Quality of Life, Anxiety, and Depression in Patients With an Untreated Intracranial Aneurysm or Arteriovenous Malformation

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Background and Purpose—The objective of this study was to assess the health-related quality of life and symptoms of anxiety and depression in patients who are aware of the presence of a patent aneurysm or arteriovenous malformation.

Methods—Participants were retrospectively identified and invited to participate in the study; consenting participants were interviewed in a face-to-face setting by means of 2 questionnaires assessing health-related quality of life (Sickness Impact Profile [SIP] and the MOS Short Form-36 [SF-36]) and psychological state (Hospital Anxiety and Depression Scale [HADS]). We used Student’s t test statistics to compare the scores of the study population with the scores of reference populations.

Results—We identified 21 patients, of whom 9 had an aneurysm and 12 had an arteriovenous malformation. Compared with the reference population, these patients had a reduced quality of life for sleep and rest (difference of SIP means, 6.8; 95% CI, 3.1 to 10.5), emotional behavior (10.1; 95% CI, 5.7 to 14.6), mobility (5.4; 95% CI, 2.1 to 8.7), social interactions (5.3; 95% CI, 1.6 to 8.9), and alertness behavior (11.9; 95% CI, 6.2 to 17.5). The SIP psychosocial subscore (7.1; 95% CI, 3.9 to 10.2) and total SIP score (4.7; 95% CI, 2.2 to 7.2) were also significantly impaired. For the SF-36 domains, social functioning was significantly decreased compared with the reference population (8.9; 95% CI, 0.1 to 17.7). HADS scores for depression were similar for patients and the reference population.

Conclusions—Our study shows that knowledge of harboring an unoccluded untreated intracranial aneurysm or arteriovenous malformation reduces quality of life, most prominently on the psychosocial domains, without leading to substantially raised levels of anxiety and depression. (Stroke. 2002;33:440-443.)

Key Words: intracranial aneurysm ■ quality of life ■ vascular malformation

Approximately 1% to 2% of the population has an intracranial saccular aneurysm.\(^1\) The detection rate of arteriovenous malformations (AVMs) is estimated at 19 per 100 000 person-years.\(^2\) With the increasing use of imaging facilities, the number of patients in whom an AVM is detected by chance increases. Because of the poor prognosis after rupture of intracranial aneurysms and AVMs, these incidental lesions are often treated. In some patients, the risks of treatment do not outweigh the benefits. This applies in patients >60 or 70 years of age, in patients with severe comorbidity, or in patients in whom the lesion characteristics make treatment very difficult and risky.

Patients with migraine are often screened for the presence of an AVM because of a possible relation between migraine and AVMs, even though this relation has been disputed.\(^3\) The risks and benefits of screening have not yet been properly assessed. Evaluations of the effectiveness of screening are often limited to the risk of rupture and its consequences and the risks of complications from treatment. Yet the implications of detecting but not treating AVMs in some patients should also be incorporated into the evaluation. Including these psychological factors in the equation is not straightforward, because little is known about their importance.\(^4\) Thus, we evaluated health-related quality of life (QOL) and symptoms of anxiety and depression in patients with an untreated aneurysm or AVM.

Methods

Patients

We retrospectively identified a series of patients with an untreated or incompletely treated AVM or aneurysm admitted to 1 of 2 university centers. We recruited these patients from a database of unruptured aneurysms and a list of all patients with cerebrovascular diseases who had visited the outpatient clinic between 1996 and 1999. Inclusion criteria for patients with an AVM were (1) untreated or incompletely treated AVM; (2) no neurological deficit; (3) if epileptic seizures were the presenting symptom of the
AVM, the patient had to be free of seizures for at least 1 year. Patients were excluded if they had other diseases causing restriction of lifestyle.

Criteria for inclusion for patients with an aneurysm were: untreated or incompletely occluded aneurysm, confirmed by CT angiography, MR angiography, or digital subtraction angiography. Patients with aneurysms were excluded if (1) they had had a subarachnoid hemorrhage, (2) they had other conditions leading to a handicap, or (3) they had symptoms from compression by the aneurysm.

Instruments
We assessed QOL by means of the validated Dutch version of 2 well-studied questionnaires: the MOS Short Form (SF-36) and the Sickness Impact Profile (SIP).\(^5,6\) We selected these 2 instruments because of their psychometric qualities and because of practical aspects. To determine states of anxiety and depression, we administered the Hospital Anxiety and Depression Scale (HADS).\(^7,9\)

Data Collection
The study was approved by the medical ethics committees of the participating hospitals. All patients were contacted by mail through their consultant physicians. The letter provided information on the study; fourteen days later, we contacted the patient by telephone, and if the patient agreed to participate, we made an appointment for a home visit. All questionnaires were administered in a face-to-face interview and were performed by 1 observer (I.C. van der S.). Four patients had participated in a screening program for familial aneurysms.\(^10\) In these 4 patients, an aneurysm had been found but was not treated, most often because of the small size of the aneurysm. During the face-to-face interview at the patients’ homes, patients were told that they could contact their general practitioner or specialist if they felt help was needed.

Data Analysis
We compared data on QOL from patients with an untreated or incompletely treated AVM or aneurysm with scores from validation studies of the Dutch versions of the SIP and SF-36 in the general population. The respective reference populations consisted of a representative sample of 1063 Dutch persons for the SF-36 and 594 Dutch persons for the SIP.\(^5,6\) Similarly, we used data from a general population sample as reference scores for the HADS.\(^9\)

To assess differences in QOL between the patient group and respective reference populations, we performed an analysis of the difference between means (Student’s \(t\) test). We also calculated 95% confidence intervals. We compared the mean scores on the HADS in our patient population with those of the reference population by means of Student’s \(t\) test statistics.

Results
Patients
Fourteen patients with an unruptured, untreated aneurysm and 17 patients with an untreated or incompletely treated AVM fulfilled the inclusion criteria. Of these 31 patients, 3, known to be alive, had moved and could not be contacted; 7 declined the invitation to participate. Eventually, we included 9 patients with an aneurysm and 12 patients with an AVM. Three of the patients with an AVM had had a bleeding that did not result in permanent neurological deficit. Of these 21 patients, 14 were women and 7 were men. Their mean age was 45.9 years. The mean period of follow-up after diagnosis was 3.75 years (range, 3 months to 11 years).

Quality of Life
Figure 1 shows the mean SIP scores of the 21 patients and the reference group. Patient SIP scores were higher, indicating greater impairment in QOL, for all domains except ambulation, for which scores were similar. The difference was statistically significant for sleep and rest (difference of means, 6.8; 95% CI, 3.1 to 10.5), emotional behavior (10.1; 95% CI, 5.7 to 14.6), mobility (5.4; 95% CI, 2.1 to 8.7), social interactions (5.3; 95% CI, 1.6 to 8.9), alertness behavior (11.9; 95% CI, 6.2 to 17.5), the SIP psychosocial subscore (7.1; 95% CI, 3.9 to 10.2), and the total SIP score (4.7; 95% CI, 2.2 to 7.2).

Figure 2 shows the total SIP scores and aggregated physical and psychosocial subscores of the patients and reference population. Twelve patients (57%) had a lower QOL (higher total SIP score) compared with the average of the reference population. In 5 of these 12 patients, the score was within the normal range. The other 7 patients (33% of included patients) had a moderate to severe dysfunction compared with 13% in the reference population.

The mean SF-36 scores of the 21 patients are shown in Figure 3. Their scores were lower than those in the reference population, indicating a reduced QOL, for almost all the SF-36 domains. For the social functioning domain, this difference (difference of means, 8.9; 95% CI, 0.1 to 17.7) was statistically significant. The patient group had higher scores for the physical role limitations (3.1; 95% CI, –10.1 to 16.3) and physical functioning (8.6; 95% CI, 2.7 to 14.5) domains.

On individual analysis, an average of 9 patients (43% of the patient group) per domain had a score that was worse than the mean score of the reference population.

![Figure 1. Mean SIP scores for the patient and reference groups for each SIP domain separately. A higher SIP score indicates a lower QOL.](image)

![Figure 2. Psychosocial and physical subscores and SIP total scores of patient and reference populations. Shown are the percentages of patients and individuals from the reference population categorized according to no (SIP > 10), mild (SIP > 6 to 10), moderate (SIP > 6 to 10), severe (SIP > 15) dysfunction.](chart)
After exclusion of 4 patients who had participated in a screening program for familial aneurysms, the results were essentially the same for all domains of the SIP and SF-36, including the psychosocial domains that reflect the level of anxiety and depression. After exclusion of the 3 patients with an AVM who had had a bleeding, results were also comparable.

States of Anxiety and Depression

The mean subscore for anxiety was 5.5 (SD, 3.6), and the mean subscore for depression was 3.4 (SD, 3.4). In the reference population, the mean score for anxiety was 5.1 (SD, 3.6), and the mean score for depression was 3.4 (SD, 3.3). The difference between the score for anxiety in the patients and the reference group was not statistically significant (difference of means, 0.4; 95% CI, −1.4 to 2.2). Seven patients (41%) had a higher score for anxiety than the reference population (indicating more anxiety), but in only 2 of them was the score in the pathological range. Four patients (24%) had a higher score for depression than the reference population, 2 of whom were in the pathological range.

Discussion

Our study shows that the knowledge of harboring an untreated intracranial aneurysm or AVM affects QOL, particularly on psychosocial domains, without leading to raised levels of anxiety and depression.

A number of factors may have influenced our results. First, 4 patients in the study group (19%) were privately insured, whereas none of the patients in the reference group for the SIP were. This may have introduced a bias toward less dysfunction in this series of patients, because QOL is related to income, even in patients who have had a vascular event.11

Second, 7 patients were contacted but did not want to participate. Their reasons may be associated with a relatively good or a relatively poor QOL. It is unknown whether these 2 opposing factors were in balance.

Third, 3 patients had received medication to prevent epileptic seizures. Two patients had received medication for migraine. Side effects of medication may have led to an overestimation of the reduction in QOL caused by the presence of the aneurysm or the AVM. Three of our patients had migraine. In general, patients with migraine have a reduction in QOL, most prominently in the domains of role functioning (physical) and bodily pain.12 Because mean scores on physical functioning and pain were not significantly lower in our patients compared with the reference population (Figure 3), we do not think that inclusion of these patients with migraine has biased our results.

Fourth, patients had been informed about the AVM or aneurysm by their treating physician. This information probably was not uniform. It is unknown to what degree differences in patient communication affect QOL.

Of the group of 21 patients, 3 patients had had a bleeding from an AVM, which had not resulted in any permanent neurological deficit. Four other patients had participated in a screening program for familial aneurysms. Inclusion of these patients may have influenced the results toward more or less dysfunction. However, the results of all SIP domains and of all SF-36 domains were essentially the same after exclusion of these patients.

Patient QOL was particularly reduced in the psychosocial domains, whereas scores for anxiety and depression were essentially the same as those in the reference population. The psychosocial domains of the SIP and SF-36 reflect not only anxiety and depression but also other psychosocial aspects such as social interaction, alertness, and communication. The higher scores for patients in the physical functioning domain of the SF36 and the lower scores for psychosocial functioning cannot be explained by differences in age or sex, because the age and sex ratios in the patient and reference groups were comparable.

In recently published guidelines for the treatment of unruptured aneurysms, the lack of data on QOL of patients with an untreated aneurysm was commented on, and the apparent need for such data was stressed. In the absence of such studies, we cannot compare our results with other data in the same type of patients. In a study of patients with conservatively treated, small, abdominal aortic aneurysms, a QOL impairment of 7% has been reported.13 QOL was measured with screenQL, a validated generic and global QOL measure. We conclude that the awareness of having an incompletely treated or untreated aneurysm or AVM impairs QOL. This impairment deserves attention in the evaluation of screening and in the decision as to whether to treat a vascular lesion in a particular individual.

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References


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