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Restrictions and satisfaction with participation in patients who are ADL-independent after an aneurysmal subarachnoid hemorrhage

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Background: Most survivors of an aneurysmal subarachnoid hemorrhage (aSAH) are ADL-independent, but they often experience restrictions in (social) activities and, therefore, cannot regain their pre-morbid level of participation.

Objective: In this study, participation restrictions and participation satisfaction experienced after aSAH were assessed. Moreover, possible predictors of participation after aSAH were examined to identify goals for rehabilitation.

Method: Participation restrictions experienced by a series of 67 patients visiting our SAH outpatient clinic were assessed as part of standard clinical care using the Participation Restrictions and Satisfaction sections of the Utrecht Scale for Evaluation of Rehabilitation Participation (USER-Participation) 6 months after aSAH. Cognitive impairments, cognitive and emotional complaints, and symptoms of depression and anxiety, assessed 10 weeks after aSAH, were examined as possible predictors of participation by means of linear regression analysis.

Results: Although patients were ADL-independent, 64% reported one or more participation restrictions and 60% were dissatisfied in one or more participation domains. Most commonly experienced restrictions concerned housekeeping, chores in and around the house, and physical exercise. Dissatisfaction was most often reported about outdoor activities, mobility, and work/housekeeping. The main predictors of participation restrictions as well as satisfaction with participation were cognitive complaints (subjective) ($\beta = -.30$, $p = .03$ and $\beta = -.40$, $p = .002$, respectively) and anxiety ($\beta = .32$, $p = .02$ and $\beta = -.34$, $p = .007$, respectively).

Conclusions: Almost two-thirds of the ADL-independent patients experienced problems of participation 6 months after aSAH. Cognitive complaints (subjective) and anxiety symptoms showed the strongest association with participation restrictions and satisfaction. Cognitive rehabilitation and anxiety-reducing interventions may help to optimize rehabilitation and increase participation after aSAH.

Keywords: Subarachnoid Hemorrhage, Participation, Cognition, Anxiety, Depression

Introduction

Two-thirds of patients with an Aneurysmal Subarachnoid Hemorrhage (aSAH) survive.¹ Although most of these patients regain independence in basic activities of daily living (ADL), many nevertheless report restrictions in resuming more complex activities such as housekeeping, work, and social relationships.² These complex activities can be described as ‘participation’, which is defined in

the International Classification of Functioning, Disability and Health (ICF) as ‘the involvement of an individual in a life situation’ and represents the social perspective on functioning.³ It is especially because aSAH patients are relatively young that restrictions in participation can have a major impact on their lives.

Clinical rehabilitation aims to minimize the consequences of aSAH with the ultimate goal of restoring participation. ADL-independent patients are usually not referred to outpatient therapy programs. Being ADL independent does however not mean that someone is able to

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resume his or her previous level of social functioning and can return to the premorbid role in community. The level of participation in these patients might therefore not completely be regained.

Some studies have described elements of participation after SAH, especially the ability to return to work.⁴⁻⁶ These studies have led to an extension of knowledge about the impact and determinants of reintegration into work. However, other aspects of participation, such as leisure or contact with family or friends, have received less attention. When a patient is able to return to work, these other complex activities and someone's social role fulfillment might still be hampered and of great importance to the patient and his or her environment. As far as we are aware, there are no studies in aSAH patients which studied all aspects of participation. This study will therefore obtain an overview of the level of the different aspects of participation after aSAH.

The second aim of this study was to identify what factors are associated with participation after aSAH. Cognitive impairments (objective), cognitive complaints (subjective), and psychological factors such as mood and anxiety have often been related to adverse functional outcome after aSAH.² In a previous study on participation after ischemic stroke, better participation was associated with both higher (cognitive) independence as well as less mood problems.¹¹ Based on these findings, this study will determine the associations between cognitive and psychological factors and participation among ADL-independent aSAH patients. Insights into the associations can help clinicians decide what aspects to focus on in rehabilitation to improve participation after aSAH.

Materials and methods

The study was approved by the University Medical Center Utrecht (UMCU) Medical Ethics Committee. Data were derived from a prospective data collection according to clinical care as usual; therefore, no informed consent was used.

aSAH patients and procedure

In this consecutive case series, patients with an SAH caused by an aneurysm as proven by CT, MR, or conventional angiography were included. According to standard clinical care at the UMCU, these patients are invited to visit the SAH outpatient clinic 10 weeks after discharge. Less than a week before visiting the outpatient clinic, patients are asked to fill in the Hospital Anxiety and Depression Scale (HADS), which is sent by mail, and take the completed questionnaire to their appointment at the SAH outpatients clinic. At this clinic, patients are first seen by a nurse-practitioner specialized in SAH who administers the Checklist for Cognitive and Emotional consequences following stroke (CLCE-24). After this, patients are seen

by a neuropsychologist for a brief cognitive assessment, which includes a cognitive screening instrument, consisting of 18 items measuring orientation, memory function, language, attention, executive functioning, and visuospatial functioning (for details, see online supplement). Finally, a rehabilitation physician performs a physical examination and evaluates the need for additional therapy based on the presence of physical, cognitive, or emotional deficits or complaints and already provided care. Six months after the aSAH, patients are invited by mail to complete and return the Restrictions and Satisfaction sections of the Utrecht Scale for Evaluation of Rehabilitation Participation (USER-Participation), which measures the level of restrictions and satisfaction of patients' participation. For this study, data are used from patients who had visited the outpatient clinic between February 2010 and February 2011 and were functionally independent. Functionally independence was measured with the 10-item version of the Barthel Index. Only patients with a maximal score (Barthel score: 20/20) were included in the study. Patients who had not completed the brief cognitive assessment or questionnaires (CLCE-24, HADS, USER-Participation) were excluded from the analyses.

Participation (6 months after aSAH)

Six months after the aSAH participation was assessed by means of the Restrictions subscale and the Satisfaction subscale of the USER-Participation instrument.¹¹⁻¹³ This instrument specifically aims at participation and is validated in a previous study using the Frenchay Activities Index (FAI), the Participations subtotal score of the ICF Measure of Participation and Activities Screener (IMPACT-SP) and the Participation Scale as reference measures.¹² The FAI, IMPACT-SP, and Participation Scale measure functional status or participation and can be used to monitor recovery during rehabilitation. The FAI records the frequency of instrumental activities of daily living (IADL) performed by the patient in the last 3–6 months by scoring 15 activities on a scale from 0 (never) to 3 (high frequency, which is per activity described in more detail).¹⁴ The IMPACT-SP measures experienced limitations in participation in 15 items, which need to be scored on a 4-point scale ranging from 0 (no, no limitations whatsoever) to 3 (yes, I cannot do that at all).¹⁵ The Participation Scale is a self-report instrument to assess the level of participation compared to peers on 18 items. In case of a lower level of participation, the extent to which the respondent experiences this as a problem can be described in a 4-point scale ranging from score 1 (no problem) to score 5 (large problem).¹⁶ The USER-participation, which was used to measure participation in this study, has strong correlations with the FAI, IMPACT-SP, and the Participation Scale. Moreover, the USER-Participation

shows good reproducibility.¹³ The Restrictions subscale of the USER-Participation instrument consists of 10 items and concerns activities of daily life such as work, household, leisure, and visiting others. The score on each item ranges from 0 (not possible) to 3 (without difficulty). The Satisfaction subscale contains 9 items relating to satisfaction with various aspects of participation, e.g., self-care, leisure, work, and social relationships. Each item score ranges from 0 (very dissatisfied) to 4 (very satisfied). The sum scores of the Restrictions and Satisfaction subscales are both converted to a 0–100 scale. Higher scores indicate good levels of participation (less restrictions, greater satisfaction). The prevalence of restrictions and dissatisfaction is expressed by dichotomizing these scores based on the presence (1) or absence (0) of a restriction or dissatisfaction regarding the activity.

Possible predictors of participation

Demographic data and SAH characteristics were obtained from the collected database of the Department of Neurology and Neurosurgery of the UMCU. Level of education was measured by a Dutch classification system ranging from 1 (did not complete primary school) to 7 (university degree) and dichotomized as low (0–5) and high education (6–7).¹⁷

The aSAH characteristics include clinical condition on admission, the location of the aneurysm, the method used to occlude the aneurysm and complications after the aSAH. The clinical condition on admission was measured with the World Federation of Neurosurgical Societies (WFNS) SAH grading scale, which is a SAH grading scale based on the Glasgow Coma Scale (GOS) and additionally differentiates in the presence or absence of focal neurological deficits for GCS scores 13 and 14.¹⁸ For this study, the WFNS scores were dichotomized into good (I–III, GCS 13–15) and poor (IV–V, GCS 3–12) clinical condition on admission. Location of the aneurysm was categorized into anterior and posterior circulation.

Cognitive and emotional complaints were assessed by administering the Checklist for Cognitive and Emotional consequences following stroke (CLCE-24).¹⁹ This is a valid instrument that consists of 13 items for cognitive complaints and 9 items for emotional complaints. Scores on each item were dichotomized into 0 (no complaints) and 1 (complaints).

The presence of cognitive impairments was assessed by means of a brief cognitive assessment using 18 items to screen the main cognitive domains (see online supplement). All items of this instrument are based on the concepts of standard neuropsychological tasks. First, orientation in time, place, and person is checked. Memory functions are measured by direct and delayed reproduction of five words and the location of five coins in place. Also

patients are asked what they had for dinner yesterday. Language is examined by spontaneous speech, writing their name, reading a sentence, story comprehension, and naming objects and colors. Attention is assessed by means of the verbal trail making task and by patients to name the months of the year backwards. The letter-fluency ('A'), meander-task, and a maze measure executive functioning and items for visuospatial functioning include clock- and cube drawing. Each item is scored on a 3-point scale in which 0 = unimpaired representing an adequate response, 1 = mildly impaired representing a partly correct response and 2 = severely impaired in case of an incorrect or missing response. Overall cognitive functioning is measured using a sum score of all 18 items ranging from 0 (no cognitive impairments) to 36 (severe cognitive impairments).

Anxiety and depressive symptoms were assessed with the Dutch version of the Hospital Anxiety and Depression Scale (HADS)²⁰ which shows a good validity and reliability.²¹ This screening instrument contains 7 symptoms for anxiety and 7 symptoms for depression. The maximum score for each subscale is 21. The cutoff score was set at 11 for both the Anxiety and Depression subscales, as this value reflects symptomatology indicative of clinical depression or anxiety disorders.²³

Statistical analyses

For each of the two outcome measures (Participation Restrictions and Satisfaction with participation), univariable regression analyses were performed to identify potential predictors with respect to demographics (sex, age, and education), aSAH characteristics (WFNS, location of the aneurysm, presence of medical complications, and treatment of aneurysm), cognitive variables (cognitive functioning and cognitive complaints) and emotional variables (emotional complaints, symptoms of depression, and symptoms of anxiety). From the results of the univariable analyses, possible predictors with a p -value ≤ 0.1 were selected and entered into a one-block forward linear regression analysis. All predictors were checked for collinearity. In these linear regression analyses, we considered $p < .05$ to represent statistical significance. A sensitivity analysis was performed to control for potential bias due to missing data.

Results

aSAH sample

Of the 87 patients with an aSAH who visited the outpatient clinic, 20 (23%) were not included in this study because of a Barthel Index score <20 ($n = 4$), missing CLCE-24 scores ($n = 3$) or HADS scores ($n = 5$), incomplete neuropsychological examination due to (severe) aphasia ($n = 1$), severe fatigue ($n = 1$), or missing or incomplete

Table 1 Characteristics of aSAH patients (n = 67)

		<i>n</i>		%
<i>Demographic characteristics</i>				
Women		45		67.2
Mean age in years (SD)		53.2	(11.2)	
Education level				
	Low	46		68.7
	High	21		31.3
<i>aSAH characteristics</i>				
Mean follow-up time after aSAH in weeks (SD)		10.0	(3.1)	
WFNS SAH grading scale on admission				
	I-III, GCS 13-15	61		91.0
	IV-V, GCS 3-12	6		9.0
Aneurysm location				
	Anterior circulation	33		49.3
	Posterior circulation	34		50.7
Treatment received				
	Coiling	36		53.7
	Clipping	30		44.8
	None*	1		1.5
Complications (yes %)				
	Rebleeding	2		3.0
	Secondary ischemia	5		7.5
	Hydrocephalus	9		13.4
	Hydrocephalus and rebleeding	1		1.5
	Hydrocephalus and ischemia	1		1.5
Outcome measures		<i>M</i>	<i>SD</i>	
CLCE-24				
	Cognitive complaints [0-13]	2.9	2.3	
	Emotional complaints [0-9]	2.8	1.8	
Neuropsychological assessment				
	Cognitive impairments [0-36]	4.6	4.2	
HADS				
	Anxiety [0-21], (% score ≥ 11)	5.6	4.9	(20.9)
	Depression [0-21], (% score ≥ 11)	4.6	4.3	(13.4)

*For a basilar top aneurysm including both posterior cerebral arteries in a patient with bilateral occluded carotid arteries.
 Note: aSAH = aneurysmal subarachnoid hemorrhage; WFNS = world federation of Neurosurgical Societies; GCS = glasgow coma score;
 HADS = hospital anxiety and depression scale.

USER-Participation scores (*n* = 6) six months after aSAH. These patients did not differ from the included group with respect to age, sex, education, and WFNS score (all *p* > 0.5). At the time of their visit to the outpatient clinic, 56 (84%) of the 67 included patients were living at home, 9 (13%) were in a rehabilitation center and 2 (3%) were living in a nursing home. Table 1 lists the characteristics of the included patients.

Cognitive and emotional complaints

Fifty-four patients (81%) reported at least one cognitive complaint (subjective). Most frequently reported cognitive complaints were mental slowness (69%), problems remembering new information (42%), taking initiative (40%), and attention problems (40%). One or more emotional complaints were expressed by 64 patients (96%). Most of the emotional complaints concerned fatigue (93%), anxiety (39%), irritability (37%), and/or depression (33%).

Cognitive functioning

Fifty-four patients (81%) had a mild impairment, and more than half of the patients (57%) were severely impaired regarding at least one item on the brief neuropsychological assessment. Within the memory domain, 24% of the patients were mildly and 8% severely impaired in encoding five words. The delayed recall of these words was mildly impaired in 34% of the patients and severely impaired in 36%. Items tapping executive functioning showed mild or severe impairments in 8% of the patients. Other cognitive domains in which impairments were found included attention and visuospatial functioning. The orientation and language domains were unaffected in most of the patients.

Anxiety and depression

Nine patients (13%) had a HADS score suggestive of depression, whereas 14 patients (21%) had a score suggestive of an anxiety disorder.

Table 2 Participation restrictions and dissatisfaction with participation 6 months after aSAH as assessed with the USER-Participation instrument (n = 67)

	n	%		n	%
<i>Restrictions</i>			<i>Dissatisfaction</i>		
Housekeeping	28	41.8	Outdoor activities	23	34.3
Chores in/around house	26	38.8	Mobility	20	29.6
Physical exercise	25	37.3	Work/housekeeping	20	29.6
Outdoor activities	24	35.8	Cognition	19	28.4
Work/education	21	31.3	Leisure indoors	15	22.4
Going out	20	29.9	Contact with friends	7	10.4
Visits to family or friends	18	26.9	Partner relationship	7	10.4
Leisure indoors	13	19.4	Family relationships	4	6.0
Visits from family or friends	12	17.9	Self-care	3	4.5
Telephone/computer contact	10	14.9			

Notes: aSAH = aneurysmal subarachnoid hemorrhage; USER = Utrecht scale for evaluation of rehabilitation. Restrictions (not possible, with assistance or with difficulty). Dissatisfaction (very dissatisfied, dissatisfied, or neutral).

Table 3 Predictors of participation restrictions 6 months after aSAH (n = 67)

	Univariable analyses		Multivariable analysis, β (p-value)	
	β	p-value	Model I	Model II
<i>Demographic characteristics</i>				
Age	0.04	.77		
Sex (female)	-0.13	.29		
Education (high)	-0.008	.95		
<i>aSAH characteristics</i>				
WFNS (high)	0.12	.32		
Location of aneurysm (anterior)	0.20	.11		
Complications (yes)	-0.10	.41		
Treatment (clipping)	-0.09	.47		
<i>Cognitive and psychological variables</i>				
Cognitive functioning	-0.17	.16		
Cognitive complaints	-0.49	<.001*	-	-0.30 (.028)
Emotional complaints	-0.36	.003*	-	-
Depression (yes)	-0.43	<.001*	-	-
Anxiety (yes)	-0.50	<.001*	.50 (<.001)	-0.32 (.017)
Explained variance (R^2)			.254	.309
R^2 change				.055

Note: aSAH = aneurysmal subarachnoid hemorrhage. *Variables with $p \leq 0.1$ were entered in multiple analyses.

Restrictions and dissatisfaction with participation 6 months after aSAH

The mean Restrictions score on the USER-Participation instrument was 83.7 (SD 17.5). Forty-three patients (64%) reported one or more participation restrictions. The mean Satisfaction score was 77.9 (SD 16.7). Forty patients (60%) were dissatisfied with one or more domains of participation. The most commonly experienced restrictions concerned housekeeping, chores in and around the house, and physical exercise. Dissatisfaction with participation was also reported regarding housekeeping. Other most reported activities, which were experienced as dissatisfying at the level of participation, concerned outdoor activities and mobility (Table 2). A sensitivity analysis showed minimal bias as a consequence of excluding patients due to incomplete forms.

Predictors of participation restrictions

Univariable and multivariable associations between potential predictors and participation restrictions after 6 months are shown in Table 3. Cognitive complaints (subjective) ($p < .001$), emotional complaints ($p = .003$), depression ($p < .001$), and anxiety ($p < .001$) were significantly associated with participation restrictions. No relationship was found between demographic, aSAH characteristics, and the objective measure of cognitive functioning and participation restrictions. The multiple regression analysis yielded two models. In model I, anxiety explained 25.4% of the variance. In model II, cognitive complaints (subjective) added 5.5% to the outcome of model I, increasing the total explained variance to 30.9%.

Table 4 Predictors of dissatisfaction with participation 6 months after aSAH (n = 67)

	Univariable analyses		Multivariable analysis, β (p -value)	
	β	p -value	Model I	Model II
<i>Demographic characteristics</i>				
Age	0.007	.96		
Sex (female)	-0.09	.46		
Education (high)	-0.12	.34		
<i>aSAH characteristics</i>				
WFNS (high)	0.05	.69		
Location of aneurysm (anterior)	0.08	.54		
Complications (yes)	-0.02	.91		
Treatment (clipping)	-0.06	.62		
<i>Cognitive and psychological variables</i>				
Cognitive functioning	-0.12	.39	–	–
Cognitive complaints	-0.60	<.001*	-0.60 (<.001)	-0.40 (.002)
Emotional complaints	-0.47	<.001*	–	–
Depression (yes)	-0.35	.003*	–	–
Anxiety (yes)	-0.58	<.001*	–	-0.34 (.007)
Explained variance (R^2)			.361	.431
R^2 change				.070

Note: aSAH = aneurysmal subarachnoid hemorrhage.

*Variables with $p \leq 0.1$ were entered in multiple analyses.

Predictors of satisfaction with participation

Table 4 shows the univariable and multivariable associations between possible predictors of satisfaction with participation 6 months after aSAH. Besides cognitive complaints (subjective) ($p < .001$), all psychological measurements, e.g., emotional complaints ($p < .001$), depression ($p = .003$), and anxiety ($p < .001$), were significantly related to satisfaction with participation, whereas demographic, aSAH characteristics, and the objective measure of cognitive functioning were not associated with satisfaction. The multiple regression analysis rendered two significant models, in which cognitive complaints (subjective) showed the largest effect (36.1%) and anxiety increased the fit of the model by 7.0% to a total explained variance of 43.1%.

Discussion

Two of every three aSAH patients who were ADL-independent 6 months after aSAH experienced *restrictions* in participation, and a similar proportion were *dissatisfied* with their level of participation. Most commonly experienced restrictions concerned housekeeping, chores in and around the house, and physical exercise. Dissatisfaction was most often reported about outdoor activities, mobility, and work/housekeeping. This confirms previous findings about the problems aSAH patients experience with social- and complex activities.² The participation restrictions and the level of dissatisfaction with the participation in our study overlap to a large extent, but not completely. For example, although patients often reported restrictions regarding visits from or to friends and family, they were nevertheless usually satisfied with these relationships. This example shows that measuring both restrictions and satisfaction

offers better insights into the impact of participation restrictions.

Symptoms of anxiety and cognitive complaints (subjective) appeared to be associated with restrictions of and dissatisfaction with participation after aSAH. In this study, one-fifth of the patients reported severe levels of anxiety. Both the prevalence of anxiety symptoms and the relation of these symptoms with reduced levels of participation are in line with previous findings.²⁴ In contrast to cognitive complaints, cognitive impairments did not appear to be associated with participation. This finding suggests that besides emotional state of a patient, participation after aSAH is for a considerable part dependent on the experience of a patient's level of functioning rather than the objective level of functioning. It should however be noted that both cognitive complaints and participation are subjective measures, which in general show weaker associations with objective measurements of these concepts.^{10,12,25,26} Furthermore, although we used a comprehensive cognitive assessment to detect cognitive impairments, more subtle impairments that still could hamper participation cannot be ruled out completely.

Although this study gives a good first overview of the level of participation after aSAH, limitations of the study deserve mentioning. Most importantly, the generalizability of our results is limited because we deliberately chose to include only ADL-independent patients. This group represents the majority of all aSAH survivors who are nevertheless often not taken care of by health professionals. These patients, therefore, do not reach an optimal level of functioning, which is a missed opportunity. To improve participation in ADL-independent patients, a better understanding of factors associated with restricted

levels of participation is needed. Secondly, no previous studies are found on participation in aSAH patients to contrast our results with. The level of participation restrictions described in patients one year after stroke, of whom more than three-fourths was functionally independent, was similar to our findings.¹³ In a more broader context, our aSAH patients reported higher levels of participation than those described for patients with a spinal cord injury,²⁷ patients during inpatient rehabilitation recovering from acquired brain injury (stroke, TBI, tumor, post anoxic brain damage, neuroinflammatory disease)²⁸, and rehabilitation outpatients (several medical conditions such as musculoskeletal, brain injury, heart condition, chronic pain).¹² This is most likely due to the fact that the patients in these three studies were more physical dependent as compared to our patients. A third limitation of our study is the sample size. Although the sample can be considered substantial as compared to the literature,^{6–11} it is still small. Results should, therefore, be interpreted with caution.

The predictors of participation after aSAH found in our study explained a total of almost one-third of the variance of the restrictions experienced and almost half of the variance of dissatisfaction with participation. Although a portion of the variance remains unexplained, the explained variance found in this study is substantial and higher than reached in, for instance, quality-of-life research.²⁹

Conclusions

Measuring participation gives insight in the consequences of aSAH and thereby reveals concrete goals for rehabilitation. It provides guidance on what problems in complex and social activities to focus on. In addition, since cognitive complaints (subjective) and anxiety symptoms are risk factors for a decreased level of participation, cognitive rehabilitation and anxiety-reducing interventions after aSAH can be helpful to enhance the outcome. As this is the first study on participation after aSAH, in the future more studies are necessary to confirm our findings. Moreover, to improve our understanding of participation after aSAH, future studies should consider other factors as predictors of the level of participation such as PTSD symptoms, social support, personality characteristics, coping strategies, and fatigue.^{30–32} In addition, it would be interesting to know more about the level of participation and satisfaction with participation in the longer term after aSAH.

Supplementary material

The supplementary material for this article is available online at <http://dx.doi.org/10.1080/10749357.2016.1194557>

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