Quality of Life in Patients and Partners After Aneurysmal Subarachnoid Hemorrhage

Jeannette W. Hop, MD; Gabriel J.E. Rinkel, MD; Ale Algra, MD; Jan van Gijn, MD, FRCPE

Background and Purpose—Outcome after subarachnoid hemorrhage (SAH) is often graded as “poor,” “fair,” or “good.” Such categories are usually based on physicians’ assessments of physical abilities of patients rather than on how patients themselves perceive their physical, psychological, and social well-being. We assessed functional outcome and quality of life (QoL) in patients with SAH and their partners.

Methods—In a consecutive series of 64 patients and 51 partners studied 4 months after the SAH, we assessed functional outcome by means of the Rankin Scale, and QoL by means of the SF-36, the Sickness Impact Profile (SIP), and a visual analogue scale. Additionally, we asked two “simple questions” about dependency and recovery. All questionnaires were completed in an interview setting. The scores on the QoL instruments from patients and partners were stratified according to the Rankin grades of the patients and were compared with data from a Dutch reference population.

Results—Only patients who had no symptoms at all (Rankin grade 0) had no reduction in QoL compared with the reference population; some of these patients even indicated an improvement in QoL from before the SAH according to the visual analogue scale. Patients who had symptoms but were independent (Rankin grades 1 to 3) and therefore usually designated as having “good outcome” often had reductions in QoL, on both the physical and psychosocial subscores of the SIP and SF-36. The QoL of partners was considerably reduced in several psychosocial domains.

Conclusions—SAH has a considerable impact on the QoL of patients and their partners. Only patients without residual symptoms (Rankin grade 0) have a good outcome in terms of physical performance and QoL. (Stroke. 1998;29:798-804.)

Key Words: outcome ■ quality of life ■ subarachnoid hemorrhage

The case-fatality rate in patients with SAH still approximates 50%, and many studies on outcome after aneurysmal SAH mainly focus on this high case-fatality rate. In studies that describe patients who survived the hemorrhage, outcome is often graded as “poor,” “fair,” or “good.” These categories are sometimes based on specified outcome measures, such as the Glasgow Outcome Scale or the Rankin scale, but more often on the presence or absence of obvious neurological deficits. On scales of that nature, “good outcome” generally means that a patient has no or only minor focal neurological deficits and is independent in activities of daily life. However, the absence of obvious neurological deficits does not necessarily imply that the patient has made a complete recovery from the hemorrhage. Studies that used extensive neuropsychological testing showed that many patients, even those who were independent and had no focal deficits, had cognitive impairment after recovery from SAH. Still, the mere presence or absence of functional or cognitive deficits does not give insight into the patients’ subjective feelings of physical, psychological, and social well-being. This comprehensive outcome level is conceptualized as a person’s QoL.

In a prospectively collected, consecutive series of patients with aneurysmal SAH, we studied QoL 4 months after the hemorrhage. Because the current experience on QoL assessment after SAH is limited, we applied two validated QoL instruments and a visual analogue scale. To study the association between functional outcome and QoL, we compared the QoL assessments with the scores on the Rankin scale, a functional outcome instrument frequently used in stroke research. To study the impact of SAH on the partners of patients, we also assessed the partners’ QoL.

Subjects and Methods

Patients and Partners

We studied a prospectively collected, consecutive series of patients with SAH from a ruptured aneurysm who were admitted to the Utrecht University Hospital between September 1995 and September 1996. The diagnosis of SAH was inferred from the presence of extravasated blood in the basal cisterns on CT, or if CT was negative, from xanthochromia of the cerebrospinal fluid. Also, in all patients included in our study the aneurysm was demonstrated by spiral CT angiography, catheter angiography, or both. Patients with nonaneurysmal perimesencephalic hemorrhage and those with a traumatic, other nonaneurysmal, or unknown cause of the subarachnoid hemorrhage were excluded. We assessed the clinical condition on admission by means of the WFNS scale, a universal SAH grading scale recommended by the World Federation of Neurological Surgeons. The patient’s closest significant other (a spouse, life...
The SIP is easy to administer because it is an analogue scale. The SIP contains 136 items about sickness-related morbidity in daily life: ambulation, mobility, body care, and movement (which together can be aggregated into a physical subscore); social interaction, alertness behavior, emotional behavior, 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 clinical outcome research. Scores can be calculated for the instrument as a whole, for each category, and for the physical and psychosocial subdimensions. The SIP is easy to administer because the questions are in a “yes-no” format, but it is also time consuming (20 to 30 minutes).

The SF-36 is brief (5 to 10 minutes) and can be self-administered. The SF-36 measures 8 health-related domains: physical functioning (10 items), role limitations because of physical health problems (4 items), bodily pain (2 items), social functioning (2 items), general mental health (psychological distress and psychological well-being; 5 items), role limitations because of emotional problems (3 items), vitality (4 items), and general health perceptions (5 items). A single item is added to assess any change in health compared with 1 year before. The validity and reliability of the SF-36 have been studied in several populations. To assess functional outcome we used a modified Rankin scale. The Rankin scale is a 6-point handicap scale that focuses on restrictions in lifestyle (Table 1). The Rankin scale, frequently used in stroke outcome research, is easy to administer, available in a validated Dutch version, and reliable in terms of interobserver agreement.

Additionally, we applied two simple questions that were developed to measure outcome of stroke in large clinical trials. One question regarded dependency (“Do you require help from another person for everyday activities?”) and the other recovery (“Do you feel you have made a complete recovery from your stroke [in this case, SAH?”]).

We assessed QoL by means of the SIP, the SF-36, and a visual analogue scale. The SIP contains 136 items about sickness-related dysfunction in 12 domains of daily life: ambulation, mobility, body care, and movement (which together can be aggregated into a physical subscore); social interaction, alertness behavior, emotional behavior, 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 clinical outcome research. Scores can be calculated for the instrument as a whole, for each category, and for the physical and psychosocial subdimensions.

### Instruments

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

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### Data Collection

We informed the patients and partners about the study shortly before discharge from hospital and assessed outcome at an outpatient visit 4 months after the bleed. Patients or partners who were not able to visit the outpatient clinic for practical or emotional reasons, or who were otherwise likely to get lost to follow-up, were visited at home, in a rehabilitation center, or nursing home. We conducted interviews at home with 6 patient-partner couples and 2 partners of patients who resided in nursing homes, at a rehabilitation center with 1 patient-partner couple, and at the nursing home where the patients stayed with 2 partners. All questionnaires were administered in a face-to-face interview setting and performed by one observer (J.W.H.). We applied all instruments to the patients; in the partners only the SF-36, the SIP, and the VAS were applied. Patients and partners were not separated during the interview, but were requested to answer the questions individually. After a general introduction, the two simple questions regarding dependency and recovery were asked. Then we applied the SF-36, the SIP, and the VAS. Patients and partners were given the opportunity to add extra items or remarks that were important to their QoL, but which were not mentioned in the questionnaires. At the end of each interview, the interviewer assessed

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### Selected Abbreviations and Acronyms

- **QoL**: quality of life
- **SAH**: subarachnoid hemorrhage
- **SF-36**: Short Form (36-Item) Health Survey
- **SIP**: Sickness Impact Profile
- **VAS**: visual analogue scale

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**TABLE 1.** Patient Characteristics, Categorized by Rankin Grade of the Patients at Follow-up

<table>
<thead>
<tr>
<th>Total</th>
<th>Rankin Grade</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 (n=9)</td>
</tr>
<tr>
<td><strong>WFNS, on admission</strong></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>35</td>
</tr>
<tr>
<td>II</td>
<td>16</td>
</tr>
<tr>
<td>III</td>
<td>5</td>
</tr>
<tr>
<td>IV</td>
<td>4</td>
</tr>
<tr>
<td>V</td>
<td>4</td>
</tr>
<tr>
<td><strong>Female, n</strong></td>
<td>45</td>
</tr>
<tr>
<td><strong>Mean age male, y</strong></td>
<td>51.0</td>
</tr>
<tr>
<td><strong>Mean age female, y</strong></td>
<td>51.9</td>
</tr>
<tr>
<td><strong>Qol assessable, n</strong></td>
<td>55</td>
</tr>
<tr>
<td><strong>Partner participation, n</strong></td>
<td>51</td>
</tr>
</tbody>
</table>

WFNS indicates World Federation of Neurological Surgeons. A Rankin grade of 0 indicates no symptoms; Rankin 1, minor symptoms that do not interfere with lifestyle; Rankin 2, minor handicap, symptoms that lead to some restriction in lifestyle but do not interfere with the patient’s capacity to look after himself; Rankin 3, moderate handicap, symptoms that clearly prevent independent existence; Rankin 4, moderately severe handicap, symptoms that clearly prevent independent existence, although not needing constant attention; and Rankin 5, severe handicap, totally dependent patient requiring constant attention night and day.
the Rankin grade of the patient. If the patient was not able to answer a questionnaire because of aphasia or severe cognitive deficits (i.e., patients with a Rankin grade of 5), we recorded only the Rankin grade of the patient and the QoL of the partner. The study was approved by our institutional review board.

Data Analyses
We calculated standard scores for the SF-36 and the SIP by dividing the differences between the scores of the study group and the reference population by the standard deviation of the reference population. These standard scores indicate the number of standard deviations by which the SF-36 and the SIP scores of the study group differ from the scores of 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.34,39 The relationships between the QoL scores and the Rankin grades were calculated with the Somers’ D statistic. This is an asymmetrical index of the relationship between two ordered nonparametric variables, with ranges from $-1$ to $1$. The extremes reflect a perfect association, whereas the value 0 indicates an absence of association.40

Results
Ninety-eight patients with aneurysmal SAH were admitted during the study period of 1 year. Thirty patients died in the hospital. Two patients were excluded from our study because they did not speak Dutch; at 4 months, they had Rankin grades of 1 and 3. Two patients refused participation at 4 months’ follow-up because of severe emotional lability; both patients had a Rankin grade of 4. The mean and median time of follow-up was 4 months (SD, 1 month; range, 2.5 to 7 months).

The baseline characteristics of the 64 patients in whom follow-up data were obtained are listed in Table 1, categorized by Rankin grade at follow-up. Nine of the 64 patients were not able to fill out the QoL questionnaire because of severe cognitive deficits. Thus, QoL was assessed in 55 patients. We assessed QoL in 51 partners, including 8 partners of patients who were not able to fill out the QoL questionnaire. In 46 instances the partner was a spouse or a cohabitant and in 5 instances a close relative who had daily contact with the patient.

The mean SIP scores of patients with Rankin grade 0 (“no symptoms”) did not differ by more than 0.5 standard deviation from the scores of the reference population, with the exception of the subcategory “work” (Fig 1). For this reason we made a distinction between patients with Rankin grade 0 and patients with other Rankin grades. Fig 1 shows the mean standard SIP scores for patients with Rankin grade 0, Rankin grades 1 to 3 (“independent”), Rankin grade 4 (“dependent”), and the reference population. There was a marked difference in mean SIP scores between patients with Rankin grades 1 to 3 and patients with Rankin grade 4. This difference was most prominent for the domains “body care and movement,” “household management,” “ambulation,” and the “physical subscore.” Patients with Rankin grades 1 to 3 had relatively worse scores on the psychosocial subscore of the SIP compared with the physical subscore. The nonparametric correlation coefficient, Somers’ D statistic for the relationship of the Rankin score, and the SIP varied from 0.2 to 0.4 for the psychosocial domains and from 0.3 to 0.6 for the physical domains. For the SIP total, Somers’ D was 0.6; for the physical and psychosocial subscores, 0.4.

Fig 2 shows the mean standard scores on the SF-36 for patients with Rankin grades 0, 1 to 3, and 4. Patients with Rankin grade 0 had even better scores than the reference population, except for the category “role limitations from physical problems.” There was a marked difference in “physical functioning” between patients with Rankin grades 1 to 3 and those with Rankin grade 4. The differences in “role limitations from emotional problems” were less prominent between these two patient groups. All patient groups had relatively good scores on “general health perception.” Somers’ D varied from 0.2 for “pain” to 0.6 for “role limitations from physical problems.”

Fig 3 shows the mean standard scores on the SIP for the partners of patients compared with the Rankin grades of the
patients. The QoL in partners of patients with Rankin grade 0 was unaffected compared with the reference population, with the exception of the subcategory “emotional behavior.” The reduction in QoL in partners of patients with Rankin grades 1 to 5 was most prominent for the categories “emotional behavior,” “social interactions,” “work,” and “recreation and pastimes.” A similar pattern was found for the SF-36 (Fig 4). The QoL of partners of patients with Rankin grade 0 was worse than in the reference population only for the domain “role limitations from emotional problems.” Strikingly, this reduction was higher for partners of patients with Rankin grade 0 than for the patients themselves. The Somers’ D statistic for the SF-36 scores of the partners varied from 0.00 for “physical functioning” to 0.4 for “social functioning.”

Fig 5 shows the mean estimated changes in QoL on the VAS for patients and partners. None of the patients with Rankin grade 0 reported a reduction in QoL; four patients even reported an improvement. For all other Rankin grades, QoL decreased in both patients and partners. Partners of patients with Rankin grade 5 had an estimated 50% reduction in QoL on the VAS.

Table 2 shows the distribution of the answers to the simple questions about dependency and recovery according to the Rankin grade of the patient. Fifteen of the 19 patients who answered that they were dependent on others had Rankin grades 4 or 5; 7 of the 10 patients who regarded themselves as having recovered from the hemorrhage had Rankin grade 0.

Discussion

Our study shows that SAH has a considerable impact on the QoL of patients who survive the hemorrhage and also on that of their partners. Only patients with Rankin grade 0 (no
symptoms) seem to have a relatively unaffected QoL. The higher scores on the items “work” on the SIP and “role limitations from physical problems” on the SF-36 can be explained by the small proportion of patients that have returned to their previous jobs at 4 months after the bleed (30%; always part-time). The majority of patients with a Rankin grade 0 answered “yes” to the question regarding whether they felt they had made a complete recovery from the bleed. Some patients with Rankin grade 0 even reported an improvement in QoL on the VAS. This favorable outcome is also observed in patients with perimesencephalic hemorrhage, a nonaneurysmal, benign subtype of SAH with an acute onset of severe headache and almost invariably an uncomplicated course.14,41,42 A possible explanation is a changed appreciation of life after the complete recovery of an acute, life-threatening illness.

For patients with Rankin grades 1 to 3, who are independent and therefore often classified as having a good outcome, QoL is considerably reduced for both physical and psychosocial domains. The closer correlation for the physical domains and the Rankin grade than for the psychosocial domains and the Rankin grade indicates that the Rankin scale mainly reflects physical abilities. This is exemplified at the often-used cutoff level between patients with Rankin grades 1 to 3 and those with a Rankin grade 4: the most conspicuous difference in QoL between these two groups is in the physical domains. The low Somers’ D statistic for psychosocial domains in relation to the Rankin grade suggests that the Rankin scale is insufficient to detect reductions in QoL in the psychosocial domains.

The simple questions reliably discriminated between Rankin grades 4 and 5 (dependent, not recovered); Rankin grades 3, 2, and 1 (independent, not recovered), and Rankin grade 0 (independent and recovered).

It is difficult to compare our results with previous studies on QoL after SAH,2,3,10,43 because in these studies QoL was assessed only with semistructured interviews or self-rating scales and not with the validated instruments we used. The SIP and the SF-36 have been applied to stroke patients in general but not to the subset of patients with SAH.12,35,39,44,45 Two findings support the separate study of outcome in SAH: the mean age is much lower in SAH patients than in stroke patients in general; and the brain damage in SAH is more likely to be diffuse or multifocal as a result of global ischemia (caused by a reduction in cerebral perfusion shortly after the aneurysmal rupture or during secondary ischemia or hydrocephalus), whereas the lesions in patients with intracerebral infarction or hemorrhage are usually localized.

We found that SAH also has considerable impact on the QoL of partners of patients, most prominently in the psychosocial domains. This is in keeping with an increased emotional distress found in spouses or caregivers of stroke patients in general.46–50 Partners of patients with Rankin grade

Figure 4. SF-36 profiles of partners, categorized according to the Rankin grade of the patients. Deviations from reference data are expressed in mean standard scores.

Figure 5. Patients’ and partners’ mean differences between overall QoL before and 4 months after the SAH, on a VAS, categorized according to the Rankin grade of the patients.
0 had even lower QoL scores than the patients themselves in the domain “role limitations from emotional problems.” This can be explained by the partners’ reported feelings of anxiety and uneasiness. Some partners were afraid to leave the patient alone, especially if they had witnessed the initial event.

Because the instruments we used were not designed to measure QoL in partners of patients, some specific aspects might have remained undetected. This especially concerns the SIP, which designates only limitations in daily functioning as reduction in QoL. For example, many partners had to spend more rather than less time in household management than before, with possible implications for their overall QoL. This extra burden in the domain “household management” remains undetected by the SIP but might eventually result in a lower perceived health-status, as reflected by lower scores on other subdomains.

Many patients and partners made extra comments about SAH-related factors that had influenced their QoL. In a positive sense, gratitude to have survived the hemorrhage and to get a “second chance” were mentioned by patients and partners. Social relationships were appreciated more than before. Some patients felt less stressed than before. In a negative sense, many patients reported a persistent tiredness, easily provoked anxiety by unspecified sensations in the head, and general uneasiness. In particular, patients who had amnesia, with no recollection of the event or the days or weeks that followed, had difficulty realizing and coping with what had happened. A specific item that was mentioned four times by patients and partners was fear of having sex, especially if the hemorrhage had occurred during sexual intercourse.

Two factors may have caused the QoL scores in our study to be too favorable. First, we chose not to assess QoL in partners of patients who had died from their SAH, because this might induce unnecessary distress. However, a severely reduced QoL is likely in these partners, and excluding them from our study group might have resulted in a positive bias. Second, QoL is probably severely reduced for patients who were not able to comprehend the QoL questionnaire, and exclusion of these patients also overestimates the QoL for all SAH patients in our study group.

Our primary aim was to relate the QoL of our study group to the current outcome assessments of good, fair, and poor. To facilitate the interpretation of the QoL scores of patients with SAH and their partners, we included reference data from the Dutch validation studies of the SIP and the SF-36 in the figures. In these studies, SIP and SF-36 scores both were not significantly different between sexes, but were influenced by age. For the SF-36, we used the age-adjusted reference data. For the SIP, these data were not available. The mean age of the population in which the SIP was validated was 42 years. Because the mean age of our study group is 51 years, the differences from the reference scores may have been slightly overestimated.

The current outcome categories of good, fair, and poor for patients after SAH need to be redefined; not only the physical status but also the psychosocial well-being of patients should be taken into account. Only patients with Rankin grade 0 really have a good outcome, because not only their physical condition but also their QoL is satisfying. The Rankin scale is therefore a valuable and practical instrument to make this distinction. The cutoff point between fair and poor outcomes could be set between Rankin grades 3 and 4, although this is based mainly on the physical abilities of the patient and is not equivalent for all psychosocial domains of QoL. In large clinical trials, the distinction between good, fair, and poor outcomes can be made by asking the two simple questions about dependency and recovery. We recommend that in future studies attention be paid not only to the proportion of patients who are independent but also to the proportion of patients with no symptoms at all.

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References


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