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ORIGINAL REPORT

UNMET NEEDS, COMMUNITY INTEGRATION AND EMPLOYMENT STATUS FOUR YEARS AFTER SUBARACHNOID HAEMORRHAGE

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Objective: **To assess long-term unmet needs in relation to community integration and employment status 4 years after subarachnoid haemorrhage.**
Design: **Four-year follow-up of a prospective cohort.**
Patients: **Sixty-seven patients with subarachnoid haemorrhage.**
Methods: **Employment status was assessed and the Community Integration Questionnaire-Revised and Southampton Needs Assessment Questionnaire were used.**
Results: **The mean age of subarachnoid haemorrhage onset was 52.5 years (standard deviation (SD) 10.7 years) and 39% of subjects were male. Four years after subarachnoid haemorrhage, 23.9% of subjects had symptoms of depression, 43.3% had mild cognitive impairment, 67.2% were unemployed and 67.2% had one or more unmet needs. Most subjects reported a need for information (59.7%). Unemployed patients had more unmet needs than employed patients ($p = 0.034$), but no independent relationship was found. The community integration score was moderate (mean 15.1; SD 4.4). A higher level of unmet needs was independently related to a lower level of community integration (B = –0.25; $p = 0.018$), adjusted for age and comorbidity.**
Conclusion: **A large proportion of patients have unmet needs and are unemployed 4 years after subarachnoid haemorrhage. There is an inverse relationship between unmet needs and community integration. Future research should investigate whether dealing with information needs during rehabilitation contributes to better community integration in these patients.**

Key words: subarachnoid haemorrhage; long-term effects; community integration; unmet needs.

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INTRODUCTION

Subarachnoid haemorrhage (SAH) accounts for 5% of all cases of stroke and, in approximately 85% of cases, is caused by a ruptured aneurysm in one of the cerebral vessels, known as aneurysmal subarachnoid haemorrhage (A-SAH). In approximately 10% of cases no aneurysm is found, and the haemorrhage is restricted to the cisterns surrounding the brainstem and the suprasellar cistern, known as perimesencephalic subarachnoid haemorrhage (PM-SAH) (1, 2). The remaining 5% of cases are categorized as SAH of unknown origin.

After SAH, patients may face long-term impairments, such as fatigue, cognitive disorders, mood disturbances and reduced quality of life (3–7). The mean age of SAH onset is 50 years, which is relatively low compared with the other types of stroke which show a mean age of onset of 75 years (8). Therefore, SAH may have a long-lasting and profound impact on social participation, including return to work (9, 10). Several studies have addressed return to work (RTW) after SAH. The studies of Passier et al. (10) and Harris et al. (11) found that approximately 40% of patients with A-SAH ($n = 141$ and $n = 134$) did not return to work 1–4 years after A-SAH (10, 11). Alfieri et al. (12) found that more than 10% of patients with non-aneurysmal SAH (a group without objective impairment) did not return to work 7 years after SAH (12). RTW up to 8 years after different types of SAH was found to be related to marital status, age and depression (10–12). In young stroke patients (mean age 55 years), Kersten et al. (13) found that people who were unable to return to work and those with poorer mobility report most unmet needs (13).

RTW is only one aspect of community integration. Community integration is described as participation in home, social and community activities (14). Not much is known about community integration in patients with SAH. A recent study by Buunk et al. (15) showed that resumption of previous leisure and social activities is seriously impaired 4–10 years after A-SAH. The presence of executive, cognitive and emotional problems, such as unemployment, is associated with this outcome (15). Also, the study ($n = 10$) by Ravnik et al. (7) found that cognitive impairment, but also RTW, were related to the level of community integration after SAH (7). Whether patients with SAH face unmet needs in relation to RTW and community integration has not been studied previously. SAH should be considered a lifelong condition rather than an incident. Therefore, more effort should be invested in optimizing long-term outcome, minimizing unmet needs and maximizing community integration.

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The current study therefore focused on long-term outcome after SAH (4 years post-onset) with community integration, employment status, and the presence of unmet needs as outcomes of interest. The aim of this study was to evaluate whether patients face unmet needs 4 years after onset of SAH, and whether these unmet needs are related to community integration and/or employment status.

METHODS

Participants and procedures

On a yearly basis, approximately 100 patients diagnosed with SAH are admitted to the Erasmus University Medical Centre Rotterdam, of whom 50% survive. All patients who survived SAH and were hospitalized between April 2006 and August 2009 at the neurology and neurosurgery department of our hospital were invited to participate in a prospective cohort study with measurements within 1 and 4 years post-onset (16). Assuming that 85% of subjects would be willing to participate, we aimed for inclusion of 100 patients within the inclusion period of 2.5 years. The current study focuses on the long-term outcome of this cohort. Inclusion criteria were: at least 18 years of age at onset and survival of SAH. Exclusion criteria were: serious comorbidity resulting in a short life expectancy less than one year and insufficient knowledge of the Dutch language. Informed consent was obtained from all participants. The study was approved by the medical ethics committee of Erasmus MC.

Data collection

During hospitalization baseline socio-demographic data and clinical characteristics were collected by the staff of the neurology and neurosurgery departments, including origin of SAH and severity of SAH using the World Federation of Neurological Surgeons (WFNS) grading scale. A trained research psychologist visited the patients at home to collect additional measurements 4 years post-onset. A structured interview was performed to collect data on current employment status. Patients were classified as employed if they had a paid full-time or part-time job. Patients were defined as not employed if they did not have a paid job, but only had unpaid voluntary work, were students, or were retired.

Measurement instruments

The Community Integration Questionnaire (CIQ) measures community integration based on 3 subscales: Home competency, Social integration, and Productivity activity. The revisited CIQ scale with 13 questions based on the article of Sander et al. (17) was used. Each question was scored on a 3-point rating scale, ranging from 0 to 2, with a total score range of 0–25. A high score indicates a high level of community integration (17, 18). The CIQ was originally developed for patients with traumatic brain injury, but the psychometric properties have also been evaluated in stroke patients with aphasia. The internal consistency (Cronbach's $\alpha = 0.75$) is good, and the test-retest reliability (intraclass correlation coefficient = 0.96) is excellent (19).

The summary section of the Southampton Needs Assessment Questionnaire (SNAQ) was used to assess the unmet needs of patients after SAH. Patients fill in which unmet need they face in dealing with the consequences of their SAH. The SNAQ consist of 66 items divided over 10 domains (information, mobility, social activities, work or training, family, voluntary organizations, finances, housing, formal health services, and formal social services). Possible responses are yes (score 1) and no/not applicable (score 0). A total score is calculated. Higher scores indicate more unmet needs. The questionnaire is validated in a group of people with disabilities including patients with stroke (20).

The Center for Epidemiological Studies Depression scale (CES-D) was used to measure symptoms of depression. The CES-D is a 20-item scale, and is validated in stroke patients (21). Scores range from 0 to 60 and the higher the score the more depressive symptoms are present. Scores of 16 or higher indicate the presence of depression (21–23).

Comorbidity was measured with the Cumulative Illness Rating Scale (CIRS). This list comprises 14 disorders and diseases, rated on a 5-point rating scale, ranging from 0 (disorder/disease not present) to 4 (life-threatening disorder/disease present) (24).

The Coping Inventory for Stressful Situations (CISS) measures multidimensional coping, by asking the respondents how they generally react to stressful situations. The CISS consists of 48 items that can be answered on a 5-point scale, from not at all to very strong. Scores can be calculated for 3 scales, each existing of 16 items with a maximum score of 80: task-oriented coping, emotion-oriented coping and avoidance-oriented coping (25).

The Montreal Cognitive Assessment (MoCa) was used to screen for global cognitive dysfunction (26). It contains 11 tasks focused on the different domains of attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. The maximum attainable score is 30, with a cut-off score of > 26 considered as normal (27). The following ranges may be used to grade severity: 18–26 = mild cognitive impairment; 10–17 = moderate cognitive impairment; and less than 10 = severe cognitive impairment (28).

The Trail Making Test (TMT), was used to measure cognitive functioning on the domains speed of information processing (part A) and divided attention (part B). The measured time to complete the task (with a maximum of 180 s), including extra time for correcting potential errors, was recorded to calculate a time score (29).

Statistical analysis

Statistical analyses were performed using IBM SPSS Statistics version 21 (SPSS Inc., Chicago, IL, USA). Descriptive statistics were used to describe the characteristics of the total study sample and the subgroups of employed and unemployed patients. Means and standard deviations (SD) were calculated for interval variables and numbers and percentages for categorical variables. Independent-samples *t*-tests and χ^2 test were used to test differences between the employed and the unemployed subgroups.

To investigate relationships between patient characteristics (age, gender, living with a partner, and education), clinical characteristics (SAH type, length of stay, and WFNS grade) and independent variables (CIRS, CES-D, MoCa, CISS and SNAQ) with the dependent variable community integration (CIQ), univariable and multivariable regression analysis were performed. To investigate the same variables in relation to the dichotomous variable employment status, univariable and multivariable logistic regression analyses were performed. Variables that were significant ($p < 0.05$) in univariable regression analysis were entered into the multivariable regression analysis using forward selection. Variables that mostly contributed to a significant change ($p < 0.05$) in the variance explained (R^2) of the multivariable model were selected one by one if $p < 0.05$, and variables were removed from the multivariable model if $p > 0.10$.

RESULTS

Study population

A total of 96 out of 228 consecutive patients with SAH, who were hospitalized in the neurology and neurosurgery departments of Erasmus MC between April 2006 and August 2009, agreed to participate in the study. Of these, 67 patients participated in the 4-year follow-up measurement, with a mean time of 3.9 (SD 0.8) years after SAH. The flow of patients is shown in Fig. 1. Three patients were excluded from long-term follow-up for the following reasons: one did not comprehend the questionnaires, one moved abroad, and one had recently

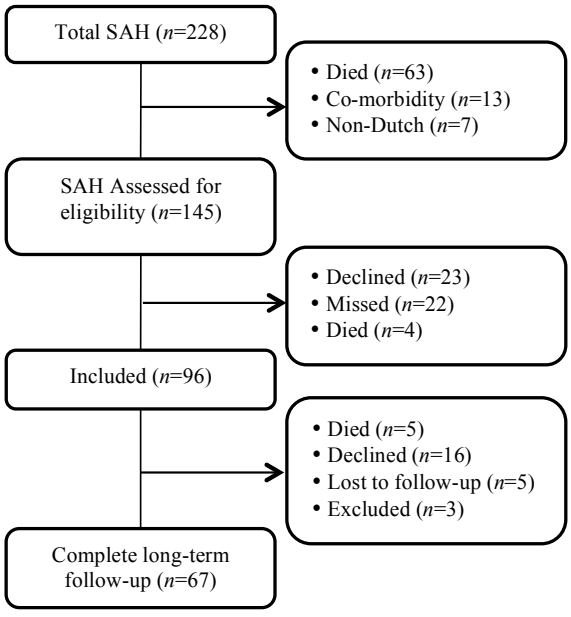

Fig. 1. Flow of patients. SAH: subarachnoid haemorrhage.

had a recurrent stroke. Five patients were untraceable or could not be contacted and were considered lost to follow-up.

The mean age of the study population was 52.5 years (SD 10.7 years) and 39% were men. The majority of patients had an aneurysmal SAH (88%), and 23.9% were classified with a poor WFNS grade (grade 3–5). Patient characteristics for the total and subgroups are shown in Table I. Four years after SAH, 67.2% of the sample was unemployed. The subgroup of unemployed patients contained significantly more women, were older, had fewer years of education, a longer length of hospital stay, and more surgical procedures compared with employed patients (Table I).

Table I. *Demographic and clinical patient characteristics for employed and unemployed patients 4 years after subarachnoid haemorrhage (SAH)* (n = *67)*

	Total group *n* = 67 *n* (%)	Employed *n* = 22 *n* (%)	Unemployed *n* = 45 *n* (%)
Age, years, mean (SD)	52.5 (10.7)	45.0 (8.8)	56.2 (9.6)*
Gender, men, *n* (%)	26 (38.8)	14 (63.6)	12 (26.7)*
Living together with a partner, yes, *n* (%)	48 (71.6)	17 (77.3)	31 (68.9)
Education, years, mean (SD)	12.9 (3.9)	14.4 (3.6)	12.2 (3.8)*
Employed before SAH[a]	37/56 (66.1)	15/18 (83.3)	22/38 (57.9)
SAH type (aneurysmal)	59 (88.1)	17 (77.3)	42 (93.3)
Length of hospital stay (days), mean (SD)	15.7 (10.4)	10.9 (6.0)	18.1 (11.3)*
Severity of SAH (WFNS), *n* (%)			
Grade 1	36 (53.7)	15 (68.2)	21 (46.7)
Grade 2	15 (22.4)	4 (18.2)	11 (24.4)
Grade 3	3 (4.5)	1 (4.5)	2 (4.4)
Grade 4	5 (7.5)	0 (0.0)	5 (11.1)
Grade 5	8 (11.9)	2 (9.1)	6 (13.3)
SAH treatment, *n* (%)			*
Coiling	41 (61.2)	13 (59.1)	28 (63.6)
Clipping	15 (22.4)	3 (13.6)	12 (27.3)
Other	2 (3.0)	0 (0.0)	2 (4.5)
No treatment	8 (11.9)	6 (27.3)	2 (4.5)
Discharge destination, *n* (%)			
Home	40 (59.7)	17 (77.3)	23 (51.1)
Outpatient rehabilitation	10 (14.9)	3 (13.6)	7 (15.6)
Inpatient rehabilitation	14 (20.9)	2 (9.1)	12 (26.7)
Nursing home	3 (4.5)	0 (0.0)	3 (6.6)

*Significant difference between employed and unemployed subgroups ($p < 0.05$).

[a]Employed before SAH, missing data in total group: $n = 11$, of which 4 in the employed and 7 in the unemployed group.

SD: standard deviation; LOS: length of hospital stay; WFNS: World Federation of Neurosurgical Societies; CIRS: Cumulative Illness Rating Scale.

Unmet needs

Two-thirds of the patients (67.2%) experienced 1 or more unmet needs 4 years after SAH, with a mean number of unmet needs of 3.5 (SD 4.7) and a median of 2 (interquartile range (IQR) 0–6). The unmet needs were divided into 10 domains, with the highest proportions of patients with unmet needs found in the domains information (59.7%), formal social services (20.9%) and mobility (19.4%). These proportions for each domain are shown in Fig. 2.

Differences in outcome between employed and unemployed patients

After 4 years, depression was found in 23.9% and (mild) cognitive impairment in 43.3% of the total study sam-

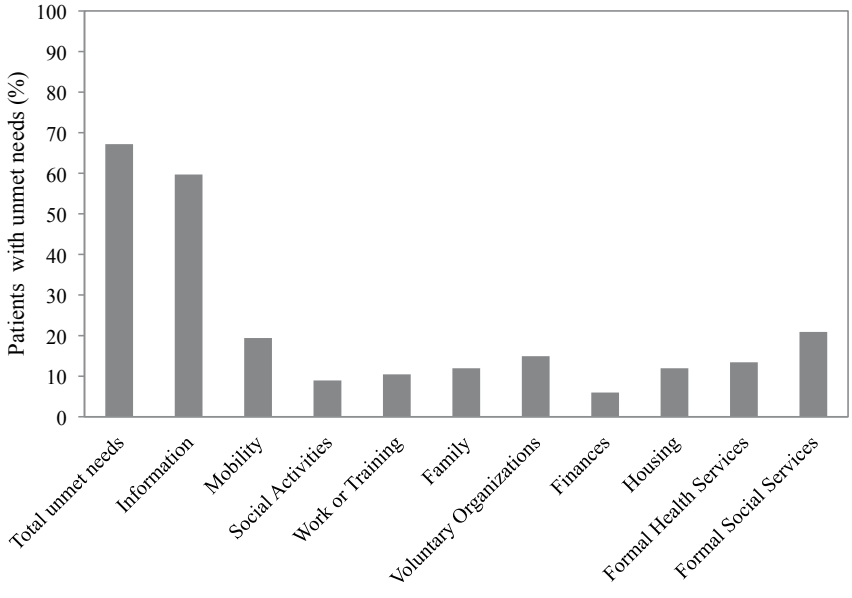

Fig. 2. Proportions of patients with unmet needs for each domain.

Table II. *Differences 4 years after subarachnoid haemorrhage (SAH) between employed and unemployed patients (*n = *67)*

	Employed *n* = 22	Unemployed *n* = 45	*p*-value
Comorbidity			
Comorbidity score (CIRS), mean (SD)	5.3 (3.6)	7.2 (4.8)	0.098
Depression			
Depression score (CES-D), mean (SD)	6.2 (4.2)	13.0 (10.5)	**<0.001**
Depressed (CES-D > 16), *n* (%)	1 (4.5)	15 (33.3)	**0.009**
Coping (CISS), mean (SD)			
Task-oriented coping	53.8 (9.7)	50.4 (13.0)	0.277
Emotion-oriented coping	28.5 (8.2)	33.9 (10.1)	**0.034**
Avoidance-oriented coping	38.1 (11.3)	36.4 (11.0)	0.560
Cognitive Functioning			
Cognitive Functioning score (MoCa), mean (SD)	26.7 (2.8)	24.7 (2.9)	**0.010**
Mild cognitive impairment (18–26), *n* (%)	10 (45.5)	34 (75.6)	**0.015**
Attention and concentration, mean (SD)			
Trail Making Test, part A	33.0 (12.3)	50.3 (29.8)	**0.002**
Trail Making Test, part B	73.7 (28.9)	110.9 (44.7)	**<0.001**
Community integration (CIQ), mean (SD)			
Total score	17.5 (4.2)	14.0 (4.1)	**0.002**
Home Competency Score	6.1 (3.0)	6.4 (2.6)	0.693
Social Integration Score	7.7 (2.0)	6.5 (2.3)	**0.035**
Productive Activity Score	3.6 (0.8)	0.9 (1.5)	**<0.001**
Unmet needs (SNAQ), mean (SD)			
Total unmet needs	2.2 (2.1)	4.3 (5.5)	**0.034**

Significant values are shown in bold ($p < 0.05$).
CIQ: Community Integration Questionnaire; CISS: Coping Inventory for Stressful Situations; SNAQ: Southampton Needs Assessment Questionnaire; CIRS: Cumulative Illness Rating Scale; CES-D: Center for Epidemiological Studies Depression scale; MoCa: Montreal Cognitive Assessment; SF-36: Short Form-36 Health Survey; SD: standard deviation.

ple. Unemployed patients had significantly more symptoms of depression (mean 13.0; SD 10.5 vs mean 6.2; SD 4.2) and used a more emotion-oriented coping style (mean 33.9; SD 10.1 vs mean 28.5; SD 8.2). Unemployed patients also scored worse on the cognitive screening test MoCa (mean 24.7; SD 2.9 vs mean 26.7; SD 2.8) than employed patients and needed more time to complete the cognitive functioning tasks of information processing TMT-A (mean 50.3; SD 29.8 vs mean 33.0; SD 12.3) and divided attention TMT-B (mean 110.9; SD 44.7 vs mean 73.7; SD 28.9). Moreover, unemployed patients had a lower community integration score (mean 14.0; SD 4.1 vs mean 17.5; SD 4.2), and more unmet needs (mean 4.3; SD 5.5 vs mean 2.2; SD 2.1) than employed patients. The subgroup outcomes are shown in Table II.

Multivariable logistic regression analysis showed that female gender, older age of onset, higher depression score (CES-D) and worse cognitive functioning (MoCa) were independently associated with unemployment 4 years after SAH (Table III). Adjusting the model for pre-SAH employment status did not affect the significance of these variables.

Table III. *Variables associated with unemployment 4 years after subarachnoid haemorrhage (SAH)*

	Unemployment			
Variables	B	*p*-value	OR	95% CI
Age (at onset)	0.169	0.008	1.184	1.20–1.31
Gender (women vs men)	2.567	0.002	13.030	1.96–86.70
Depression score (CES-D)	0.118	0.031	1.126	1.01–1.25
Cognitive Functioning score (MoCa)	–0.338	0.036	0.713	0.52–0.99

CES-D: Center for Epidemiological Studies Depression scale; MoCa: Montreal Cognitive Assessment; OR: odds ratio; 95% CI: 95% confidence interval.

Community integration

The mean community integration score was 15.2 (SD 4.4) out of a maximum of 25. None of the patients reached the maximum score of 25, and 50% of patients scored between 12 and 19. The highest scores were found in the subdomains Home Competency (mean 6.3; SD 2.7) and Social Integration (mean 6.9; SD 2.3) and a relatively low score was found in the subdomain Productive Activity (mean 1.8; SD 1.8). Table II shows the scores per subgroup of employment status.

Age, comorbidity score, depression score, divided attention score (TMT-B), and unmet needs score were significantly associated with community integration (Table IV). Multivariable linear regression analyses showed that an older age of onset (B = –0.17; $p < 0.001$), higher comorbidity score (B = –0.25; $p = 0.023$), and more unmet needs (B = –0.25; $p = 0.018$) were independently related to a lower community integration score ($R^2 = 0.32$).

Table IV. *Variables associated with community integration*

	Community integration score			
	Univariable		Multivariable	
Variables	B	*p*-value	B	*p*-value
Age (at onset)	–0.16	**0.002**	–0.17	**<0.001**
Gender (men)	–0.14	0.200		
Living with a partner	–1.07	0.384		
Education (years)	–0.08	0.546		
SAH type (aneurysmal)	–1.23	0.463		
Length of stay (days)	–0.02	0.666		
WFNS score (good vs poor)	0.83	0.529		
Comorbidity (CIRS)	–0.38	**0.001**	–0.25	**0.023**
Depression score (CES-D)	–0.15	**0.016**	–	ns
Cognitive Functioning score (MoCa)	0.31	0.104		
TMT-A	–0.29	0.161		
TMT-B	–0.33	0.010	–	ns
Task-oriented coping (CISS)	0.08	0.104		
Emotion-oriented coping (CISS)	–0.04	0.514		
Avoidance-oriented coping (CISS)	0.09	0.085		
Unmet Needs (SNAQ)	–0.24	**0.041**	–0.25	**0.018**

Significant values are shown in bold ($p < 0.05$).
CIQ: Community Integration Questionnaire; CISS: Coping Inventory for Stressful Situations; SNAQ: Southampton Needs Assessment Questionnaire; CIRS: Cumulative Illness Rating Scale; CES-D: Center for Epidemiological Studies Depression scale; MoCa: Montreal Cognitive Assessment.

DISCUSSION

Four years after SAH 67.2% of patients were unemployed, 67.2% reported one or more unmet needs, and the mean score for community integration was 15.2 (SD 4.4). Unmet needs were inversely related to community integration. The high proportion of patients with at least one unmet need is comparable to figures found in young stroke survivors >1 year after stroke (13, 30). The highest proportion was found for unmet information needs; almost 60% of the patients indicated 1 or more unmet need in this category. Low et al. (30) and Kersten et al. (13) also found provision of information about strokes to be the most frequently reported unmet need in young stroke patients (13, 30). Despite the availability of patient information about stroke on websites, booklets and patient forums, specific information for the subgroup of patients with SAH may be lacking (13). Because the general stroke group is older, the information given may not apply to younger patients with SAH (31). Therefore, future research should reveal whether tackling unmet needs, specifically with regard to information on the causes, consequences and prevention of SAH, may be beneficial for patients with SAH.

We showed that the unmet needs score was independently associated with community integration 4 years after SAH. The total community integration score of 15.2 (SD 4.4) in the current study seems reasonable and is somewhat higher than, for example, the scores found in patients with traumatic brain injury (TBI) (mean 14.3; SD 5.52) (17), brain tumours (mean 13.3; SD 5.54) (32) and neurological/neuropsychiatric disorders (mean 12.6; SD 4.23) (33). Equivalent scores were found on the Social Integration scale across these samples. On the Home Competency scale we found higher scores in patients with SAH compared with those with TBI. This may be explained by gender differences between the patient populations; 60% of patients with SAH are female, whereas 75% of patients with TBI are male. Women appear to have significantly higher scores on the Home Competency scale than men (33). In our study, only 32.8% of patients were employed 4 years after SAH. Comparable proportions of long-term employment after SAH (35–44%) were found in other studies (13, 15, 34). The employment proportion in our study cannot be compared with return-to-work proportions in some other studies, in which only previously employed persons are selected. For example, Passier et al. (10) found that 61.4% of previously employed patients with SAH returned to work, of which only 35.1% had completely resumed their former work within 2–3 years follow-up. In line with Kersten et al. (13), we found that unemployed patients reported more unmet needs than employed patients. Moreover, we showed that unemployed patients had worse scores on global cognitive functioning than employed patients, more specifically on the domains of speed of information processing and divided attention, which is also in accordance with other studies (7, 34). The cognitive tests we used (MoCa and TMT) are part of a standardized neuropsychological assessment for patients with A-SAH, which was recently proposed by Zweifel-Zehnder et al. (35). For practical reasons we were not able to study all domains of cognitive functioning.

Although we did not find an independent relationship between unmet needs and employment status, we found that the level of unmet needs was independently related to the level of community integration. Likewise, we found that older patients showed lower levels of community integration. A similar age effect was found in patients with TBI (36) and adults with neurological/neuropsychiatric disorders (33). As patients with SAH are usually older than patients with TBI, the total community integration score can be assumed to be fairly good. However, compared with controls (18) or to retrospectively obtained pre-TBI total scores (36), patients with SAH do show restrictions in community integration. Comorbidity score was also related to community integration. This is in line with Carter et al. (37), who described depression and physical disability as important factors associated with impaired overall reintegration 1–6 years post-SAH (37) and with Baseman et al. (38), who found that functional status, depression and overall stroke recovery were related to social integration > 6 months after ischaemic stroke. These studies show that limitations both in physical and psychosocial health are barriers to community integration (37).

Study limitations

This study has some limitations. First of all, the lack of appropriate norm scores for the CIQ-Revised made it difficult to draw conclusions on these scores. Another limitation is that we did not collect detailed information on whether the level of employment or job satisfaction before SAH differed from follow-up. Furthermore, no causal relationships could be established, because all outcome variables are measured at the same point in time. Finally, due to the relatively small number of patients, the number of variables that could be included in the regression analyses was limited.

Conclusion

The results of this study suggest that 4 years after SAH a large proportion of patients is unemployed and faces unmet needs, with an inverse relationship between unmet needs and community integration. Future research should investigate whether dealing with unmet needs, by, for example, expanding and improving information services, especially for patients with SAH, contributes to better community integration in these patients.

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