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Perspective: Inadequate Long-term outcomes in female paraplegics of the 2005 Pakistan earthquake: looking beyond the gender discrimination

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Earthquakes are known to cause long term disabilities including SCI (Reinhardt, Li et al. 2011). The October 2005 Pakistan earthquake resulted in largest number of SCI reported from any natural disaster (estimates were 650-750 (Rathore, Rashid et al. 2007; Mallick M 2010). Management and rehabilitation of SCI is a focused and specialized job that is most appropriately carried out by a multidisciplinary team of dedicated rehabilitation professionals. These services cannot be delivered by any physician, allied health care professional , social worker or well-meaning people with "no medical expertise and good intentions alone"(Rathore, Gill et al. 2011), as was the case with many makeshift SCI centers in 2005 earthquake(Rathore, Farooq et al. 2008).

Our team of physiatrists (rehabilitation medicine physicians), physical therapists, occupational therapist, prosthetist and clinical psychologist directly and indirectly managed/ supervised approx. 400 SCI patients after the 2005 earthquake. We have previously documented and shared our experience in support of early rehabilitation interventions in these patients.(Rathore, Rashid et al. 2007; Rathore, Farooq et al. 2008; Rathore, Butt et al. 2008) .

The experience with earthquakes elsewhere in Iran (2003) (Priebe 2007; Raissi 2007)China (2008) and Haiti (2010) (Landry, McGlynn et al. 2010; Landry, O'Connell et al. 2010) has also demonstrated the value of providing dedicated early rehabilitation services to SCI patients. In the case of the Pakistan earthquake ,SCI patients under the care of a physiatrist had reduced length of stay, reduced incidence of complications (like deep vein thrombosis, urinary tract infections, and depression and pressure ulcers)(Rathore, Butt et al. 2008; Rathore, Hanif et al. 2008; Rathore, Gill et al. 2011) better understanding of their disability and lesser readmissions.

SCI management is still neglected in Pakistan and the 2005 earthquake only compounded the problem. In fact they were considered to be "the most neglected of all patients injured in the earthquake"(Umer, Rashid et al. 2006). Pre hospital care was not adequate, and resulted in worsening of neurological damage in some cases (Rathore, Farooq et al. 2008). There was no central trauma/SCI registry to document the actual burden of SCI and the data collection had some major flaws (Rathore, Farooq et al. 2008). Those injured in the 2005 tragedy, like in other developing countries died of preventable complications like pressure ulcers and urinary tract infections(Rathore, Butt et al. 2008; Rathore, Gill et al. 2011). There is still no national plan to follow up hundreds of SCI patient who went back home in the mountainous Kashmir area, only to die of neglect and complications. In fact we doubt if any of the survivors with tetraplegia from the 2005 earthquake is still alive. One of the authors (FR) has received calls from patients from Kashmir where they narrate horrible stories of remaining confined to their small houses for months. They are forced to reuse the disposable catheters for weeks and can't arrange for their medicines. Some of them are still holding on to the wheel chairs issued in 2005, as they are unable to find a replacement. Therefore it is necessary that the poor outcomes in female paraplegics of 2005 earthquake should not be considered a gender specific problem

only.

A great amount of funds were spent on establishing the SCI unit of the National Institute of rehabilitation medicine (NIRM). Hundreds of doctors and allied health professionals were employed.(Mallick M 2010)[4] The aim of a SCI rehabilitation unit is to prevent secondary complications, promote independence and encourage community reintegration of the disabled. Unfortunately NIRM is working as more of a shelter home for the severely disabled paraplegics who have been abandoned by their family members. As per the author's description, even after three years patients have pressure ulcers and are dependent on their care givers for their feeding, prevention ulcer prevention, mobility and toilet care(Irshad, Mumtaz et al. 2011). This negates the image of NIRM as a spinal rehabilitation unit. In addition NIRM still doesn't have a full time physiatrist as its staff member (Rathore, Farooq et al. 2008). The only physiatrist is a WHO consultant working as a visiting physician.

We had warned against unregulated monetary support in form of alms, charity and government sponsored stipend to these SCI victims a few years back. This article only confirms that over the years this strategy has failed and instead of achieving independence for these patients, has reinforced the disability as a source of charity and steady income. It would have been much better if this monetary support was used to generate a central fund, which would have generated jobs and opportunities of respectable earning for these SCI patients. Some Non-Governmental Organizations have utilized their funds wisely to establish pre-fabricated wheel chair accessible houses for these paraplegics. This is a model worth following.

We agree that low educational status and cultural taboos preferentially affect the female patients, but inadequate patient counseling and poor explanation of the prognosis at the time of injury was also a major contributing factor. Patients were given false reassurances about prognosis and sexual rehabilitation was never discussed (Rathore, Farooq et al. 2008). Over the years many of these patients have wasted their resources in exploring various options for cure ranging from stem cell transplant, claims of surgical repair of the spinal cord, use of herbal medicines, subcutaneous placement of (supposedly) magnetic needles and spiritual healing. Many, if not all are still waiting for the ability to walk again. All this would have been averted if an interdisciplinary SCI rehabilitation team approach would have been offered in the beginning, along with an honest explanation of the long term prognosis. In addition fears and concerns about the negative affect of SCI on the marital lives of these paraplegics were voiced as early as Nov 2005(e.news 2005); but unfortunately they were never addressed.

After the earthquake community based rehabilitation programs were launched by the government, United Nations, WHO and national NGO's working in the field of disability. Except for one run by Chal foundation, none included a physiatrist as a team member. Moreover there was no coordination between different actors and there was duplication of efforts and overuse of resources.

In addition to the inadequate outcomes in 2005 earthquake, SCI survivors have been further impacted by the poor understanding of disability and the negative attitudes prevalent in the Pakistani society. Rehabilitation Medicine is still confused with physiotherapy and exercises alone rather than with a concept of a multidisciplinary team work, even by health care professionals(Rathore, Rashid et al. 2007). This society still considers disability a stigma and doesn't accord respect to the disabled (Rathore, New et al. 2011). The authors describe patients who complain "pushing wheel chair has become a nuisance for their families"(Irshad, Mumtaz et al. 2011) In contrast person with SCI (especially with paraplegia) hardly requires any assistance for pushing the wheel chair. The admittance by patients that they were "deliberately creating pressure ulcers to prolong their hospital stay in order to avoid their abusive families" is a shame for our society. The attitude of Pakistani society towards a disabled paraplegic was honestly described in 2005 as follows(e.news 2005)

""*The society is cruel. They (the paraplegic women) will be out on the streets unless they can get a skill and become independent. A young woman who does not walk, who has no control over her bladder, has no real chance in this society. I hope to God the world will not forget them"*

Despite these largely negative outcomes for the female paraplegics of 2005 earthquake, there are some encouraging examples of successful community re-integration of female paraplegics who were supported by their families to find a respectable place in the society.(Watch 2010)

Let us learn from our past and build a vision for the future.

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