

ORIGINAL REPORT

## PREDICTING COMMUNITY PARTICIPATION AFTER SPINAL CORD INJURY IN THAILAND

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**Objective:** To identify the predictors of community participation after spinal cord injury.

**Design:** Cross-sectional design.

**Methods:** A total of 139 persons with spinal cord injury living in the community completed 4 instruments: the Impact on Participation and Autonomy (IPA-Thai version), the Craig Hospital Inventory of Environmental Factors (CHIEF-SF-Thai version), the Personal Resource Questionnaire (PRQ2000-Thai version), and a personal history questionnaire. Functional performance was assessed using the Functional Independence Measure (FIM) motor subscale.

**Results:** Participants comprised 79% males. Fifty-one percent of variance in community participation was explained by social support, functional performance, age, and age at time of injury.

**Conclusion:** Key predictors of community participation were the availability of social support and the individual's functional performance. These predictors should be emphasized when developing interventions in rehabilitation and community settings.

**Key words:** community participation; spinal cord injury; rehabilitation.

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### INTRODUCTION

The ultimate rehabilitation outcome for persons with spinal cord injury (SCI) is to fulfil their social role and optimize community participation. However, many persons with SCI are restricted in these aspects due to individual and environmental factors. Previous studies have reported improved quality of life (QoL) and adjustment after SCI if community participation concerns are included during the rehabilitation process (1, 2).

Participation is defined by the International Classification of Functioning, Disability and Health (ICF) as a person's involvement in a life situation (3). Recently, the concept of participation was expanded to include issues of active and meaningful engagement, choice and control, and access and

opportunity (4, 5). Thus, the individual perspective of participation was highlighted in order to capture the experiences of people with disabilities.

The ICF illustrates the dynamic interaction between health condition, body functions and structures, activities, participation, and contextual factors. In particular, participation is described as being affected by impairments, activity limitations, environmental factors, and personal factors (3).

Impairments and activity limitations, and personal and environmental factors that facilitate participation after SCI have been investigated in order to direct intervention as well as to promote optimal adjustment and enhanced quality of life (QoL). Impairments and activity limitations that identify aspects of functioning also predict the amount of participation (6–8). However, reports regarding the impact of secondary complications and sexual problems on participation in persons with SCI are rare (1). These comorbid health conditions need to be explored in more detail in order to understand how they impact on participation.

Environmental and social support factors have been described by Lund et al. (9) as having a greater impact than demographic or injury characteristics. In contrast, Scelza and co-workers (10) reported that environmental factors had only a small influence on participation, while family support, self-esteem, information support and coping style had a much greater impact. Compared with other factors, social support has been investigated extensively, with some reports suggesting its primary importance.

Within the personal category, educational level was very important (2, 6), in addition to age at time of injury, level of injury, time since injury, chronological age, gender, marital status, and employment status (2, 6, 11–13). Although, these personal variables are not likely to be altered by rehabilitation, they must be recognized and addressed by the rehabilitation team.

In Thailand a high incidence of SCI prevails, particularly among young males (14). The Thai healthcare system designs rehabilitation services in hospitals and rehabilitation centres. Physical therapy and occupational therapy services are routinely incorporated into rehabilitation, but vocational and social training are seldom available. In addition, community participation and role fulfilment may be different for individuals with SCI in Thailand compared with other countries because of cultural factors, including environmental barriers, social support and government financial support (welfare) (8, 15, 16).

Determinants of community participation for Thai individuals with SCI have not been investigated previously. Moreover, factors impacting on participation, assessed from the individual perspective, may differ from factors assessed from the societal perspective, as has been done in previous research.

The aim of the present study was to identify factors influencing participation among persons with SCI in Thailand, using measures based on the concept of participation according to the ICF.

## MATERIAL AND METHODS

### Participants

Eligible participants comprised individuals who had sustained traumatic SCI at least one year previously, aged between 18 and 55 years, and had a neurological classification of SCI as tetraplegia or paraplegia American Spinal Injury Association (ASIA) grade A, B or C. Inclusion criteria included that the person lived in the community, used a wheelchair as their primary mobility tool, did not have traumatic brain injury, and did not have depression, as determined by a score of 11 or less on the Thai version of the Hospital Anxiety and Depression Scale.

### Instruments

*Impact on Participation and Autonomy Questionnaire – Thai version (IPA-Thai version).* The IPA assesses the degree of participation based on the ICF concept. This self-administered scale has 2 sections. Perceived participation in various life situations consists of 32 items in 5 domains: autonomy indoors; autonomy outdoors; family role; social life and relationships; and work and education. These are graded on a 5-point scale, from 0 (very good) to 4 (very poor). The problems experienced section includes 8 items: mobility; self-care; family role; financial situation; leisure; social life and relationships; work; and education. This section is graded on a 3-point rating, from 0 (no problem) to 2 (severe problem). All item responses are summed to provide the 2 domain scores. Good reliability and validity have been demonstrated (17).

The IPA-Thai version was translated following the guidelines for cross-cultural adaptation of self-report measures and tested for its psychometric properties. The IPA-Thai version showed good reliability and acceptable validity (18).

*Craig Hospital Inventory of Environmental Factors Short Form – Thai version (CHIEF-SF-Thai version).* The CHIEF-SF was used to assess the frequency and magnitude of perceived environmental barriers (19). This scale consists of 12 items with 5 subscales: physical and structural barriers; attitudinal and support barriers; barriers to services and assistance; policies; and barriers at work and school. Each item is scored by multiplying the frequency (range: never 0; daily 4) and magnitude scores (range: little problem 1; big problem 2) to yield a product or overall “impact” score. The final score is the mean value of the 12 items. A higher score demonstrates greater limitation due to environmental barriers. The CHIEF-SF-Thai version was translated following the guidelines for cross-cultural adaptation of self-report measures and tested for its psychometric properties. The reliability of this scale (Cronbach’s alpha) was 0.72 (20).

*Personal history questionnaire.* The personal history questionnaire comprises 4 parts: demographics; injury-related factors; secondary complications; and sexual problems.

- *Demographic factors:* chronological age (years), gender (male/female), marital status (married/single, divorced, widowed), educational level (primary school or below/secondary school/college or above), and current employment status (employed/unemployed).
- *Injury-related factors:* age at time of injury (years), time since injury (years), and level of injury (tetraplegia/paraplegia).
- *Secondary complication factors in the past 3 months:* number of health problems including pain, spasticity, pressure sores, and bowel

and bladder function. Answers were either present or absent and a total score comprised the number of complications presented.

- *Sexual problems factor:* presence or absence of the problem.

*Functional Independence Measure (FIM-motor subscale).* The FIM measures functional performance. The FIM-motor subscale consists of 13 items: eating; grooming; bathing; dressing upper extremity; dressing lower extremity; toileting; bowel management; bladder management; transfer to bed, chair or wheelchair; transfer to tub or shower; transfer to toilet; walking or wheelchair propulsion; and stair climbing. Each item is measured on a 7-point ordinal scale (1 = total dependence to 7 = total independence). The sum of all items is the final score, ranging from 13 (total dependence) to 91 points (total independence) (21). Reliability and validity are well proven (21, 22).

*Personal Resource Questionnaire–Thai version (PRQ2000-Thai version).* The PRQ2000 measures the perceived level of social support (23). The PRQ2000 contains 15 items rated on a 7-point Likert scale, from 1 (strongly disagree) to 7 (strongly agree). Scoring is the summing of items, with a range from 15 to 105. A higher score represents higher levels of perceived social support. The reliability of this scale in the present study was Cronbach’s alpha = 0.76.

### Procedure

The study was approved by the ethics committee, Mahidol University Institutional Review Board. The initial participants were victims of drunk driving and members of the “Don’t Drive Drunk Foundation”. A snowball sampling technique was used to recruit other participants. Persons who met the criteria were invited to join the study. The purpose of the study was explained and informed consent was obtained. A trained physical therapist assessed functional performance using the FIM-motor subscale. Participants were asked to complete all questionnaires: the personal history questionnaire, the IPA-Thai version, the CHIEF-SF-Thai version, and the PRQ2000-Thai version. Appropriate time was allowed in order to avoid mental fatigue, which might have influenced the answers. The participants completed the questionnaires at home or in a convenient location. The researcher met with the participants to check the completed questionnaire to ensure that the data was complete.

### Data analysis

Statistical analysis was performed using SPSS version 17.0, and statistical significance was set at  $p < 0.05$  level. Descriptive statistics were used to summarize the demographic data. Means and standard deviations were used for continuous variables and frequencies and percentages for categorical variables. Multiple regression analysis was employed for each of the participation outcomes, using a step-wise forward selection technique to identify the predictive variables. The criterion for adding a variable to the model was to select the independent variable with the most significant probability of correlation (partial  $F$  statistic) and to recalculate the partial  $F$  statistic for the remaining independent variables; then, to continue to add independent variables until the probability of the partial  $F$  statistic for a new solution was above a maximum probability of 0.05. The primary outcome variable was the IPA total score, and supplementary analyses were performed for each of the IPA subscale scores. Independent variables were: demographic and injury-related factors; secondary complications; sexual problems; functional performance; social support; and environmental factors. A power analysis showed that a minimum of 135 patients should be included in order to achieve 80% power, medium-effect size (0.15) and a significance level of 0.05.

## RESULTS

The 139 participants were mostly male paraplegics in their mid-30s, with a mean time since injury of 10 years. The majority were not married, and most were employed, volunteered or

were students and had completed secondary education. Over 90% reported at least 3 secondary complications (Table I).

Table II presents the results of regression analysis as R<sup>2</sup> of the variables that explain the total score and 5 domain scores of the IPA. The highest percentage (51.3%) was explained by the PRQ2000, FIM score, age at time of injury, and current age. The 6 variables not included in the regression model were: gender, marital status, educational level, level of injury, secondary complication, and CHIEF-SF Thai-version score.

Four factors explained 50.6% of the variance in the IPA autonomy outdoor domain: PRQ2000 score, FIM score, sexual problems, and employment status. Models with both PRQ2000 score and sexual problems predicted the social relationship domain score and the work and education domain score. Persons who reported being in employment tended to have a high participation score. However, educational level was not a predictor for participation in work.

Four factors: FIM score, PRQ2000 score, time since injury, and age at time of injury, explained the autonomy indoor and family role domain scores. These factors explained 45.7% of the variance in the autonomy indoor domain and 29.5% of the variance in family role.

Table I. Characteristics of spinal cord injury participants

| Characteristics                                 |            |
|---|------------|
| Age, years, mean (SD)                           | 34.2 (8.4) |
| Range   | 18–55      |
| Age at time of injury, years, mean (SD)         | 23.5 (6.9) |
| Range   | 3–46       |
| Time since injury, years, mean (SD)             | 10.6 (7.1) |
| Range   | 1–38       |
| Gender, <i>n</i> (%)                            |            |
| Male  | 110 (79.1) |
| Female  | 29 (20.9)  |
| Marital status, <i>n</i> (%)                    |            |
| Married   | 34 (24.5)  |
| Single/divorced/widowed                         | 105 (75.5) |
| Education level, <i>n</i> (%)                   |            |
| Primary school or below                         | 16 (11.5)  |
| Secondary school                                | 74 (53.2)  |
| College or above                                | 49 (35.3)  |
| Employment, <i>n</i> (%)                        |            |
| Working (full-time/part-time/student/volunteer) | 113 (81.3) |
| Not working (unemployed)                        | 26 (18.7)  |
| Level of injury, <i>n</i> (%)                   |            |
| Quadriplegia                                    | 49 (35.3)  |
| Paraplegia                                      | 90 (64.7)  |
| Secondary complications, <i>n</i> (%)           |            |
| 0   | 1 (0.7)    |
| 1   | 4 (2.9)    |
| 2   | 8 (5.8)    |
| 3   | 16 (11.5)  |
| 4   | 30 (21.6)  |
| 5   | 36 (25.9)  |
| 6   | 29 (20.9)  |
| 7   | 15 (10.8)  |
| Sexual problem, <i>n</i> (%)                    |            |
| Yes   | 66 (48.2)  |
| No  | 71 (51.8)  |

SD: standard deviation.

Table II. Regression analysis

| IPA variable                 | Predictors            | R <sup>2</sup> |
|------------------------------|-----------------------|----------------|
| IPA Total                    | PRQ2000               | 0.513          |
|                              | FIM                   |                |
|                              | Age at time of injury |                |
| IPA Autonomy outdoors        | Age                   | 0.506          |
|                              | PRQ2000               |                |
|                              | FIM                   |                |
|                              | Sexual problem        |                |
| IPA Autonomy indoors         | Employment status     | 0.457          |
|                              | FIM                   |                |
|                              | PRQ2000               |                |
|                              | Time since injury     |                |
| IPA Social and relationships | Age at time of injury | 0.415          |
|                              | PRQ2000               |                |
|                              | Sexual problem        |                |
| IPA Work and education       | PRQ2000               | 0.376          |
|                              | Employment status     |                |
|                              | Sexual problem        |                |
| IPA Family role              | PRQ2000               | 0.295          |
|                              | Age at time of injury |                |
|                              | FIM                   |                |
|                              | Time since injury     |                |

IPA: Impact on Participation and Autonomy Questionnaire; PRQ2000: Personal Resource Questionnaire; FIM: Functional Independence Measure.

## DISCUSSION

The predictors of community participation identified by the total participation and autonomy score among Thai persons with SCI in this study were: social support (PRQ2000); functional performance (FIM); age at time of injury; and current age. This implied that persons with SCI who had greater social support, better functional performance, were injured at a younger age, and were currently older were more likely to have greater community participation. Social support and functional performance had the strongest impact on participation of the 13 variables. Social support was the greatest contributor of all IPA subscale scores, except for the autonomy indoor subscale. Previous studies have revealed that social support helps people to develop confidence to cope with difficulties, creates a feeling of autonomy, and motivates them to control their illness, which leads to appropriate coping. Support may help people with disabilities to relieve stress, by facilitating healthy behaviours (24, 25). The positive influence of social support was in accordance with other existing quantitative findings (9, 26). Song (26) found that family support had a positive impact on social integration in Korean persons with SCI. In a Swedish population of persons with SCI, Lund et al. (9) reported that access to social support was highly correlated with participation. These findings suggest that professionals should pay attention to social support needs sooner in the rehabilitation process in order to facilitate more successful participation. For example, family members may need to be instructed how to provide appropriate physical and emotional support in order to enhance the confidence needed for community re-integration, and continued social support mechanisms need to be in place in order for persons with SCI to be functional community

participants. The effects of physical therapy management in encouraging family support, specifically emotional and social aspects, are not reported in the related literature. Further research is needed into this issue, regarding at what level it is available in Thai society, and how, when and by whom, it should be provided.

The functional performance assessed by the FIM was a facilitator to participation. People with a higher level of functional performance were more likely to report a higher level of community participation, especially in the family role and indoor and outdoor autonomy. In the autonomy indoor domain measuring self-care activity, functional performance was a stronger predictor than social support. The autonomy indoor measure focuses on the individual's perception of participation in daily activities. It assesses where, when and what equipment and assistance they require. In addition, persons who cannot achieve their maximum potential or cannot take care of themselves (due to the level of their injury) also need social support. Rehabilitation, either as an inpatient or outpatient, should maximize functional ability in order to optimize community participation.

In order to account for the functional differences between persons with tetraplegia and paraplegia, an analysis was performed on the 2 groups. The results showed that social support explained the autonomy indoor domain in both groups. In Thailand, the length of hospital stay for SCI was relatively short (73 days). Most persons with SCI might not have achieved their optimal goal in terms of functional performance before returning home (14). The rehabilitation team and health insurance system should emphasize adequate rehabilitation time in order to maximize the potential of persons with SCI to participate in physical activity and society. Rehabilitation time includes access to outpatient facilities to achieve maximal functional outcomes. Interestingly, functional performance did not predict social life and relationships, work and educational domains of the IPA. Anderson et al. also found similar results, and explained that beginning or maintaining social relationships and returning to education or work might be minimally influenced by physical function (6).

Persons with SCI who were injured at a younger age were more likely to have greater levels of participation. Whiteneck and colleagues (27) also reported that people with SCI who were injured at a younger age were more likely to report higher participation than those injured at an older age. Age at onset of injury has been reported to be a common predictor of long-term adjustment, and especially of productivity status (7). Previous studies have reported that individuals with SCI decreased community participation as their age increased (2, 11). However, in the present study we found that older persons showed greater community participation than younger persons. These conflicting results might be due to the difference in age range in the different studies. The chronological age of SCI participants in the current study was relatively young compared with the other 2 studies. People with a longer time since injury, who were employed, and who did not report sexual problems were more likely to have better participation. People who reported no sexual problems may have maintained a better relationship

with their spouse, thus influencing the individual's emotional status. The influence of sexual problems on community participation has rarely been mentioned in previous research. One study revealed that improving sexual function would enhance QoL (28). Spousal support and assistance facilitates community participation in the person with SCI. Addressing, and assisting with, sexual function after SCI should be an aspect of rehabilitation. However, this study had a greater proportion of participants with single/divorced/widowed status and participants who responded "no" to the single question "Do you have a problem in sexual relationships? (yes/no)". Therefore, their answers might depend on their perception of "having a problem or not", and not depend on their marital status.

Some studies have shown that a higher level of education is related to greater participation and a higher rate of return to work (2, 29). This did not appear to be the case in the current study. Our findings were that over 80% of persons with SCI were employed, but only 35% had graduated from college. However, the employment measure included volunteering or being a student. The social context regarding employment for disabled people in Thai society may differ from that found elsewhere. Most disabled Thai people do not return to their previous work, but become lottery ticket vendors. They encounter discrimination in entering other employment due to negative social stigma about their potential employment performance.

Similar to the findings of other reports (6), gender and level of injury were not predictors of community participation. Interestingly, the environmental factors variable was not included in any of the predictive models. This variable may have less impact on community participation when considered in conjunction with the influence of personal factors, health status, and social support. People with SCI who reported a low level of participation may rarely go outside, and thus may not encounter environmental barriers. In contrast, people with high participation may have found ways to overcome the barriers. Whiteneck et al. (27) also reported that environmental factors contributed less than 5% of the variance in community participation. It was anticipated that the environmental factors variable would be included in the predictors of community participation. The CHIEF-SF assessed environmental factors via the frequency and magnitude of perceived environmental barriers. Community participation, as measured in this study, was based on the definition in the ICF model of "involvement in a life situation". The concept of involvement means being engaged or participating in an area of life, including indoor activities, but not requiring outdoor activities.

Previous studies have reported that secondary complications are important factors in QoL (30–32). An increased number of medical complications correlated with decreased community participation (1). However, the current results showed that secondary complications after SCI did not explain the level of community participation. This might be due to the fact that persons with SCI in this study, who reported secondary complications, such as neurogenic bladder and bowel dysfunction, might already have adequate management. Thus, this might not impact on their participation ability.



*Study limitations*

In this study, subjects with SCI were recruited from an urban community; therefore, the results may not generalize to subjects who live in rural areas, due to differences in environmental accessibility. The snowball technique was used in the recruiting process, and this may introduce limitation in terms of participant variability.

*Conclusion*

The present study found that the availability of social support and the individual's functional performance level are key contributors to community participation in persons with SCI. Rehabilitation professionals and the families of persons with SCI therefore require a thorough understanding of, and focus on, the management of these influential factors. These factors should be used in interventions in both rehabilitation and community settings in order to optimize community participation and the meaningfulness of life for each individual. The healthcare authorities must also understand these factors in order to improve the efficiency of rehabilitation services and social support for enhanced community participation of persons with SCI.

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