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ORIGINAL RESEARCH

Participation Restrictions and Satisfaction With Participation in Partners of Patients With Stroke

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Abstract

Objective: To investigate participation restrictions and satisfaction with participation in partners of patients with stroke.

Design: Cross-sectional study.

Setting: Five rehabilitation centers and 3 hospitals in The Netherlands.

Participants: A consecutive sample of 54 partners of patients with stroke. The patients were participating in a multicenter randomized controlled trial.

Interventions: Not applicable.

Main Outcome Measures: Participation restrictions as a result of the patient's stroke and satisfaction with participation measured with the Utrecht Scale for Evaluation of Rehabilitation—Participation.

Results: The number of participation restrictions differed between partners of patients with stroke. The median number of participation restrictions experienced was 2 for the 11 activities assessed. Most participation restrictions were reported regarding *paid work, unpaid work, or education*, *relationship with partner (ie, patient)*, and *going out*. Partners were least satisfied regarding *going out*, *sports or other physical exercise*, and *day trips and other outdoor activities*. The participation restrictions and satisfaction with participation were significantly correlated ($\rho=0.65$; $P<.001$), although this relation between participation restrictions and satisfaction with participation differed for the various activities. Differences between satisfied partners with participation restrictions and dissatisfied partners concerned anxiety ($U=93.0$; $P=.026$), depression ($U=81.5$, $P=.010$), and the number of restrictions experienced ($U=50.0$; $P<.001$).

Conclusions: There is great variety in restrictions experienced by partners regarding different activities and in their satisfaction with these activities. Specific assessment is therefore important when supporting partners of patients with stroke.

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Stroke is a major global health problem and a leading cause of serious long-term disability.[1] The physical and cognitive impairments as well as changes in patients' emotions and behavior also affect their informal caregivers.[2,3] Caregivers of patients with stroke therefore experience numerous negative consequences, such as high burden,[2,4-6] anxiety,[5] depression,[2,4-6] and poor quality of life.[2,4,6] Caregiving not only affects physical and psychological functioning, it also influences caregivers' social life, resulting in reduced social relations[4] and participation restrictions.[3,7,8]

Participation is defined in the International Classification of Functioning, Disability and Health as "involvement in a life situation."[9(p10)] These situations include vocational, leisure, and social activities. Limitations regarding these activities are referred

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to as participation restrictions. Although caregivers of patients with stroke are known to experience participation restrictions, little is known in the current literature about the specific activities for which they experience restrictions. One study among 105 informal caregivers of patients with stroke showed that 47% of them experienced participation restrictions, with restrictions regarding cultural activities, sports, traveling for pleasure, and visiting restaurants and bars being mentioned most.[10]

Restricted participation is a negative consequence of caring for a loved one. One framework describing the negative caregiving outcomes and the underlying processes is Pearlin's Stress Process model,[11] which explains that caregivers who are exposed to the same stressors may experience different negative outcomes, determined by protective intrapersonal factors such as self-esteem and mastery. Some studies among caregivers of patients with stroke found that greater mastery correlates with greater psychological well-being and fewer participation restrictions.[3,12]

In addition to negative consequences of caregiving, there are also positive aspects that should be taken into account. Positive caregiving experiences can buffer the detrimental effects of negative consequences and are associated with greater life satisfaction in caregivers of patients with stroke.[13] It is therefore relevant for participation research to investigate not only the restrictions but also the level of satisfaction with the various participation items. Research among patients has shown that a person experiencing restrictions regarding a particular activity can still be satisfied with this activity.[14] In studies investigating satisfaction among partners of patients with stroke, partners indicated dissatisfaction with the relationship with their partner,[15,16] their sex life,[15-17] occupational situation,[15] leisure time activities,[15,16] social contacts,[15] and life as a whole.[15-17] However, these studies of satisfaction with participation did not investigate the participation restrictions they experienced.

It is important to support partners of patients with stroke regarding their participation because this can prevent depression and improve their quality of life.[5,7,8] Support programs should take participation restrictions as well as satisfaction with participation into account. To date, this has not been investigated in partners of patients with stroke. Furthermore, exploring differences between partners who are satisfied with participation despite the restrictions they experience and partners who are dissatisfied with participation may reveal factors that protect against the negative consequences of caregiving. Support programs for partners of patients with stroke can then target these factors.

The objectives of this study were to (1) identify the activities for which partners of patients with stroke experience restrictions; (2) investigate their satisfaction with these activities; (3) compare the restrictions and satisfaction for the various activities; and (4) explore the differences between those partners with participation restrictions who are satisfied and those with participation restrictions who are dissatisfied with their participation.

List of abbreviations:

USER-P **Utrecht Scale for Evaluation of Rehabilitation −Participation**

Methods

Participants

For this study, we used the baseline data of the Restore4Stroke Self-Management study, a multicenter randomized controlled trial conducted in 3 hospitals and 5 rehabilitation centers in The Netherlands.[18] This secondary data analysis was not part of the primary study objectives. Patients with stroke and their partners were included from February 2012 until May 2014 using consecutive sampling. Inclusion criteria for the patients were a clinically confirmed diagnosis of first or recurrent stroke, having problems regarding at least 2 items of the restriction scale of the Utrecht Scale for Evaluation of Rehabilitation−Participation (USER-P), and being 18 years or older. Exclusion criteria for the patients were insufficient mental abilities to understand and benefit from the self-management intervention, disturbance in production or comprehension of language as determined with a score <5 on the shortened version of the Aphasia Scale,[19] inability to function in a group because of behavioral problems, having major depression, and already taking part in structured psychological counseling aimed at proactive coping after stroke. A rehabilitation physician or nurse practitioner clinically judged these criteria.

Partners were included if they were living together with the stroke survivor taking part in the study and were 18 years or older. Clinically judged exclusion criteria for the partners were inability to function in a group because of behavioral problems and insufficient command of Dutch.

The medical ethics committee of the University Medical Center Utrecht and the ethics committees of the participating institutes approved the study. All participants gave written informed consent.

Procedure

Eligible patients with stroke were selected by rehabilitation physicians and nurse practitioners by means of case finding. Patients were invited to participate during regular consultations. Interested patients received an information letter, and their partners were also invited to participate. The researcher phoned the patients and partners after 5 days to check their willingness to participate. Baseline measurements were conducted by the researcher or a research assistant at the patients' home or at the participating institute. The researcher or research assistant provided examples for the various participation activities and made sure it was clear to the partner that the restrictions they reported should be a result of the patient's stroke.

Measures

The USER-P[20] was used to determine participation of the partners. The USER-P has been shown to be a valid[21] and responsive[22] instrument. In this study, we used the Restrictions and Satisfaction subscales of the USER-P. The Restrictions subscale consists of 11 items and assesses whether the caregiving partner experiences participation restrictions as a result of the patient's condition. The items cover 11 activities of daily life in different domains. Partners can indicate whether the activity is "not possible" (0), "possible with assistance" (1), "possible with difficulty" (2), or "possible without difficulty" (3). An option of "not applicable" is available for each activity, which is selected when an activity is not relevant to the partner or when the restriction experienced is not related to the patient's health status. A total score for the Restrictions subscale can be calculated and ranges from 0-100, with higher scores indicating fewer participation restrictions. The Satisfaction subscale consists of 10 items asking about satisfaction with participation in similar domains. Partners can indicate whether they are "very dissatisfied" (0), "dissatisfied" (1), "neutral" (2), "satisfied" (3), or "very satisfied" (4). An option of "not applicable" is available for the items *paid work, unpaid work, or education* and *relationship with partner.* A total score for the Satisfaction subscale can be calculated and ranges from 0-100, with higher scores indicating greater satisfaction. Both subscales are presented in appendix 1.

Demographic characteristics (age, sex, educational level) were recorded for both partners and patients. Employment status was recorded for the partners. Depression and anxiety symptoms of the partners were assessed with the Hospital Anxiety and Depression Scale.[23] This instrument contains 7 items measuring anxiety and 7 items measuring depression. Subscale total scores >7 indicate an anxiety disorder or depression, respectively.[23] The Hospital Anxiety and Depression Scale has shown good validity and reliability.[24] Stroke characteristics were derived from medical charts: type of stroke, first or recurrent stroke, and time since stroke. Cognitive functioning of the patient was determined with the Montreal Cognitive Assessment, a screening instrument with scores ranging between 0 and 30.[25] Scores <26 suggest cognitive impairment.[26,27] Patients' performance in activities of daily living was assessed using the Barthel Index,[28] with scores ranging from completely dependent (0) to completely independent (20).

Statistical analyses

Data were analyzed using SPSS Statistics version 22 for Windows.[a] The normality of distribution was assessed using visual inspection and the Shapiro-Wilk test. Descriptive analyses were applied to describe the study sample with mean and standard deviation for normally distributed data and median with interquartile range for data with no normal distribution. Subscale total scores were calculated for the Restrictions and Satisfaction subscales of the USER-P. Spearman rank correlation was used for bivariate analysis of the relation between the total scores on the Restrictions and Satisfaction subscales. Each item of the USER-P was dichotomized to calculate the number of restrictions experienced and to link the restrictions with satisfaction scores. The restriction items were dichotomized into "restriction" (1) for the answering options *not possible*, *with assistance*, and *with difficulty* and "no restriction" (0) for the answering option *without difficulty.* The satisfaction items were dichotomized into "satisfied" (1) for the answering options *satisfied* and *very satisfied* and "dissatisfied" (0) for the answering options *very dissatisfied*, *dissatisfied*, and *neutral*. To link the activities in both subscales, we had to cluster items. The Restrictions subscale contains 3 items (i, j, and k) on activities involving social contacts other than the partner, whereas the Satisfaction subscale contains 2 items (i and j) on these activities. Partners reporting a restriction for 1 or more of the 3 items were labeled as having "restriction" regarding social contacts, and partners reporting to be satisfied with both items were labeled as "satisfied" with social contacts. Two groups were distinguished: (1) partners who experienced participation restrictions but were nevertheless satisfied with all of these activities and (2) partners who experienced participation restrictions and indicated being dissatisfied with 1 or more of these activities. Differences between these groups regarding partners' and patients' characteristics were explored using *t* tests for normally distributed continuous data, Mann-Whitney *U* tests for continuous data with no normal distribution, and chi-square tests for categorical data.

Results

A total of 167 patients and 83 partners were recruited for the original study.[18,29] One partner did not meet the inclusion criteria and 25 partners declined to participate, resulting in 57 partners. For our analyses we excluded 3 partners who had data missing on all items of the USER-P Restrictions subscale. Hence, the study sample consisted of 54 partner-patient pairs (table 1). Patients and partners were relatively young, and half of the partners were in employment. More than a third of the partners had symptoms of anxiety, and almost a quarter of them experienced depressive symptoms. The majority of patients (n=32) scored at ceiling on the Barthel Index. For the other patients scores ranged from 4-20. Almost two-thirds of patients scored below the Montreal Cognitive Assessment cutoff score suggesting cognitive impairment.

Participation restrictions

The median number of participation restrictions experienced was 2 for the 11 activities assessed (fig 1). Twelve partners experienced no participation restrictions at all, and 4 reported participation restrictions for 9 activities. The mean total score for the Restrictions subscale was 86.6, with a standard deviation of 14.9.

The largest number of participation restrictions was reported for *relationship with partner (ie, patient)* (n=25), followed by *going out* (n=15) and *household duties* (n=15). After correction for "not applicable," the highest percentages of restrictions regarded *paid work, unpaid work, or education* (48.4%), *relationship with partner (ie, patient)* (48.1%), and *going out* (42.9%). All participation restrictions are shown in table 2.

Satisfaction with participation

Partners indicated to be least satisfied regarding *going out*, *sports or other physical exercise*, and *day trips and other outdoor activities*. They were most satisfied with *outdoor mobility*, followed by *paid work, unpaid work, or education* and *leisure activities at home*. The mean total score on the Satisfaction subscale was 68.6±15.7. The satisfaction with participation is displayed for each activity in table 3.

Relationships and comparisons between participation restrictions and satisfaction with participation

The total scores on the Restrictions and Satisfaction subscales were significantly correlated ($\rho=0.65$; $P<.001$). Experiencing fewer participation restrictions was positively related to greater participation satisfaction. In comparing participation restrictions and satisfaction with participation differences were noted. The majority of the partners who experienced restrictions regarding *outdoor mobility* and *social contacts* reported being satisfied with these activities. Partners who experienced restrictions regarding *day trips and other outdoor activities* and *household duties* were

Table 1 Partners' and patients' characteristics (N=54)

Partner Characteristics	Value
Age, mean ± SD (y)	59.0±8.4
Sex, n (%)	
Male	23 (42.6)
Female	31 (57.4)
Educational level, n (%)	
Low	5 (9.3)
Medium	30 (55.6)
High	15 (27.8)
Missing data	4 (7.4)
Employed, n (%)	27 (50.0)
Anxiety (HADS-A), median (IQR)	6 (4.5)*
Anxiety (HADS-A>7), n (%)	20 (37.0)
Depression (HADS-D), median (IQR)	5 (6.0)*
Depression (HADS-D>7), n (%)	13 (24.1)
Patient Characteristics	**Value**
Age, mean ± SD (y)	58.6±8.5
Sex, n (%)	
Male	30 (55.6)
Female	24 (44.4)
Educational level, n (%)	
Low	4 (7.4)
Medium	35 (64.8)
High	15 (27.8)
Type of stroke, n (%)	
Ischemic stroke	46 (85.2)
Hemorrhagic stroke	7 (13.0)
Other	1 (1.9)
First or recurrent stroke, n (%)	
First	43 (79.6)
Recurrent	10 (18.5)
Missing data	1 (1.9)
Time after stroke, median (IQR) (mo)	6.8 (14.4)
Cognitive functioning (MoCA), mean ± SD	24.2±2.8
Cognitive functioning (MoCA<26), n (%)	34 (63.0)
ADL-independence (Barthel Index), median (IQR)	20 (2)

Abbreviations: ADL, activities of daily living; HADS-A, Hospital Anxiety and Depression Scale—Anxiety subscale; HADS-D, Hospital Anxiety and Depression Scale—Depression subscale; IQR, interquartile range; MoCA, Montreal Cognitive Assessment.

Educational level: low=did not complete secondary school; medium=completed lower level secondary school; high=completed upper level secondary school and/or university degree

* 1 missing.

least satisfied. An overview of the comparisons between participation restrictions and satisfaction with participation is displayed in table 4.

Differences between satisfied and dissatisfied partners with participation restrictions

There were 42 partners who experienced participation restrictions for 1 or more activities. Eleven of these partners reported being satisfied with all of these activities. The other 31 partners reported dissatisfaction with 1 or more of these activities. We explored whether these 2 groups differed in terms of partner and patient characteristics. Differences were found for the partner characteristics of anxiety (U=93.0; P=.026), depression (U=81.5; P=.010), and number of restrictions experienced (U=50.0; P<.001). Satisfied partners experienced fewer participation restrictions and had lower anxiety and depression scores. No significant relations were found regarding patient characteristics (first or recurrent stroke, time after stroke, cognitive functioning, activities of daily living—independence) and other partner characteristics (age, sex, educational level, employment status).

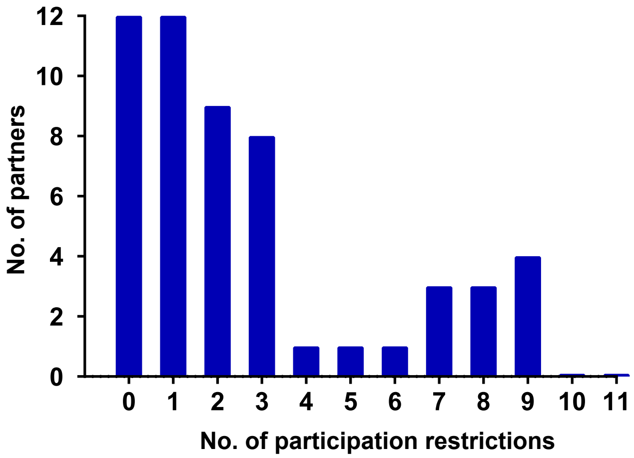

Fig 1 Number of activities for which participation restrictions were experienced (N=54).

Discussion

In this study we examined the reports of participation restrictions and satisfaction with participation in partners of patients with stroke and without aphasia who were in outpatient rehabilitation facilities because of participation problems.

We found that participation restrictions differed considerably between partners. Some partners experienced restrictions for 9 of the 11 activities we considered, whereas others reported no participation restrictions at all. The largest numbers of restrictions were reported regarding the relationship with the patient. Almost half of the partners who were in work or education reported restrictions for these activities. This is in agreement with previous research, in which 40% of the stroke caregivers reported reductions in the amount of work they were able to perform.[30]

Our second objective was to investigate satisfaction with activities. Although the most commonly reported restriction regarded the relationship with the patient, 70% of the partners were satisfied with this relationship. Comparable results were found in previous research, where 65% of the partners were satisfied with their relationship 4 months after stroke and 76% were satisfied after 7 years.[15,16] In our study 72% of the partners were satisfied with their contacts with friends and acquaintances, which is slightly higher than in previous research: 67% after 4 months and 62% after 7 years.[15,16]

Regarding the relation between participation restrictions and satisfaction with participation, we found that, on the whole, fewer participation restrictions were associated with greater participation

Table 2 Participation restrictions among partners (N=54)

	Participation Restricted			Participation Not Restricted	
Item	Not Possible n (%)	Possible With Assistance n (%)	Possible With Difficulty n (%)	Possible Without Difficulty n (%)	Not Applicable n (%)
Paid work, unpaid work, or education (n=52)	2 (3.8)	4 (7.7)	9 (17.3)	16 (30.8)	21 (40.4)
Household duties	0 (0)	4 (7.4)	14 (25.9)	33 (61.1)	3 (5.6)
Outdoor mobility	0 (0)	4 (7.4)	5 (9.3)	42 (77.8)	3 (5.6)
Sports or other physical exercise (n=53)	1 (1.9)	1 (1.9)	6 (11.3)	32 (60.4)	13 (24.5)
Going out	5 (9.3)	1 (1.9)	12 (22.2)	24 (44.4)	12 (22.2)
Day trips and other outdoor activities	2 (3.7)	1 (1.9)	12 (22.2)	31 (57.4)	8 (14.8)
Leisure activities at home	1 (1.9)	0 (0)	7 (13.0)	39 (72.2)	7 (13.0)
Relationship with partner (ie, patient) (n=53)	2 (3.8)	1 (1.9)	22 (41.5)	27 (50.9)	1 (1.9)
Going to visit family or friends	1 (1.9)	1 (1.9)	13 (24.1)	37 (68.5)	2 (3.7)
Family or friends coming to visit at your home	1 (1.9)	0 (0)	11 (20.4)	39 (72.2)	3 (5.6)
Contacting other by phone or computer (n=53)	0 (0)	1 (1.9)	6 (11.3)	44 (83.0)	2 (3.8)

satisfaction. The correlation we found (0.65) is much stronger than the 0.31 value found by Bergstrom et al.[10] Whereas they used 1 question about overall life satisfaction, we assessed satisfaction for individual activities, namely the same activities we used to measure the participation restrictions. Partners can experience a restriction regarding a particular activity and still be satisfied with this activity. For example, the majority of the partners in our study were satisfied with their outdoor mobility and social contacts despite their restrictions for these activities. On the other hand, partners who experienced restrictions regarding household duties or day trips and other outdoor activities were less satisfied with these activities. These results emphasize the importance of determining both participation restrictions and satisfaction with participation when supporting partners for their participation problems. This is in line with previous research among patients.[10,14,31] Moreover, it is important to not merely measure them as general concepts but to assess the restrictions and satisfaction at the level of specific activities. A noteworthy finding is the number

Table 3 Satisfaction with participation among partners (N=54)

	Not Satisfied			Satisfied		
Item	Very Dissatisfied n (%)	Dissatisfied n (%)	Neutral n (%)	Satisfied n (%)	Very Satisfied n (%)	Not Applicable* n (%)
Paid work, unpaid work, or education	1 (1.9)	2 (3.7)	6 (11.1)	17 (31.5)	8 (14.8)	20 (37.0)
Household duties	0 (0)	5 (9.3)	19 (35.2)	23 (42.6)	7 (13.0)	-
Outdoor mobility (n=53)	0 (0)	4 (7.5)	4 (7.5)	33 (62.3)	12 (22.6)	-
Sports or other physical exercise (n=53)	1 (1.9)	9 (17.0)	18 (34.0)	17 (32.1)	8 (15.1)	-
Going out	3 (5.6)	7 (13.0)	19 (35.2)	19 (35.2)	6 (11.1)	-
Day trips and other outdoor activities	2 (3.7)	6 (11.1)	19 (35.2)	22 (40.7)	5 (9.3)	-
Leisure activities at home (n=53)	0 (0)	4 (7.5)	11 (20.8)	28 (52.8)	10 (18.9)	-
Relationship with partner (ie, patient)	0 (0)	6 (11.1)	10 (18.5)	12 (22.2)	26 (48.1)	0 (0)
Relationship with your family (n=53)	0 (0)	2 (3.8)	15 (28.3)	15 (28.3)	21 (39.6)	-
Contacts with friends and acquaintances	0 (0)	4 (7.4)	11 (20.4)	24 (44.4)	15 (27.8)	-

* This option is only available for the items *paid work, unpaid work, or education* and *relationship with partner*.

Table 4 Partner reports of participation restrictions and satisfaction with participation (N=54)

Item	Activity Restricted, Not Restricted or Not Applicable n (%)	Satisfied With Activity* n (%)
Paid work, unpaid work, or education (n=52)[†]		
Restricted	12 (23.1)	6/12 (50.0)
Not restricted	16 (30.8)	15/16 (93.8)
Not applicable	24 (46.1)	
Household duties		
Restricted	18 (33.3)	4/18 (22.2)
Not restricted	33 (61.1)	24/33 (72.7)
Not applicable	3 (5.6)	
Outdoor mobility (n=53)[‡]		
Restricted	8 (15.1)	5/8 (62.5)
Not restricted	42 (79.2)	39/42 (92.9)
Not applicable	3 (5.7)	
Sports or other physical exercise (n=53)		
Restricted	8 (15.1)	3/8 (37.5)
Not restricted	32 (60.4)	20/32 (62.5)
Not applicable	13 (24.5)	
Going out		
Restricted	18 (33.3)	5/18 (27.8)
Not restricted	24 (44.4)	18/24 (75.0)
Not applicable	12 (22.2)	
Day trips and other outdoor activities		
Restricted	15 (27.8)	3/15 (20.0)
Not restricted	31 (57.4)	23/31 (74.2)
Not applicable	8 (14.8)	
Leisure activities at home		
Restricted	8 (14.8)	3/8 (37.5)
Not restricted	39 (72.2)	34/39 (87.2)
Not applicable	7 (13.0)	
Relationship with partner (ie, patient) (n=53)		
Restricted	25 (47.2)	9/25 (36.0)
Not restricted	27 (50.9)	27/27 (100.0)
Not applicable	1 (1.9)	
Social contacts (n=53)		
Restricted	20 (37.7)	12/20 (60.0)
Not restricted	32 (60.4)	29/32 (90.6)
Not applicable	1 (1.9)	

* Nos. do not match with the nos. in table 3; partners who reported to be satisfied but indicated "not applicable"' on the restriction item are categorized as "not applicable."

[†] 3 partners who reported restriction but answered "not applicable" to the satisfaction item are categorized as "not applicable."

[‡] 1 partner reported restriction but had missing data on the satisfaction item.

of partners who were dissatisfied with particular activities, even though they did not experience restrictions for these activities. This was reported most frequently for household duties and sports or other physical exercises. These same results, however, are found in the general population.[32]

The results relating to our last objective showed that among the partners with participation restrictions, the satisfied partners had lower anxiety and depression scores and fewer participation restrictions compared with dissatisfied partners. These analyses were explorative, and the results should be interpreted with caution because multiple comparisons were made. Although the differences in anxiety and depression scores between the 2 groups are interesting, the causal relationship is unclear because this was a cross-sectional study. Partners with anxiety and depression symptoms may be less resilient and therefore less satisfied when they experience participation restrictions. On the other hand, partners who are less satisfied with their participation may be more susceptible to developing an anxiety disorder or depression. In a study investigating only participation restrictions, Grigorovich et al found depression to be a determinant,[3] while Nieboer et al concluded that participation restrictions lead to more depressive symptoms.[8] It is conceivable that there is a reciprocal influence between participation restrictions and depression. A similar reciprocity may exist between depression and the combination of participation restrictions and satisfaction with participation. However, our cross-sectional data cannot confirm or refute this hypothesis, and additional longitudinal research is needed to elucidate this relation.

Our findings can be related to the Stress Process model by Pearlin,[11] which describes how exposure to the same stressors may have different effects on different caregivers. If we consider participation restrictions to be a stressor, we can conclude that its effect on partners of patients with stroke differs in terms of their satisfaction with participation. Some partners may be dissatisfied with certain participation restrictions, while others with the same restrictions may be satisfied. We found that partners who experienced participation restrictions and were dissatisfied with their participation experienced more symptoms of anxiety and depression. Dissatisfied partners may differ from satisfied partners concerning additional characteristics, which we did not investigate. Differences may be found in intrapersonal factors such as self-esteem, resilience, or mastery.[11] These factors should be taken into consideration to get a more complete picture of the problems partners of patients with stroke encounter and to uncover the mechanisms behind it, which in turn is important for effective support for partners.

Study limitations

The USER-P allows measurement of both participation restrictions and satisfaction with participation for various activities. A limitation, however, is that participants are able to report a certain activity as applicable on one of the subscales and answer "not applicable" for the corresponding item on the other subscale. Furthermore, the USER-P has hardly been used in partners.[33] The psychometric properties of the USER-P in partners of patients with stroke require further investigation.

Patients were only included in the original study when they experienced at least 2 participation restrictions and had no aphasia. Partners of these patients may experience different participation problems than partners of patients with less participation restrictions or with aphasia. Our results can be generalized to partners of patients with stroke and without aphasia who are in outpatient rehabilitation facilities because of participation problems. Our study sample was rather small, which may have influenced the power of our analyses. The available data was cross-sectional, which prevented us from drawing conclusions about causal relationships. To enable stronger conclusions, a study should be conducted in a larger sample. Moreover, longitudinal research is needed to investigate the development of participation problems over time and to determine the causal relations between participation problems and other factors, such as burden, anxiety, depression, quality of life, coping, and mastery.

Conclusions

Partners of patients with stroke experience participation restrictions that vary for different activities. Satisfaction with participation is also different for the various activities. It is therefore important to measure both the participation restrictions and satisfaction with participation. When health care professionals want to support partners in coping with the negative consequences of caregiving, they should take restrictions and satisfaction for individual activities into account.

Supplier

a. SPSS Statistics version 22 for Windows; IBM.

Keywords

Caregivers; Community participation; Rehabilitation; Social participation; Spouses; Stroke

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