

Functional outcome and quality of life 5 and 12.5 years after aneurysmal subarachnoid haemorrhage

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Abstract Patients who recover from aneurysmal subarachnoid haemorrhage (SAH) often remain disabled or have persisting symptoms with a reduced quality of life (QoL). We assessed functional outcome and QoL 5 and 12.5 years after SAH. In a consecutive series of 64 patients with mean age at SAH of 51 years, initial outcome assessments had been performed at 4 and 18 months after SAH. At the initial and current outcome assessments, functional outcome was measured with the modified Rankin Scale (mRS) and QoL with the SF-36 and a visual analogue scale (VAS). We studied the change in outcome measurements over time. We used the non-parametric Wilcoxon test to compare differences in mRS grades and calculated differences with corresponding 95% confidence intervals in the domain scores of the SF-36 and the VAS.

After 5 years, seven patients had died and five patients had missing data. Compared with the 4-month follow-up, the mRS had improved in 29 of the 52 patients, remained similar in 19 patients. The overall QoL (SF-36 domains and VAS score) was better. At 12.5 years an additional six patients had died. Compared to the 4-month study, 25 of the 46 remaining patients had improved mRS, 12 had remained the same and in nine patients the mRS had worsened. Between the 5 and the 12.5 years follow-up, the improvement in mRS had decreased but patients reported overall a better QoL. Among long-time survivors, QoL may improve more than a decade after SAH.

Keywords Cerebral aneurysm · Subarachnoid haemorrhage · Quality of life

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Introduction

Subarachnoid haemorrhage (SAH) from a ruptured aneurysm carries a poor prognosis. Within the first month after the haemorrhage, one-third of the patients die [1]. Of those who survive the initial weeks, one-third are disabled in the first month after the haemorrhage [1, 2], but recovery continues after this period. In a cohort study 4 and 18 months after the haemorrhage, half the patients had improved on the modified Rankin Scale (mRS) with at least one point [2, 3]. Of the patients who were independent (mRS <4) at 18 months after the haemorrhage, many experienced a reduced quality of life (QoL). Because most patients are between 40 and 60 years old at the time of the haemorrhage, functional disability and QoL may further improve. If disability and QoL remain reduced in the long term, this can have considerable impact for patients and for health economics. We assessed the extent of changes in

functional outcome and QoL after 5 and 12.5 years in a prospectively collected cohort of patients with aneurysmal SAH.

Methods

We studied a prospectively collected, consecutive series of 98 patients with aneurysmal SAH admitted to the University Medical Centre Utrecht between September 1995 and September 1996. Aneurysmal SAH was diagnosed if CT scanning confirmed the presence of subarachnoid blood and if an aneurysm was found on conventional-, CT- or MR-angiography. Patients with a non-aneurysmal cause of the SAH were excluded. Thirty of the 98 enrolled patients had died during their clinical course, two had been excluded from the previous study because they did not speak Dutch and two patients had declined participation in the study. Thus, our study consisted of 64 patients. Between 4 and 18 months three patients had died [3], but their deaths were not directly related to the SAH.

For the 5- and 12.5-year outcome assessments, we first contacted the general practitioner of the patient to find out if the patient was still living. If not, we asked for the date and cause of death. If the address of the patient was unknown to the general practitioner, we verified it via the municipal archives. Patients who had no telephone were sent a letter and asked to call us. We asked the patient by telephone to answer the same questionnaire as the one we used at the 4- and 18-month follow-ups.

Instruments

For assessment of disability, we applied the mRS [4], a frequently used functional outcome instrument in stroke. The mRS is a 6-point handicap scale that focuses on restrictions in lifestyle. The Rankin scale is easy to administer, available in a validated Dutch version and reliable in terms of interobserver agreement [4]. This Dutch version is also validated for telephone assessment [5]. For assessment of QoL we used the medical outcome study short form 36 (SF-36), a validated instrument to assess general QoL and a visual analogue scale (VAS). The SF-36 is brief (5–10 min) and measures eight health-related domains: physical functioning (10 items), role limitations due to physical health problems (4 items), bodily pain (2 items), general health perceptions (5 items), vitality (4 items), social functioning (2 items), role limitations due to emotional problems (3 items) and general mental health (5 items). The SF-36 scores are calculated by assignment of predefined weights to the different items and range per domain from 0 (maximum reduction in QoL) to 100 (no reduction in QoL). The validity and reliability of the SF-36

have been studied extensively, including the Dutch version [6–9]. The VAS ranged from 0 (poor) to 100 (excellent) just by asking the patient to put a mark on this scale for overall well-being.

Data collection

All questionnaires were administered in a semi-structured telephone interview by one experienced research nurse (PG). We started the interview with a short introduction and reminder of the 4- and 18-month QoL studies. If the patient was not able to answer the questions because of severe cognitive deficits, we only recorded the Rankin grade of the patient based on information obtained from the partner.

Data analyses

To compare differences in Rankin grades and QoL scores between 4 months and 5 years, 4 months and 12.5 years, and 5 years and 12.5 years we used the non-parametric Wilcoxon test. We calculated differences in the domain scores of the SF-36 and of the VAS; the corresponding 95% confidence intervals (95% CI) were based on the paired *t* test.

Results

Of the 64 patients with a 4-month follow-up, 45 (70%) were women. The mean age at that time was 51 (\pm SD 12.6) years. Fifty-six patients (88%) were in good clinical condition on admission, as assessed with the World Federation of Neurological Surgeons (WFNS) [10] scale (WFNS I *n* = 35; WFNS II *n* = 16; WFNS III *n* = 5), and eight were in poor clinical condition (WFNS IV *n* = 4; WFNS V *n* = 4). At time of the 18-month follow-up the study population consisted of 61 patients.

For the 5-year outcome assessment, the mean period of follow-up was 5.5 years after the SAH (range 5.3–5.7 years). Four patients (3 women, 1 man) had died between the 18-month and 5-year outcome assessment. In one patient, the general practitioner said that the cause of death was an unverified SAH that had occurred abroad, and in three it was cancer. We could no longer contact another four patients, as no telephone number was available and the patients did not respond to our letter. Another patient was found, contacted by telephone, but was too deaf to be interviewed. The remaining 52 patients could be contacted and all participated in the 5-year outcome assessment.

For the 12.5-year follow-up, the mean follow-up was 13.3 years after SAH (range 12.8–13.5 years). An additional six patients had died between the 5- and 12.5-year

outcome assessments. Four of the five patients who were not interviewed at the 5-year outcome assessment were again not interviewed but were still living. One patient declined further participation. The remaining 46 patients, 34 women and 12 men, could be contacted by telephone for the 12.5-year outcome assessment.

Functional outcome

Figure 1a provides an overview of the mRS grade distribution among patients who were living, deceased or with missing data at the four outcome assessments. Figure 1b shows the mRS grade distribution among patients who were living and the patients who had died at each outcome assessment and Fig. 1c shows the mRS grade distribution at each outcome assessment for only those patients who were living. The changes in mRS grades between 4 months and 5 years, 4 months and 12.5 years, and 5 and 12.5 years are shown in Tables 1, 2 and 3. In the 4-month and 5-year follow-up, 19 patients remained the same and 29 patients

improved. In 18 of these 29 patients the mRS had improved one point, in 10 it had improved two points, and in one patient it had improved three points. In 12 patients the mRS grade remained the same at the 4-month and the 12.5-year follow-ups. In 25 patients the mRS grade improved, 16 by one point, seven by two points, and two patients by three points. Between the 5- and the 12.5-year follow-up the improvement declined with one patient reporting a heart operation, one a myocardial infarction and another patient a colon cancer. In 30 patients the mRS grade remained the same at 5- and 12.5-year follow-up.

Quality of life in patients

Table 4 shows the differences for the domains of the SF-36 and the VAS score between 4 months and 5 years, 4 months and 12.5 years, and 5 years and 12.5 years. For the SF-36 domains, role limitations because of physical health problems and role limitations because of emotional problems, the scores are clearly higher (improvement) after

Fig. 1 a Proportion of surviving patients with distribution of mRS grades, deceased and missing patients. **b** Proportion of surviving patients with distribution of mRS grades, deceased patients. **c** Proportion of surviving patients with distribution of mRS grades

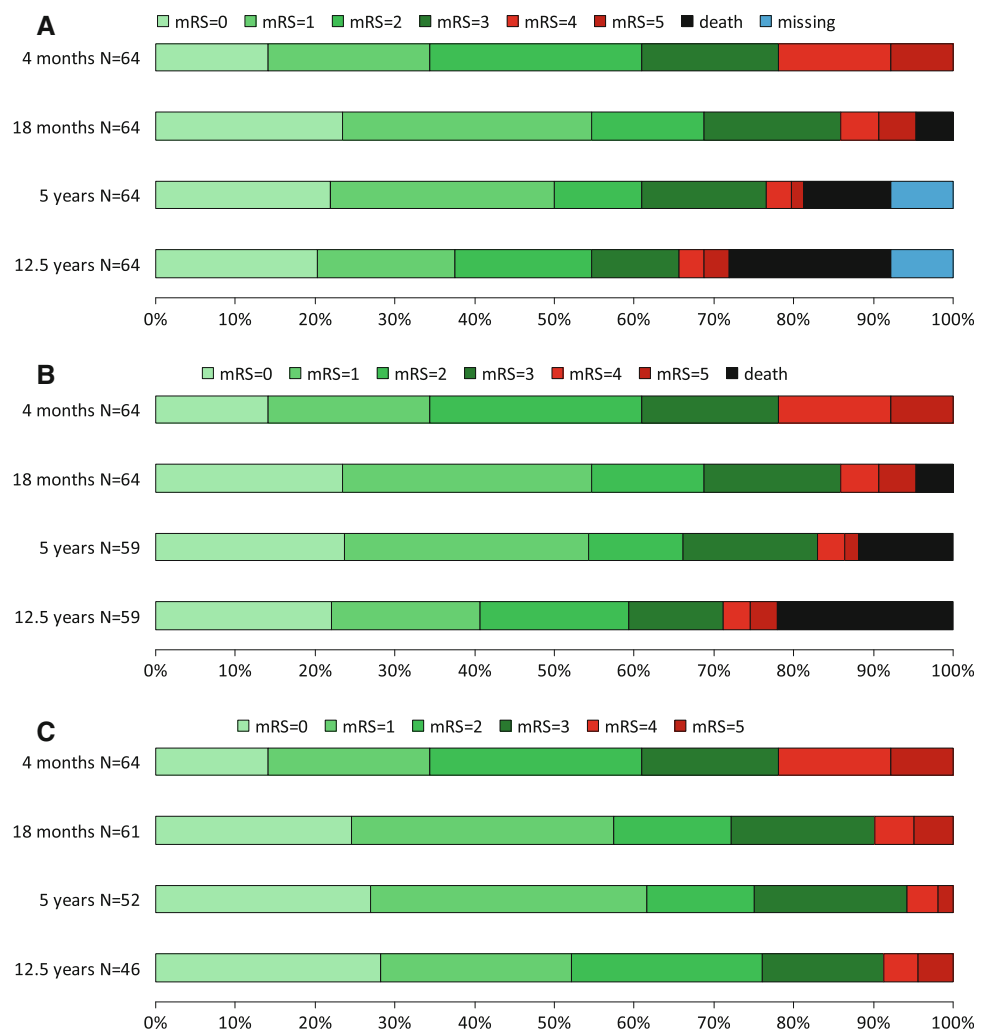


Table 1 Modified Rankin grades at 4-month and 5-year follow-ups

	5 years								Total
	0	1	2	3	4	5	Dead	Missing	
4 months									
0	7	2	–	–	–	–	–	–	9
1	3	5	1	2	–	–	1	1	13
2	3	6	3	–	–	–	4	1	17
3	1	5	2	2	–	–	–	1	11
4	–	–	1	5	1	–	–	2	9
5	–	–	–	1	1	1	2	–	5
Total	14	18	7	10	2	1	7	5	64

Table 2 Modified Rankin grades at 4-month and 12.5-year follow-ups

	12.5 years								Total
	0	1	2	3	4	5	Dead	Missing	
4 months									
0	4	2	–	–	–	–	2	1	9
1	4	2	3	1	–	–	2	1	13
2	4	4	3	2	–	–	4	–	17
3	1	2	5	1	–	–	1	1	11
4	–	1	–	2	1	1	2	2	9
5	–	–	–	1	1	1	2	–	5
Total	13	11	11	7	2	2	13	5	64

5 years than at 4 months and further increased after a 12.5-year follow-up. The physical functioning and general mental health scores had worsened. Figure 2 shows the VAS scores after 4-, 18-month, 5- and 12.5-year follow-ups. Also, surviving long-term follow-up patients reported improvement in their wellbeing compared with their score at 4 months. At the 5-year follow-up, most patients reported their functional, social and physical problems as SAH-related: persistent tiredness, slowness, impairment of memory, change in personality, headache and concentration problems.

Discussion

This study shows that recovery among patients who have survived an episode of SAH continues in the long-term. Between 4 months and 5 years after the haemorrhage, half the surviving patients showed an improvement on the mRS of at least one point. Between 5- and 12.5-year follow-ups there was no further improvement with even a slight decrease in functional outcome. At the 12.5-year follow-up, patients reported the functional status to be “normal for my age”, despite a decline in physical

functioning. They attributed this reduced physical functioning to other diseases they had, such as osteoporosis, emphysema, cancer, diabetes, heart failure, and impairment of vision and hearing. Despite a reduction in physical functioning between the 5- and 12.5-year outcome assessments, QoL had improved over this period. This suggests that patients continue to adapt and improve while coping with restrictions in functioning. Psychological adaptation has been described also in other chronic diseases [11]. The overall good QoL indicates an improved appreciation of life long after a life-threatening illness. Similar observations have been done in long-term survivors of TIA or minor ischemic stroke who have an overall QoL not much different than the general population [12].

Some limitations of the current study have to be mentioned. To assess disability in terms of functional outcome and QoL, we used the mRS, the SF-36 and a VAS. These outcome measurements had also been used before at the 4- and 18-month follow-ups, before the current study was developed. The sickness impact profile (SIP) was also used in the initial outcome assessments, and had similar outcomes at the 4- and 18-month time points but did not discriminate between patients with improved or static

Table 3 Modified Rankin grades at 5- and 12.5-year follow-ups

	12.5 years								Total
	0	1	2	3	4	5	Dead	Missing	
5 years									
0	9	1	–	1	–	–	2	1	14
1	4	9	4	1	–	–	–	–	18
2	–	1	6	–	–	–	–	–	7
3	–	–	1	4	1	–	4	–	10
4	–	–	–	–	1	1	–	–	2
5	–	–	–	–	–	1	–	–	1
Dead	–	–	–	–	–	–	7	–	7
Missing	–	–	–	1	–	–	–	4	5
Total	13	11	11	7	2	2	13	5	64

Wilcoxon tests for comparisons of mRS: 4 months–5 years, $p = 0.12$; 4 months–12.5 years, $p = 0.58$; 5–12.5 years, $p = 0.01$

m Rankin scale: 0, no symptoms at all; 1, no significant disability despite symptoms; 2, slight disability; 3, moderate disability; 4, moderately severe disability; 5, severe disability

Table 4 Differences over time in SF-36 and VAS

	Means				Differences (95%CI)	
	4 months	5 years	12.5 years	4 months–5 years ^a	4 months–12.5 years ^b	5–12.5 years ^b
SF-36						
PF	68.7	74.7	77.2	6.5 (0.6 to 12.4)	5.9 (–0.3 to 11.4)	–1.7 (–8.0 to 4.6)
RP	24.6	62.5	91.3	34.8 (18.9 to 50.6)	64.0 (50.9 to 77.1)	25.0 (7.9 to 42.1)
BP	75.1	85.9	92.2	7.6 (1.2 to 13.9)	14.4 (6.3 to 22.6)	6.0 (–1.7 to 13.6)
GH	70.7	73.4	71.9	0.5 (–6.4 to 7.4)	–1.2 (–8.2 to 5.8)	–4.1 (–9.4 to 1.1)
VT	60.1	59.8	65.3	–2.2 (–7.9 to 3.5)	3.4 (–2.5 to 9.4)	3.9 (–0.5 to 8.3)
SF	66.3	80.7	90.4	12.0 (2.9 to 21.0)	22.6 (13.1 to 32.0)	6.4 (–3.0 to 15.8)
RE	59.5	81.3	96.9	18.8 (3.3 to 34.4)	39.0 (25.9 to 52.1)	13.8 (1.4 to 26.3)
MH	70.1	70.4	73.8	0.4 (–5.0 to 5.9)	4.5 (–1.3 to 10.3)	2.8 (–1.2 to 6.8)
PCS	42.8	48.6	51.1	4.7 (2.1 to 7.4)	6.7 (3.8 to 9.6)	1.5 (–1.2 to 4.2)
MCS	47.2	49.4	52.7	1.5 (–1.8 to 4.9)	5.9 (2.7 to 9.1)	2.8 (0.2 to 5.8)
VAS	59	72	76	11 (5 to 17)	16 (9 to 23)	3 (–6 to 7)

PF physical functioning, RP role limitations because of physical health problems, BP bodily pain, GH general health perceptions, VT vitality, SF social functioning, RE role limitations because of emotional problems, MH general mental health, PCS physical summary scale, MCS mental summary scale

^a 46 pairs; ^b41 pairs

Rankin grades [3]. The SIP contains 136 items and is very time-consuming. For both of these reasons we decided not to continue using the SIP for the 5-year and the 12.5-year follow-ups. A disease specific QoL list was not used in 1995. Therefore, we cannot distinguish between disability remaining from the SAH and disability as a result of other, age-related diseases. Another limitation is that the initial cohort of 64 patients is relatively small and all interviews were administered by telephone. However, we

demonstrated that telephone assessment of the mRS with a structured interview has as good results as face-to-face assessment [5]. Strong points are that, at the 12.5-year time point, there was no loss to follow-up and all interviews were performed by the same research nurse. As far as we know, this is the first attempt to assess changes in functional outcome and QoL for longer than a decade in patients with SAH. Therefore, we could not compare our results with those from other studies. We conclude that it is

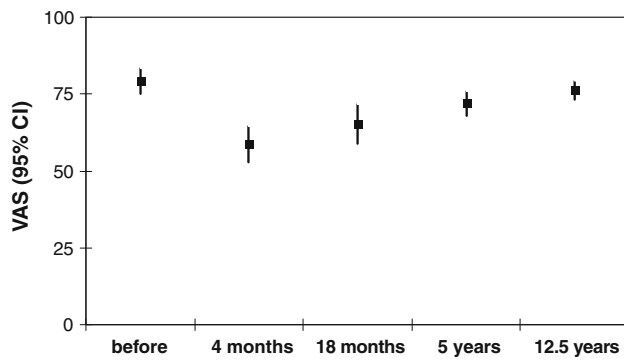


Fig. 2 VAS score according to time

important for patient care to inform patients and their partners that QoL may improve more than a decade after SAH. In further studies the relationship between functional outcome and QoL should be assessed by long-term follow-up studies, as well as determinants of good outcome long after the SAH.

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