



Quality of life in patients and caregivers after aneurysmal subarachnoid hemorrhage: a Flemish population study

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Abstract

Background and aims Aneurysmal subarachnoid hemorrhages (aSAH) have high mortality and morbidity. However, the impact on Quality of Life (QoL) of patients remains poorly documented, and data on primary caregiver burden is even scarcer.

Methods This is a single center, cross-sectional study performed at the Antwerp University Hospital, Belgium. We included aSAH patients during follow-up at the outpatient clinic and assessed the QoL, by using the Stroke Specific Quality of Life scale (SSQoL). Caregiver burden was evaluated by the Caregiver Strain Index (CSI). The aSAH severity and functional outcome (at 90 days) were assessed, respectively, by mFisher score and modified Ranking Scale (mRS). Statistical analysis was performed using SPSS version 27.

Results In total, 22 aSAH patients were included, on average 15.5 (range 4–45) months after the aSAH. The SSQoL score was 3.7 ± 0.7 , with a mean psychosocial domain score of 3.2 ± 0.8 and physical domain of 4.2 ± 0.8 . Psychosocial factors, especially decreased energy levels and cognitive impairment, had a negative impact on the QoL ($p = 0.02$ en $p = 0.05$). No association was found between QoL and mFisher, nor between QoL and mRS. Fifteen primary caregivers completed the CSI. Only 3 (20%) of them reported a high care burden ($CSI > 6$), although changes in daily life and personal plans were reported, respectively, by 73% ($n = 11$) and 67% ($n = 10$) of caregivers. We only found a correlation between the mFisher score and CSI ($p = 0.01$).

Conclusion Our results emphasize that there is an important psychosocial impact on the QoL of patients after aSAH, and their primary caregivers. More research is warranted.

Keywords Quality of Life · Aneurysmal subarachnoid hemorrhage (aSAH) · Caregiver · Care burden

Introduction

Subarachnoid hemorrhage caused by rupture of an intracranial aneurysm, accounts for approximately 7% of all strokes [1]. In Western society, the incidence of aSAH is between 4 and 19 per 100,000 persons per year, and mostly occurs at a relatively young age, on average around the age of 45–55 [2, 3]. aSAH has a high mortality and morbidity [4], caused by a high frequency of secondary complications in the (sub) acute phase, including rebleeds, hydrocephalus, vasospasms and delayed cerebral ischemia. Of the 65% patients that survive an aSAH many will experience long-term deficits, including physical dependence, cognitive impairment, such as memory problems and executive function deficits, and a decreased Quality of Life [5, 6]. Therefore, the long-term impact of aSAH on the Quality of Life is often underestimated. Furthermore, not only patients are affected by these long-term deficits, also the patients' environment, especially

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the primary caregiver, can experience a significant impact on their personal and professional life [7]. Giving patients and their caregivers a perspective on long-term outcome, is important and could also help improve rehabilitation programs.

The aim of our study was to assess the long-term physical dependence and QoL after aSAH in patients with aSAH, and their primary caregiver. We also determined whether baseline characteristics and physical factors (age, aSAH characteristics, disability, and discharge destination) after aSAH were predictors of a lower QoL.

Methods

Subjects

This cross-sectional study is a single center study and was performed at the department of neurosurgery at the Antwerp University Hospital, Belgium, a specialized neurovascular tertiary care stroke center. We included patients with aSAH, who visited our outpatient clinic [Antwerp Neurovascular Center (NVCA)] for follow-up, between January 2020 and November 2020. Patients with a decline in daily functioning and self-care, defined as premorbid modified mRS ≥ 3 , patients with a non-aneurysmal SAH and all patients with the inability to speak Dutch were excluded. Patients, who agreed to participate in this study, were asked to complete two self-reported questionnaires (personal questionnaire and SSQoL questionnaire) [8]. We also asked the primary caregiver to participate and complete two similar self-reported questionnaires (personal questionnaire and CSI) [9]. All patients and primary caregivers gave written informed consent. The study was approved by the Medical Ethics Committee of the Antwerp University Hospital (B300201941924).

Baseline characteristics

Baseline demographics (age, gender, and premorbid mRS) and clinical features (location and size of the aneurysm, treatment of aneurysm, assessment of complications, mFisher, Glasgow Outcome Scale (GOS), discharge destination, and mRS after 3 months) were taken from the electronic patient record.

Outcome measurement

Stroke Specific Quality of Life questionnaire

SSQoL is a validated outcome measurement and is often used to evaluate health-related Quality of Life of the patient after stroke [10]. The SSQoL consists of 49 items, divided

into two domains, namely a physical domain and a psychosocial domain. The different items of each domain are further divided into six subcategories. The physical domain contains the following subcategories: language, self-care, vision, mobility, work and upper extremity function. Energy, mood, social roles, family roles, thinking and personality are the six subcategories of the psychosocial domain. Items are rated on a 5 point Likert scale, of which a higher score indicates a better outcome function. We used more specifically the original Dutch version written by Nys GMS and Van Zandvoort MJE based on the original version as developed by Williams LS with a Cronbach alpha score of 0.97 [8, 11].

Caregiver Strain Index

The CSI is a validated questionnaire and consists of a 13-question screening tool to identify primary caregivers with high strain related to care provision. This questionnaire contains at least one item regarding each of the five following factors: time management, physical and emotional condition, social status, employment and finance. The questions can be answered with yes (= 1 point) or no (= 0 point). If the total score of the CSI is above 6, high care load is suspected [9, 12].

Personal questionnaire

The study-specific patient questionnaire assessed living conditions, current work situation, relationship status and presence of medical comorbidities (anxiety, depression,...). For the primary caregivers, it contained questions about living conditions, work and relation status, as well as adaptation of their professional life (see supplemental data).

Statistical analysis

The statistical analysis was performed by SPSS statistics version 27. The results are presented as median with range. For comparisons between groups, nonparametric tests (Mann–Whitney *U* test or Kruskal–Wallis) were used because of the low amount of data and asymmetric distribution. We used the Chi-square test (or Fisher exact if expected count was less than 5) for testing relationships between categorical variables and Spearman for correlations. Statistical significance was set at $p < 0.05$ (2-tailed).

Results

Study population

Between January 2020 and November 2020, 44 patients with an aSAH presented at the outpatient clinic of the Antwerp

University Hospital. In total, 26 patients (59%) participated in this study (see Fig. 1). There were no statistically significant differences between the patients, who responded and who declined to participate regarding demographic and aSAH characteristics (data not presented). Table 1 shows baseline patient characteristics. The median age was 51 (range 38–72) and 72% ($n=16$) were female. The median time of follow-up was 15.5 (range 4–45) months after aSAH. The majority of the aneurysms were located in the anterior circulation (68%; $n=15$), with a median size of the aneurysm of 7 (range 1.4–18) mm. Of these, 73% ($n=16$) were treated with an endovascular approach using coils, the remaining patients were treated surgically. In total 59% ($n=13$) had no complications in the acute phase of the aSAH. Delayed cerebral ischemia and hydrocephalus were reported in, respectively, six and five patients (27%

and 23%). Glasgow Outcome Scale by discharge was in most cases a score of 4 ($n=11$). After discharge from the hospital, seven (32%) patients went to a rehabilitation facility. At the time of the survey, 42% ($n=9$) of the patients resumed their professional activities, and about half of those were able to resume work as before the event (same job content with the same working hours).

Quality of Life

Table 2 summarizes the SSQoL scores of our study population. The median score of the SSQoL was $3.7 (\pm 0.7)$. Further, it seems that patients report lower scores (3.2 ± 0.8) on the psychosocial level compared to the physical level (4.2 ± 0.8). The subcategories thinking and energy had the lowest scores, respectively, $2.7 (\pm 1.0)$ and $2.8 (\pm 1.2)$.

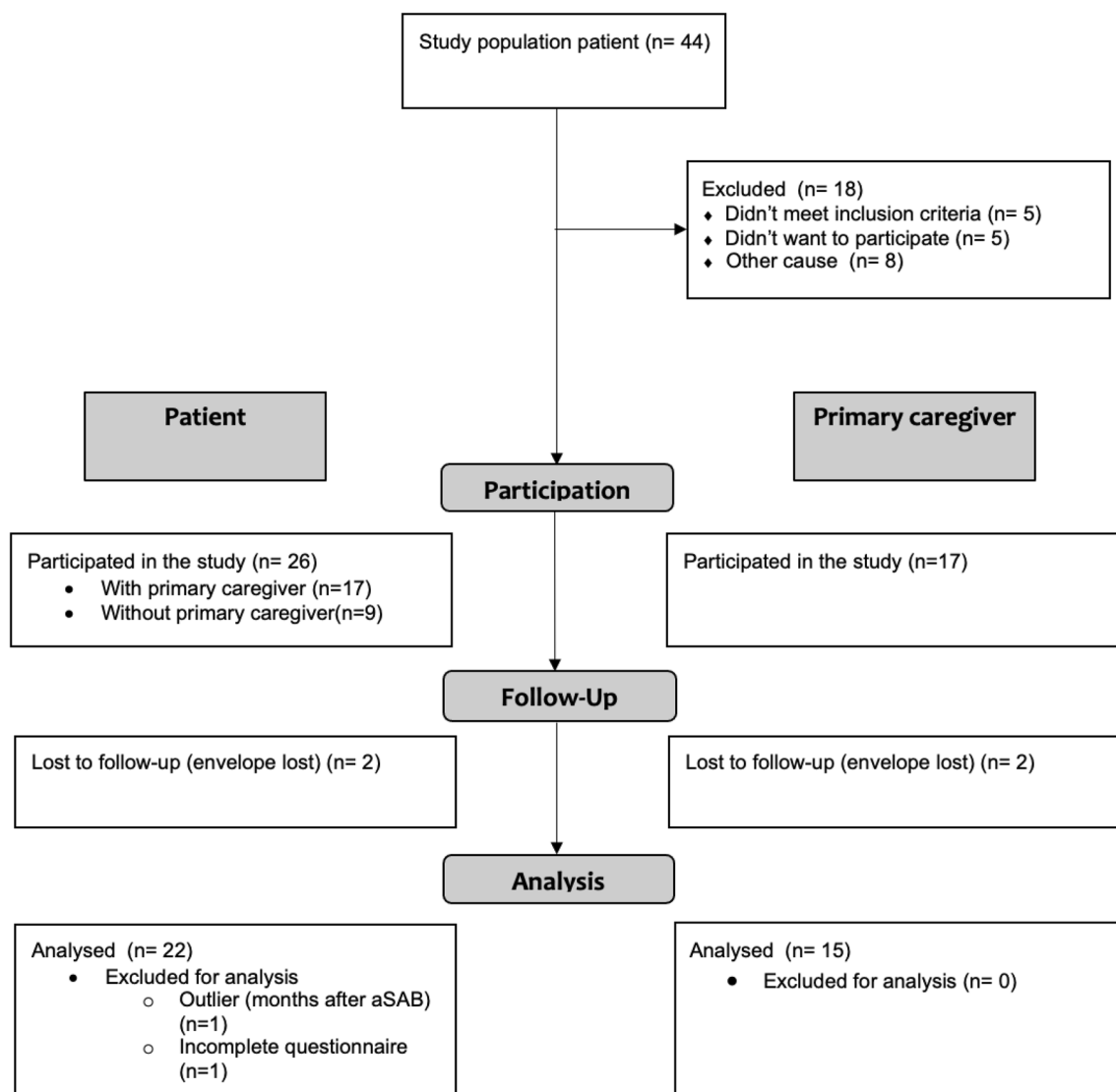


Fig. 1 Consort diagram

Table 1 Patients characteristic

	<i>N</i> = 22
Age (median + range; years)	51 (38–72)
Female (%)	16 (72)
Premorbid mRS ^a (%)	
0	14 (67)
1	4 (19)
2	3 (14)
mRS D90 ^b (%)	
0	1 (5)
1	3 (15)
2	10 (50)
3	3 (15)
4	3 (15)
mFisher ^b (%)	
1	11 (55)
2	2 (10)
3	3 (15)
4	4 (20)
GOS discharge ^b (%)	
3	7 (35)
4	11 (55)
5	2 (10)
Complications after aSAH (%)	
No complications	13 (59)
DCI ^a	4 (18)
Hydrocephalus	3 (14)
DCI ^a + hydrocephalus	2 (9)
Location aneurysm ^a (%)	
ACOM/anterior cerebral artery	11 (52)
Vertebro-basilar circulation	3 (14)
Medial cerebral artery	4 (19)
PCOM/posterior cerebral artery	3 (14)
Size aneurysm (median + range; mm) ^a	7.0 (1.4–18.0)
Treatment aneurysm (%)	
Coiling	16 (73)
Clipping	15 (23)
Combination coiling and clipping	1 (4)
Time between onset and inclusion (median + range; months)	15.5 (4.0–45.0)
Discharge home (%)	15 (68)

mRS modified Rankin scale, GOS Glasgow Outcome Scale, aSAH aneurysmal subarachnoid hemorrhage, DCI delayed cerebral ischemia, ACOM anterior communicating artery, PCOM posterior communicating artery

^a*n* = 21

^b*n* = 20

We also determined whether baseline characteristics (age and premorbid mRS) and physical factors (aSAH characteristics, disability, discharge destination, and work situation) after aSAH were predictors of low QoL. However,

Table 2 Results SSQoL

	Mean (SD)
Physical domain	4.2 (0.8)
Language (L)	4.2 (0.9)
Self-care (SC)	4.2 (0.8)
Vision (V)	4.5 (0.7)
Mobility (M)	4.1 (1.0)
Work (W)	3.7 (1.2)
Upper extremity function (UE)	4.4 (0.9)
Psychosocial domain	3.2 (0.8)
Thinking (T)	2.7 (1.0)
Personality (P)	3.3 (0.9)
Mood (MD)	3.6 (0.9)
Family role (FR)	3.7 (1.0)
Social role (SR)	3.0 (1.0)
Energy (E)	2.8 (1.2)
Total score SSQoL ^a	3.7 (0.7)

^aStroke Specific Quality of Life

the SSQoL was not related with gender, premorbid mRS, relationship, living conditions and work situation (data not presented). With increasing age, patients scored significantly lower on the total QoL ($p = 0.00$) and the physical domain ($p = 0.00$). The presence of an anxiety disorder caused a negative influence on the QoL ($p = 0.02$). None of the other medical conditions had an influence on the QoL (data not presented).

Caregiver burden

We included 15 caregivers, the majority of which were male (67%). Only three (20%) primary caregivers reported a high caregiver burden (CSI > 6). The median score of the CSI was 5 (range 0–9). The questions about change in daily activity and plans were positively answered by 11 and 10 caregivers (respectively, 73% and 67%). Only two caregivers reported significant change in their professional life. There was no relation between any of the primary caregiver characteristics and the caregiver experienced by the primary caregiver (data not presented).

Comparison patient and primary caregiver

There was no significant relation between the QoL reported by the patient and the caregiver burden (data not presented). However, it should be noticed that caregivers of patients with the lowest total SSQoL scores experienced a higher caregiver burden. There was no association between the caregiver burden and personal demographics (such as age, gender, mRS and GOS) of the patient with aSAH (data not presented). However, there was a significant association

between the caregiver burden and mFisher score ($p=0.005$). The higher the mFisher, the higher the reported score on the CSI.

Discussion

Our study shows that patients with aSAH, experience a significant impact on the QoL, especially in the psychosocial domain. It seems that patients mainly experience deficits with regard to cognition and fatigue. Therefore, it is important for practitioners to pay attention to these determinants of the patient's QoL. Primary caregivers also experience a significant impact on their daily life, regardless of the functional outcome of the patient.

Our results confirm the results of other studies on QoL in aSAH. Visser-Meily et al. reported a SSQoL total score of 4.0 (± 0.7). Their study population also reported lower scores on the psychosocial domain scored compared to the physical domain [13]. The reason for this tendency is not well understood, but a possible explanation could be the anterior location of the aneurysm or diffuse global brain tissue damage, although the literature is not unequivocal [14]. We chose to use the SSQoL because this questionnaire is specially designed for stroke and validated for use in aSAH patients. Some other studies have used the SF-36. Both questionnaires can be used but some differences have been noted. It was concluded that SSQoL generally had higher mean scores and higher internal consistency. Use of disease specific SSQoL scale is priorly recommended for the evaluation of the QoL of acute stroke patients [15].

The QoL of primary caregivers is very poorly documented. This is one of the first studies which assesses the QoL of the primary caregivers of patients with aSAH. We only found one comparable study, Mezue et al., who found that 53.8% of caregivers experiencing social or emotional stress [16].

Our study has several limitations. We only included patients between January 2020 and November 2020, which is a narrow time period. Furthermore, patients were assessed at one single moment, therefore data on long-term follow-up are missing and we cannot make assumptions about possible effects of interventions, nor of the effect of rehabilitation. It is plausible that patients, who are still in (the beginning of their) rehabilitation at the time of inclusion, score lower on QoL.

Due to the presence of specific neurological or residual cognitive symptoms, questionnaires may not have been completed correctly. There may also be a reduction in patients' motivation to participate due to the confrontation with the consequences of the aSAH, or due to any underlying conditions such as depression. To correct for this, we assessed concomitant neuropsychological problems,

including depression. Since the questionnaires were sent by post, there is a potential report bias that the questionnaires of the patients and caregivers were not completely independent of each other.

We excluded all patients with premorbid mRS score ≥ 3 ; however, this premorbid mRS only provides information about the patients' functioning in the period before the aSAH. The coexistence of other relevant comorbidities, which could also have a negative effect on the QoL, was not excluded. However, we tried to limit this bias by only including patients with no restrictions in their daily activities before the aSAH.

Last, this study took place during the COVID-19 pandemic. This may have had a negative impact on our results, especially the psychosocial score of the SSQoL questionnaire and the caregiver burden, as this was a difficult period for many people due to the many restrictions [17, 18].

Further research is warranted. A longitudinal study, with a larger study population, and with multiple time points, over a longer period of time, might give more insights in the long-term QoL after aSAH and the caregiver, and could better estimate in which domains patients and the caregivers need extra support during follow-up and could optimize individual rehabilitation.

Conclusion

aSAH has a significant impact on the biopsychosocial aspect of the patient's life, especially on the psychosocial domain. Additionally, a significant part of primary caregivers report a high burden of care in daily life. Addressing psychosocial and emotional needs of patients and caregivers during follow-up is important to reduce disease and caregiver burden after aSAH.

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Declarations

Conflict of interest The authors declare that there is no conflict of interest regarding the publication of this article.

Ethical approval This study was reviewed and approved by Regional ethics committee [reference: Medical Ethics Committee of the Antwerp University Hospital (B300201941924)].

Informed consent All participants provided written informed consent to participate in this study.

Consent for publication Written informed consent was obtained.

References

1. von Vogelsang AC, Forsberg C, Svensson M, Wengstrom Y (2015) Patients experience high levels of anxiety 2 years following aneurysmal subarachnoid hemorrhage. *World Neurosurg* 83(6):1090–1097
2. Meyer B, Ringel F, Winter Y, Spottke A, Gharevi N, Dams J et al (2010) Health-related quality of life in patients with subarachnoid haemorrhage. *Cerebrovasc Dis* 30(4):423–431
3. de Rooij NK, Linn FH, van der Plas JA, Algra A, Rinkel GJ (2007) Incidence of subarachnoid haemorrhage: a systematic review with emphasis on region, age, gender and time trends. *J Neurol Neurosurg Psychiatry* 78(12):1365–1372
4. Steiner T, Juvela S, Unterberg A, Jung C, Forsting M, Rinkel G et al (2013) European Stroke Organization guidelines for the management of intracranial aneurysms and subarachnoid haemorrhage. *Cerebrovasc Dis* 35(2):93–112
5. Rinkel GJE, Algra A (2011) Long-term outcomes of patients with aneurysmal subarachnoid haemorrhage. *Lancet Neurol* 10:349–356
6. Carter BS, Buckley D, Ferraro R, Rordorf G, Ogilvy CS (2000) Factors associated with reintegration to normal living after subarachnoid hemorrhage. *Neurosurgery* 46(6):1326–1333
7. Hop JW, Rinkel GJ, Algra A, van Gijn J (2001) Changes in functional outcome and quality of life in patients and caregivers after aneurysmal subarachnoid hemorrhage. *J Neurosurg* 95(6):957–963
8. Nys GM, van Zandvoort MJ (2002) Stroke-Specific Quality of Life scale [Available from: maatinstumentenzorg.nl.]
9. Robinson BC (1983) Validation of a caregiver strain index. *J Gerontol* 38(3):344–348
10. Boosman H, Passier PE, Visser-Meily JM, Rinkel GJ, Post MW (2010) Validation of the Stroke Specific Quality of Life scale in patients with aneurysmal subarachnoid haemorrhage. *J Neurol Neurosurg Psychiatry* 81(5):485–489
11. Williams LS, Weinberger M, Harris LE, Clark DO, Biller J (1999) Development of a stroke-specific quality of life scale. *Stroke* 30(7):1362–1369
12. Schure LM (1985) Caregiver Strain Index [Available from: maatinstumentenzorg.nl.]
13. Visser-Meily JM, Rhebergen ML, Rinkel GJ, van Zandvoort MJ, Post MW (2009) Longterm health-related quality of life after aneurysmal subarachnoid hemorrhage: relationship with psychological symptoms and personality characteristics. *Stroke* 40(4):1526–1529
14. Al-Khindi T, Loch Macdonald R, Schweizer T (2010) Cognitive and functional outcome after aneurysmal subarachnoid hemorrhage. *Stroke* 41(8):e519–e536.
15. Oren B, Zengin N, Dagci S (2020) Quality of life in patients with acute stroke: comparison between the short form 36 and the stroke-specific quality of life scale. *Authorea*. <https://doi.org/10.4274/tnd.2020.12316>
16. Mezue W, Mathew B, Draper P, Watson R (2003) The impact of care on carers of patients treated for aneurysmal subarachnoid haemorrhage. *Br J Neurosurg* 18(2):135–137. <https://doi.org/10.1080/02688690410001680984>
17. Sciensano. Zevende COVID-19-Gezondheidsenquête. Eerste resultaten. Brussels, Belgium; Depot number: D/2021/14.440/51. [Available from: <https://doi.org/10.25608/4e6z-qa15>]
18. Peeters B, Doggen K, Demarest S et al (2021) Power to care. De enquête naar het welzijn van zorgverleners, hulpverleners en mantelzorgers. Belangrijkste resultaten van de tweede nationale enquête, maart 2021. Sciensano. Brussels, Belgium.

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