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## **SCIPPER**

### **Medical Neuro-Rehabilitation and Creating an Ongoing Sustainable System of Medical Care**

#### ***Assessment of Patient Demographics***

- ⇒ Over 600 spinal cord injury (SCI) patients may have survived the 2005 Pakistan Earthquake.
- ⇒ These are mostly women and children who have developed thoracic and lumbosacral spinal cord injuries with cauda-equina and adjacent vertebral and soft tissue damage. Some of these have had spinal stabilization and other surgeries done. Very few quadriplegics with cervical (neck) SCI have survived, as they could not get medical support in time.
- ⇒ The survivors have varying degrees of paralyse of both their legs (paraplegia or paraparesis) and urine and stool incontinence, in addition to the effects of the severe psychosocial trauma they have experienced.
- ⇒ During the first few weeks and months after the earthquake, a large number of these identified patients were managed in field clinics, camps and distant facilities in Islamabad and Rawalpindi (DHQ, Holy Family, Melody Center, etc). Some patients were also taken to Muzzafarabad (AIMS), Abbottabad, Peshawar, Lahore, Karachi and rarely to neighboring countries.
- ⇒ The majority of SCI patients have returned to shelters and tents that have been put up by surviving family members close to the debris of their original village home. They are mostly lying helplessly, often depressed and hopeless, in these shelters which are scattered throughout the northern Himalayan terrain. Their living conditions are extremely sub-optimal. Some have been taken to rented shelters in nearby towns or cities. For example, over 150 SCI patients have been registered at the Balakot PIPOS Limb Clinic for Amputees.
- ⇒ There are probable additional SCI survivors located in distant mountains, who have not been registered at any health facility since the earthquake. They need to be located, their demographics documented and an attempt made to rehabilitate them.

#### ***Assessment of the Current Health Infrastructure for SCI Management in Northern Pakistan***

- ⇒ The earthquake hit an extensive mountainous region of approximately 15,000 km. This rugged terrain lacked rehabilitation resources and infrastructure before the disaster struck. Of 564 basic health facilities in the affected areas, 291 (52%) were totally destroyed, including district hospitals in Muzzafarabad and Mansehra, and an additional 74 (13%) seriously damaged (Brennan RJ and Waldman RJ. NEJM, April 2006).
- ⇒ We only found 3 tertiary urban facilities in northern Pakistan with neuro-rehabilitation expertise, personnel and equipment in December 2005. These are AFIRM (Armed Forces Institute of Rehabilitation Medicine) in Rawalpindi, the Peshawar Paraplegic Center and Shifa Hospital, a private teaching hospital in Islamabad.
- ⇒ Since then, the government has been running the NIH-D and the NIH, where some SCI patients are still living in Islamabad. They are still at this facility, because they do not have shelters or homes to go back to. A few women SCI-survivors have been abandoned by their families. Others cannot go back to family shelters because they are quadriplegics, and too fragile to be able to survive in the wilderness without

medical care and trained and devoted caregivers. Many such paralyzed women are separated from their children who are living with surviving family in distant shelters. Similarly SCI children can be found at such a facility with a grandparent caregiver, while their parents are in shelters.

- ⇒ A large number of SCI patients (over 90 in December 2005) were admitted to the DHQ, a government facility in Rawalpindi. The ones still at DHQ were abruptly asked to leave this facility in August 2007. The current location of these patients is not known to us.

### ***Medical Rehabilitation for the Spinal Cord Injury Survivors of the Pakistan Earthquake: SCIPPER Proposal***

#### ***The Balakot PIPOS Clinic for Amputees: Conversion and Capacity Building of this Facility into a Regional Spinal Cord Injury Rehabilitation Center***

The Balakot PIPOS Limb Support Clinic for Amputees is a strategically located facility close to the epicenter of the earthquake.

It is run by **PIPOS** (Pakistan Institute of Prosthetic & Orthotic Sciences), Peshawar. PIPOS is an internationally accredited institute that is also running rehab centers for amputees in Bagh, Batagram, Mansehra and Besham. These have been funded by various local and international donors and organizations. These Rehab Centers established at District Headquarter Hospitals belong to the respective Health Departments of the provinces of NWFP and Kashmir.

**The Balakot Clinic** has registered more than 150 spinal cord injury patients from the surrounding region, who have been able to visit the clinic at least once. Although the clinic was addressing the needs of the local amputees, more recently it has been converted to a referral center for amputees who are now being referred and managed at the PIPOS Mansehra Limb Center.

This clinic has a good basic infrastructure. It also has a small committed rehabilitation staff, with good training and experience in the management of artificial limbs. It does not have the equipment, medicines or the supplies needed for the optimal medical management of SCI patients nor does not have staff with spinal cord injury rehabilitation training.

Geographically, the Balakot Clinic is ideally located and can become a key component in a system of medical care and rehabilitation created for SCI patients in the region. It can be developed into an Out Reach Spinal Cord Injury Rehabilitation Center, with minimum accepted international standards, ultimately sustained with indigenous financial and human resources.

This view is, also shared by Dr. Bakht Sarwar, Director of PIPOS, as well as Mr. Haamid Jaffer, who is the Director of CHAL. **CHAL** is a Pakistan based network of individuals and organizations that have come together to fund many projects to rehabilitate the disabled in the earthquake affected areas. CHAL has committed to support this endeavor for 3 years and has pledge to raise \$ 100,000/- to provide as seed money and initial funding.

**The Armed Forces Institute of Rehabilitation Medicine (AFIRM)** in Rawalpindi is well-staffed and equipped rehab military institute that trains physiatrists. Their team has agreed to visit the Balakot Center, once every 3 months to evaluate and manage SCI patients registered there. They made their first trip on August 25-26, 2007.

**The Shifa Hospital Rehab Team** in Islamabad, runs an active outpatient neuro-rehabilitation program at a private teaching hospital in Islamabad. They also have trained and experienced rehab staff in their group and have also agreed to make 3 monthly visits to the Balakot Center. It is hoped that the logistics of this will be worked out soon.

**The Peshawar Paraplegic Center** is also an established facility, solely devoted to treating and rehabilitating spinal cord disorder patients. It has a very experienced staff and it is hoped that their Center will also be able to participate in this endeavor in the future.

**SCIPPER** is a volunteer network of individuals, organizations and donors, based at UCLA, California, who are collaborating to help facilitate the rehabilitation of the Pakistan Earthquake spinal cord injury survivors. SCIPPER would also like to help with the Balakot Clinic capacity building efforts.

**Real Medicine Foundation (RMF)**, a Los Angeles based, nonprofit organization, has been running a Basic Health Unit to serve the Balakot region since the earthquake. RMF has agreed to collaborate with SCIPPER in this endeavor without charging an overhead in the USA. RMF and SCIPPER hope to raise \$50,000 for the medical rehabilitation of SCI patients. The funds raised will be used to provide medicines and medical supplies needed at the Balakot Clinic and help create a SCIPPER Tele-Neuro-Rehabilitation Team.

**Direct Relief International (DRI)** is a Santa Barbara, California based nonprofit that has funded various rehabilitation projects for the disabled in the regions affected by the Pakistan earthquake. It will be providing an additional \$50,000 for this project.

### **SCIPPER Tele-Rehabilitation (Tele-Medicine) Pilot Project**

SCIPPER proposes to create a Tele-Rehabilitation System of Care for the spinal cord injury survivors of the Pakistan earthquake. This system should be designed and adapted to the unique demographics of these patients in their Himalayan habitat. The goal of this project is to educate, monitor and connect a spinal cord injury survivor located in a remote mountain shelter, with secondary or tertiary rehabilitation centers in the region, thus optimizing and facilitating their ongoing medical care. Such a model can potentially be developed to do meaningful, quality of life and outcome measure assessments, monitor and address evolving medical issues and educate SCI patients and their families.

### **LOGISTICS PROPOSED**

- ⇒ Create 'Primary Tele-Rehab Teams' comprising of 1-2 Tele-Coordinators and 1-2 Tele-Supervisors
- ⇒ Location and Constituents of Primary Teams
  - ***Balakot Center Tele-Rehab Team*** (Tele-Coordinators: Suggestions: Mr. Aziz and the receptionist or others proposed by Balakot; Tele-Supervisors: Visiting Rehab physicians from AFIRM funded by CHAL/DRI)
  - ***AFIRM Tele-Rehab Team*** (Tele-Coordinators: 2 physiatry residents (or suggested students); Tele-Supervisors: AFIRM physiatrists, funded by CHAL/DRI)
  - ***SHIFA Tele-Rehab Team*** (Tele-Coordinators: a rehab staff member and a resident/student; Supervisors: Dr. Arsalan Ahmed and other faculty, funded and monitored by RMF/ SCIPPER)

- **SCIPPER Tele-Rehab Team** (Tele-Coordinators: Mr. Mohd Ali Butt, a spinal cord injury survivor and Mrs. Butt, who have received training as SCI Educators; Supervisor: Dr. Zahoor of Hashoo Foundation and AFIRM) (located at NIH-D and later at their future residence in Pindi, funded by SCIPPER-Hashoo Sponsorship Program, monitored by RMF)
- **PIPOS-Mansehra Tele-Rehab Team** (Tele-Coordinator: Ms. Kulsoom Bibi, a SCI patient who was a Health Visitor for Family Planning before the earthquake and is living in Mansehra with her brothers family; Supervisor: Dr. Zahoor of HF and Balakot Visiting Teams, funded by SCIPPER-HF Sponsorship Program)
- **Peshawar Paraplegic Center Tele-Rehab Team**
  - ⇒ Formulate a One Page SCI Medical and Psychosocial Monitoring Screening Template
  - ⇒ Goal to provide every registered SCI patient or caregiver with a mobile / cell phone
  - ⇒ SCIPPER Tele-Rehab Patient Registry and Case History Files at AFIRM and Balakot Center
  - ⇒ Each Tele-Team given 25-50 patients to monitor, preferably including those patients that may have been managed at their center. SCIPPER-Hashoo Foundation Tele –Team will follow the 50 patients in the Sponsorship Program.
  - ⇒ The Tele-Coordinators will call the patients and fill the SCI screening template. Frequency, at least monthly screening call for stable patients and more frequent calls for patient with complications. Coordinators to be educated by supervisors when to alert them about a complication that needs urgent attention.
  - ⇒ Tele-Supervisor Reviews the collected data once a month with his Tele-Coordinators and files the collected data and recommends interventions for specific patients.
  - ⇒ The Balakot Center is notified by the Tele-Coordinator, and the patients visit to the Balakot Center is facilitated; or a home visit by the Mobile Rehabilitation Team is arranged; or the patient transferred to a tertiary care facility if needed.
  - ⇒ The Tele-Rehabilitation teams should have annual meetings to discuss project improvement.

#### **Balakot Mobile Rehabilitation Team for SCIPPER**

- ⇒ A Mobile Rehabilitation Team based at the Balakot Center should make home visits to monitor and educate those patients and families who cannot come to the clinic.
- ⇒ The team members should have at least one member trained in spinal cord injury rehabilitation.
- ⇒ Ongoing training and education of the Balakot Clinic and Mobile Team members should be done. They should do training electives at the tertiary rehab facilities.
- ⇒ Suggested routine home visits should be made at least once every 6 months.
- ⇒ Data submitted by various Tele-Rehab Teams, should be reviewed at the Balakot Center, by visiting rehab team members and the Mobile team advised about which patient needs to be visited more urgently.
- ⇒ The Mobile Team should facilitate and coordinate the care of the patients they visit in their homes, with the Balakot Clinic and tertiary rehab facilities.
- ⇒ The funding, staffing and monitoring of the Mobile Rehab Team is to be done by PIPOS, AFIRM and CHAL.