Changes in functional outcome and quality of life in patients and caregivers after aneurysmal subarachnoid hemorrhage

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Object. Although the case-fatality rate after subarachnoid hemorrhage (SAH) does not change considerably after the first 4 weeks, functional outcome and the quality of life (QOL) may. To assess the extent of changes in functional outcome and QOL after SAH, the authors conducted a follow-up study at 18 months in patients and caregivers who had participated in a previous study of QOL 4 months after SAH.

Methods. In a consecutive series of 98 patients admitted with SAH, 68 had survived until 4 months postbleed, at which time an initial outcome assessment had been performed in 64 of them. This series of 64 patients was contacted again at a median of 18 months after SAH. In all patients, functional outcome was assessed by means of the modified Rankin Scale (mRS). In 48 patients and 35 caregivers QOL was assessed using the SF-36, the Sickness Impact Profile (SIP), and a visual analog scale. The results were compared with the scores that had been obtained at 4 months after SAH.

Thirty-two patients (50%) had improved at least one point on the mRS, in 23 patients functional outcome had remained unchanged, six patients had deteriorated one point on the mRS, and three had died. No major changes in the QOL of patients and caregivers could be found on the SIP, but on the SF-36 an improved QOL was detected in patients with better Rankin grades. On both instruments, the QOL at 18 months was still reduced compared with the reference population in all patients.

Conclusions. Functional outcome improves significantly between 4 months and 18 months post-SAH; studies on functional outcome after SAH can be compared only if outcome is assessed at the same time interval. The improved functional outcome seems to be accompanied by an improved QOL.

KEY WORDS • subarachnoid hemorrhage • outcome • quality of life

THE most frequently used outcome assessments for patients with SAH are case fatality rates and functional outcome in terms of handicap. A few studies have added QOL assessments to the spectrum of outcome measurements by means of semistructured interviews or validated instruments. The timing of outcome assessment varies considerably between studies, ranging from 2 weeks to more than 1 year posthemorrhage. Survival curves for patients with SAH show a steep decline in the first 2 weeks after the hemorrhage, a less steep slope in the 3rd and 4th week, and a more or less horizontal course after the initial month. In contrast, functional outcome and the QOL may change substantially between 1 month and 1 year after the hemorrhage. If this is so, the timing of outcome assessment might considerably influence the results of a clinical study and its comparability with other studies. To determine the changes over time, we compared assessments of functional outcome and QOL in patients and their caregivers at 4 months and 18 months posthemorrhage. Additionally, we compared the QOL assessments after SAH with data from a reference population, and we studied the relationship between functional outcome and QOL.

Clinical Material and Methods

Patients and Caregivers

We studied a prospectively collected, consecutive series of 64 patients with aneurysmal SAH who were admitted to Utrecht University Hospital between September 1995 and September 1996, and who had participated in a previous assessment of functional outcome and QOL 4 months after SAH. These 64 participants had been selected from a total of 98 patients with aneurysmal SAH who were admitted during this time interval, of whom 30 had died during their clinical course, two had been excluded from the previous...
TABLE 1

Distribution of mRS grades at 4 months and 18 months of follow up*

<table>
<thead>
<tr>
<th>mRS Grade at 4 Mos (no. of patients)</th>
<th>Total W/mRS Grade at 18 Mos</th>
</tr>
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<tbody>
<tr>
<td>Factor 0 1 2 3 4 5 at 18 Mos</td>
<td>Factor 0 1 2 3 4 5 at 18 Mos</td>
</tr>
<tr>
<td>mRS grade at 18 mos</td>
<td></td>
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<tr>
<td>0 6 5 4 0 0 15</td>
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<tr>
<td>1 3 7 7 3 0 20</td>
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<td>2 0 1 3 4 1 9</td>
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<td>3 0 0 1 3 6 1 11</td>
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<td>4 0 0 0 0 2 1 3</td>
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<td>5 0 0 0 0 1 2 3</td>
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<tr>
<td>6 0 0 1 0 0 2 3</td>
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<tr>
<td>total w/mRS grade at 4 mos</td>
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<tr>
<td>9 13 16 10 10 6 64</td>
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</table>

* Description of mRS grades: 0 = no symptoms; 1 = minor symptoms that do not interfere with lifestyle; 2 = minor handicap—symptoms that lead to some restriction in lifestyle but do not interfere with capacity for self; 3 = moderate handicap—symptoms that significantly restrict lifestyle and prevent totally independent existence; 4 = moderately severe handicap—symptoms that clearly prevent independent existence though not needing constant attention; 5 = severe handicap—totally dependent and requiring constant attention; 6 = dead.

The diagnosis of SAH was based on the presence of extravasated blood in the basal cisterns on CT scans, or if CT scans were negative, xanthochromia of the cerebrospinal fluid was considered to be diagnostic. In all patients included in the study, the aneurysm had been demonstrated by spiral CT angiography, catheter angiography, or both.

For the second outcome assessment, at least 1 year post-SAH, we first contacted the family doctors of all 64 patients to check whether the patients were still alive. If they were, a letter was sent inviting the patient and his or her caregiver to participate in this follow-up study. The patient’s closest significant other (a spouse, life companion, or close family member who had daily contact with the patient) was considered to be the caregiver for the purpose of this study. Patients or caregivers who did not respond to the invitation were contacted by telephone and asked about the reason for nonparticipation. If physical or emotional problems made it difficult to visit the hospital, we interviewed patients and caregivers at home. If they were not willing to participate, only a Rankin grade for the patient was obtained by telephone. This study was approved by our institutional review board.

**Instruments Used for Assessment**

The mRS. We chose our instruments on the basis of psychometric qualities (validity, reliability) and practical aspects (length, difficulty). To assess functional outcome we used the mRS. The mRS is a 6-point handicap scale that focuses on restrictions in lifestyle (Table 1). The mRS is frequently used in stroke outcome research, is easy to administer, is available in a validated Dutch version, and is reliable in terms of interobserver agreement.

The SIP. We assessed the QOL by means of the SIP, the SF-36, and a VAS. The SIP contains 136 items about sickness-related dysfunction in 12 domains of daily life: ambulation, mobility, and body care and movement (which can be aggregated into a physical subscore), social interaction, alertness behavior, emotional behavior, and communication (which can be aggregated into a psychosocial subscore), sleep and rest, eating, work, recreation and pastimes, and home management (which are independent categories). The SIP has been validated both in English and Dutch and is frequently used in stroke outcome research. The scores range from 0 (no reduction in QOL) to 100 (maximum reduction in QOL), and are calculated by assignment of predefined weights to the different items. Scores can be calculated for the instrument as a whole, for each category, and for the physical and psychosocial subdimensions. This test is easy to administer because the questions are in a yes/no format, but it is also time consuming (20–30 minutes).

The SF-36. The SF-36 is brief (5–10 minutes), and can be self-administered. The SF-36 measures eight health-related domains: physical functioning (10 items), role limitations because of physical health problems (four items), bodily pain (two items), social functioning (two items), general mental health (psychological distress and psychological wellbeing; five items), role limitations because of emotional problems (three items), vitality (four items), and general health perceptions (five items). The SF-36 scores are calculated by assignment of predefined weights to the different items and range per domain from 0 (no reduction in QOL) to 100 (maximum reduction in QOL). The validity and reliability of the SF-36 scores have been studied in several populations, including stroke patients. The psychometric qualities of the Dutch version have been tested in a random population sample.

The VAS. The VAS ranged from 0 (poor) to 100 (excellent), and included the following questions: “how did you do before the hemorrhage?” (for caregivers: “how did you do before your partner’s hemorrhage?”) and “how are you now?” Patients and caregivers were asked to respond by putting a mark on the scale, taking into account their overall physical, psychological, and social wellbeing. The difference between the two marks was then calculated. The VAS has been validated among stroke patients.

**Data Collection**

All questionnaires were administered in a face-to-face interview setting by a trained research nurse or by the observer (J.W.H.) who had interviewed all patients and caregivers at the 4-month follow up. For the mRS assessment, the interobserver agreement is good. To ensure a uniform style in interviewing, both observers saw the first three patients and caregivers together. All instruments were applied to the patients; in the caregivers only the SF-36, the SIP, and the VAS were assessed. Patients and caregivers were not separated during the interview, but we requested that they answer the questions individually. We started the interview with a general introduction, including some questions regarding comorbidity, occupation, and changes in social status. The observer then applied the SF-36, the SIP, and the VAS, followed by assessment of the patient’s Rankin grade. Both patients and caregivers were invited to add items or remarks on what had influenced their QOL. If the patient was unable to understand or answer the question-
naire because of severe cognitive deficits, we recorded only the patient’s Rankin grade and the caregiver’s QOL.

Data Analyses

Because data on functional outcome and QOL are ordinal, we used nonparametric statistics for paired data (Wilcoxon matched-pairs signed-rank test) to compare differences between 4-month and 18-month mRS grades and QOL scores. For this purpose only patients and caregivers of whom complete data were available for the two assessments were included in the analyses.

To compare the results of the SF-36 and the SIP at 4 months and 18 months with data from a reference population,21,36 we calculated standard scores by dividing the differences between the scores of the study group and the reference population by the SD of the reference population. These standard scores indicate the number of SDs by which the SF-36 and SIP scores of the study group differ from the reference population. Presented as line graphs, the standard scores allow comparisons between the study group and the reference population across the entire profile of the SF-36 and the SIP tests.16

To assess whether differences in functional outcome were reflected by differences in QOL scores, we performed a between-groups analysis (by means of the Mann–Whitney U-test) in patients with improved Rankin grades and those whose Rankin grades had remained unchanged. Because there were only a few patients with worsened Rankin grades, we did not include this subgroup in the comparison. For this comparison we used SPSS version 6.1; a probability value less than 0.05 was considered statistically significant.

Results

Functional Outcome

The study population consisted of 45 women (mean age at SAH 51.9 years) and 19 men (mean age at SAH 51 years). The mean and median time of follow up was 18 months after SAH (SD 2 months, range 13–21 months). Of the 64 patients who had survived until the first outcome assessment, three were dead by the time of the second assessment. Two patients with Rankin Grade 5 died of pneumonia in a nursing home, and one patient with Rankin Grade 2 died unexpectedly of cardiac arrest. In the remaining 61 patients, functional outcome was assessed either in a personal interview (50 patients) or by telephone (11 patients). The differences in functional outcome at the 18-month compared with the 4-month follow up are shown in Table 1.

Thirty-two patients (50%) had improved compared with their Rankin grade at 4 months; of these patients nine had improved 2 points. Eight of 16 patients who had been fully dependent on others (Rankin Grade 4 or 5) were now independent.

In addition to the three patients who had died, another six patients had deteriorated by one point on the mRS in the interval between the outcome assessments. Three of them had developed minor symptoms (Rankin Grade 1) despite an apparently full recovery (Rankin Grade 0) at 4 months. The Rankin grades of the remaining 23 patients had remained unchanged. The differences in Rankin grades between the first and the second outcome assessment were significant (p = 0.007).

The QOL for Patients

The QOL was assessed in 49 of the 61 patients who had survived. Seven patients refused to participate: one because of time constraints (Rankin Grade 0), three because of emotional distress (one with Rankin Grade 1, two with Grade 2), and three did not give a specific reason (two with Rankin Grade 1, one with Grade 2). Five patients were not able to answer the QOL questionnaires because of cognitive deficits (three with Rankin Grade 5, one with Grade 4, and one with Grade 3). The QOL data of one patient were excluded from the comparison between the assessments at 4 and 18 months of follow up, because severe cognitive deficits had precluded QOL assessment at 4 months.

Figure 1 upper shows the mean standard scores of the total population of patients on the SF-36 at 4 and 18 months of follow up. At 18 months, patients scored relatively better on almost all domains of the SF-36, with significant improvements in the domains “physical functioning” (p < 0.05), and “physical role limitations” (p < 0.01). Compared with the reference population (reference line at 0), the QOL was reduced for all domains; with significant reductions at 4 months for the domains physical functioning (p < 0.01), social functioning (p < 0.001), physical role limitations (p < 0.001), emotional role limitations (p < 0.001), mental health (p < 0.01), and vitality (p < 0.01); and at 18 months the reductions were still significant for the domains social functioning (p < 0.05), physical role limitations (p < 0.001), and emotional role limitations (p < 0.01).

Figure 1 lower shows the absolute differences in SF-36 scores at 18 months compared with 4 months, separately for the group of patients with an unchanged Rankin grade (18 patients) and the group of patients who had improved on the mRS (25 patients). The reference line (at 0) indicates no differences in the QOL between 4 months and 18 months. Patients who had improved on the mRS showed improvements in QOL on most domains of the SF-36, whereas the QOL in patients with unchanged Rankin grades was slightly reduced, with minor improvement for physical role limitations only. The differences in QOL scores between both groups were statistically significant for the domains physical functioning (p < 0.05), physical role limitations (p < 0.001), emotional role limitations (p < 0.05), mental health (p < 0.05), and vitality (p < 0.05).

Figure 2 upper shows the mean standard scores of the patients according to the SIP at 4 and 18 months of follow up. For most domains, the SIP scores at 18 months of follow up deviated more from the reference population than at 4 months, indicating a reduction in the QOL. Significant differences were found for the subdomains household management (p < 0.01), recreation and pastimes (p < 0.05), and eating (p < 0.01). The complete profile of the SIP is below the reference line, indicating a reduction in QOL compared with the reference population on all domains; this reduction was significant for all domains (p < 0.05) for communication at 18 months and bodycare and movement at 4 months; all other p values < 0.001), except eating at 4 months (p = 0.4).
The absolute differences in SIP scores between patients with no change in their Rankin grade and patients with improved grades are shown in Fig. 2.

A significant difference between these groups was found for the subdomain household management only; patients with improved scores showed a reduction in the QOL (p < 0.05).

The mean deterioration in the QOL before and after SAH as assessed by means of the VAS was 19% at 4 months of follow up and 13% at 18 months, indicating an improvement of 6% (p = 0.16). There were no significant differences in VAS scores between groups with or without changes in the Rankin grade.

The QOL for Caregivers

We assessed the QOL in 35 caregivers; 10 were caregivers of patients with Rankin Grade 0; 10 with Grade 1; four with Grade 2; nine with Grade 3; and two with Grade 4. The caregivers of patients who had died were not contacted. Of the five patients with cognitive deficits, only one caregiver participated: two refused for emotional reasons, one could not be traced, and one patient had no "significant other." Five caregivers of other patients did not participate for practical reasons. Thirty-three of the caregivers were spouses, and two were children.

Figure 3 shows the SF-36 and SIP profiles at 4 months and 18 months of follow up, expressed as mean standard scores. The results vary considerably, with significant improvements for the categories social functioning (p < 0.05) and mental health (p < 0.05) on the SF-36, and significant reductions for the categories of pain (p < 0.05) and health perception (p < 0.05) on the SF-36 and body care and movement (p < 0.05), ambulation (p < 0.05), and physical shortcomings.

The charts show the changes in QOL over time for different groups of patients and caregivers, illustrating the impact of SAH on both patient and caregiver wellbeing.
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SIP (p < 0.05) on the SIP. Compared with the reference population, the QOL of the caregivers was significantly reduced at 4 months for the domains emotional behavior (p < 0.001), social interactions (p < 0.01), work (p < 0.001), recreation and pastimes (p < 0.01), psychosocial SIP (p < 0.05), and total SIP (p < 0.05); at 18 months significant reductions were found for the domains sleep and rest (p < 0.05), emotional behavior (p < 0.05), and recreation and pastimes (p < 0.01). The mean reduction in the QOL of the caregivers after the SAH in the patient, which was assessed using the VAS, was 13% at 4-month follow up and 10% at 18 months (p = 0.46). The results did not change appreciably when analyzed according to the condition of the patient (functional outcome improved or not).

Occupational Impact

Of the 17 patients who had a job before their SAH, only one had resumed his previous occupation entirely. One patient worked full time, but was placed in a position with less responsibility, although he felt capable of performing his previous job. Both patients were classified as Rankin Grade 0. Six patients worked 50% of their previous hours (three patients with Rankin Grade 0, three with Rankin Grade 1). Nine patients were considered medically unfit (two with Rankin Grade 1, two with Grade 2, four with Grade 3, and one with Grade 4). The five patients with Rankin Grade 0 at 18 months who had resumed their jobs entirely or in part represented all patients with Rankin Grade 0 at that time who were professionally employed before the SAH. The other 10 patients with Rankin Grade 0 at 18 months were either housewives (eight patients) or they had retired before the hemorrhage (two patients).

Of the 35 caregivers interviewed, 16 had held paid jobs before the patient’s SAH; at 18 months post-SAH six worked shorter hours, one caregiver went bankrupt, and one lost his executive position. All changes were directly related to the patient’s SAH.

Extra Items and Remarks

Three patients had developed epileptic seizures, and all three indicated that their QOL was impaired by these seizures. One spouse obtained a divorce at 6 months postbleed because of the patient’s behavioral difficulties. Two other caregivers reported “severe marital distress” caused by the patients’ personality changes.

Discussion

Half of the patients with SAH improved at least one point on the mRS between 4 months and 18 months. This improvement in functional outcome was paralleled by an improved QOL on almost all domains of the SF-36. The SIP did not show relevant differences between 4 months and 18 months of follow up, or between patients with improved and unchanged Rankin grades. A possible explanation for this difference is related to the inherent responsiveness of a questionnaire. Sensitivity to detection of changes in health status over time is believed to be limited for the SIP.18,24,35 Good responsiveness has been reported for the SF-36,8 although authors of a recent study in stroke patients were concerned about this aspect of the SF-36 because of large SDs.12 Although we also found large SDs in the differences in SF-36 scores, the comparable trends in the mRS and SF-36 indicate that the change in SF-36 scores reflects an actual improvement in the QOL. Another explanation for the different findings in the SF-36 and SIP testing might be related to differences in validity between the instruments. The SIP defines QOL only in behavioral terms, whereas the SF-36 includes questions on feelings of well-being, health perception, and life satisfaction.9

We found no significant differences on the VAS, indicating limited responsiveness of this instrument. The SF-36 and SIP may not be suitable instruments to assess changes in the impact of having a partner with SAH, because their responsiveness is even more limited within a relatively healthy population. Moreover, caregivers of patients with good functional outcome were overrepresented in our sample. Nevertheless, we found that many caregivers of pa-
tients with SAH reported a considerable burden, both on their personal and professional lives. This burden seems to be expressed by a reduced health perception, possibly resulting in physical symptoms, because the scores on physical domains of the SIP were reduced over time.

The proportion of patients who resumed their previous professional status after the hemorrhage is very low. The difference between the large proportion of patients with Rankin Grade 0 after 18 months and the small proportion of patients who resumed their work after 1 year is explained by the fact that two thirds of the patients with Rankin Grade 0 after 1 year were not professionally employed before the hemorrhage. All patients with Rankin Grade 0 and half of the patients with Rankin Grade 1 who had a paid occupation before the hemorrhage resumed their work after 1 year, although not always full time. Apparently, a gap remains between a good mRS score and the ability to resume work in the same way as before the hemorrhage. This is in agreement with our previous study on QOL after SAH, which showed that the scores on the SIP of patients with Rankin Grade 0 did not differ markedly from the scores of a reference population, with the exception of the subcategory “work.”

This is in keeping with results from two other studies, but it contradicts findings from a British study, in which most employed people had returned to work within 3 months post-SAH, initially part time, with most working full time within weeks. In that same study, of the 31% of patients who found their work capacity to be reduced, only 4% attributed this change to the SAH. These results applied only to the proportion of patients without neurological deficits, however, and may be biased by the interpretation of the authors, who estimated the contribution of the illness to the QOL of patients on the basis of semistructured interviews.

A potential limitation in the interpretation of our study results is that, as in most longitudinal studies, part of the initial sample was lost. It is possible that factors that led people to refuse to participate in this follow-up study were related to their state of health. Moreover, both in the initial study and the present follow-up study we excluded patients with cognitive deficits, in whom a reduction in the QOL is likely. The exclusion of this category of patients can be overcome by proxy rating. A recent study among stroke survivors has shown that proxy ratings for noncommunicative patients outweigh their limitations.

From the results of our investigation we infer that studies on functional outcome after SAH cannot be compared unless outcome is assessed at the same time interval after the hemorrhage. Moreover, because the proportion of patients with an independent outcome increases over time, the difference between treatment groups in clinical trials that dichotomize between independent and dependent patients may decrease over time as the latter category diminishes. Knowledge about the changes in functional outcome over time is of great prognostic value for patients with SAH and their caregivers.

Conclusions

Functional outcome in patients with SAH depends on the time of assessment. Between 4 months and 18 months after the hemorrhage, 50% of patients showed an improvement according to the mRS. This improvement in functional outcome seems to be accompanied by an improved QOL. From these findings we infer that differences between treatment groups in clinical trials may decrease over time.

Acknowledgment

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