# PARTICIPATION RESTRICTIONS IN PATIENTS AFTER SURGERY FOR CEREBRAL MENINGIOMA

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**Objectives:** To examine participation restrictions in patients after surgery for cerebral meningioma and to explore possible determinants of participation. **Design:** Cross-sectional study.

*Patients:* Patients who had surgery for cerebral meningioma at the University Medical Center Utrecht, The Netherlands, between 2007 and 2009.

*Methods:* Clinical data were retrieved from medical files, and patients completed a postal questionnaire. Participation restrictions were measured with the Utrecht Scale for Evaluation of Rehabilitation-Participation.

*Results:* Of the 194 eligible patients, 76% (*n* = 136) participated in this study. Mean time after surgery was 32.6 months (standard deviation 10.6 months). Overall, patients showed favourable levels of participation. Nevertheless, many patients reported one or more problems of participation. Restrictions were most frequently reported regarding household duties, work or education. Twenty-three patients (32.9% of those who were in work before the meningioma) were not able to resume their job after surgery. Dissatisfaction was reported particularly regarding sports or other physical exercise. The presence of cognitive or emotional problems, multiple comorbidities and epilepsy were related to more participation problems.

**Conclusion:** Patients who have had surgery for cerebral meningioma experience participation restrictions. The results of this study can be used to identify patients at risk of developing participation problems and to tailor rehabilitation goals.

Key words: meningioma; participation; outcome; quality of life.

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Meningiomas are tumours arising from the meninges. Of all tumours of the central nervous system, meningiomas are the most prevalent, at 36.4%

# LAY ABSTRACT

Cerebral meningiomas are tumours arising from the meninges, the membranes that envelop the brain. Of all tumours of the central nervous system, meningiomas are the most prevalent, at 36.4%. This study examined the participation restrictions that patients may experience following surgery for cerebral meningioma. A total of 136 former patients participated in the study and completed a questionnaire about the frequency of participation in productive, leisure and social activities, experienced participation restrictions and satisfaction with participation. Overall, participants showed favourable levels of participation. Nevertheless, many reported one or more participation problems. Restrictions were most frequently reported regarding household duties, and work or education. Of those who were in paid work before surgery, one-third were not able to resume their work after surgery. Dissatisfaction was reported particularly regarding sports or other physical exercise. The presence of cognitive or emotional problems, multiple concurring health conditions, and epilepsy were related to more participation problems. The results of this study can be used to identify patients at risk of developing participation problems and to tailor rehabilitation goals.

(1). More than 90% of meningiomas are histologically benign (2). In the last decades, improvements in surgical and radiotherapeutic treatments have increased the life expectancy of patients with meningiomas, and current 5-year survival rates in this patient population are high (3). Hence, the impact of meningioma, including surgery, on long-term functioning and health-related quality of life (HRQoL) is increasingly recognized as an important outcome.

A recent review of studies indicated impaired HRQoL in some patients with meningioma even years after tumour surgery (4). Compared with healthy controls they had lower scores on various domains, including physical, social and role functioning. Rehabilitation treatment may therefore help patients after meningioma surgery to cope with long-lasting problems and to increase their level of participation, and to resume work and their previous lifestyle. In rehabilitation medicine, participation is an important outcome measure. Participation is related to higher life satisfaction and even more strongly related to quality of life than impairment or disability (5, 6).

Only a few studies have investigated problems in participation after treatment for cerebral meningioma, mainly focussing on the possibility of resuming paid employment (7, 8). These studies found that 17–19% of patients were not able to return to their previous jobs or their premorbid level of daily activities after treatment for cerebral meningioma. Reasons for this inability were a combination of comorbidity and postoperative physical and cognitive problems (8).

More detailed knowledge of participation restrictions in a broader perspective than only resumption of work is needed for planning of rehabilitation interventions and goals.

The objectives of this study were therefore: (i) to describe participation restrictions in patients after surgery for cerebral meningioma, including frequency of participation, participation restrictions experienced and satisfaction with participation; and (ii) to explore associations between participation and demographic and clinical characteristics, and emotional and cognitive problems (9, 10).

# METHODS

#### Patients

The aim of this study was to describe 100 patients after meningioma surgery. With a 3-year inclusion window, almost 200 patients were invited to participate. With an estimated response rate of 60%, it was expected that at least 100 patients would be included. Therefore all patients operated on between January 2007 and December 2009 for cerebral meningioma at the University Medical Center Utrecht (UMCU) were invited to participate in this study. Other inclusion criteria were: age  $\geq 18$  years and sufficient command of the Dutch language to complete the questionnaire. The outcome of this study cohort in terms of cognitive and emotional sequelae has been described previously (10).

# Procedure

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Contact addresses were retrieved from the hospital database and checked. In January 2011, information about the study, an informed consent form and the study questionnaire were sent to all patients known to have survived. Patients were asked to complete and return the questionnaire and informed consent form if they agreed to participate. One reminder was sent to non-responders several weeks after the initial mailing. Medical files were searched for data about the meningioma and comorbidities. The medical ethics committee of the UMCU approved the protocol of this study (registration number 10/312).

#### Assessment

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The study questionnaire included general questions about demographic characteristics and medical information such as comorbidities and care characteristics. Medical files were searched to complete the information regarding comorbidities and to find information about the meningioma, including location, World Health Organization (WHO) grade (11), completeness of resection, neurological deficits after operation, postoperative radiotherapy and the post-operative course.

Participation was assessed by the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) (12). This self-report questionnaire consists of 3 scales. (i) The Frequency scale contains 11 questions, asking about the frequency of vocational activities in the last week and leisure and social activities in the last 4 weeks. Each item is scored from 0 (not at all) to 5 (36 h or more/19 times or more). (ii) The Restrictions scale consists of 11 items on restrictions in participation experienced due to the health condition. Each item can be scored between 0 (not possible at all) and 3 (no difficulty at all), or "not applicable". (iii) The Satisfaction scale asks about the degree of satisfaction patients feel with various domains of participation. Items can be rated from 0 (not satisfied at all) to 4 (very satisfied). The items concerning vocational activity and relationship with the partner can be answered with "not applicable". For all 3 scales, a sum score is calculated and converted to a 0-100 scale. Higher scores indicate better levels of participation. Reproducibility was shown to be good (intraclass correlation 0.65-0.85) (13). In previous studies, Cronbach alpha coefficients, of 0.70-0.73 for the Frequency scale, 0.91-0.93 for the Restrictions scale and 0.88–0.89 for the Satisfaction scale, were found (14, 15).

The Cognitive Failures Questionnaire (CFQ) measures limitations in everyday cognitive functioning (16). It consists of 25 items, all items scored between 0 (never) and 4 (very often). A higher score indicates worse perceived cognitive functioning. The psychometric properties of the Dutch translation of the CFQ are good, with a test-retest stability of 0.83 and Cronbach alphas of 0.75 and 0.81 (17).

The Hospital Anxiety and Depression Scale (HADS) is a screening instrument for the presence of anxiety (7 items) or depressive states (7 items) (18, 19). Each item is given a score between 0 and 3. As a result, both subscores can vary between 0 and 21. Higher scores indicate more emotional problems. The HADS has shown satisfactory to good psychometric qualities in a Dutch population (18).

#### Statistical analyses

SPSS version 18.0 was used for all analyses. Individual items of the Restrictions and Satisfaction scales were dichotomized (14). For the items in the Restrictions scale, the answer option "without difficulty" was defined as "no restrictions", the option "not applicable" was defined as missing, and all other options were defined as "restrictions". In the Satisfaction scale, the answer options "satisfied" and "very satisfied" were defined as "satisfaction", the option "not applicable" was defined as missing, and all other options were defined as "dissatisfaction".

Age was dichotomized, with 65 years as the cut-off value. The presence of comorbidities was dichotomized as absent (0–2 comorbidities) or present (3 or more comorbidities). Epilepsy was taken into account as a separate determinant, as this frequently occurs in patients with meningioma, either as 1 of the presenting symptoms or after resection. The level of education was measured according to the Dutch classification system. This score was dichotomized as low education (1–3) and high education (4–5). Peri- and post-operative complications were categorized as no complications, neurological/neurosurgical/operative complications or non-neurological medical complications, or both.

The scores of the CFQ and the HADS were both dichotomized. Mean scores from 2 general population studies were used to

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To assess the bivariate relationships between possible determinants and the USER-Participation outcome measure, appropriate non-parametric tests were used, as the scale scores were not normally distributed. A *p*-value <0.05 was considered statistically significant. If applicable, *post-hoc* Mann–Whitney *U* tests were done, using a Bonferroni adjustment. When calculating the relationship between the determinant of location of the meningioma and the outcome measures, the "intraventricular meningioma" and "meningioma in multiple locations" groups were not taken into account, as these groups were too small and, consequently, could distort the findings. No adjustment for multiple comparisons was made across the number of bivariate analyses of relationships between outcome variables and determinants.

### RESULTS

# Study population

A total of 194 patients were operated on for cerebral meningioma at the University Medical Center Utrecht during the study period. Twelve patients died, and contact details of 3 patients were missing. As a result, 179 patients were invited to participate in this study and 136 patients (76.0%) agreed to do so. No significant differences in demographic, meningioma or care characteristics were found between participants and non-participants (Table I).

#### Participation

*Frequency*. The median score on the Frequency scale of the USER-Participation was 33.9 (interquartile range (IQR) 26.7–40.4). Before the operation, 70 patients (52.6%) had had paid employment. Twenty-three of the patients (32.9%) did not return to paid work after surgery. Most of the patients who were in work after surgery worked 17 h or more a week (36 patients). Almost all patients performed household duties, more than half of them for 1–16 h a week. Other activities that were performed most often included sports and physical exercise, leisure activities at home and contacting others by telephone or computer.

*Restrictions*. The median score on the Restrictions scale was 92.6 (IQR 66.7–100.0). Forty-nine patients (36.0%) did not indicate any participation restriction and had the maximum score of 100. Areas of participation in which patients reported restrictions most frequently included household duties, paid work, unpaid work or education and sports or other physical

Table I. Characteristics of participants and non-participants

Characteristics	Participants n = 136	Non- participants n = 43
Demographic characteristics		
Women, <i>n</i> (%)	106 (78)	33 (77)
Age, years, mean (SD)	59.1 (12.7)	61.1 (15.1)
Living with partner, n (%)	96 (71)	Unknown
High education level, n (%)	54 (40)	Unknown
Employed before surgery, $n$ (%)	71 (52)	Unknown
Meningioma characteristics		
Location of meningioma, n (%)		
Convexity	66 (48)	22 (51)
Falx	10 (7)	5 (12)
Anterior and middle cranial fossa	43 (32)	10 (23)
Posterior fossa/ cerebellar	16 (12)	5 (12)
Intraventricular	1(1)	0(0)
Multiple locations	0(0)	1 (2)
WHO classification of meningioma, $n$ (%)		
WHO grade 1	117 (86)	34 (79)
WHO grade 2	17 (12)	9 (21)
WHO grade 3	2 (2)	0(0)
Complete resection of meningioma, n (%)	96 (71)	24 (56)
Relapse of meningioma, or meningioma in other		
location, n (%)	20 (15)	10 (23)
Medical/care characteristics		
Time since resection, months, mean, (SD)	32.6 (10.6)	32.0 (11.5)
No neurological deficits after surgery, n (%)	83 (62)	19 (44)
Radiotherapy after operation, n (%)	21 (15)	4 (9)
Number of patients with epilepsy, $n$ (%)	18 (13)	Unknown
Discharged home without rehabilitation care,		
n (%)	58 (43)	19 (46)

SD: standard deviation: WHO: World Health Organization.

exercise. Areas with the least reported restrictions included contacting others by telephone or computer, being visited by family or friends or leisure activities at home (Table II).

*Satisfaction.* The median score on the Satisfaction scale was 72.2 (IQR 57.9–83.3). Areas in which dissatisfaction was reported most frequently included sports or other physical exercise, going out, day trips and other outdoor activities and household duties. Only a small proportion of the participants reported dissatisfaction with family relationships, contacts with friends and acquaintances and relationship with their partner (Table II).

# Determinants of participation

Age and sex were related only to the USER-Participation Frequency scale score (Table III); higher age and male sex were associated with worse participation. No meningioma characteristics were found to be related to the Frequency, Restrictions or Satisfaction scale scores. Patients who had 3 or more different comorbidities had worse scores on all 3 scale scores. Epilepsy was related to worse Restrictions and Satisfaction scale scores. The presence of perioperative or postoperative complications was related to a worse Frequency scale score. *Post-hoc* analysis showed a significant difference between patients with medical complications only and

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**Table II.** USER-Participation Restrictions and Satisfaction scores with dichotomized items to reflect persisting problems of participation

	%
Frequency scale	
Paid work $(n = 135)$	
Not at all	65.2
Yes	34.8
Unpaid work ( $n = 135$ )	
Not at all	69.6
Yes	30.4
Education $(n = 135)$	
Not at all	94.1
Yes	5.9
Household duties $(n = 135)$	24.4
< 8 h per week	31.1
$\geq 8$ h per week Sports or other physical exercise ( $n = 133$ )	68.9
<3 times per 4 weeks	30.1
$\geq 3$ times per 4 weeks	69.9
Going out $(n = 129)$	05.5
Not at all	28.7
$\geq 1$ time per 4 weeks	71.3
Day trips and other outdoor activities $(n = 133)$	
< 3 times per 4 weeks	46.6
≥ 3 times per 4 weeks	53.4
Leisure activities at home $(n = 135)$	
< 3 times per 4 weeks	18.5
≥3 times per 4 weeks	81.5
Visiting family or friends $(n = 133)$	
< 3 times per 4 weeks	22.6
≥3 times per 4 weeks	77.4
Being visited by family or friends $(n=135)$	
< 3 times per 4 weeks	29.6
$\geq$ 3 times per 4 weeks	70.4
Contacting others by telephone or computer $(n = 135)$	20.0
< 6 times per 4 weeks	28.9
≥6 times per 4 weeks	71.1
Restrictions scale (restricted)	41.1
Paid work, unpaid work or education $(n = 73)$ Household duties $(n = 123)$	41.1 41.5
Outdoor mobility $(n = 127)$	41.5 34.6
Sports or other physical exercise $(n = 114)$	40.4
Going out $(n = 120)$	35.0
Day trips and other outdoor activities ( $n=128$ )	37.5
Leisure activities at home $(n = 121)$	21.5
Relationship with partner $(n = 93)$	26.9
Visiting family or friends $(n = 130)$	35.4
Being visited by family or friends $(n = 127)$	21.3
Contacting others by telephone or computer $(n = 123)$	17.9
Satisfaction scale (dissatisfaction)	
Paid work, unpaid work or education $(n = 68)$	29.4
Household duties ( $n = 125$ )	36.0
Outdoor mobility $(n = 127)$	34.6
Sports or other physical exercise $(n = 122)$	43.4
Going out $(n = 122)$ Day trips and other outdoor activities $(n = 125)$	41.0 36.8
Leisure activities at home $(n = 127)$	26.8
Relationship with partner $(n = 92)$	17.4
Relationship with family $(n = 124)$	12.9
Contacts with friends and acquaintances $(n = 127)$	16.5

USER-Participation: Utrecht Scale for Evaluation of Rehabilitation-Participation.

patients with both neurological/neurosurgical/operative and medical complications, the latter showing worse Frequency scale scores (*p*-value 0.006).

The presence of anxiety or depressive symptoms was related to worse scores on all three USER-Participation scales. Problems of cognitive functioning were related to lower scores on the USER-Participation Restrictions and Satisfaction scales.

## DISCUSSION

This study showed that, overall, patients surgically treated for cerebral meningioma had favourable levels of participation, when considering the high overall score on the Restriction scale. Nevertheless, many patients reported 1 or more moderate or severe problems regarding their ability to participate in daily life. A similar pattern was found regarding emotional problems and cognitive complaints in this group of patients. Although our patients generally also showed relatively few problems in these areas, there is a group of patients with considerable problems who need to be identified to be provided with proper care (10). Regarding HRQoL a similar pattern can be observed. Jakola et al. (23) showed that nearly half of their patients showed improvement in HROoL after an operation for cerebral meningioma, nevertheless 1 in 5 patients showed a deterioration.

The median scores on the Frequency, Restrictions and Satisfaction scales of the USER-Participation were 33.9, 92.6 and 72.2, respectively. To put these scores in perspective, we compared the scores to the known scores among other groups of patients with chronic conditions. In a patient group without brain injury, i.e. a group of patients with spinal cord injury, median scores on the Frequency and Satisfaction scales of the USER-Participation were similar, i.e. 36.1 and 72.2, respectively. The median score on the Restrictions scale was lower in the group of spinal cord injury patients, namely 75.8 (24). In a patient group with brain injury, one year after subarachnoid haemorrhage, only the median score on the restriction scale was reported and similar to our patient group, namely 90.0 (25). The 32.9% of patients who could not resume their previous job is higher than the proportions of 17-19% reported by other studies for patients unable to return to their previous jobs or premorbid level of daily activities after cerebral meningioma surgery (7, 8). This difference may partly be explained by the higher mean age of our study population and therefore by the effect of natural ageing on the ability to work. Also, in this study we could not make a distinction between patients who did not return to their premorbid job by choice and those who were forced to retire, a distinction which was made in one of the other studies (7).

Although not the majority, there were still a substantial number of patients who experienced participation problems, making it important to identify which patients are at risk of such problems. The presence of cognitive and/or emotional problems was associated

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Table III. Overview of relationships between possible determinants and scores on USER-Participation Frequency, Restrictions and Satisfaction scales

	Frequency			Restrictions			Satisfaction		
Determinant	n	Median score	<i>p</i> -value	n	Median score	<i>p</i> -value	n	Mediar score	
Demographic characteristics									
Sex									
Men	30	30.4	0.03*	30	93.0	0.78	27	72.2	0.65
Women	105	35.0		102	92.6		98	72.5	
\ge									
< 65.0 years	89	36.4	0.002*	87	96.3	0.05	85	72.5	0.09
≥65.0 years	46	30.3		45	81.0		38	65.8	
Iarital status	96	34.4	0.50	94	93.3	0.39	89	72.5	0.18
Living with partner Living alone	37	33.6	0.50	36	83.3	0.39	34	68.7	0.18
evel of education	57	55.0		50	05.5		74	00.7	
Low educated	74	32.7	0.16	71	93.3	0.75	68	72.4	0.46
High educated	54	36.2	0.10	54	91.3	0170	50	73.8	01.10
leningioma characteristics									
ocation of meningioma									
Convexity	65	32.1	0.22	63	93.9	0.11	61	72.5	0.39
Falx	10	35.2		10	68.2		8	65.0	
Anterior and middle cranial fossa	43	35.0		42	96.5		40	75.0	
Posterior fossa and cerebellar	16	31.6		16	73.7		15	63.9	
/HO grade									
Grade 1	116	34.6	0.16	114	92.6	0.54	108	72.5	0.54
Grade 2-3	19	27.5		18	82.7		17	72.2	
ompleteness of operation									
Complete resection	95	34.5	0.27	92	93.3	0.44	87	72.5	0.54
Incomplete resection	40	32.0		40	85.7		38	70.4	
ther/relapse meningioma									
No other meningioma	115	34.6	0.06	113	92.6	0.32	107	72.5	0.79
Known with relapse meningioma or meningioma in other location	20	27.5		19	90.0		18	71.8	
ledical/care characteristics 3 comorbidities									
Yes	72	35.4	0.008*	70	77.7	< 0.001*	63	65.0	0.001
No	63	30.5		62	100.0		62	75.0	
pilepsy									
Yes	18	29.5	0.17	18	66.7	0.003*	15	63.9	0.01*
No	117	34.5		114	93.3		110	73.8	
leurological deficit after operation	0.2	25.0	0.20	70	02.0	0.10	70	72.4	0.00
No neurological deficit Neurological deficit – cranial nerves	82		0.29	79	93.9	0.19	76	72.4 73.8	0.68
Neurological deficit – parenchymal	13 31	34.6 30.0		13 31	93.3 76.7		12 28	73.8 67.7	
Neurological deficit – cranial nerves and parenchymal	8	33.6		8	87.4		20 8	75.2	
eri- or post-operative complications	0	33.0		0	07.4		0	13.2	
No complications	59	33.9	0.04*	57	90.9	0.17	55	72.5	0.16
Neurological/neurosurgical/operative complications	32	32.1	0.04	32	92.6	0.17		70.0	0.10
Medical complications	23	37.5		23	93.9			75.0	
Neurological/neurosurgical/operative and medical complications	17			16	73.8		14	63.4	
ostoperative treatment									
None	114	34.8	0.10	112	92.6	0.96	106	73.8	0.35
Radiotherapy	21	28.6		20	92.1		19	71.4	
motional problems									
ADS anxiety									
<8	94	35.0	0.03*	93	96.7	< 0.001*	87	75.0	< 0.001
≥8	39	32.1		37	76.7		36	57.8	
IADS depression subscore									
< 8	102	36.4	<0.001*	100	96.7	< 0.001*	97	75.0	< 0.001
≥8	31	27.5		30	63.2		26	50.0	
ognitive problems									
FQ									
<43.5	104	35.0	0.07	101	96.3	0.004*	96	75.0	< 0.001
≥43.5	30	32.0		30	72.1		28	55.6	

\*p-value < 0.05. USER-Participation: Utrecht Scale for Evaluation of Rehabilitation-Participation; CFQ: Cognitive Failures Questionnaire; CNS: central nervous system; HADS: Hospital Anxiety and Depression Scale; WHO: World Health Organization.

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with lower participation in this study, confirming the negative influence of cognitive problems on HRQoL in patients with meningioma reported in an earlier study (9). The influence of anxiety and depressive symptoms on participation in patients after a meningioma resection has not been investigated previously. Other studies of brain injury patients also found this relationship between mood and participation, as measured with the USER-Participation (14, 25).

The presence of 3 or more comorbidities was negatively related to the level of participation. Patients with multiple comorbidities may have a worse health status in general and therefore experience more restrictions and less satisfaction regarding their opportunities for participation. The presence of epilepsy was negatively related to the Restrictions and Satisfaction scale scores, whether caused by the epilepsy itself or the use of antiepileptic drugs (9, 26). Like Mohsenipour et al. (26), who studied quality of life impairments in patients after meningioma surgery, we found a negative correlation with higher age.

To our knowledge, this study is the first to comprehensively investigate participation in patients after meningioma surgery and to provide more detailed insight into productive roles, social networks and leisure activities. Other strengths of this study are the high response rate of 76% and the relatively large size of the study sample. Nevertheless, the study was subject to some limitations. A postal questionnaire was used, implying a risk of under- or over-reporting of participation restrictions. Forty-nine patients (36.0%) obtained the maximum score of 100 on the Restrictions scale, which may have made it more difficult to find relationships between determinants and the Restriction score. We do not have pre-operative USER-Participation scores. Also, a control group is lacking. Caution must therefore be taken in interpreting the scores. Low USER participation scores can reflect restrictions attributable the meningioma and the surgery, but could also reflect the situation that was already present before surgery.

In conclusion, the results of this study indicate that patients after meningioma surgery generally showed favourable levels of participation. However, as many patients reported one or more moderate or severe problems in their abilities to participate in daily life, it clearly points to the necessity of effective patient education and follow-up. Patients at risk for participation problems should be identified and a rehabilitation plan should be drawn up matching the participation restrictions experienced. Healthcare professionals must especially be attentive to participation problems when patients with meningioma have cognitive and emotional problems, multiple comorbidities or epilepsy. Further research is needed to investigate the longitudinal course of participation problems and the correlation with other factors, such as coping strategies, environmental factors and social support. In addition, research into tailored rehabilitation interventions for this group of patients is important.

The authors have no conflicts of interest to declare.

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