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

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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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Submitted September 13, 2011; accepted January 16, 2012

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 biopsychosocial 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 showed 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, 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>
<thead>
<tr>
<th>Variables</th>
<th>Mean (SD)</th>
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<tbody>
<tr>
<td>Age, years</td>
<td>52.6 (15.8)</td>
</tr>
<tr>
<td>Gender, %</td>
<td>42.3</td>
</tr>
<tr>
<td>Male</td>
<td>57.7</td>
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<tr>
<td>Marital status, spinal cord injury, %</td>
<td>69.2</td>
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<tr>
<td>Married</td>
<td>53.8</td>
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<tr>
<td>Single</td>
<td>46.2</td>
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<tr>
<td>Education, %</td>
<td>15.4</td>
</tr>
<tr>
<td>Illiterate</td>
<td>849 (503)</td>
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<tr>
<td>Annual family income ($)</td>
<td>SD: standard deviation.</td>
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</table>
Level and severity of spinal cord injury
The patients were categorized into 5 groups according to functional prognosis: C7 and above, C8–T6, T7–L2, L3–S2, and S2 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 T7–L2 (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 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 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.

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 II. Level and severity of spinal cord injury (AIS) |
|-----------------|-----------------|-----------------|-----------------|-----------------|
| AIS                | ≥C7            | C8–T6          | T7–L2          | L3–S2          |
|                   | n (%)          | n (%)          | n (%)          | n (%)          |
| A                  | 1              | 1              | 1              | 2              |
| B                  | 3              | 1              | 1              | 2              |
| Total             | 3              | 1              | 1              | 2              |
| n (%)             | 26 (100)       | 6 (23.1)       | 2 (7.60)       | 11 (42.3)      |


<table>
<thead>
<tr>
<th>Complications</th>
<th>≥C7</th>
<th>C8–T6</th>
<th>T7–L2</th>
<th>L3–S2</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>26 (100)</td>
</tr>
<tr>
<td>Pressure sore</td>
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<tr>
<td>Neurogenic bladder</td>
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<tr>
<td>UTI</td>
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<tr>
<td>Bladder stone</td>
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<td>HO</td>
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<tr>
<th>Table IV. Functional status</th>
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<table>
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<tr>
<th>At discharge</th>
<th>In community</th>
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<tbody>
<tr>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>MBI a</td>
<td>71.2 (25.8)</td>
</tr>
<tr>
<td>WISCI II b</td>
<td>5.81 (7.00)</td>
</tr>
<tr>
<td>VAS c</td>
<td>5.38 (1.38)</td>
</tr>
<tr>
<td>PHQ-9 d</td>
<td>10.5 (5.38)</td>
</tr>
</tbody>
</table>

aThe variables were normally distributed and differences between baseline and follow-up were tested by paired t-tests.
bThe variables were not normally distributed and differences between baseline and follow-up were tested by Wilcoxon test.
cMBI: Modified Barthel Index; WISCI II: Walking Index for Spinal Cord Injury II; VAS: visual analogue scale; PHQ-9: Patient Health Questionnaire Depression Module.

do not 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>
<thead>
<tr>
<th>Table V. Total score and each domain of quality of life (WHOQOL-BREF)</th>
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<table>
<thead>
<tr>
<th>At discharge</th>
<th>In community</th>
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<tbody>
<tr>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
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<tr>
<td>Total score a</td>
<td>68.3 (12.6)</td>
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<tr>
<td>QoL (self-rated)a</td>
<td>2.65 (1.09)</td>
</tr>
<tr>
<td>Health (self-rated)a</td>
<td>2.65 (1.23)</td>
</tr>
<tr>
<td>Physical health a</td>
<td>19.0 (4.98)</td>
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<tr>
<td>Psychological health</td>
<td>17.0 (3.89)</td>
</tr>
<tr>
<td>Satisfied with social relationships a</td>
<td>8.27 (2.31)</td>
</tr>
<tr>
<td>Environment a</td>
<td>24.1 (5.65)</td>
</tr>
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</table>

aThe 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.
of these subjects who walked with walking devices remained
Comencement of rehabilitation soon after injury, good adher-
ability. However, improvement in AdLs in our study did not
recovery after non-earthquake SCI are mobility and self-care
concluded that the most important components in functional
participation (18). Our study showed that functional status, as
community, since those with higher AdL functioning depend
vocational ability and social integration were reduced and
improvement in physical independence and mobility compared
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-earth-
quake setting suggested that physical independence, mobility,
vocational ability and social integration were reduced and
social participation was significantly decreased 1 year after
threatened. Amatachaya et al. (22) suggested that SCI patients
who were independently ambulatory encountered a greater
chance of falling 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 de-
pression 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 sub-
jects’ psychological status remained effectively unchanged
despite primary institutional rehabilitation. Psychotherapy is
generally recognized as beneficial adjunctive therapy follow-
ing 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 relation-
ships, 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 reason-
ably 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 gen-
eral 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 participa-
tion 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-earth-
quake setting suggested that physical independence, mobility,
vocational ability and social integration were reduced and
social participation was significantly decreased 1 year after

(China, 1976) showed that uremia 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 re-
fractory chronic pressure sores 18 years later; some died from
related infections (18). Other studies on long-term complica-
tions 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 mo-
bility) 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 participa-
tion/community integration.

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

<table>
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<th>Table VI. Total score and each area of social participation/community integration (CHART-SF)</th>
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<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Total score†</td>
</tr>
<tr>
<td>Physical independence†</td>
</tr>
<tr>
<td>Cognitive independence‡</td>
</tr>
<tr>
<td>Mobility§</td>
</tr>
<tr>
<td>Occupation§</td>
</tr>
<tr>
<td>Social integration‡</td>
</tr>
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</table>

†The variables were normally distributed and mean differences tested by paired t-test.
‡The variables were not normally distributed and differences tested by Wilcoxon test.

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

ACKNOWLEDGEMENTS

This study was supported by funding from the Caring For Children Foundation and Handicap International, as well as by a rehabilitation training fellowship sponsored by the Department of Physical and Rehabilitation Medicine of the Mianzhu People’s Hospital.

REFERENCES

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