The Perceived Handicap Questionnaire : A Self Perceived Handicap Measurement in Patients with Spinal Cord Injury

VILAI KUPTNIRATSAIKUL, M.D.*,
ORAWAN SMERASUTA, BN.S.**,
POUNGTONG KLOMJAIYEN, BN.S.**

Abstract

Handicap exists when individuals with impairment or disability are unable to fulfill one or more of the roles that are considered normal for their age, gender, and culture. In fact, handicap is one of the most poorly measured of all rehabilitation outcomes. This study was performed to measure the subjective experience of handicap in spinal cord injury (SCI) patients who had permanent disabilities and were often faced with environmental barriers. Eighty-three new traumatic SCI patients with a mean age of 33 years were interviewed during follow-up outpatient clinic visits using the Perceived Handicap Questionnaire (PHQ). This test provides a global measurement of the extent of self-perceived handicap across five dimensions based on the WHO's classification of handicap. When compared with normal persons, SCI subjects perceived themselves as more handicapped in all dimensions especially mobility and physical independence. In contrast, the majority of SCI subjects perceived themselves as less handicapped than others with SCI in physical independence, and equally handicapped in social integration and in economic self-sufficiency. In addition, the Barthel Index Score of self-care activities was negatively correlated with the PHQ score, but the depression score and hospitalization period were positively correlated with the PHQ score. Rehabilitation professionals should pay attention to the measurement of societal functioning or handicap in addition to disability.

Key word : Handicap, Spinal Cord Injury, Disability

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* Department of Rehabilitation Medicine,
** Department of Nursing, Faculty of Medicine Siriraj Hospital, Mahidol University, Bangkok 10700, Thailand.

Rehabilitation clients who can not return to their previous roles may be considered handicapped. According to the World Health Organization (WHO) (1), a handicap exists when individuals with impairment or disability are unable to fulfill one or more of the roles that are considered normal for their age, gender, and culture. In fact, patients with disabilities need not be handicapped at all, and their ability to function in society varies widely, even with similar disabilities and impairments. Handicap is one of the most poorly measured of all rehabilitation outcomes(2).

The WHO's model provides a framework of six dimensions used to measure social function. These are composed of: 1) orientation, the ability to orient oneself to the surroundings; 2) physical independence, the ability to sustain an effective independent existence; 3) mobility, the ability to move about effectively in the surroundings; 4) occupation, the ability to occupy time in a manner appropriate to the person's sex, age, and culture; 5) social integration, the ability to participate in and maintain social relationships; and 6) economic self-sufficiency, the ability to sustain economic activity and independence.

Patients with spinal cord injury (SCI) who have permanent disabilities in many areas, experience a depressive reaction to their loss of function and independence(3-5). They are often faced with environmental barriers (i.e., inconvenient transportation, architectural barriers, inadequate support services). Handicap is defined as the physical and social barriers experienced by the individual in his or her environment after SCI. This study aimed to measure the subjective experience of handicap in SCI patients.

MATERIAL AND METHOD

Eighty-three SCI patients agreed to participate in the study. They were interviewed during follow-up at outpatient clinic visits using the instruments described below. All subjects had a fairly recent diagnosis of traumatic SCI and were injured between 1997 and 2001. They were aged between 10-68 years. The participants were classified neurologically into three groups: quadriplegia Frankel Grades A, B, C; paraplegia A, B, C; and Frankel D incomplete injuries (6). (Frankel classification as follows: A, complete motor and sensory injury; B, incomplete preserved sensation only ; C, incomplete preserved motor (non-functional) ; D, incomplete preserved motor function below level of injury). Individuals with major psychiatric (i.e. major depression, schizophrenia) and cognitive disorders (i.e., moderate to severe head injury, mental retardation and organic brain disorders) were excluded from the study.

The Perceived Handicap Questionnaire (PHQ) developed by Tate et al(7), is an instrument which provides a global measure of the extent of self-perceived handicap across each of the five CHART dimensions (The Craig Handicap Assessment and Reporting Technique), which is based on the WHO's classification of handicap(8). The PHQ asks subjects about their perceived ability to function in comparison with others with SCI and with normal individuals. It represents the SCI subjects' perceptions of the extent to which they view themselves as handicapped along five dimensions; physical independence, mobility, occupation, social integration and economic self-sufficiency.

In addition, the subjects were interviewed about their physical ability to perform self-care activities using the Barthel Index Score(9) (scores ranged from 0-100) and also concerned about mental health using the Center for Epidemiologic Studies Depression scale (CES-D)(10) (scores ranged from 0-60 and scores of 19 or higher were considered indicative of depression). Analysis was then performed to determine whether there was any correlation between the PHQ, the Barthel Index Score, hospitalization period and the CES-D score.

Statistical analysis

Demographic data and PHQ scores were calculated and shown as frequencies. Pearson Correlation analysis was used to see if there was any relationship between PHQ and other factors.

RESULTS

The demographic characteristics of the samples are summarized in Table 1. Subjects were predominantly men which is typical of a traumatic SCI population(11). With respect to neurological classification at the time of discharge from rehabilitation, 25.3 per cent were diagnosed as having quadriplegia with a Frankel Grade A, B or C, 33.7 per cent as having paraplegia with a Frankel Grade A, B or C and 41.0 per cent as Frankel Grade D or incomplete injuries.

The frequency of response distribution of the five dimensions of the PHQ compared with normal individuals, and with others with SCI is shown in Table 2. When compared with normal individuals,

Table 1. Demographic characteristics of the SCI patients

Data	No	Per cent
Age (years)	33.2 ± 11.7	
Sex		
Male	66	79.5
Female	17	20.5
Marital status		
Married	44	53.0
Not married	39	47.0
Educational level		
Primary school	22	26.5
Secondary school	23	27.7
Under graduate	38	45.8
SCI neurological classification		
Quadriplegia ABC	21	25.3
Paraplegia ABC	28	33.7
Frankel D	34	41.0

SCI subjects perceived themselves as more handicapped in all dimensions especially mobility and physical independence. In contrast, the majority of SCI study subjects perceived themselves as less handicapped than others with SCI in physical independence, and equally handicapped in social integration and in economic self-sufficiency. With respect to mobility and occupation handicaps, 37 per cent of SCI rated themselves to be more handicapped and 34.6 per cent to be less handicapped when compared with others with SCI.

The average Barthel Index score of self-care activities and CES-D score were 51.88 ± 31.77 (range from 0-100) and 17.25 ± 12.07 (range from 0-60) respectively. Thirty-three subjects (39.8%) were diagnosed as being depressed by the CES-D scale.

The correlation between the PHQ score and the Barthel Index score, depression and period of hospitalization was performed using Pearson correlation analysis. The Barthel score had a negative correlation ($r=-0.587$, $p<0.001$) but the depression score ($r=0.357$, $p=0.001$) and hospitalization period ($r=0.369$, $p=0.001$) had a positive correlation with the PHQ score.

DISCUSSION

Handicaps occur in the presence of an underlying impairment or disability. Impairments or disabilities can, and frequently do, result in social disadvantages, and the reference point is the society in which the individual lives. Thus, the goal of rehabilitation is to return individuals to the society they left, measurement of handicap in terms of the expectations of the society seems not only appropriate, but vital(8).

The goal of this study was to measure social stressors, represented by the concept of handicap as defined subjectively by the PHQ. Participants viewed themselves as handicapped along five dimensions; physical independence, mobility, occupation, social integration and economic self-sufficiency. The present findings revealed that patients with SCI perceived themselves as more handicapped in all dimensions when compared with normal persons.

The study of Tate et al(7) did not find perceived handicap in social integration and economic self-sufficiency because of the different social support and welfare systems in their country. The patients with disabilities were able to maintain social activity because of convenient public transportation. There are ramps or parking lots and services for vehicle modification or motorized wheelchairs. Patients are eligible for payments from a social security disability system and some can do part-time jobs. In develop-

Table 2. The frequency of response distribution of five dimensions for the PHQ in comparison with normal persons and with others with SCI.

	Perceived Handicap Questionnaire											
	SCI *vs* Normal						SCI *vs* Other SCI					
Handicap	1	%	2	%	3	%	1	%	2	%	3	%
PI	0	0.0	10	12.3	71	87.8	33	40.7	23	28.4	25	30.9
MO	2	2.5	5	6.2	74	91.4	28	34.6	23	28.4	30	37.0
OC	1	1.2	21	25.9	59	72.8	28	34.6	23	28.4	30	37.0
SI	2	2.5	27	33.3	52	64.2	24	29.6	36	44.4	21	25.9
ECON	3	3.7	19	23.5	59	72.8	24	29.6	33	40.7	24	29.6

Note: PI = physical independence, MO = mobility, OC = occupation, SI = social integration, ECON = economic self-sufficiency.
PHQ ratings varied : 1 (less handicapped), 2 (equal) and 3 (more handicapped)

ing countries, those with SCI have to face many barriers, such as architectural or physical barriers, economic and cultural barriers.

When compared to other patients with SCI, the majority of subjects perceived themselves as less handicapped in physical independence or in the ability to sustain an independent existence, in taking care of themselves or doing household chores. The reason for this was that three-fourths of the presented subjects were paraplegia and incompletely preserved motor function below the level of injury. These patients had good upper extremity function. But with regard to mobility and the ability to work or recreation, the majority of participants (37%) perceived themselves to be more handicapped compared to others with SCI, but surprisingly 34 per cent perceived themselves as less handicapped. This means that mobility and occupation did not depend only on their physical ability. There might be other factors involved such as psychological (motivation or depression), socio-cultural barriers or availability of transportation for those with disabilities.

In addition, nearly half of the subjects (39.8%) were diagnosed as having depression. Their average score for self-care activities was at a dependent level (score below 60). This might be further evidence to confirm that the presented subjects perceived themselves as more handicapped in mobility and occupation. The authors also found a negative correlation between the Barthel score and the PHQ, and a positive correlation between the depression score and the hospitalization period to the PHQ score. Participants who had been hospitalized for a long time were usually quadriplegic or had a complete high paraplegia and tended to be more depressed. These patients had a higher PHQ score. Subjects who reported higher levels of self-perceived handicap, especially in social integration when compared with able-bodied persons, during the first year of study, were more likely to become depressed during the second year(3,5).

Handicap, in particular, has been variously perceived as the result of service gaps and architectural and attitudinal barriers in society, social oppression, failure to become reintegrated into the community, failure to be employed, and undesirable or involuntary deviance from what society thinks is normal or appropriate(8). Many therapists do not know how to measure handicap appropriately, so rehabilitation professionals and researchers should attempt to measure societal functioning, or handicap, along with disability.

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แบบประเมินความด้อยโอกาสทางสังคมในผู้ป่วยบาดเจ็บไขสันหลัง

วิไล คุปต์นิรัติศัยกุล, พ.บ.,*
*อรวรรณ เสมรสุต, พย.บ.**, พวงทอง กล่อมใจเย็น, พย.บ.***

ผู้ด้อยโอกาสทางสังคม (handicap) เกิดขึ้นเมื่อผู้พิการไม่สามารถดำเนินบทบาทอันเหมาะสมกับอายุ, เพศหรือวัฒนธรรมของตนได้ และระดับความด้อยโอกาสทางสังคมนั้นเป็นสิ่งที่วัดได้ยาก วัตถุประสงค์ของการศึกษานี้คือ ประเมินความรู้สึกของผู้ป่วยถึงระดับความด้อยโอกาสทางสังคมในผู้ป่วยอัมพาตจากไขสันหลังได้รับบาดเจ็บ ซึ่งจะมีความพิการถาวรและเป็นกลุ่มผู้ป่วยที่ต้องเผชิญกับอุปสรรคทางสภาพแวดล้อมต่างๆ ผู้ป่วยที่เข้าร่วมโครงการมีจำนวน 83 ราย อายุเฉลี่ย 33 ปี ถูกสัมภาษณ์โดยใช้แบบสอบถาม Perceived Handicap Questionnaire (PHQ) ซึ่งเป็นแบบสอบถามความรู้สึกผู้ป่วยถึงความสามารถทางสังคม 5 ด้าน ได้แก่ การดูแลตนเอง การเคลื่อนไหว ความสามารถในการทำงานอาชีพ–งานอดิเรก การเข้าสังคม และการพึ่งพาตนเองทางเศรษฐกิจ เปรียบเทียบกับคนปกติและผู้ป่วยบาดเจ็บไขสันหลังรายอื่น พบว่าผู้เข้าร่วมโครงการประเมินว่ามีความด้อยโอกาสทางสังคมมากกว่าคนปกติในทุกด้าน โดยเฉพาะการเคลื่อนไหว และความสามารถดูแลตนเอง แต่ถ้าเปรียบเทียบกับผู้ป่วยบาดเจ็บไขสันหลังรายอื่น ผู้ป่วยในโครงการประเมินว่ามีความด้อยโอกาสทางสังคมน้อยกว่าในด้านความสามารถดูแลตนเอง ส่วนด้านการเข้าสังคมและการพึ่งพาตนเองทางเศรษฐกิจนั้นมีโอกาสเท่ากับผู้ป่วยรายอื่น นอกจากนี้ยังพบความสัมพันธ์ในทางลบระหว่างคะแนน PHQ กับคะแนนความสามารถในการทำกิจวัตรประจำวัน (Barthel Index Score) และความสัมพันธ์ในการบวกระหว่างคะแนน PHQ กับคะแนนความซึมเศร้าและระยะเวลานอนโรงพยาบาล บุคลากรทางด้านเวชศาสตร์ฟื้นฟู ควรให้ความสนใจประเมินความสามารถทางด้านสังคมของผู้ป่วยควบคู่ไปกับความพิการทางร่างกาย

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* ภาควิชาเวชศาสตร์ฟื้นฟู,
** ฝ่ายการพยาบาล, คณะแพทยศาสตร์ศิริราชพยาบาล, มหาวิทยาลัยมหิดล, กรุงเทพ ฯ 10700