time there is a significant drop in prevalence due, in large part, to the patient's ability to cope and the presence of family supports.

The prevalence of a psychiatric diagnosis is more common in patients who were injured as a result of an attempted suicide. As one would expect, these are individuals who were distressed and had poor coping skills prior to the injury. As a general rule, better health and length of time since injury are associated with decreasing the risk of psychopathology.

## Clinical Psychologists

Psychologists typically provide individual or group psychotherapy as well as evaluations for patients who may have cognitive difficulties as a result of the accident. In many areas, psychologists work at the SCI centres, meeting with patients on a regular basis and consulting with staff members around behavioural or motivational problems that may emerge.

Each patient with a SCI should have the opportunity to meet with the psychologist shortly after admission to the rehabilitation facility. Typically, a brief psychosocial assessment is completed in order to identify potential risk factors. When possible, psychologists may see patients or family members in

counselling during rehabilitation and after discharge. During team meetings, in which treatment goals are discussed among rehabilitation staff members, the psychologist provides input as to motivation, learning style, emotional needs and coping style.

Ultimately the goal of the psychologist is to maximize the patient's ability to make physical and psychological gains during rehabilitation. Toward this end, the psychologist promotes the perception of the individual as a person with feelings, goals and aspirations and not simply as a patient.

## **Social Workers**

Social workers often provide family counselling and organise services that will be available in the community following discharge. They promote the social approach to disability. Typically, social workers are familiar with resources in the community and may be able to help with issues such as finances, housing, home services and referral to other agencies and organisations that provide services to people with disabilities. Vocational guidance towards economic independence is another important area of responsibility for the social worker.

Like psychologists, social workers are trained in providing individual counselling although their focus may change from one SCI centre to another. In most SCI programmes, social workers often are involved in helping the patient and family arrange for funding to pay for rehabilitation services and ultimately to prepare for discharge.

Planning for discharge should begin at the time of admission to the SCI centre and include information regarding the primary caregiver, accessibility of the house, financial considerations, employment status and resources in the family and community. It requires the participation of all team members, as well as the individual and family. Most often, primary discharge planning is coordinated through the team social worker and should be discussed at team meetings throughout rehabilitation.

## **Occupational Therapists**

Occupational therapists also play an important role in addressing the psychosocial needs of an individual with spinal cord injury. They often evaluate and focus on building skills that allow the individual to function in various roles in life. Their unique training gives them a well-developed perspective on the integration of the person, environment and task. Along with

other professionals, occupational therapists offer interventions for problem solving, confidence building, social skills, communication, sexual functioning and a variety of cognitive skills.

In rehabilitation, there is always some degree of overlapping among disciplines. This overlap of services helps to insure that the emotional wellbeing of the individual is being addressed from various vantage points. The occupational therapist offers interventions with a focus on function that ultimately enhances a quality participation in life.

## Peer Counsellors

The peer counsellor is a member of the rehabilitation team who is responsible for assisting the patient with his/her psychological adjustment. Peer counsellors serve as role models for newly injured patients through involvement in sports, participation in social activities, suggestions, education and counselling. Often, peer counsellors are former patients with SCI who have made a successful re-entry into the community. These individuals have an interest in counselling and have the skills necessary to form positive relationships with patients and families.

In addition to their work with patients, peer counsellors show by example that life after SCI can be meaningful, rewarding and fulfilling. The peer counsellor must be astute enough to recognise how best to intervene so that the patient is not overwhelmed and the rehabilitation program can progress smoothly. To help the person adjust to the injury, the peer counsellor may use direct counselling, emotional support, serving as a role model, skills training and problem solving techniques. Typically, peer counsellors can use their experience to demonstrate how best to manage the injury in a practical manner that conforms to the individual's life style.

For the newly injured person, having a supportive peer who has experienced a similar injury can be a powerful motivator. The knowledgeable peer counsellor however realises that having a disability is not enough for counselling to be successful. To be successful, the counsellor must have the skills, communication abilities and sensitivity to help the person with a SCI.

In addition, the peer counsellor must have the motivation and sensitivity to help other people who are in emotional distress and need support. To accomplish this, the peer counsellor must have the motivation to learn and the ability to

serve as a coach and mentor. They must have been successful in their own re-entry into the community.

The peer counsellor is the member of the team who helps the patient recognise that life does continue after a SCI and that quality of life is possible. He or she teaches by example. The peer counsellor teaches advocacy skills by modeling, coaching and demonstrating rather than by militant, anti-social or violent means. Although psychiatrists, psychologists and social workers have clinical and ethical guidelines established by their professional associations, this is not the case for peer counsellors.

With this in mind, there is a need for standards of practice, training guidelines and ethical principles for individuals serving as peer counsellors. It is our hope that these ASCoN guidelines will meet this existing need and help to ensure a role for peer counsellors on the rehabilitation team.

## **Levels of Intervention**

In defining the role of a peer counsellor and their role as providers of psychosocial services, one suggestion is to consider various levels of intervention.

### **Level 0**

Taking into account the specific situation in ASCoN countries, it may be possible that no peer counsellor is available (yet) and/or can address all the needs in his department. Therefore, it should be foreseen that in absence of a peer counsellor, a service provision of counselling can be done through sensitisation that can lead to referral and localising peer counselling services on a given department. This level of intervention requires that each professional in the rehabilitation team should have basic information and advice available for the patient and his family (through booklets, folders, audio visual features) by explaining that anxiety, depression and stress are mostly part of the normal process of adjustment after SCI. Advice to patients and families should come from specific briefing for all patients (in group - all of them) where one dedicated professional explains the counselling needs to all (patient and families) with possibility for questions and answers supported by the information materials provided. This intervention may lead to breaking the news to the patient and his family (by a doctor and member of the team) when

it is technically possible and justified. If the peer counsellor is not available in this level, it will surely clear the way for his involvement in the remaining stay of the patient in the rehabilitation centre...

## Level 1

The first level of intervention involves developing a relationship between peer counsellor and the patient and/or family. It establishes an initial rapport and provides an opportunity for the person with SCI to discuss feelings, reactions and problems. The peer counsellor typically meets with the person with a SCI on a regular basis to assist them in the adjustment process. Meetings may be informal between physical or occupational therapy sessions or at other convenient times. Often at this level the peer counsellor may provide some orientation to the rehabilitation unit, explain the process of rehabilitation and answer questions. Often it is helpful for the patient to know the various disciplines involved in his/her rehabilitation. From the time of the patient's admission, the peer counsellor needs to be attending planning meetings, case conferences and rounds. This helps to insure that the peer counsellor is an integral and respected member of the team and is aware of the patient's total rehabilitation programme. The real purpose of this level of intervention is to establish a therapeutic relationship and provide information regarding the process of rehabilitation as well as the injury.

## Level 2

A peer counsellor meets with patients and families to discuss how counselling fits into the rehabilitation programme and also offers some specific suggestions on how to deal with the emotional reactions that they are having.

Suggestions may be anything from talking about feelings, getting involved in recreation/sports, spending time with family members, meditation and communicating with other patients. At times, the peer counsellor may provide some skills training or be involved in recreation and sports with the patient. Often at this level, the peer counsellor can provide information about SCI and its complications such as bladder and bowel functioning. This is a question and answer time in which patients and families can learn information about the injury and what to expect. They can also learn from each other and from patients and families who are further along in the process. Pamphlets, movies, speakers, and hand-outs could all be utilized in this level. This information sharing allows the family and patient to get to know the counsellor and further establishes a sense of trust. The counsellor also offers emotional support to both the patient and family.

### Level 3

Level three is the specific counselling, which can be done on a regular basis and should be included in the patient's daily schedule. The counsellor needs to be giving feedback to the physician and team so that the doctor has a sense of the patient's emotional adjustment and will know when to refer to level 4 if necessary. On level three, the peer counsellor also interacts with the staff in order to help them support the patient and family. Staff needs to know the patient's emotional condition and how to intervene in a positive manner. There may be behavioural problems such as lack of motivation, suicidal thinking or lack of interest in rehabilitation. Staff needs to be united in addressing these types of issues and assisting the patient in any way possible. To accomplish the goals of level three, the peer counselling needs to be seen by the staff as equally important to the physical needs of the patient. In addition, the peer counsellor needs to be recognised as an integral member of the team.

### Level 4

This level is intended for people with more serious mental health needs or who are not responding to other levels of service such as Peer Counselling service. It may include suicidal patients, patients who need psychotropic medications, severe behavioural problems, or patients not cooperating with rehabilitation. It is extremely important that the PC has the capacity to identify such problems and to refer the patient to other mental health professionals such as the psychiatrist. At times, professional referrals of family members may be necessary as well.

## Duplication of Service

The role of the various disciplines in rehabilitation tends to be fluid and somewhat overlapping at times. This is especially true among various psychosocial providers who are all providing similar services to people with SCI. Responsibilities for assessment, education and intervention do not have precise boundaries and frequently are shared by various disciplines. Since psychiatrists, psychologists, social workers, occupational therapists and peer counsellors are qualified to perform some of the same functions in the provision of psychosocial care, it is important that they communicate among themselves and work collaboratively. In addition, they should work cooperatively with other disciplines in facilitating the personal and psychological growth of the person with SCI.

## Staffing Patterns

Staffing patterns for psychosocial providers vary from one SCI centre to another. Often, they are decided by financial considerations since each centre must determine how best to allocate its limited resources. Each centre, however, should have one individual whose primary responsibility is the assessment and delivery of psychosocial services. As noted previously, this may be a peer counsellor, psychiatrist, psychologist or social worker. In other centres it may be an occupational therapist or a nurse with psychiatric training. In an ideal SCI centre, a psychiatric consultant is available while the services of a psychologist or social worker are supplemented by one or two peer counsellors.

## Training and Professional Development

Psychiatrists, psychologists, social workers, peer counsellors and others who focus on mental health issues should receive an orientation to the philosophy and goals of the SCI programme, the administrative procedures governing the SCI programme, the roles and responsibilities of the different team members and any SCI-specific related issues. It is important that any mental health provider who will be providing services to the patient and family has both the knowledge of counselling as well as knowledge regarding SCI rehabilitation. They should understand both the psychological process as well as the physical implications of the injury.

Since formal training programmes are not always available, education regarding SCI is often obtained on the job or by talking with other rehabilitation staff members. One excellent source of information and education about SCI is [www.elearnSCI.org](http://www.elearnSCI.org) developed by the International Spinal Cord Society (ISCoS). Another resource available to those interested in learning about SCI is IPSCI by ISCoS in collaboration with WHO.

Education regarding rehabilitation should provide ample opportunities for discussion, networking and exchange of ideas. A comprehensive training programme for mental health providers in SCI rehabilitation should include information regarding the following topic areas:

- Comprehensive Overview of Rehabilitation

- Physical Consequences of SCI
- Pressure Sore Prevention and Management
- Bowel Management
- Bladder Management
- Team Functioning in a Rehabilitation Setting
- SCI Complications and Effect on Rehabilitation
- Assistive Technology
- Personal physical exercise programmes for maintaining functional mobility
- Medications used in SCI Rehabilitation
- Sexuality and Fertility
- Social Skills
- Recreation and Sports after SCI
- Vocational and Educational Pursuits
- Community Reintegration
- Core Elements of Counselling
- Family and Caregiver Adjustment
- Psychosocial Adjustment for Patient and Significant Other
- Substance Abuse

## Ongoing Education

Psychologists, social workers and counsellors must adhere to any guidelines for continuing education that exist in their perspective countries. All mental health providers should take advantage of continuing education opportunities when possible. As noted above, one such resource is [www.elearnSCI.org](http://www.elearnSCI.org) developed by the International Spinal Cord Society.

In addition, if feasible providers should attend SCI related conferences such as the annual ASCoN and ISCoS conferences. As professional networks are developed for psychiatrists, psychologists, social workers and counsellors in SCI, individuals should be encouraged to join and to be as active as possible. Professional networking is an important means to gain knowledge, peer support and to keep abreast of new developments in the field.

## Qualities of the Counsellor or Psychosocial Provider

In order to successfully function on a SCI unit, the mental health provider should possess the necessary qualities that will allow them to function most effectively and to be recognised as an equal member of the team. The qualities of psychosocial providers in SCI rehabilitation may include the points noted below:

1. Should complete an orientation and a comprehensive training programme on SCI.
2. Should have good communication and listening skills.
3. Should possess empathy, sensitivity and understanding of the adjustment process.
4. Should have been successful in managing their own physical and psychological condition if they have a SCI.
5. Should possess good social skills and be an active member of the community.
6. Should have the abilities to assist in multiple perspectives such as health education, skills training and vocational rehabilitation while assisting with the psychological response to the injury.
7. Peer counsellors should serve as a positive role model by demonstrating that good a quality of life is possible with a SCI.
8. Should be aware of new developments and research in the field and incorporate this information into their daily responsibilities.
9. Should recognise that self-disclosure may be part of the counselling role. However, should also be aware of when and how much to disclose about the self.
10. Should be aware that people with a SCI have their own unique adjustment style.
11. Should be non judgmental and accepting of individual differences.
12. Should have the communication and interpersonal skills to work collaboratively with other members of the team.
13. Should remain aware of ethical and professional boundaries at all times.
14. Should be willing to participate in research (ongoing), education and skills development.
15. Should be involved in continuing education activities and participate in learning opportunities.

The role of a psychosocial provider in SCI centres does not end with providing services to the individual with a SCI. Within the rehabilitation

centre, knowledge of psychological principles can help create a treatment environment that promotes positive growth, motivation and a healthy and inclusive community spirit. The psychosocial provider typically can promote such an environment in a multitude of ways. These may include:

1. Encouraging positive and open communication among team members.
2. Creating a safe environment that is non-judgmental and accepting of emotions and individual differences.
3. Injecting a positive spirit and affirmative attitude into the programme.
4. Modeling appropriate behaviours, boundaries and setting limits when necessary.
5. Providing support to team members from all disciplines.
6. Addressing conflicts, anger related outbursts and disruptive behaviour as needed.
7. Educating team members on positive behavioural approaches to patient care.
8. Advocating for the rights and privileges of the person with SCI whenever possible.

It is important to remember that although psychosocial providers function in many SCI centres, all members of the team play an important role in facilitating the psychological adjustment of the patient and the family. The mental health professional may provide counselling and other services, however nurses, physical therapists and occupational therapists spend a great deal of time with the patient and play a very large role in the patient's adjustment. For this reason, it is important that they be oriented and receive ongoing education regarding psychological issues related to adjustment.

Often, the psychosocial provider serves in a secondary capacity. The patient will usually look to the rehabilitation physician to answer questions about functioning and the future. Patients look to their physical therapists, occupational therapists and nurses to provide reassurance about life after discharge. It is the members of the rehabilitation team including nurses, physiotherapists and occupational therapists who convey the message that a positive and fulfilling life is possible after a spinal cord injury

## **General Principles of Counselling in SCI Rehabilitation**

The psychosocial provider is an individual who uses general counselling principles and applies these principles to individuals and families following

SCI. Although occupational therapists and nurses with psychiatric training may not provide counselling in the “strictest” sense, the same principles apply to anyone facilitating the emotional well-being of the individual with SCI. General counselling principles include listening without judgment, offering suggestions, creating a safe environment for the person to share feelings, providing emotional support and insuring the safety of the individual.

Psychological counselling requires that the counsellor listens to the patient and encourages the patient to share their experiences, emotions and thoughts. The counsellor must facilitate this process and should ask open ended questions that encourage sharing and the expression of personal feelings.

The counsellor also realises that there are no “right or wrong” feelings and that each individual has the right to his or her personal beliefs and experiences. Often, peer counsellors may use various techniques such as the sharing of their own experiences to help an individual who is in emotional pain. However, at all times counsellors must separate their own emotions from the emotions of the person with SCI. For the counsellor, it is always important to remember that counselling must serve the needs of the patient and not the needs of the counsellor.

## **Referral to Other Mental Health Providers**

As psychosocial providers in SCI care, it is important that all providers be aware of their role on the rehabilitation team, clinical skills and standards of care within their profession. For example, any individual with SCI or family member that expresses serious symptoms of depression or suicidal ideation should be brought to the attention of the physician in charge. These individuals may require a comprehensive evaluation for potential anti-depressant medication and a treatment plan that monitors and ensures their safety. Some indications that a referral to a higher level of care is necessary are listed below:

1. Persons expressing suicidal or homicidal thoughts or intentions.
2. Persons with significant symptoms of depression, anxiety, post-traumatic stress disorder or other reactions to the injury.
3. Persons exhibiting psychotic symptoms such as paranoia, hallucinations or delusional thinking.

4. Persons who demonstrate symptoms of a personality disorder such as extreme self-centeredness, serious fluctuations of mood or anti-social behaviour.
5. Persons who seriously lack motivation or refuse to participate in rehabilitation activities.
6. Persons who are abusing illicit substances or alcohol during rehabilitation.

## **The Rehabilitation Team**

The person with a spinal cord injury and family members should be primary members of the rehabilitation team. Since members of the family will most likely serve in the capacity of care givers, their input is especially important.

From the onset, it is important that family caregivers be identified and that they learn the physical and psychological needs of the person with SCI. The family caregiver's own needs and concerns must be addressed as well. Family members need to feel comfortable that they can articulate their own fears, hopes and expectations without being judged. After individual assessments are completed, there should be regular, formal team meetings to review and document the individual's progress and to modify the treatment plan as goals are accomplished.

During team meetings, in which treatment goals are discussed among rehabilitation staff members, the mental health provider's role is to give suggestions regarding motivation, engagement in rehabilitation, and progress with adjustment issues. It is important for all members of the rehabilitation team to be aware of the patient's coping abilities, perception of the injury and meaning attached to the injury.

Toward this end, it is important that team members be sensitive and empathic to the patient and the family. All team members need to see the individual, not as a diagnostic entity, but as a human being who has suffered a catastrophic injury and is in severe emotional pain. If staff members are able to identify with the needs and vulnerabilities of the person, they are often able to interact with the patient and family members in a more caring and empathic manner.

As a general rule, the psychosocial provider should be the member of the rehabilitation team who best understands the importance of direct and honest communication. Often, this involves understanding the nonverbal language of the individual with SCI and helping the person with SCI to articulate his or her needs. For the person with SCI, the ability to clearly articulate one's needs is a valuable skill that will serve the person well in any future context. Finally, the psychosocial provider should be available to model and facilitate direct communication between patient, family and staff members.

## **Other Responsibilities of the Psychosocial Provider**

### **Providing Support to Other Staff Members**

Psychiatrists, psychologists, social workers, and counsellors serve as resources for the entire treatment team. Occupational therapists and nurses with psychiatric training can also serve as a mental health resource for the rehabilitation team. Psychosocial providers have specialised training in group processes, problem solving, communication skills, and interpersonal skills may help the treatment team function more effectively and efficiently. They facilitate communication, provide in-service education, serve as sources of support and act as consultants on difficult, behavioural or sensitive matters.

Either formally or informally it is not unusual for psychosocial providers at an SCI centre to provide emotional support to staff members regarding their work with patients. Working with people who have a SCI can be emotionally draining for anyone. Providing emotional support can be accomplished informally on an individual basis or through regularly scheduled staff support groups. The emotional support provided to staff members is often helpful as staff members experience their own emotional reactions to patients. Frustration, anger or a close attachment with patients all can interfere with the professional interactions and professional care between staff member and the person with SCI.

Staff “burn out” is another area in which the support of the psychosocial provider may be helpful. In these cases, “burn out” is often characterized by exhaustion, lack of motivation and a loss of enthusiasm for work. Working in SCI care can be emotionally challenging and over a period of time can be demanding on the emotional resources of the staff member. It is not

unusual for staff members working on a SCI unit to experience feelings of guilt, helplessness and frustration. At other times, personal issues at home can intensify the demands of work and lead to withdrawal or increased interpersonal conflict at home or at work. For both persons with SCI and staff, techniques such as meditation, relaxation training and mindfulness can be very helpful in managing stress and emotions.

## Conducting a Psychosocial Evaluation of the Person with SCI:

Psychiatrists, psychologists, social workers, and counsellors bring to the team a psychosocial orientation focused on emotions, cognitions and coping. Their education and clinical training prepares them to play particular roles in the rehabilitation process. When possible, their unique expertise should be utilised to conduct a thorough psychosocial assessment upon which a psychosocial treatment plan can be devised and appropriate interventions used.

Comprehensive assessments by psychiatrists, psychologists, social workers, counsellors and occupational therapists focus on the individual's current appraisal of the injury, coping status and accommodation to the SCI in the context of person, family, and society. In this regard, the occupational therapist may have a somewhat different perspective since they often view the individual in terms of the person's roles in the home and community.

The psychosocial provider typically conducts a diagnostic interview with each person shortly after admission. Currently, there are no accepted screening instruments universally used for this evaluation. Rather, the questions posed and the history taken by the psychosocial provider is based on clinical judgment and the information provided by the individual with SCI. The psychological evaluation is a semi structured intervention that usually occurs at the first opportunity after admission. In general, it is never too early to begin developing a therapeutic alliance and to better understand the background and needs of the patient. The evaluation typically occurs at the bedside, if the patient has a private room, or in any area that is private and ensures confidentiality.

The psychological evaluation usually begins with the patient's description of the injury. This provides the mental health provider with a basic understanding as to the patient's perception and knowledge of the injury. Information about family, earlier relationships, support systems, coping mechanisms, substance abuse, strengths, weaknesses, abuse histories, traumas and interpersonal

relationships will all shed light on the person's appraisal of the injury and the coping mechanisms that they will utilize in processing the injury.

Although peer counsellors may not have the expertise to conduct a psychiatric or psychological evaluation, they play an important role in providing support, serving as a role model and gaining the trust of the individual with SCI. In some cases, the person with SCI may feel most comfortable talking to a peer and the peer counsellor can gain valuable insight as to the needs of the patient, motivation and how best to work with the person with SCI. In building a relationship with the person who has a SCI, the peer counsellor should be mindful of individual strengths, lifestyle and interests of the individual.

This is a time of emotional trauma for the patient. Providing education regarding rehabilitation and what to expect during the hospitalisation can provide a sense of stability and control. Each patient however should be assessed individually to determine his or her educational level, understanding and readiness to grasp the information being provided. Often, information may need to be repeated and reemphasised at different points in time.

While engaged in rehabilitation, the patient needs assurance regarding his or her physical and psychological safety. In addition, the person with a SCI needs an available professional to express anxiety, ask questions and seek reassurance. Mental health professionals, peer counsellors and all members of the team can serve in this supportive capacity.

Given that the rehabilitation experience is essentially a learning process, it is also important for the mental health professional to have a basic understanding of the individual's learning abilities and potential cognitive strengths and weaknesses. Knowledge as to earlier attentional deficits, learning disabilities, neurological injuries and learning style will be helpful in assisting the team members to customise the rehabilitation programme according to the individual's most effective method of learning. The initial assessment of the person with SCI should include information such as indicated in the following points:

## Issues to Explore in the Initial Evaluation of the Person with SCI

1. Educational and vocational background.

2. Previous coping mechanisms in times of stress.
3. History of alcohol and substance use.
4. Marital status and social relationships.
5. Previous history of psychological difficulties and trauma.
6. Presence of learning disabilities, cognitive issues or memory impairment.
7. Brain injury at the time of the injury or in previous accidents.
8. Presence of depression, anxiety or other emotional distress.
9. Presence of any feelings of responsibility or self-blame regarding injury.
10. Presence of any suicidal or self-harm thoughts or desires.
11. Understanding of rehabilitation process, knowledge of the injury and expectations for the future.
12. Motivation for rehabilitation.
13. Identification of positive qualities, strengths, interests, recreational activities and sports.
14. Any signs that may indicate a more serious psychiatric difficulty such as delusions, hallucinations or feelings of paranoia.

## Conducting a Psychosocial Evaluation of the Family

A comprehensive evaluation of the family is another important function of the psychosocial provider in a SCI centre. Again, there is no standard evaluation, but the questions asked are determined by the clinical judgment of the psychosocial provider. An evaluation of the family usually occurs shortly after admission and is aimed at determining the needs, strengths and resources of the family. This is also a time of trauma for the family and emotional support, reassurance and empathy are important to help the family function in a time of such stress.

As the family begins to stabilise and adjust to the injury, the social worker will begin to identify the family's understanding of the injury and expectations for the future. Potential caregivers are identified and education about rehabilitation is provided when needed. Although all members of the rehabilitation team will be interacting with the family, it is typically the social worker who should try to understand the overall emotional, financial and social impact of the injury on the family's functioning. With an eye toward discharge, this means understanding the needs of the siblings, extended family and family involvement in the community. The assessment should include information such as indicated in the following points:

## Issues to Explore with the Family of the Person with SCI

1. Financial concerns and limitations of the family.
2. Patient's ability to financially contribute to the family's day to day expenses.
3. Identification of possible caregivers.
4. Accessibility of the home and community environment.
5. Family's emotional response to the injury.
6. Ability of the partner, parent, child or sibling to serve as caregiver.
7. Role of denial among family members.
8. Family's understanding of the injury and rehabilitation programme.
9. Family's ability to recognise unnecessary dependence.
10. Family's expectation of the future.
11. Family's ability to handle stress.
12. Family's strengths, resources and supports.
13. Family's method of coping.
14. Family's ability to care for themselves.

## Conducting Educational Groups

In many SCI centres, psychosocial providers participate in educational activities for persons with SCI and family members. Educational focused groups are very useful in SCI rehabilitation and provide an opportunity to give information to the person with SCI as well as provide an opportunity for the person to express his emotions regarding the injury. Topics commonly discussed in these groups include sexuality, body image, disability rights, assertiveness and social skills. Experience has also shown that having a former patient or peer counsellor share experiences with newly injured individuals in a group setting can also be educational and extremely valuable. Finally, people with SCI should be informed as to how information regarding SCI can be obtained from the internet and educational websites.

## Providing Services Related to Alcohol/Substance Abuse

At some SCI centres, substance abuse related counselling by the mental health professional is provided as needed. For some people with SCI there may be substance abuse issues prior to the injury. These issues can then become problematic after the injury. In a time of emotional crisis and distress, it is not unusual for individuals with SCI to turn to illicit substances to help cope with the distress and emotional pain of the injury. Usually, any use of these substances at a SCI centre is prohibited. However, clinical experience has

demonstrated that a high return to substance abuse post discharge is a problem worthy of follow up and careful monitoring.

Mental health providers should be aware of substance use and assist individuals with SCI to employ more positive and productive coping mechanisms. Peer counsellors may be especially effective with these issues by encouraging individuals with SCI to become involved in recreation and sports as a means of coping with depression and anxiety. This is an important area for a positive role model who demonstrates healthy coping skills.

### **Addressing Issues Related to Assistive Technology**

Mental health providers often work closely with Assistive Technology especially around issues of wheelchair prescription and home modifications. Readiness to accept a wheelchair assessment often creates anxiety for the person with SCI by confronting their belief that paralysis is temporary and that walking is realistic. Supportive counselling is often beneficial as individuals with SCI work through the process of using adaptive equipment and assistive technology to improve their functional skills.

### **Providing Services Related to Educational/Vocational Issues**

Vocational, education and employment issues are a critical factor in the adjustment of the individual to a SCI and to successful community re-integration. For young people, going to school or work is an important role in society. Yet, few young people with SCI are able to obtain community work experiences because of inaccessible housing, unavailable transportation and the lack of accommodation to disability at the work site. Both the individual with SCI and the family suffer as a result.

The ability to provide financial assistance to the family after a SCI is one of the most important factors in a positive psychosocial adjustment. Employment after SCI can be correlated with positive self-esteem, decreased medical complications after SCI, decreases in depression and increased social interaction. For these reasons, psychosocial providers should be actively engaged in helping the individual with SCI make decisions regarding vocational issues, education and employment after discharge from rehabilitation. Providing these services, promoting the social approach or serving as a role model in this capacity conveys an important message that returning to school or work after a SCI is a realistic and viable goal. This is an essential message for the person with SCI, the family and the community at large.

## Providing Services Related to Sexuality and SCI

The role of the mental health provider with regards to sex counselling and education can range from simply providing information to offering suggestions and sex counselling to patients and couples. Often, the educational aspects of sexuality are provided by doctors, physical therapists, occupational therapists and nurses in addition to the counsellor. This is the ideal approach. In a true multi-disciplinary model, each professional has much to offer within the domain of his or her own discipline.

Team conferences are usually the ideal venue to insure that issues regarding sexuality are being adequately addressed and are not simply being left to chance. Sexuality needs to be addressed in a similar manner as any other activity of daily living would be addressed at the team conference. If patients do not raise the issue, staff members should inform the person with SCI that there are professionals available to discuss this area of functioning should the patient have any concerns or wish to have questions answered.

In addition to education, people with SCI may need specific suggestions regarding exploration and resuming sexual activities. Often, these suggestions come from occupational therapists with training in this area. In some centres, private space is provided to couples who wish to explore the sexual aspects of their relationship after injury. Discussions, education and counselling about sexuality need to be conducted in a safe, confidential and respectful manner.

## The Importance of Outcome Measures

During rehabilitation, it is important to obtain a baseline measurement of life satisfaction, participation, quality of life and psychological distress for the person with SCI. For the ASCoN countries, these measures should be in line with the particular cultural environment of the patients and their families. A measurement of outcome should be done as soon as feasible after admission and repeated at least by the time of discharge. An outcome measurement should not be seen as the sole tool for determining the status and functioning of the person with SCI. It should be integrated into the total knowledge from all disciplines working with the person who has a SCI. This tool should also be used as an indicator on progress within the patient review file when meeting with the Rehabilitation team. It is the role of the psychosocial worker to brief and teach the rehabilitation team the use of this tool. One tool that is used for such purposes is the Depression, Anxiety and Stress Scale, (DASS-21). Another instrument that has been used extensively in SCI rehabilitation and is recommended is the Patient Health Questionnaire (PHQ 9).

The PHQ9 is a measurement tool that is frequently used to screen and monitor a person's level of depression. It is a brief self-report tool that is easily scored and can be administered repeatedly over a period of time. In this way, the PHQ9 can reflect either improvements or worsening of depression in response to treatment or rehabilitation.

Other measures used to assess the individual's mental health status include the Brief Cope, an abbreviated version of the Cope Inventory and the Appraisals of Disability: Primary and Secondary Scale, (ADAPSS). These scales provide information as to the individuals understanding and perception of the disability along with their ability to cope with the emotional demands of the injury.

### **Community Based Rehabilitation**

The goal of all rehabilitation is to promote independence, well-being and the ability to care for one's self. Toward this end, community based rehabilitation, as promoted by the WHO is an important concept to be implemented and embraced by psychosocial and all rehabilitation providers. It is a strategy that empowers people with disabilities to access and benefit from education, employment, health and social services in the community. It requires the combined efforts of the person with a SCI, the family, care providers as well as relevant government and social agencies.

### **Professional Ethics**

Ethical principles are critical and must always be a priority for all individuals providing psychosocial care. Psychiatrists, psychologists, social workers, and counsellors should always act in accordance with the highest standards of professional integrity and ethical behaviour. Staff members need to be aware of professional boundaries and set limits when needed. Especially in the area of sexuality, it is essential for the person with SCI to feel safe and for clear boundaries to be respected. Setting clear limits and boundaries clarifies the role and responsibility of staff members to the patient.

Psychiatrists, psychologists, social workers, and counsellors shall assure confidentiality of patient information in accordance with professional ethics, local laws and policies of their health care facility. Individuals with SCI should be advised that confidentiality is not an absolute concept and that necessary sharing of information does occur in the context of treatment planning and discharge planning.

## Psychological Response to SCI as a Result of Natural Disasters

Natural disasters in the form of floods, earthquakes, hurricanes, monsoons, fires, collapsed buildings and tsunamis all can contribute to high numbers of individuals sustaining disabilities such as spinal cord injury. For example in recent years, the collapse of the Rana Plaza garment building in Savar, Bangladesh resulted in 1129 lost lives and more than 70 individuals sustaining spinal cord injuries. On the other side of the globe, earthquakes in Haiti during January 2010 caused more than 60,000 deaths and more than 150 individuals with a spinal cord injury. Similarly, the 2015 earthquakes in Nepal resulted in the death of more than 8000 people with 200 to 400 individuals suffering a spinal cord injury.

Recently, persons with SCI in the aftermath of natural disasters and/or victims of armed conflict have added to a growing concern among humanitarian providers. Although context and resources available in these situations are known to be very challenging in providing rehabilitation and psychosocial services, it remains important to stress that the latter should be part of the services package for people with SCI. Often services may need to be streamlined with the other services that are provided to individuals in distress. It is possible to design adapted and minimum service delivery for these individuals with SCI, including psychosocial services for the person with the injury and their caretakers. Management of the adjustment process requires early screening and assessment, timely provision of management measures such as education, information regarding available support services and resources, counselling, medication, and sustained monitoring over the long term. Peer mentoring and support is becoming an important component of rehabilitation programmes for people with SCI and can be especially effective in the wake of a natural disaster.

Individuals who suffer a spinal cord injury, as a result of a natural disaster, often experience not only the grief associated with an injury but also additional losses such as the death of family members, the collapse of their homes and the loss of all potential sources of income. For example, of the 144 earthquake survivors with spinal cord injuries treated at the Spinal Injury Rehabilitation Centre in Nepal, over 90% lost their homes. Of these individuals, it was not uncommon for them to have also experienced the death of their children, parents and other loved ones as a result of the devastation caused by the earthquakes and aftershocks.

For these people, the goals of rehabilitation often are seen as secondary to the needs of their family and loved ones. Many patients with SCI would prefer to leave rehabilitation as soon as possible in order to attend to matters at home or to care for their children who were left with neighbours.

Other patients cling to the safety of the rehabilitation facility as long as possible. In many cases, their homes may be inaccessible or destroyed. These patients, with severe emotional conditions, experience a variety of symptoms. They are often fearful of the dark, experience nightmares, are fearful of further injury, experience panic attacks and become easily overwhelmed. They are emotionally fragile and unstable. In order for rehabilitation to proceed, they must first become emotionally stable and capable of learning new techniques.

To further complicate an already difficult scenario, rehabilitation staff members are frequently placed in situations that are overwhelming and require tremendous emotional resilience. For example, in recent disasters in Nepal, the number of patients admitted with a spinal cord injury were triple the Centre's bed capacity. This added tremendous stress to a staff who were already working at maximum capacity. Staff members are also not immune to the perils of a natural disaster. In Nepal, multiple rehabilitation staff members also experienced the loss of their homes while attempting to provide around the clock medical and rehabilitation care.

As one might expect, physical devastation of this magnitude carries with it a tremendous and powerful emotional toll. The psychological symptoms associated with multiple losses of this extent can be extreme, debilitating and unbearable for patients, family members and rehabilitation staff members. Major depression, overwhelming anxiety with panic attacks and post-traumatic stress disorder, (PTSD) are often the psychological conditions most frequently observed.

This psychological emergency demands the full response of the mental health team and other individuals who can provide emotional support and psychological services. An organised approach in treating these severe emotional conditions is required at the earliest possible time.

A Critical Incident Stress Debriefing, (CISD) is usually the first line of defense. It is a short term group intervention that is aimed at enabling people to function more effectively and with less likelihood of experiencing post-traumatic stress

disorder. These individuals whether patients or staff members, are gathered in a group format and asked to talk about the incident without judgment or criticism. The purpose of the meeting is to diffuse the trauma and assure all individuals that their feelings are normal and understandable.

The second portion of the CISD addresses both the cognitive appraisal of the situation and the emotional response to the crisis. It is again completed in a group format and encourages participants to talk about their experience, how it has affected them and how they are coping with the experience. The group format also identifies individuals at risk that may benefit from a more intensive, individual treatment plan.

Similar services are also beneficial for patients and family members. A support group format for patients with SCI is an effective intervention that allows individuals to obtain support from one another and to gain resilience in coping with the tragedy. For example, after the Nepal earthquakes SIRC organised a series of group interventions designed either for people who had lost family members or their home or for individuals nearing discharge but with nowhere to go. Other support groups were designed specifically for family care providers who could share their stories and emotions with each other.

Putting people together who share common themes in their lives allows them to cognitively appraise the situation and facilitates the expression of positive emotions. These positive emotions strengthen the individual's ability to persist and succeed with the task of acceptance. The power of one's belief in one's self influences the choices that a person will make; and determines how the individual will ultimately approach the challenge that lies ahead.

For staff members, the support and acknowledgement of their commitment by hospital administration is critical in their ability to care for their patients. Their needs are as critical as the needs of the patients and families. Staff members must feel validated, appreciated and nurtured at every opportunity.

In Nepal, this was accomplished after the earthquake by providing assistance with housing when needed, staff support groups, and cultural festivities that were designed to be bonding and validating in nature. The administration cultivated a sense of family and teamwork.

## **Conclusion**

In conclusion, the psychosocial provider is an important member of the rehabilitation team and is responsible for the emotional well-being of the person with SCI and the family. To function successfully in this role, it is important that the emotional and social well-being of the person with SCI be seen as an essential aspect of the rehabilitation programme. Although the duties of a psychiatrist, psychologist, social worker or peer counsellor may vary from centre to centre, the goal and responsibility of this individual is always focused on improving the psychological condition and psychosocial adjustment of the patient and family.

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