

## PERCEPTIONS OF PARTICIPATION AND PREDICTORS OF PERCEIVED PROBLEMS WITH PARTICIPATION IN PERSONS WITH SPINAL CORD INJURY

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**Objective:** To describe how persons with spinal cord injury perceived their participation in life situations and to determine the relationship between their participation and perceived problems therewith. The purpose was also to evaluate the influence of age, sex, level of injury, time since injury, marital status and access to social support on perceived problems with participation.

**Design:** Cross-sectional.

**Subjects:** One hundred sixty-one persons with spinal cord injury.

**Methods:** A postal questionnaire including socio-demographic characteristics and a Swedish version of the Impact on Participation and Autonomy questionnaire.

**Results:** A majority of the respondents perceived their participation as sufficient in most activities addressed. Still, a majority of the respondents perceived one or more severe problems with their participation. Access to social support was the most influencing variable in predicting perceived severe problems with participation as compared with certain personal and health-related factors.

**Conclusion:** The results suggest that it is important to consider access to social support along with other factors in the person-environment interaction and their influence on severe problems with participation in enhancing clients' participation in rehabilitation.

**Key words:** patient participation, activities of daily living, rehabilitation, personal autonomy, social support, disabled persons.

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### INTRODUCTION

Participation, defined as social involvement in a life situation (1), is described as a central goal of rehabilitation when the International Classification of Functioning, Disability and Health (ICF) is used as a conceptual framework for rehabilitation (2).

Since the ICF has recently replaced the former classification, the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (3), participation is a rather new concept in the context of rehabilitation. In ICIDH (3) the counterpart to participation was termed handicap and was defined as restrictions in the fulfilment of roles that were considered as normal from a societal perspective. In ICF (1), the concept has been redefined in a positive way as participation with the intention of increasing the understanding of the persons' lived experience of involvement in life situations. This shift in focus has consequences for the assessment of social involvement, as instruments used should be based on the new concept: *participation*. A review of instruments used to provide insight into the social involvement of persons with disabilities revealed in most cases that the instruments were based on the former concept of handicap (4). Therefore, Carr & Thompson (5) and others (4, 6) have emphasized the need for a deeper knowledge of disabled persons' own perceptions; this is in contrast to conventional investigations of the occurrence of handicap situations from an outsider perspective. Consequently, there is a lack of knowledge about persons' perceived participation in different domains such as domestic life, work and social life, which in turn impede the possibility of addressing participation in rehabilitation programmes.

Recently, Cardol and co-workers (7–10) presented a new instrument – the Impact on Participation and Autonomy (IPA) – based on the concept of participation including autonomy (11). This significantly enhances the possibility of examining the participation of individuals with disabilities in various aspects of life. As IPA has been developed in the Netherlands, the original version was translated to enable examination of participation among people with disabilities in Sweden. Since persons with spinal cord injury (SCI) represent a wide range of disabilities and ages, it was considered particularly relevant to examine this in this population. Furthermore, knowledge about participation among individuals with SCI is sparse, as research concerning the social involvement of persons with SCI has mainly used instruments based on the former concept of handicap (6, 12).

When researchers have tried to identify factors that may explain problems with the social involvement of persons with SCI, they have concentrated on personal and health-related

characteristics, producing mixed results. For example, the severity of the injury has been found to decrease social involvement (13–16), but other factors, such as age, the amount of time passed since the injury and marital status lead to both an increase and decrease in social involvement (6, 13, 14, 17). The influence of the physical and social environment on the participation of persons with SCI has received less attention than personal and health-related factors. Hence, several researchers (6, 18, 19) have emphasized the need to study how environmental “mechanisms” facilitate or obstruct the social involvement of persons with SCI.

In summary, studies focusing on the self-reported participation of persons with SCI are rare in contrast to studies of societally perceived handicap. Consequently, the influence of different factors in the interaction between the person and their environment on person perceived participation in persons with SCI has not yet been investigated satisfactorily. In addition, it is important to consider that factors related to the person, the health condition and the environment are all important when examining the social involvement of persons with SCI. Knowledge of this will increase our understanding of the perspective of the client and is essential in the implementation of client-centred rehabilitation that targets individuals’ needs.

Thus, the purpose of this study was to describe how persons with SCI perceive their participation in life situations and to determine the relationship between their participation and perceived problems herein. The purpose was also to evaluate the influence of age, sex, level of injury, time since injury, marital status and access to social support on perceived problems with participation.

## METHODS

### *Design and sample*

The potential respondents to this cross-sectional study included all individuals with SCI admitted to a specialized SCI rehabilitation centre in southern Sweden between 1993 and 2001. At the time of the study, the catchment area of this rehabilitation centre had approximately 1.7 million inhabitants. Two hundred and ninety-six persons were identified in the database at the rehabilitation centre. Fourteen of these had died and 4 could not be reached. Among the remaining 278 persons, 62 declined to participate, 47 gave no response and 8 questionnaires were returned due to an incorrect address. The final sample included 161 persons, giving a response rate of 58%. For those in the sample who did not return the questionnaires, 2 repeat mailings were sent to optimize the number of responses. The study was approved by the Research Ethics Committee of Lund University, Sweden (LU 294-02).

### *Data collection procedures and instruments*

A covering letter and the questionnaires, assessing sociodemographic characteristics including social support in activities and participation were sent to the sample of potential respondents. Briefly, the socio-demographic variables taken into account were sex, age (years), time after injury (years), marital status (single or cohabiting/married), level of injury (para- or tetraplegia), cause of injury (traumatic or non-traumatic), transfer ability (using wheelchair, walking aid or no aid) and social support in activities of daily living (no need for support, the support is sufficient or the support is insufficient). Participation including autonomy comparison (11) was examined with the Impact on Participation and Autonomy (IPA) questionnaire (7–10). This generic self-report questionnaire was chosen as it focuses on the individuals’ perceptions of participation and autonomy rather than what is generally considered

as the norm from a societal perspective. As the questionnaire was not available in Swedish, a forward-backward translation procedure (20, 21) was performed in co-operation with professional translators.

The IPA questionnaire (9) addresses perceived participation and autonomy using 31 items in 5 domains reflecting different life situations: (i) autonomy indoors; (ii) autonomy outdoors; (iii) family role; (iv) social relationships; and (v) work and education. The respondents graded their perceived participation and autonomy on a 5-point rating scale (very good; good; fair; poor; very poor). A second rating reflects the personal burden of a perceived restriction in participation in everyday life: the perceived problems are in each of 8 items (mobility; self-care; family role; financial situation; leisure; social relations; work; and education) estimated on a 3-point rating scale, from no problem to severe problem. The construct, convergent and discriminant validity of the original IPA questionnaire has been supported, even if a few items were considered to be psychometrically weak (7, 8). However, neither the construct validity nor the convergent and discriminant validity of the domain work and education and of the items addressing problem experience has been tested. The test-retest reliability of the IPA has been found to be good (7, 8). Tests of responsiveness show that IPA detects within-person improvement over time (10).

The respondents were instructed to answer the questionnaire by themselves, or, if needed, to get help filling them in. Twenty-five respondents reported that they received help filling in the answers, but that they had answered the questionnaire by themselves.

### *Statistical analysis*

The descriptive analysis of the IPA shows the relative frequency distribution for each ordinal level of all items. Furthermore, 2 types of summarized scores were calculated: (i) for each of the 5 domains of participation by summing the number of poor/very poor reports in the items included in the domain; (ii) for the perceived restriction in participation by summing the number of reports of severe problems in the 8 IPA items on problem experience for each respondent. The correlation between the summarized scores for each of the 5 domains in participation and the 8 items for perceived problems with participation was analysed using Spearman’s rank-order correlation.

Logistic regression was conducted in order to analyse the influence of age, sex, level of injury, time since injury, marital status and the access to social support on perceived problems with participation. The items for perceived problems with participation was dichotomized into no or minor problems, or severe problems, respectively, as a dependent variable in the process of the analysis. The odds ratio, resulting from the logistic regression, shows the impact of an independent variable in predicting perceived problems with participation. An odds ratio higher than 1.0 indicates a greater risk of perceiving severe problems with participation, and conversely, an odds ratio below 1.0 indicates a lower risk. Overall percentage correct classification tells us to what extent each model correctly predicts the dependent variable for the respondents participating in the study. Nagelkerke R-Square is an attempt to provide a logistic analogy to R-Square in linear regression. The Nagelkerke R-Square varies from 0 to 1.

Given occasional missing data, the sample size for each statistical procedure varies somewhat. All statistical calculations were performed with SPSS version 11.0.

## RESULTS

A comparison of basic socio-demographic characteristics of the respondents with those of the non-respondents (Table I) shows that the respondents are reasonably representative of the base population in terms of basic demographic characteristics. About half of the respondents (52%) used a wheelchair, 18% a walking aid and the remaining 30% did not use a mobility aid. Most of the respondents reported that the social support received in activities of daily living was sufficient (43%) or that they did not need any support (44%), but 13% reported that the support was insufficient.

Table I. Characteristics of the respondents and non-respondents with spinal cord injury (SCI)

	Respondents (n = 161)	Non-respondents (n = 117)
Sex, male/female, %	63/37	64/36
Age, mean (SD) range (years)	52 (18.2) 17–84	51 (19.8) 15–91
Level of injury, paraplegia/tetraplegia, %	62/38	58/42
Cause of SCI, traumatic/non-traumatic, %	52/48	49/51
Time since SCI, median (Q1,Q3) range, years	5 (3, 8) 1–58	4 (3, 6) 1–21
Marital status, single/cohabiting or married, %	36/64	–

Overall, in the domain of social relations more than 90% reported their participation as sufficient in most of those items (very good, good or fair) (Table II). Eighty percent or more

reported that their autonomy indoors, measured in terms of several items related to self-care and mobility, was sufficient. Reports of insufficient (poor or very poor) participation were mostly found in items in the domains of family life, autonomy outdoors, work and education. Less than half of the respondents perceived that their participation was sufficient when it came to getting a different job, doing repairs and housework. About half of the respondents reported sufficient participation in their intimate relationship, heavy housework, going on trips and holidays, and living life in the way one wants.

More restrictions in participation (i.e., responses of “poor”) were perceived in the domains of family role and autonomy outdoors than in autonomy indoors, social relations and in work and education (Table III). A large proportion (40–56%) of the respondents perceived minor problems in all 8 aspects of participation, and 23–33% of the respondents perceived that they had severe problems with mobility, self-care, in fulfilling a family role, leisure, work and education (Table IV). A small proportion

Table II. Percentage of participation levels, as measured by the Impact on Participation and Autonomy (IPA), in a sample of people with spinal cord injury (n = 161). Numbers of responses on each item are given in parentheses

IPA items per participation domain	Very good	Good	Fair	Poor	Very poor
<b>Autonomy indoors</b>					
Getting around indoors where one wants (160)	36	28	28	5	3
Getting around indoors when one wants (160)	40	28	21	7	4
Washing, dressing, grooming the way one wants (160)	34	32	19	6	9
Washing, dressing, grooming when one wants (160)	35	33	16	8	8
Going to bed when one wants (159)	43	26	14	8	9
Going to the toilet when one needs (157)	37	30	13	11	9
Eating and drinking when one wants (160)	57	27	11	3	2
<b>Family role</b>					
Contributing to looking after the home (160)	25	26	22	16	11
Minor housework jobs the way one wants (160)	42	22	18	10	8
Heavy housework jobs the way one wants (159)	18	16	23	20	23
Getting housework done when one wants (159)	27	21	23	18	11
Repairs and upkeep the home (151)	11	18	19	26	26
Fulfilling the one’s role at home (155)	23	21	26	19	11
Spending income as wished (158)	27	36	20	13	4
<b>Autonomy outdoors</b>					
Visiting friends when one wants (160)	28	24	17	20	11
Going on trips and holiday one wants (159)	16	15	28	16	25
Spending leisure time the way one wants (159)	30	24	21	17	8
Frequency of social contacts (160)	21	27	29	17	6
Living life the way one wants (156)	12	21	24	26	17
<b>Social relations</b>					
Communication with nearest (161)	64	22	12	1	1
Relationship with nearest (161)	61	26	8	3	2
Respect from nearest (160)	62	29	5	2	2
Relationship with acquaintances (159)	33	38	20	7	2
Respect from acquaintances (160)	31	41	21	6	1
Intimate relationship (155)	15	22	21	18	24
<b>Work and education</b>					
Doing work one wants to* (80)	19	22	23	20	16
Doing work the way one wants (93)	16	29	17	18	20
Contacts with colleagues (88)	47	25	11	5	12
Achieving or maintaining a job one wants (85)	31	23	21	6	19
Getting a different job (80)	17	14	14	20	35
Getting training or education one wants** (74)	23	15	23	23	16

\* 76 persons reported that the item was not relevant to them and therefore many of them also according to the instructions in the questionnaire chose not to answer the following items on work.

\*\* 82 persons reported that the item was not relevant to them.

Table III. Percentage of reports of insufficient (poor or very poor) participation in different domains of participation in a sample of people with spinal cord injury (n = 161). Higher frequency indicates more restrictions in participation

Reports of insufficient participation (%)				
Items in each domain	0	1–2	3–4	≥5
Domains of IPA				
Autonomy indoors (7 items)	67	17	10	7
Family role (7 items)	39	23	17	20
Autonomy outdoors (5 items)	44	24	24	8
Social relations (6 items)	58	34	7	1
Work and education (6 items)	57	23	14	6

IPA = Impact on Participation and Autonomy.

(15–17%) of the respondents reported severe problems with their financial situation and social relations. The calculation of summarized score of responses of severe problems in the 8 IPA items on problem experience showed that more than half of the respondents (57%) reported 1 or several severe problems in different aspects of participation whereas the rest (43%) reported no severe problems.

The Spearman rank correlation analysis showed that all domains for participation and the items for perceived problems was positively correlated (Table V). The coefficients varied between 0.16–0.71 and the majority was above 0.47.

The odds ratio (Table VI), estimated by the logistic regression, showed that access to social support is the most important variable in predicting perceived severe problems with participation on all items. Individuals with insufficient access to social support had a greater risk to perceive severe problems with participation compared with those with sufficient access or no need of support. Persons with tetraplegia had a greater risk to perceive severe problems with participation compared with those with paraplegia, except for problems with social relations. Single persons had a greater risk to perceive severe problems with participation than married or cohabiting persons, except for problems with education.

## DISCUSSION

The main result of this study is that a majority of the persons with SCI perceived their participation to be sufficient in most of

Table IV. Percentage of problem experiences in various aspects of participation in a sample of persons with spinal cord injury (n = 161). Actual numbers of answers are given in parentheses

IPA items on problem experience	No problems	Minor problems	Severe problems
Mobility (158)	13	56	31
Self-care (155)	25	50	25
Family role (158)	25	52	23
Financial situation (158)	41	42	17
Leisure (159)	24	50	26
Social relations (158)	34	51	15
Work (87)*	23	44	33
Education (103)*	31	40	29

\* Many respondents reported that these items were not relevant to them and therefore omitted to answer them in accordance with instructions in the questionnaire.

IPA = Impact on Participation and Autonomy.

the activities addressed. Still, most of the persons perceived themselves to have problems with several aspects of their participation, even if these problems in most cases were minor. However, a majority perceived severe problems with one or several aspects of their participation. In addition, these severe problems with participation was to a greater extent associated with access to social support, an environmental factor, compared with the factors related to the person (sex, age and marital status) or to the state of health (level of injury and time since injury).

As stated in the introduction, previous research has focused on health conditions and personal factors as determinants of social involvement (6, 14, 22). The present results suggest that it is important to consider the influence of the access to social support along with other factors in the person environment interaction in the development of client-centred rehabilitation enhancing participation. As the data used was not based on a random sample of Swedes with SCI, the interpretations of the results must be made with caution, and, hence, overall generalization of the results is limited. Still, it is reasonable to believe that the results give an indication of the extent of participation and problems herein and also the factors predicting these problems in persons with SCI.

The present results show that even if most relationships between participation and perceived problems can be considered as strong, they clearly revealed that perceiving oneself to have

Table V. Correlation matrix giving the level of associations between the 5 domains of perceived participation and the eight items of perceived problems with participation in Impact on Participation and Autonomy in a sample of people with spinal cord injury

Perceived participation in domains	Perceived problems with participation in items							
	Mobility	Self-care	Family role	Financial situation	Leisure	Social relations	Work	Education
Autonomy indoors	0.47**	0.59**	0.48**	0.34**	0.48**	0.46**	0.43**	0.55**
Family role	0.48**	0.50**	0.65**	0.31**	0.50**	0.46**	0.60**	0.54**
Autonomy outdoors	0.62**	0.62**	0.62**	0.33**	0.68**	0.64**	0.54**	0.69**
Social relationships	0.45**	0.43**	0.48**	0.24**	0.51**	0.43**	0.40**	0.41**
Work and education	0.16*	0.18*	0.19*	0.30**	0.23**	0.19*	0.71**	0.50**

Due to missing values, as shown in Table II and IV, n ranged between 159–87 in the correlation analysis.

\*\* Correlation is significant at the 0.01% level.

\* Correlation is significant at the 0.05% level.

Table VI. Logistic regression of some variables influence on perceived problems with participation in a sample of people with spinal cord injury (odds ratios)

Independent variables	Dependent variables – perceived problems with participation							
	Mobility	Self-care	Family role	Financial situation	Leisure	Social relations	Work	Education
Sex								
Male	0.92	0.96	1.14	1.75	1.00	1.01	0.44	0.38
Female	1	1	1	1	1	1	1	1
Age	1.01	1.03	1.03	0.99	1.03	1.02	1.06	1.04
Level of injury								
Paraplegia	1	1	1	1	1	1	1	1
Tetraplegia	1.71	1.78	1.65	3.33	1.24	0.59	1.60	1.37
Social support								
Sufficient	4.95	5.96	3.30	3.03	1.63	6.39	6.44	10.24
Insufficient	12.50	26.90	11.07	3.85	14.77	28.82	9.09	36.90
No support needed	1	1	1	1	1	1	1	1
Time since injury (years)	1.01	1.03	0.99	1.04	1.00	0.90	1.03	1.03
Marital status								
Single	1.78	1.81	2.37	2.73	1.71	1.61	1.14	0.77
Cohabitant/married	1	1	1	1	1	1	1	1
Overall percentage correct classification (%)	73	80	80	83	79	87	77	83
Nagelkerke R Square	0.24	0.34	0.24	0.21	0.25	0.30	0.41	0.45

insufficient participation is not the same as perceiving this to be a problem. Conversely, perceiving oneself to have sufficient participation is not the same as having no problems with participation. These results emphasize the importance of focusing on the aspect of participation that are perceived by the client to be a problem, preferably on those problems perceived as severe, rather than focusing on participation in general during rehabilitation.

The results reinforce the importance of focusing on the influence of social support and whether the support provided for activities of daily living is ideal for the client's needs, in order to understand severe problems with participation for persons with SCI. This is in accordance with our previous results (23). Previous research focusing on social support has concentrated on what kind of support, or the amount of support persons with SCI receive (18, 24), rather than whether the support satisfies their individual needs. In a rehabilitation context, less emphasis is usually put on the environment, and most of the environmental interventions provided are limited to overcoming physical architectural barriers in the home, despite the fact that many other physical and social factors might determine the activities of persons with disabilities (25). More research is, therefore, needed on the influence of factors in social environment such as social support on problems with participation in order to improve and develop the knowledge of interventions and maximize the outcome of rehabilitation for persons with disabilities.

The results showed that, as compared with those with no support needed, the persons in need of social support and judging it as sufficient were at greater risk to perceive severe problems with participation, and those in need of social support and judging it as insufficient was pervaded with an additional greater risk. This indicates that the respondents who have sufficient support from others in their activities of daily living have

possibilities to make decisions and carry them out without external restraint. On the other hand, respondents with insufficient support have difficulties to make decisions and realize their desires. This implies that persons' self-determination in activities, despite their inability to act by themselves as they desire, is important to consider in rehabilitation in order to prevent severe problems with participation. Previous research has also found that persons with disabilities can experience greater restrictions in participation than expected from their impairments (2). Consequently, in order to obtain a better insight into their subjective perceptions of problems with participation it is important to consider each client's possibilities of engaging in activities when, where and in the way they want and the meaning attached to them, rather than just the degree of physical independence. This is also in agreement with the intention behind the concept of participation in ICF (1) as it emphasizes the understanding of the lived experience of the persons concerned.

The large influence of social support in predicting severe problems with participation as compared with the other variables (sex, age, time since injury, level of injury and marital status) might be explained by the fact that social support can overcome other obstacles influencing participation in the person environment interaction. An additional possible explanation of the relationship between perceived social support and participation is that the concepts have certain similarities as both are related to personal expectations and perceived degree of fulfilment of these. As we only examined the influence of a few variables in predicting perceived severe problems with participation, it is important to explore further the influence of other characteristics in order to understand this matter fully. Thus, other characteristics may have exerted a confounding influence on the independent variables used in the analysis. In the rehabilitation

process, not only participation but also life satisfaction or subjective well-being are described as an important goal (26, 27). In future research it will be important to explore the relationship between these concepts and factors influencing their relationships. We are now continuing with such data analyses. Moreover, further research is needed to determine whether the results of this study correspond to the perceptions of the population with SCI in Sweden, as well as with the perception of other groups of persons with disabilities. The similarity of the respondents' and the non-respondents' basic socio-demographic characteristics suggests that it is reasonable to believe that corresponding results will be found of the base population. Thus, there are reasons to believe that the results would not have been distinctly different if the response rate had been higher. As the respondents with SCI in the present study had a wide range of age and transfer ability (wheelchair, walking aid, no aid) the results of this study may give some indication of participation for Swedish people with various disabilities. However, a previous Dutch study suggests that participation differs between persons with different disabling conditions (2).

The validity and reliability of the original version of IPA needs more evaluation as these psychometric properties have been analysed only partially (7, 8). The Swedish version of the IPA is equivalent to the original version, but its validity and reliability still need to be established. The comments given by the respondents in the IPA indicate that the questions were not misinterpreted and that they followed the instructions and answered the questionnaires by themselves.

In summary, this study showed that a majority of a sample of persons with SCI perceived their participation as sufficient, but that more than half reported 1 or several severe problems with participation. Additionally, the access to social support had a greater impact on perceived problems with participation than had previously been realized; it was found to be more important than the other traditional background variables related to health or to the respondents as persons. The results indicate that it is important to focus on factors related to the social support to optimize participation during the rehabilitation process.

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