

EDITORIAL

REVISITING THE 2005 EARTHQUAKE PARAPLEGICS: WHAT HAS CHANGED IN A DECADE?

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Oct 2005 earthquake was a great tragedy, which resulted in hundreds of paraplegics. This was the largest number of Spinal cord injuries (SCI) reported in a natural disaster. The health care system of Pakistan was not well equipped to handle such a large number of major neurological disabilities. Despite these limitations, the initial response was adequate, aided by involvement and guidance from foreign medical teams skilled in management of SCI. It also resulted in strengthening and establishment of better centers for management of SCI. We hoped that this enthusiasm would continue and result in better rehabilitation and community re-integration of these individuals with a long-term disability. Unfortunately, this goal did not materialize. This editorial highlights the current situation of 2005 paraplegics, discusses the shortcomings in long term planning and presents some viable solutions for comprehensive management and rehabilitation of these SCI patients.

Keywords: Spinal cord injury; rehabilitation; disaster; earthquake; paraplegia; quadriplegia

October 2005 was a great national tragedy which resulted in colossal loss of life and many more injuries. This earthquake was unique because more than 700 spinal cord injuries (SCI) were reported in the disaster.¹ This was the largest number of SCI ever reported in a single natural disaster in the world. Most of the SCI were paraplegics and the health care system did not have enough resources to manage this huge burden of long term disabilities.^{2,3} There were only two dedicated established facilities in the country for the SCI patients. One was the spinal rehabilitation unit at the Armed Forces Institute of Rehabilitation Medicine (AFIRM) and the other was the paraplegic center, Peshawar. The AFIRM had a physiatrist (Rehabilitation medicine physician) as the team leader of the multi-disciplinary team (MDT). In the months after the disaster many makeshift SCI centers were established in twin cities of Rawalpindi and Islamabad.⁴ These centers did a great job of saving life of these paraplegics who were otherwise considered "the most neglected of all patients injured in this earthquake".⁵ But at the same time many centers were being run by untrained volunteers with good intentions but no practical experience and medical expertise to manage a major disability like SCI. In the months following the disaster AFIRM team systematically collected valuable data which was published over the next three years.^{2,4,6-8} This data was unique as it re-affirmed many known facts and presented new findings in management of SCI in disaster situations. These studies revealed that management in a dedicated SCI unit under the care of a physiatrist is better than non-physiatrist care; early and MDT rehabilitation results in fewer complications, reduced length of stay and better community re-integration; helicopter evacuation of a

suspected SCI patient is invaluable where available and good intentions of volunteers cannot replace expertise of a physician.^{4,6,7}

Many teams of SCI experts came from abroad to help and offer support. They not only managed the paraplegics but also trained the local staff in different management and rehabilitation protocols.³ Swiss Paraplegics Centre Nottwil trained seven physiatrists in a special "Spinal Cord Injury Rehabilitation Course".⁹ WHO published a manual on SCI management and rehabilitation in Urdu and English considering local context and resources. In addition the makeshift SCI center at the National Institute of Rehabilitation Medicine (then called National Institute of Handicapped and disability) was upgraded to a permanent SCI ward.⁷ These positive developments gave a hope that paraplegics in Pakistan had received the attention they deserved and things might change in future for this neglected segment of the society.

Unfortunately this did not happen! In the months and years following the earthquake, patients were discharged to homes in far flung mountainous terrain of Kashmir only to be re-admitted later with pressure ulcers and severe urinary tract infections. One year later our team couldn't trace any surviving quadriplegic from the Kashmir area⁶ (and we are still looking for one). Patients were discharged without any long term follow-up plans, rehabilitation protocols, advice for community re-integration and home modifications.⁴ Many of them spent most of their time confined to their homes as the fancy donated wheel chairs couldn't be maneuvered in the hilly terrain. Many NGOs came forward to help but didn't offer a long term sustainable plan keeping in view the needs and constraints of the patients living

in a difficult area. Many patients turned to alternative medicine and stem cells in the hope for a permanent cure.⁴ Some were exploited in the name of cure¹⁰ and many ended up with severe depression. Still there were some notable exception among these paraplegics who refused to give up and established NGO for their rights and giving a voice to this neglected segment.¹¹ Other kept on helping by establishing centers, highlighting the lives of female paraplegics in movies¹² and establishing funds to sustain the care for SCI patients of 2005 earthquake.

A decade after this tragedy the health care system of Pakistan including the professionals (specially physicians and surgeons involved in the care of SCI) have failed to respond adequately to the long term needs of paraplegics in the country. There is no national trauma or SCI registry to document the actual burden of this devastating disability. Rehabilitation medicine is still largely neglected and confused with physiotherapy rather than with a concept of a MDT. The national disaster plan does not have any input of the rehabilitation professionals and the general attitudes of the society towards disability remain negative.

There is a need to engage all stakeholders in Pakistan involved in the acute management and long term rehabilitation of SCI patients to devise a future plan. This plan should encompass not only the emergency care and acute indoor treatment but also the long term rehabilitation needs and community re-integration. At the same time there is a need to counter the negative cultural attitudes towards persons with disability in the country. Pakistan Society of Physical Medicine and rehabilitation, Pakistan society of Neurosurgeons, Pakistan Orthopedic society (spine group), Pakistan society of neuro-rehabilitation need to come together to formulate a joint strategy addressing the needs of SCI

patients in Pakistan. Only then we can ensure an adequate re-integration of the paraplegics in the society as useful and respectable members.

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