Letter to the editor

Re: Burns AS, O'Connell C. The challenge of spinal cord injury care in the developing world. J Spinal Cord Med. 2012; 35:3–8.

To the editor:

We have read “The challenge of spinal cord injury care in the developing world”¹ by Burns and O'Connell with interest. They have presented an excellent review of the Spinal Cord Injury (SCI) care in the developing world. Based on our experiences in the largest rehabilitation institute of Pakistan, we offer additional comments and perspectives, which we believe also hold true for the South Asian region in general.

1. There are some important limitations of SCI-related research in Pakistan. First, is the lack of a central trauma/SCI registry.² Secondly, all available studies on SCI in Pakistan are hospital-based surveys mostly covering only one unit or hospital with the exception of the study by Raja *et al.*³, which was a nationwide survey of different neurosurgical departments and units. There is no information available about demographics of patients with SCI living in the community. Third, most of these studies have a diverse methodology and data collection technique making a comparison between different studies difficult.
2. The number of dedicated SCI centers (providing initial care and comprehensive rehabilitation) in the country is inadequate for the large number of patients. There are only three centers; Spinal unit at the Armed Forces Institute of Rehabilitation Medicine (AFIRM), Rawalpindi; Paraplegic center Peshawar (PCP), Peshawar and Spinal Unit at the National Institute of Rehabilitation Medicine (NIRM), Islamabad. Of all these centers, only the Spinal Unit at AFIRM is managed by physiatrists employing a multidisciplinary team approach. The PCP is headed by physiotherapists⁴ and the Spinal unit at NIRM is more of a long-term shelter primarily for women with paraplegia sustained in the 2005 earthquake who have been abandoned by their families.⁵
3. Pre hospital care in Pakistan has improved a lot in the last one decade,^{6,7} but these emergency rescue services are mainly available in the urban areas. Patients with suspected SCI in the rural areas are still transported on public transport, private cars and even animal carts in some cases.²
4. The healthcare system in Pakistan is more inclined towards curative medicine rather than preventive medicine.⁸ All spinal and neurosurgical units in the country are equipped to perform costly spinal surgeries which cannot reverse the permanent neurological damage; but there is no strict enforcement of road and work place safety laws to prevent this devastating injury in the first place. (Figs. 1 and 2)
5. There is a trend toward surgical fixation of the damaged spine even when the patient presents after two weeks⁹ when there is hardly any hope for neurological recovery. However, a recent study by Shamim *et al.* has demonstrated that nonsurgical management of spinal injuries in complete SCI is superior to surgical management in our setup.¹⁰

Fig 1 An overcrowded bus is an open invitation to disaster.

Fig 2 A construction worker at a height of 50 feet without safety precautions.

6. SCI rehabilitation is a poorly understood concept for most of the health care professionals involved in SCI care in Pakistan. For the majority, rehabilitation is “some form of exercises,” rather than a concept of multidisciplinary team approach.¹¹ There are others who consider a complete SCI not worthy of any active management and rehabilitation.
7. Patient counseling and explanation of prognosis of a disease is inadequate in Pakistan.¹² This is a major contributing factor towards inadequate outcomes for the majority of the SCI patients in Pakistan. This is further complicated by low educational status of most of the patients, whose main interest lies in “their ability to walk again”.² This results in patients going from one place to another in search of a cure for the SCI. The cures offered and actually tried by the patients in Pakistan include stem cell transplant (from China), ozone therapy and hyperbaric oxygen therapy, alternative and complementary medicine (Including Ancient Greek and Arabic Medicine, homeopathy and acupuncture), along with spiritual healing. Needless to mention that these financially drain the patients and in the end, they are left with little/no resources for SCI rehab even if they desire.
8. Despite all these limitations in SCI care in Pakistan, a few brave souls attempt community re-integration and independent mobility, but they are confronted by the negative attitudes prevalent in the society. As summed up by Sarmad Tariq, the most famous patient with SCI in Pakistan, “Ignorant biases haunt the physically disabled more than their medical shortcomings”.¹³ In addition, disability is a stigma and there are many social, financial and mobility barriers for people with disabilities in Pakistan.¹⁴

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Authors' response:

The authors thank Rathore FA *et al.* for their interest in our article and their insightful commentary on the current challenges faced by individuals with spinal cord injury (SCI) in Pakistan.

Unfortunately, the issues they raise are common to most of the world. Little is known about the demographics of SCI and access to specialized, interdisciplinary care is often limited or non-existent. Farooq and colleagues also do a commendable job of highlighting how SCI is impacted by societal issues both inside and outside the confines of hospitals and institutions.

Depicted in Figures 1 and 2, conditions in the community increase the risk of sustaining a SCI. Immobilization and safe transportation is often the exception, and injuries are commonly exacerbated en route to local health care facilities. Upon arrival, widespread cultural beliefs can impact how injured individuals are counseled and cared for within institutions. Negative societal attitudes limit independence and societal roles following reintegration into the community.

We hope that articles such as ours and the above commentary by Rathore *et al.* will continue to highlight and raise awareness of the issues faced by the majority of the world, and stimulate discussion and action among the international SCI community. Increased awareness is the first step towards improving conditions for persons with SCI both within and outside our immediate communities.

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