



ENVIRONMENTAL BARRIERS, FUNCTIONING AND QUALITY OF LIFE IN 2008 WENCHUAN EARTHQUAKE VICTIMS WITH SPINAL CORD INJURY EIGHT YEARS AFTER THE DISASTER: A CROSS-SECTIONAL STUDY

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Objective: To examine environmental barriers, functioning, and quality of life in Wenchuan earthquake survivors with spinal cord injury.

Design: Cross-sectional study.

Subjects: Thirty-two adult Wenchuan earthquake survivors with spinal cord injury.

Methods: Data were collected on environmental factors with the Nottwil Environmental Factors Inventory Short Form (NEFI-SF), physical and mental functioning with the 36-item Short-Form Health Survey (SF-36), and quality of life with the World Health Organization Quality of Life-BREF (WHOQOL-BREF). Descriptive analysis of environmental barriers and comparisons of SF-36 and WHOQOL-BREF domain scores with normative data were performed. Variations in outcomes across demographic and lesion characteristics were examined using Mann-Whitney *U* test. Associations of NEFI-SF with SF-36 and WHOQOL-BREF domain scores were explored using Spearman's correlation.

Results: Wenchuan earthquake survivors with spinal cord injury were affected by a large number of environmental barriers. Their functioning and quality of life were considerably reduced in comparison with respective reference populations. Neither environmental barriers nor functioning or quality of life varied systematically by demographic and lesion characteristics. Increased numbers of perceived environmental barriers were strongly associated with decreased scores across SF-36 and WHOQOL-BREF sub-domains.

Conclusion: Wenchuan earthquake survivors with SCI faced a considerable number of environmental barriers and showed decreased functioning and quality of life. Environmental barriers were strongly related to functioning and quality of life.

Key words: earthquake; spinal cord injury; environmental factors; functioning; participation; quality of life.

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LAY ABSTRACT

Environmental barriers are important determinants of disability and reduced quality of life. This study measured perceived environmental barriers, physical and mental functioning, and quality of life in survivors of the 2008 major earthquake in Wenchuan, China, who had sustained spinal cord injuries in the disaster. The participants perceived a large number of barriers that made their life harder, and their functioning and quality of life was lower than that of the general population. The more environmental barriers the earthquake survivors perceived, the lower was their physical and mental functioning and quality of life. Targeted community-based interventions should be used to address environmental barriers in this population.

Earthquakes are sudden-onset disasters that may cause large numbers of spinal cord injuries (SCI) (1).

The Wenchuan earthquake in Sichuan Province, western China, on 12 May 2008, killed 69,227 people and injured 374,643, with 17,923 unaccounted for. According to a recent report by the government of the People's Republic of China, as of 31 October 2008 91,177 people were hospitalized, of whom 16,563 were seriously injured (2).

The number of earthquake survivors who sustained SCI is currently unknown. In one of the few multi-centre studies on the epidemiology of injury after the earthquake Qiu and colleagues (3) analysed data from 3,401 earthquake victims admitted to 11 hospitals. Spinal trauma occurred in 376 cases (11%). Of 398 locations of damage to the spine, 80 were classified as serious to critical according to the Abbreviated Injury Scale, leading to an estimate of approximately 76 cases (376/398*80) with SCI (2.2%). Given the above-mentioned 16,563 patients hospitalized for serious injuries, this leads to a conservative estimate of 364 Wenchuan earthquake survivors with SCI.

In the same study (3), approximately 60% of spinal injuries were caused by blunt trauma from falling objects, approximately 19% by falls and 15% by being crushed under the rubble. An analysis of 35 cases of

Wenchuan earthquake survivors with SCI by Liu and colleagues (4) found a similar pattern, with the most frequent aetiology being hit by falling debris from building collapse, followed by falls from a height. Thoracic-level injuries were most common in a study of 180 cases of SCI resulting from the Wenchuan earthquake conducted by Luo et al. (5), while cervical injuries were found in only approximately 8%; a majority of victims had American Spinal Injury Association (ASIA) Impairment Scale (AIS) grade C lesions and approximately 23% were classified as grade A.

Previous studies on Wenchuan earthquake survivors with SCI have focused on medical complications, pain, quality of life (QoL), functional status, and social participation (5–8).

No previous study on the role of environmental barriers in the Wenchuan earthquake population has been conducted so far, although research from other contexts suggests that environmental factors may importantly be associated with relevant outcomes, such as participation (9, 10), physical activity (11), subjective health (12) and QoL (13, 14). Ideally, in the case of disability-inclusive recovery after a disaster (“building back better”) (15), communities should be characterized by minimum physical, social and attitudinal barriers.

The objective of the present study was to examine perceived environmental barriers, functioning, and QoL of Wenchuan earthquake survivors with SCI 7–8 years after the disaster. The specific aims were: (i) to describe perceived environmental barriers, physical and mental functioning, and QoL in relation to reference values from the general population where available; (ii) to explore variations in environmental barriers, functioning, and QoL by demographic and injury characteristics; and (iii) to explore associations of environmental barriers with physical and mental function, participation and QoL.

MATERIALS AND METHODS

Design

Cross-sectional study. Since this was a community-based study, ethical approval was not required according to Chinese regulations. Informed consent was, however, obtained from the study participants and the study was performed according to the principles of the Declaration of Helsinki.

Participants

From September 2015 to March 2016 the team visited 32 Wenchuan earthquake survivors with SCI who lived in the community or in Disabled Persons Federation (DPF) residential homes and who had received physical rehabilitation at Bayi Rehabilitation Center, Chengdu or at Mianzhu County People’s

Hospital. Eligible subjects were adult persons with SCI who were able to communicate in Mandarin.

Investigators were researchers from the Institute of Disaster Management and Reconstruction (IDMR) at Sichuan University, Chengdu, rehabilitation doctors and therapists who worked in the participating hospitals and postgraduate students in physical therapy (PT) and occupational therapy (OT).

Setting and data collection procedures

Data were collected at patients’ homes (in Wenchuan, Dujiangyan, and Jiangyou counties) and DPF residential homes (in Beichuan county and Mianyang city). In Mianzhu county, participants were invited to the home of one patient who was a member of a self-help group for people with SCI. All of these counties and Mianyang city had been heavily affected by the earthquake.

Measures

Environmental barriers were measured with the Nottwil Environmental Factors Inventory Short Form (NEFI-SF), a 14-item measure of perceived barriers based on the International Classification of Functioning, Disability, and Health (ICF) Core Sets for SCI. With a Cronbach’s alpha of 0.82 the measure has demonstrated good internal consistency (16). The measure asks, for each environmental factor, about how much this factor influenced the persons’ life (0: no influence/not applicable, 1: made my life a little harder, 2: made my life a lot harder). Since this measure had not been used previously in China, the items were translated independently by 2 of the authors (HL, XZ), who then compared their translations in order to develop a synthesis, which was again reviewed by an expert committee consisting of all Chinese-speaking authors (17). The translated measure was then pre-tested with 4 Chinese persons with SCI, all of whom found the questions understandable and relevant. For some analyses NEFI-SF items were dichotomized (0: no influence vs 1: made my life a little or a lot harder; and 0: no influence or made my life a little harder vs 1: made my life a lot harder) and total scores of the number of all perceived barriers and the number of perceived severe barriers were calculated as the sum of items dichotomized as above.

Physical and mental functioning were measured with the 36-item Short Form Health Survey (SF-36, Chinese version) (18, 19). Scores in the 8 SF-36 domains were calculated according to the instruction manual (20).

QoL was evaluated with the World Health Organization Quality of Life-BREF (WHOQOL-BREF). The first 2 items assess overall QoL and health, while the following 24 items cover 4 domains, including physical health, psychological health, satisfaction with social relationships and satisfaction with environment, for each of which summary scores were calculated and transformed to a 0–100 scale following the manual’s instructions (21). Higher scores indicate higher QoL. The WHOQOL-BREF had been previously used in China demonstrating good internal consistency (Cronbach’s alpha=0.89) and good convergent validity (22).

Demographic information on the patients’ age, gender, marital status, and employment status was also obtained. Neurological level and extent of impairment (AIS grade) were determined based on physical examination according to the International Standards for Neurological Classification of Spinal Cord Injury (23).

Table I. Demographic and spinal cord injury (SCI) characteristics of 32 earthquake victims with SCI

Characteristics	
Age, years, mean (SD)	47.66 (13.52)
Female, % (n)	53.1 (17)
Married, % (n)	68.75 (22)
Unemployed, % (n)	68.75 (22)
Lesion level and completeness, n	
C1-4	
AIS A	6.25 (2)
T1-S5	
AIS A	40.63 (13)
AIS C	18.75 (6)
AIS D	12.5 (4)
Cauda equina syndrome	9.38 (3)
Central cord syndrome	3.13 (1)
Brown-Séquard syndrome	3.13 (1)
Missing	6.25 (2)

SD: standard deviation; AIS: American Spinal injury Association Impairment Scale.

Data analysis

All analyses were performed with Stata14.0 (Stata Corp., TX, USA).

Lesion characteristics are provided according to DeVivo et al. (24). We provide frequencies for NEFI-SF on the item level. Mean SF-36 domain scores were calculated and compared with the rural Sichuan reference population (25). Average scores across WHOQOL-BREF domains were compared with reference values for the Chinese general population obtained from 83,666 participants in the 2010 Chronic Non-communicable Disease and Risk Factor Surveillance Project (26). *P*-values were obtained from 1-tailed (as it was hypothesized that scores of the SCI sample would be decreased) 1-sample *t*-test.

Variations in the total number of perceived environmental barriers and the number of severe barriers, as well as SF-36 and WHOQOL-BREF domain scores, by demographics (gender, age median split: <46 vs ≥46 years; married vs not married, employed vs unemployed, living in own vs. DPF residential home) and lesion completeness (AIS A vs other) were analysed with Mann-Whitney *U* test.

Associations of perceived environmental barriers with functioning and QoL were explored with Spearman’s correlations between NEFI-SF total score and SF-36 as well as WHOQOL-BREF domain scores, taking into account the ordinal scale level of the outcomes and potential non-linear (but monotonic) relationships.

RESULTS

Detailed information about demographic and SCI characteristics of the participants is given in Table I. Four earthquake survivors (12.5%) had tetraplegia and 28 (87.5%) had paraplegia. Information on lesion completeness was missing for 2 subjects. Fifty percent

(*n*=15) of the remaining 30 study participants had complete lesions.

Perceived environmental barriers

The 30 participants who answered the NEFI-SF perceived a mean of 8.9 barriers (standard deviation (SD) 2.9) and 5.3 severe barriers (SD 2.8). Separate frequencies of answer options for the 14 environmental factors are shown in Fig. 1. More than three-quarters of the survivors reported that lack of accessibility of public places as well as friends’ and relatives’ homes, unfavourable climate, problems with long-distance transportation, and their financial situation negatively affected their lives. Seventy percent or more indicated that lack of accessibility of their friends’ and relatives’ homes, lack of long-distance transportation, and their financial situation made their lives even a lot more difficult. Half or more of the patients reported barriers due to government policies, social attitudes, short distance transportation, personal care assistance and medical supplies. Attitudes of colleagues showed the lowest impact on people’s lives.

Results of the comparison of SF-36 and WHOQOL-BREF domain scores from our sample with the rural Sichuan and mainland China reference populations, respectively, are shown in Fig. 2.

Scores for the SCI earthquake victims were significantly decreased across all SF-36 and WHOQOL-BREF

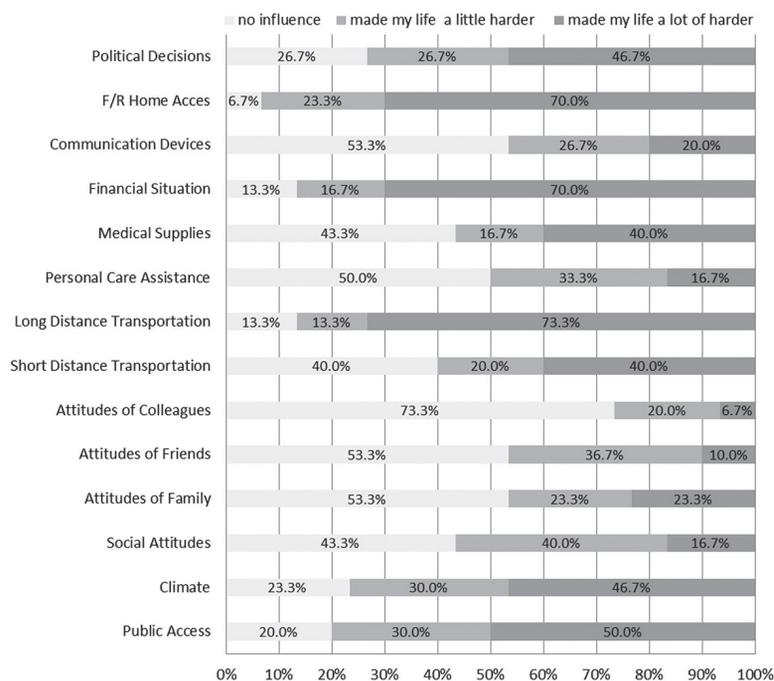


Fig. 1. Relative frequencies for victims Nottwil Environmental Factors Inventory Short Form (NEFI-SF) items. F/R: friends’ and relatives’.

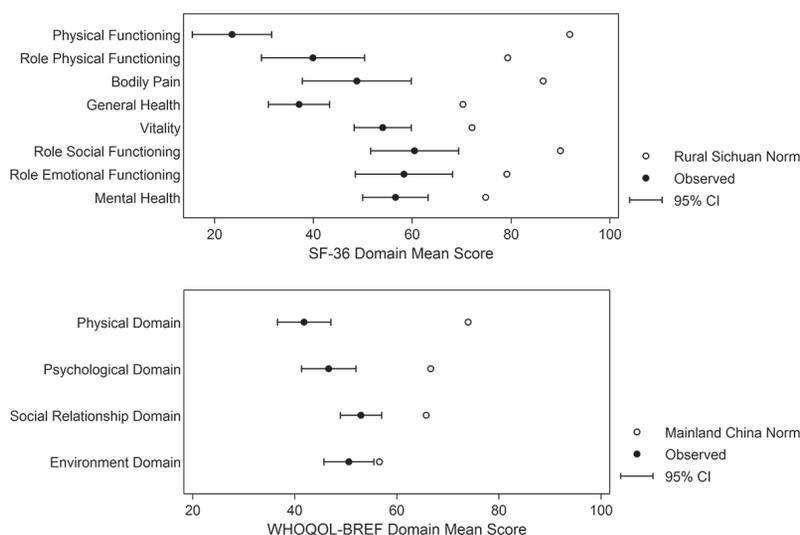


Fig. 2. Mean values and 95% confidence intervals (95% CI) of 36-item Short Form Health Survey (SF-36), and World Health Organization Quality of Life-BREF (WHOQOL-BREF), compared with general population norms.

domains (p for WHOQOL-BREF Environment < 0.05 ; all other $p < 0.01$). While approximately 20% of the participants were at least satisfied with their QoL, only 2 participants (6.5%) were satisfied with their health.

Variation in environmental barriers, functioning, and QoL by demographic and injury characteristics

There was no significant variation in the total number of perceived environmental barriers that limited people’s lives at least a little and those limiting their lives a lot by age, gender, marital status, employment status, place of residence (centre vs community), lesion level, and lesion completeness. Moreover, we found only sporadic variation in SF-36 and WHOQOL-BREF domains by demographics and SCI characteristics

Table II. Spearman’s correlation coefficients and probabilities of perceived environmental barriers (total number of perceived barriers and total number of perceived severe barriers) with functioning and quality of life outcomes

Outcomes	Total barriers		Severe barriers	
	Rho	P(rho)	Rho	P(rho)
SF-36 Physical Functioning	-0.16	0.40	-0.15	0.43
SF-36 Role Physical Functioning	-0.44	0.02	-0.47	0.01
SF-36 Bodily Pain	0.06	0.75	-0.25	0.18
SF-36 General Health	-0.58	< 0.01	-0.33	0.08
SF-36 Vitality	-0.56	< 0.01	-0.45	0.01
SF-36 Role Social Functioning	-0.63	< 0.01	-0.53	< 0.01
SF-36 Role Emotional Functioning	-0.66	< 0.01	-0.59	< 0.01
SF-36 Mental Health	-0.67	< 0.01	-0.51	< 0.01
WHOQOL Physical Domain	-0.34	0.07	-0.50	0.01
WHOQOL Psychological Domain	-0.62	< 0.01	-0.31	0.10
WHOQOL Social Domain	-0.16	0.40	-0.03	0.85
WHOQOL Environment Domain	-0.41	0.03	-0.36	0.06

SF-36: 36-item Short-Form Health Survey; WHOQOL-BREF: World Health Organization Quality of Life-BREF. Statistically significant correlations are printed in bold.

($p < 0.05$ for 3 of 60 Mann–Whitney U tests; the number that would be expected by chance alone).

Association of environmental barriers with functioning and QoL

Table II illustrates the association of NEFI-SF total number of perceived barriers as well as number of perceived severe barriers with SF-36 and WHOQOL-BREF domain scores. Apart from one, all associations were negative, indicating decreased functioning and QoL with increased perception of barriers. The strongest associations for the number of barriers perceived to make life at least a little more difficult were found with SF-36 Mental Health, Role Emotional, and Role Social Functioning as well as with the WHOQOL-BREF Psychological domain. Fourteen of 24 correlations were statistically significant. The strongest correlations for the number of barriers perceived to make life a lot harder were found with SF-36 Role Emotional Functioning, Role Social Functioning, and Mental Health, as well as with the WHOQOL-BREF Physical domain.

DISCUSSION

This study showed that Wenchuan earthquake survivors with SCI were affected by a large number of environmental barriers that negatively impacted their life, at least to some degree. At the same time, their physical and mental functioning and QoL were considerably reduced in comparison with respective reference populations. While neither perceived environmental barriers nor functioning or QoL varied systematically by demographic and lesion characteristics, perceived environmental barriers were strongly associated with reduced functioning and QoL across various sub-domains.

While it is difficult to obtain a random sample of Wenchuan earthquake victims with SCI due to the absence of a population list, we believe that our sample is fairly representative, as demographic and injury characteristics were similar to those of other studies in this population (5–8).

Not surprisingly, the proportion of people perceiving barriers was considerably higher across all environmental domains assessed than reported in a study from Switzerland (27), the only other study in which the NEFI-SF has been used so far. Consistent

with the findings of the Swiss study, perceived barriers appeared more related to physical aspects of the environment, finances and public policy than the attitudes of significant others or the society in general. Our results on impact as well as pattern of perceived environmental barriers further confirm observations made by Rauch et al. (28) in 18 SCI survivors of the 2010 Haiti earthquake. The latter study relied, however, on health professionals' ICF-based assessment and was conducted shortly after the earthquake. It is likely that accessibility of public space and transportation has not been a major priority in community reconstruction after the Wenchuan earthquake despite respective legal directives of the Chinese Law on the Protection of People with Disabilities (29), which was revised in the year of the earthquake against the background of the UN Convention on the Rights of Persons with Disabilities.

Physical and mental functioning, as measured with the SF-36, was not only significantly reduced in comparison to norm values for the Sichuan general population, but also considerably lower than domain mean scores obtained from a cluster random sample of 1,617 Wenchuan earthquake survivors living in temporary shelters approximately 8 months after the disaster (30) or scores from fracture patients from the Wenchuan earthquake 5 years after the event (with the exception of Role Emotional Function) (31). Moreover, SF-36 domain scores found in the present study were somewhat lower than those of earthquake victims with amputations assessed 4 years after the Wenchuan earthquake (32). In sum, this highlights the particular vulnerability of Wenchuan earthquake survivors with SCI, as well as the need for ongoing physical and mental rehabilitation intervention.

Our findings on WHOQOL-BREF domains were more in line with scores obtained from previous studies on Wenchuan earthquake survivors with (5, 6) and without SCI (33).

Although the power of the current study was small (approximately 47% for detecting a difference of 2 barriers between 2 equally sized groups and approximately 51% for detecting a 15-point score difference on a 0–100 scale between 2 equally sized groups, assuming pooled standard deviations, as found in this study), a further interesting finding from our study is that there was only sporadic variation in environmental barriers, functioning, and QoL by demographics and lesion completeness. This may indicate that the impact of environmental barriers was so severe that personal characteristics played a rather minor role.

Conversely, the perception of environmental barriers was often strongly associated with decreased functioning and QoL, which was particularly obvious for the

SF-36 domains related to mental functioning. This finding suggests that focusing rehabilitative intervention on the removal of environmental barriers may be an effective way to improve functioning and QoL in Wenchuan earthquake survivors with SCI.

The small sample size and the resulting problems with statistical power are certainly a major limitation of the present study which precluded meaningful adjustment for confounders in multivariate analysis. SCI is a rare condition, and large populations of people who sustained SCI due to a particular earthquake are difficult to recruit. The study thus remains explorative and findings have to be interpreted with caution. Moreover, the cross-sectional design makes it difficult to draw conclusions about causality, e.g. we do not know if decreased functioning increases the perception of barriers or an increased encountering of barriers decreases functioning. It is likely, however, that both directions play a role in feedback, with the interactions being more complex than A causes B (34). Interventions targeting functioning and those targeting environmental factors may be equally successful in improving desired outcomes. Evaluation of interventions with intelligent designs in different domains of functioning and the environment is thus a promising direction for future research.

In conclusion, Wenchuan earthquake survivors with SCI faced a considerable number of environmental barriers and showed decreased functioning and QoL 7–8 years after the disaster. Environmental barriers were strongly related to functioning and QoL. Community-based interventions should be targeted at addressing these barriers.

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The authors have no conflicts of interest to declare.

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