

## ORIGINAL REPORT

# ANALYSIS OF FUNCTIONAL STATUS, QUALITY OF LIFE AND COMMUNITY INTEGRATION IN EARTHQUAKE SURVIVORS WITH SPINAL CORD INJURY AT HOSPITAL DISCHARGE AND ONE-YEAR FOLLOW-UP IN THE COMMUNITY

Xiaorong Hu, MD<sup>1,2</sup>, Xia Zhang, PhD<sup>1,2,3</sup>, James E. Gosney, MD<sup>3</sup>, Jan D. Reinhardt, PhD<sup>3,4,5</sup>, Sijing Chen, MD<sup>1,6</sup>, Hong Jin, MD<sup>7</sup> and Jianan Li, MD<sup>1,3</sup>

From the <sup>1</sup>Department of Physical and Rehabilitation Medicine, First Affiliated Hospital of Nanjing Medical University, Nanjing, China, <sup>2</sup>Caring For Children Foundation, Hong Kong, China, <sup>3</sup>World Health Organization Liaison Sub-Committee on Rehabilitation Disaster Relief of the International Society of Physical and Rehabilitation Medicine, Assenede, Belgium, <sup>4</sup>Swiss Paraplegic Research, Nottwil, Switzerland, <sup>5</sup>Department of Health Sciences and Health Policy, University of Lucerne, Switzerland, <sup>6</sup>Handicap International, Brussels, Belgium and <sup>7</sup>Mianzhu People's Hospital, Deyang, China

**Objective:** This study compares functional status, quality of life and community integration in 2008 Sichuan earthquake survivors with spinal cord injury at hospital discharge and at 1-year follow-up in the community.

**Methods:** Twenty-six subjects with spinal cord injury completed demographic and medical questionnaires and underwent medical examination at discharge from a hospital rehabilitation department and after 1 year in the community. Functional status, quality of life and community integration were assessed by appropriate instruments over this period.

**Results:** Functional status measures showed significantly increased ( $p < 0.05$ ) scores for the Modified Barthel Index and Walking Index for Spinal Cord Injury II; depression and pain scores were reduced with no statistical significance. After discharge, nearly half of patients developed a new pressure sore and most patients had urinary complications. Self-reported quality of life, overall health, and satisfaction with social relationships increased significantly ( $p < 0.05$ ), while the environment domain was reduced ( $p < 0.05$ ). Social participation (i.e. community integration) results showed an improvement in physical independence and mobility ( $p < 0.05$ ), but a decline in cognitive independence ( $p < 0.05$ ). Only 15% of the population returned to work.

**Conclusion:** Special attention should be paid to cognitive and emotional function, occupational training and social integration during rehabilitation measures after earthquakes.

**Key words:** spinal cord injury; rehabilitation; earthquake; quality of life; community integration.

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Correspondence address: Jianan Li, The First Affiliated Hospital of Nanjing Medical University, Nanjing, China, 210029; E-mail: lijianan@carm.org.cn

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## INTRODUCTION

Spinal cord injury (SCI) was one of the most severe injuries that occurred in the 2008 Sichuan earthquake in the People's Republic

of China. SCI poses significant challenges for long-term rehabilitation. With recent developments in rehabilitation medicine and the adoption of a bio-psycho-social model for measuring health and disability, focus has shifted from improving physical function to enhancing quality of life (QoL) and community integration as the primary goals of SCI rehabilitation (1, 2).

The experience of the 2005 Kashmir earthquake in Pakistan regarding SCI patients showed the benefit of institutional rehabilitation during the emergency phase of disaster response (3). A summary of the rehabilitation rescue efforts in the Sichuan earthquake concluded that comprehensive rehabilitation measures including therapeutic interventions, training and education, and social and vocational rehabilitation should be performed immediately and concurrently with clinical treatment (4, 5). A series of studies of patients with SCI has indicated that physical rehabilitation has a significant positive effect on activities of daily living (ADL) and correlates with functional health (6, 7). Furthermore, patients who received rehabilitation training show improved social integration (8). However, the increase in QoL and participation in the community is a long-term process that requires persistence and constant adaptation, especially in the community setting (9, 10). Prospective follow-up studies of QoL and community integration of earthquake survivors with SCI after returning to their reconstructed community have not been conducted previously.

This study aims to compare the functional status, QoL and community integration of earthquake survivors with SCI at the time of discharge from primary, institution-based rehabilitation with that at one year after returning to the community. It also seeks to identify domains of QoL and areas of community integration (i.e. social participation) upon which rehabilitation should particularly focus in order to improve QoL and community integration.

## METHODS

### Design

This is a prospective cohort study measuring variables of interest in changes of functional status, QoL and community integration after re-

turning to the community. Measurements were performed at discharge immediately after rehabilitation therapy (from May to August 2009), and at 1 year as follow-up (from August to November 2010).

### Subjects

A total of 27 SCI survivors who sustained their injuries in the 2008 Sichuan earthquake in the Mianzhu County of the Sichuan Province in the People's Republic of China were identified and enrolled. Eligibility criteria were: (i) SCI; (ii) 18 years and older; (iii) had received rehabilitation therapy in the rehabilitation centre for earthquake survivors in the Mianzhu People's Hospital; and (iv) had returned to the community for at least 1 year. Exclusion criteria were: (i) SCI with traumatic brain injury and/or fractures of the extremities; and (ii) inability to complete the questionnaires, medical examinations and clinical assessment instruments. One survivor, who was under 18 years of age, was excluded. The 26 patients entered into the study group at baseline and all joined in the follow-up group, with very good compliance.

This study was approved by the ethics committee of Nanjing Medical University and written informed consent was obtained from all participants.

### Measures

The research coordination team, which comprised rehabilitation professionals, physiatrists, therapists (physical, occupational), rehabilitation nurses and volunteers, who had a degree in rehabilitation medicine and at least 2 years of clinical experience, provided both comprehensive evaluation and management of the enrolled subjects. The rehabilitation professionals performed a critical role in integrating the efforts of the rehabilitation medical team, who were from a well-developed area of China, and the local healthcare providers (11). With no psychologist, all members received professional training for accurate evaluation, especially in mental assessment.

### Demographic information

Gender, age, marital status, educational level, employment and annual family income were assessed. The American Spinal Injury Association (ASIA) Impairment Scale (AIS) was used for assessing neurological levels and severity of injury.

### Functional status evaluation

**Modified Barthel Index (MBI).** The MBI is a measure of ADL, which shows the degree of independence of a patient from any assistance. It comprises 10 domains of functioning (activities). Eight domains concern self-care activities (grooming, bathing, dieting, toileting, dressing, controlling stools, controlling urination, transfer) and two items are related to mobility (moving across an even surface on foot or in a wheelchair for 50 m, travelling up or down stairs), with higher scores indicating greater levels of independence (12).

**Walking Index for Spinal Cord Injury II (WISCI II).** This scale evaluates physical limitation in walking after SCI. Zero indicates the patient is unable to walk and 20 indicates the patient can walk without braces and/or devices for at least 10 m without physical assistance. A higher score indicates lesser impairment. The therapist assigns a score level at which the patient is considered safe (13).

**Complications.** All participants underwent a monthly medical examination to assess for complications including bladder dysfunction (including neurogenic bladder, urinary tract infection and bladder stones), renal dysfunction, heterotopic ossification and pressure sores. The visual analogue scale (VAS) was used to assess degree of chronic pain.

**Patient Health Questionnaire Depression Module (PHQ-9).** This measure of depression severity is used both to detect depression

and to guide treatment decisions. Scoring is performed as follows: 4 and below indicates that the patient does not require antidepressant treatment; 5–14 indicates therapy based on functional status and duration of symptoms; 15 and above clearly indicates antidepressant treatment (14).

**Quality of life.** The World Health Organization Quality of Life-BREF (WHOQOL-BREF) was used to assess QoL. The first 2 items are self-ratings for overall QoL and health, while the additional 24 items measure the 4 broad domains of physical health, psychological health, satisfaction with social relationships and the environment. A total score is also computed. Higher scores correlate to higher QoL (15).

**Community integration.** The Craig Handicap Assessment and Reporting Technique Short Form (CHART-SF) measures social participation/community integration in 6 areas: physical independence, cognitive independence, mobility, occupation, social integration and economic self-sufficiency. Higher scores indicate higher levels of participation/integration (range 0–100). The first 5 areas, as well as the total score, are analysed in this study (16).

### Statistical analysis

Microsoft Excel was used for data entry by trained coders, and analyses were performed with SPSS 16.0. Log-normal distributed continuous variables were described based on mean value (standard deviation (SD)) and categorical variables by frequency distribution. All continuous variables were tested by the Kolmogorov-Smirnov test for normal distribution. Comparisons of functional status, QoL and community integration at discharge and 1 year later were compared with either paired *t*-test or Wilcoxon signed-rank test, depending on the distribution of the outcomes. Alpha error level was fixed as  $p \leq 0.05$ .

## RESULTS

The subjects had a mean age of 52.6 years (SD 15.8); range 20–79. The male:female ratio was approximately 0.7:1 ( $n = 11$  and 15, respectively). Sixty-nine percent ( $n = 18$ ) were married and 30.8% ( $n = 8$ ) were single (1 spouse died from the earthquake, 3 spouses died due to other reasons). Fifty-three percent ( $n = 14$ ) had received formal education (3 beyond senior high school, 11 below senior high school) and 46.2% ( $n = 12$ ) were illiterate. Fifteen percent ( $n = 4$ ) were in paid employment by March 2011. The mean value of annual family income for all survivors was \$849 (SD 503) (Table I).

Table I. Participant demographic data

Variables	
Age, years, mean (SD)	52.6 (15.8)
Gender, %	
Male	42.3
Female	57.7
Marital status, spinal cord injury, %	
Married	69.2
Single	30.8
Education, %	
Illiterate	53.8
Literate	46.2
Employment, %	15.4
Annual family income (\$), mean (SD)	849 (503)

SD: standard deviation.

Table II. Level and severity of spinal cord injury (AIS)

AIS	≥C7	C8–T6	T7–L2	L3–S2	≤S2	n (%)
A	–	1	5	–	–	6 (23.1)
B	–	–	2	–	–	2 (7.60)
C	–	–	7	–	–	7 (26.9)
D	3	–	5	1	2	11 (42.3)
Total	3	1	19	1	2	26 (100)

AIS: American Spinal Injury Association Impairment Scale.

### Level and severity of spinal cord injury

The patients were categorized into 5 groups according to functional prognosis: C7 and above, C<sub>8</sub>–T<sub>6</sub>, T<sub>7</sub>–L<sub>2</sub>, L<sub>3</sub>–S<sub>2</sub>, and S<sub>2</sub> and below. Of the 26 cases, 23.1% ( $n=6$ ) were complete and 76.9% ( $n=20$ ) were incomplete injuries. Most patients (68.6%) were injured at level T<sub>7</sub>–L<sub>2</sub> (Table II).

### Medical complications

At 1-year follow-up in the community, all patients felt spasmodic pain along the course of one or more nerves and some reported constant pain since discharge. Forty-six percent ( $n=12$ ) had a new pressure sore, 53.8% ( $n=14$ ) had neurogenic bladder and 57.7% ( $n=15$ ) had had urinary tract infections (UTI) at least once. Two cases of bladder stones and a single case of heterotopic ossification (HO) were diagnosed (Table III).

### Functional status

Compared with data at discharge from primary rehabilitation, the MBI and WISCI II scores increased significantly ( $p<0.05$ ), indicating that ADLs and walking improved upon returning to the community. Pain and depressive symptoms decreased insignificantly (Table IV); however, 26.9% ( $n=7$ ) required antidepressant treatment and 53.8% ( $n=15$ ) psychological counselling.

### Quality of life

The total score, self-ratings of QoL and general health, and satisfaction with social relationships improved significantly ( $p<0.05$ ) in the community. However, the increases in the physical health and psychological health domains were not statistically significant. Satisfaction with the environmental domain decreased (although not significantly) (Table V).

### Social participation/community integration

The total scores of CHART-SF at 1 year in the community were higher than at discharge (not significant). Scores in

Table III. Medical complications

Complications	≥C7	C8–T6	T7–L2	L3–S2	≤S2	n (%)
Pain	3	1	19	1	2	26 (100)
Pressure sore	–	1	10	–	1	12 (46.2)
Neurogenic bladder	–	1	12	–	1	14 (53.8)
UTI	–	1	12	–	2	15 (57.7)
Bladder stone	–	–	2	–	–	2 (7.69)
HO	–	–	1	–	–	1 (3.85)

UTI: urinary tract infections; HO: heterotopic ossification.

Table IV. Functional status

	At discharge Mean (SD)	In community Mean (SD)	<i>p</i>
MBI <sup>a</sup>	71.2 (25.8)	81.9 (18.7)	0.002
WISCI II <sup>b</sup>	5.81 (7.00)	9.65 (8.15)	0.000
VAS <sup>a</sup>	5.38 (1.38)	5.04 (1.46)	0.836
PHQ-9 <sup>a</sup>	10.5 (5.38)	9.62 (5.16)	0.391

<sup>a</sup>The variables were normally distributed and differences between baseline and follow-up were tested by paired *t*-tests.

<sup>b</sup>The variables were not normally distributed and differences between baseline and follow-up were tested by Wilcoxon test.

MBI: Modified Barthel Index; WISCI II: Walking Index for Spinal Cord Injury II; VAS: visual analogue scale; PHQ-9: Patient Health Questionnaire Depression Module.

physical independence and mobility increased significantly ( $p<0.05$ ) while cognitive independence decreased significantly ( $p<0.05$ ). No statistically meaningful differences were identified in occupation and actual social integration, i.e. ability to participate in and maintain customary social relationships (Table VI).

## DISCUSSION

We analysed medical complications, functional status, and QoL and community integration in 26 SCI survivors of the 2008 Sichuan earthquake at discharge from a primary institution-based rehabilitation setting and at 1-year follow-up in the community.

Our study showed a high incidence of secondary medical complications in the community setting. These included typical secondary chronic complications after SCI, such as urinary dysfunction, neuropathic pain and pressure sores, the latter accounting for most secondary admissions. These complications may also negatively affect QoL and community integration. Clean intermittent catheterization, transurethral catheterization and suprapubic cystostomy have been reported as poor methods of bladder management in terms of QoL due to the associated high frequency of incontinence (17). A comparative, retrospective survey of SCI survivors of the Tangshan earthquake

Table V. Total score and each domain of quality of life (WHOQOL-BREF)

	At discharge Mean (SD)	In community Mean (SD)	<i>p</i>
Total score <sup>a</sup>	68.3 (12.6)	71.4 (10.2)	0.011
QoL (self-rated) <sup>a</sup>	2.65 (1.09)	3.84 (0.731)	0.000
Health (self-rated) <sup>a</sup>	2.65 (1.23)	3.81 (0.749)	0.000
Physical health <sup>a</sup>	19.0 (4.98)	20.6 (2.58)	0.117
Psychological health	17.0 (3.89)	17.8 (3.38)	0.202
Satisfaction with social relationships <sup>a</sup>	8.27 (2.31)	9.42 (1.92)	0.017
Environment <sup>a</sup>	24.1 (5.65)	23.6 (6.14)	0.657

<sup>a</sup>The variables were normally distributed and mean differences tested by paired *t*-test.

WHOQOL-BREF: World Health Organization Quality of Life-BREF; QoL: quality of life.

Table VI. Total score and each area of social participation/community integration (CHART-SF)

	At discharge Mean (SD)	In community Mean (SD)	<i>p</i>
Total score <sup>a</sup>	322 (87.0)	344 (80.8)	0.127
Physical independence <sup>a</sup>	89.4 (11.2)	96.4 (4.70)	0.001
Cognitive independence <sup>b</sup>	75.5 (23.4)	61.9 (17.4)	0.002
Mobility <sup>a</sup>	51.2 (20.5)	67.4 (28.0)	0.009
Occupation <sup>a</sup>	39.5 (32.0)	42.2 (35.4)	0.108
Social integration <sup>a</sup>	63.0 (25.5)	66.6 (27.7)	0.315

<sup>a</sup>The variables were normally distributed and mean differences tested by paired *t*-test.

<sup>b</sup>The variables were not normally distributed and differences tested by Wilcoxon test.

CHART-SF: Craig Handicap Assessment and Reporting Technique Short Form.

(China, 1976) showed that uraemia remained the primary cause of death 15 years after the earthquake, although the proportion of survivors showing recurrent urinary infections decreased significantly, from 32% in 1988 to 10.5% in 2004 (17). Of the Tangshan SCI survivors 82.4% sustained new onset pressure sores after discharge and 25% of these patients still had refractory chronic pressure sores 18 years later; some died from related infections (18). Other studies on long-term complications of persons with SCI in the community at least 1 year after discharge from primary rehabilitation (in non-disaster developed settings) reported the occurrence of pressure sores as 32.6%, urinary complications as 19.6% and pain as 45.7% (19). The high incidence of complications in our study compared with both earthquake and non-earthquake patients may be due to a relative lack of patient self-management and preventive measures practiced by their families (20). Health education will be continued in community-based rehabilitation.

ADLs are instrumental to patients' successful return to the community, since those with higher ADL functioning depend less on other family members and have greater self-esteem and QoL. Li showed that good physical function and self-care ability in daily life could help SCI patients achieve better social participation (18). Our study showed that functional status, as reflected by ADLs (comprised of self-care activities and mobility) was improved after living for 1 year in the community. Without finding any available reports focused on the changes of ADL in SCI earthquake survivors, this corresponds with results from studies conducted by Chan & Chan (21), which concluded that the most important components in functional recovery after non-earthquake SCI are mobility and self-care ability. However, improvement in ADLs in our study did not correspond with significant improvement in social participation/community integration.

Our study also showed significantly improved walking ability of SCI survivors 1 year after returning to the community. Commencement of rehabilitation soon after injury, good adherence to a training programme and a supportive social environment are believed to be contributory. However, the gait safety of these subjects who walked with walking devices remained

threatened. Amatachaya et al. (22) suggested that SCI patients who were independently ambulatory encountered a greater chance of failing to walk over obstacles. Thus, rehabilitation procedures should incorporate contextual conditions similar to the community environment, in order to minimize risk of falling and prepare them to be more independent.

Earthquakes have tremendous psychological impact on SCI patients, triggering mental illness, including depression. A healthy mental state has been shown to contribute to active participation by victims in community activities (23). Our study identified 7 cases (26.9%) that required anti-depression treatment 1 year after returning to the community. Studies conducted by Rathore et al. (24) showed the incidence of depression among 187 SCI survivors 10 weeks after the Pakistan earthquake as 5.8%, which was lower than in our study. Also, our study does not confirm a decrease in depression in patients with non-earthquake SCI who received regular rehabilitation training, as was demonstrated by Fuhrer et al. (25); our subjects' psychological status remained effectively unchanged despite primary institutional rehabilitation. Psychotherapy is generally recognized as beneficial adjunctive therapy following an earthquake, due to the significant emotional trauma sustained (26, 27).

The WHO defines QoL as "the appraisal and experience of living conditions in terms of goals, desires, standards, cultural backgrounds and value systems, including individual physical health, mental health, independence, social relationships, personal beliefs and relationships with the surrounding environment". This study showed a significant increase in QoL total score, self-ratings of QoL and general health, and satisfaction with social relationships at 1 year after discharge compared with at baseline. Other QoL sub-scores increased, except satisfaction with the "environment", which can reasonably be explained by reduced patient satisfaction with living conditions and access to health information and services in the community.

The significant increase in self-ratings of QoL and general health, and satisfaction with social relationships may be explained in part by "response shift", whereby patients have reconceptualized the impact of their SCI in the face of their overall diminished physical condition (28, 29).

Functional deficits in SCI patients may result in barriers that result in limited participation in social activities, thereby impeding community integration. Greater social participation results in increased community inclusion, which, in turn, may improve patient's feelings of self-worth, confidence and vocational potential (30). This study demonstrated significant improvement in physical independence and mobility compared with baseline, whereas vocational ability and social integration in terms of ability to participate in and maintain customary social relationships were not significantly improved after 1 year of community life. Conversely, a study conducted on a comparable sized population from rural India in a non-earthquake setting suggested that physical independence, mobility, vocational ability and social integration were reduced and social participation was significantly decreased 1 year after

discharge. The authors conclude that low mobility was the biggest obstacle to social participation (9). The significant increase in mobility and maintenance of baseline social integration in our community population may be due to participation in a SCI peer support group, which fosters social relationships and community integration.

Re-employment after injury is a significant measure of community integration, since it is necessary to maintain economic independence and to restore individual self-worth and overall QoL. The re-employment rate of patients in our study, however, was still very low 1 year after discharge from primary rehabilitation; only 15.4% (4 cases) had returned to work, a lower percentage than reported in other studies. In a much larger sample of SCI patients in Turkey, a re-employment rate of 21% in patients who had returned to the community for 1 year was reported (31). A survey conducted by Liu et al. (17) in Tangshan SCI survivors showed that 23.1% were employed 26 years after the earthquake (74.1% before injury). Most of these patients were employed either in maintenance positions or private business. Possible reasons for the low employment rate in our study include the low employment rate of these SCI patients prior to the earthquake due to advanced age, the lack of available community-based vocational rehabilitation services, and the relatively short time since injury. Berkowitz et al. (32) reported, for example, that SCI patients resumed full-time employment approximately 6.3 years after their injury. Therefore, the relatively reduced time since injury of 2.5 years may have contributed to the lower employment rate in our study. van Velzen et al. (33) concluded that the main factor related to return to work was the patient's wheelchair capacity at discharge, thus the subsequent rehabilitation training plan should focus on improvement of mobility and functional independence.

Our coordinators' study showed that institution-based physical rehabilitation in SCI patients was effective in achieving better functional rehabilitation outcomes, especially in ADL independence<sup>1</sup>. From the present study, we can deduce that rehabilitation training can also optimize QoL and social participation in SCI patients, increasing their independence and inclusion in society. Participants in this study received rehabilitative therapies, including strength, aerobic, ambulation and balance training as well as training in ADL. Notwithstanding the lack of a control group of SCI earthquake survivors without rehabilitation treatment, this case-control study demonstrated statistical improvement in participant functional status dimensions of ADL and walking, total QoL and social participation/community integration areas of physical independence and mobility. The lack of further improvement may in part be due to incomplete adherence to the prescribed rehabilitation therapy programme, especially in the community.

Limitations of this study include the small sample size and inclusion of participants only from the Mianzhu region of the

earthquake zone. However, this region is fairly representative since it includes both urban and rural areas and has the highest incidence of SCI earthquake victims. In addition, the neurological levels and severity of injury (AIS) in this study were associated with other epidemiological investigation reports of the Wenchuan earthquake (35), thus the present sample can be representative of the SCI survivors in the whole earthquake zone. Also, a community follow-up period of greater than 1 year is required to more precisely measure long-term recovery of QoL and community integration. Considering the high compliance of participants in our analyses, longitudinal, follow-up studies are planned at 3 and 10 years in the community setting. Response shift may have biased results and therefore should be considered in future studies (27, 28).

This is the first study to systematically evaluate the recovery of functional status, QoL and community integration of earthquake survivors with SCI on discharge from an institutional rehabilitation programme and at a 1-year follow-up interval in the community setting.

In conclusion, dimensions of functional status including ADL and walking improved significantly after a year, as did QoL total score, self-ratings of QoL and general health, and satisfaction with social relationships; areas of community integration including physical independence and mobility were also statistically improved. However, medical complications were increased, a high incidence of depression persisted, cognitive function statistically decreased and only a low percentage of SCI survivors had returned to work. Therefore, rehabilitation of SCI earthquake survivors should, in addition to physical rehabilitation programming, more fully address emotional and cognitive function as well as re-employment in order to achieve greater community integration. Follow-on longitudinal studies will be extremely pertinent.

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