Quality of life after perimesencephalic haemorrhage

Eva H Brilstra, Jeanette W Hop, Gabriel J E Rinkel

Abstract
Quality of life was measured by means of the sickness impact profile (SIP) questionnaire in a prospectively collected, consecutive series of 25 patients with perimesencephalic haemorrhage. A mean of two years and four months (range six months to six years) after the perimesencephalic haemorrhage, quality of life scores of the (former) patients were comparable with those of a random sample from the Dutch population. For physical aspects the patients showed even less dysfunction than controls. It is concluded that a perimesencephalic haemorrhage does not reduce quality of life or capacity to work.

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Perimesencephalic haemorrhage, a subtype of subarachnoid haemorrhage, is characterised by relatively mild symptoms at onset, confinement of the extravasated blood to the cisterns around the midbrain, and absence of an aneurysm.1 A perimesencephalic haemorrhage is found in 10% of patients with a spontaneous subarachnoid haemorrhage;1–2 this corresponds to an incidence of about six cases per one million person-years.3 The clinical course of perimesencephalic haemorrhage is uneventful and the outcome is invariably good.4–5

In a previous study none of 37 patients with a perimesencephalic haemorrhage was left with disability, but some patients had mild persisting symptoms such as non-specific headaches or forgetfulness. To assess the impact of these subtle changes on overall health, we measured quality of life in a prospectively collected, consecutive series of patients with perimesencephalic haemorrhage.

Methods
We studied a prospectively collected, consecutive series of patients with perimesencephalic haemorrhage, admitted to the Utrecht University Hospital between January 1980 and June 1995. Criteria for the diagnosis were (1) spontaneous subarachnoid haemorrhage; (2) CT within 72 hours of the first symptoms showing a distribution of blood mainly or exclusively around the mesencephalon;1 (3) No aneurysm detected on four vessel angiography.

All patients were interviewed at their homes by one of us (EHB).

To measure the quality of life, we used the sickness impact profile (SIP). The SIP is a reliable and validated 136 item functional health questionnaire, composed of 12 categories that each refer to a specific field of daily functioning: ambulation, body care and movement, mobility, household management, recreation and pastime, social interactions, emotion, alertness, sleep and rest, eating, communication, and work.6 An aggregated score can be obtained for the total SIP, for a physical dimension subset, and a psychosocial dimension subset and a score can be obtained for each category separately. The physical dimension score is derived from the categories body care and movement, mobility, and ambulation; the psychosocial dimension score is derived from the categories emotional behaviour, social interactions, alertness behaviour, and communication. Scores are presented as a percentage of maximal dysfunction ranging from 0 to 100. A total SIP score below 6 indicates no dysfunction, a total score between 6 and 10 indicates mild dysfunction, a score between 10 and 15 indicates moderate dysfunction, and a % total SIP score >15 indicates moderately severe to severe dysfunction caused by disease.7

For this study on patients with no residual disability, the SIP was chosen because this questionnaire assesses a wide range of quality of life domains in depth and has little ceiling effects.8 Because the SIP is a generic instrument and defines quality of life in behavioural terms, we included in the interview a few disease specific questions. We asked patients whether they had noticed a change in their pattern of headaches since the haemorrhage and whether they feared a rebleed. Finally patients were asked whether they had experienced any consequences of the haemorrhage the interview had failed to bring out.

As reference we used data from the validation study of the Dutch version of the SIP.9 To have comparable ages in both groups, we
selected from the population sample the 291 persons who were between 41 to 75 years old and excluded from the patient group the two patients younger than 41 years old. The Mann-Whitney U test was used to analyse differences in the 12 single category scores, the aggregated physical and psychosocial dimension scores, and the total SIP scores.

**Results**

Twenty five of the 26 selected patients were willing to participate; one patient was known to be alive but had moved and could not be contacted. In the series of patients with perimesencephalic haemorrhage there were slightly more men (60%; 95% CI 39-79% vs 43%; 95% CI 37-49%) and slightly more patients older than 51 years (84%; 95% CI: 64%-96%, mean age 58 years vs 71%; 95% CI 66-76%, mean age 57 years) than in the reference population. The mean period of follow up after the haemorrhage was two years and four months (ranging from six months to six years).

Patients with perimesencephalic haemorrhage reported less dysfunction than the reference population (figure), but the difference was significant only for the physical subscore (P<0.01). The median physical subscore was 0.0 (range 0.0-8.3), the median psychosocial subscore was 1.7 (range 0.0-12.4) and the median total SIP score of the 25 patients was 1.6 (range 0.0-9.9). In 23 patients (92%) the total score was <6, which indicates no dysfunction. In the two remaining patients the total SIP scores were 9.2 and 9.9 indicating mild dysfunction. The first was a 66 year old woman, who was interviewed 16 months after the haemorrhage and had renal failure, the other was a 62 year old man, who was interviewed 26 months after the haemorrhage and had a major depression.

For each category the number of patients with a score lower (indicating less dysfunction) than the mean score of the reference group was larger than the number of patients with a higher score (indicating more dysfunction) (table). By the Mann-Whitney U test a significant difference towards less dysfunction in patients was proved only for the categories body care and movement (P<0.01) and household management (P<0.03).

Of the 25 patients, six (24%) had more dysfunction in the category work than the reference population. Only one of these six patients related this dysfunction to the haemorrhage; this 57 year old man reported that he was more often irritated at work after the haemorrhage.

The disease specific questions disclosed that two of the 25 patients reported fear of rebleeding. Eleven patients reported a change in their headache pattern since the bleed: non-specific headaches occurred more often than before the haemorrhage in 10 patients and less often than before in one patient. None of the patients reported sudden bouts of headaches reminiscent of their haemorrhage. Four patients said that they were treated with more consideration by family and colleagues. One was excluded from a life insurance because he was considered to have a higher death risk. Two patients thought that their quality of life was improved by the haemorrhage.

**Discussion**

We found that levels of dysfunction in patients after a perimesencephalic haemorrhage were similar to those in the general population. For physical aspects the patient group reported even less dysfunction. In our study population, men outnumbered women. Although in general, men have better scores on quality of life scales than women, in stroke patients, SIP scores tend to be worse in men. Moreover, in
the validation study of the Dutch version of the SIP, the difference between men and women was not significant. Therefore we do not think that the preponderance of men in the patient group has led to bias. A factor that may have biased our results is income. In a previous study quality of life after myocardial infarction was higher in patients with a higher income. Our patient group included some patients who were privately insured, whereas none of the patients of the reference group were. Therefore the mean income in the series of patients is probably higher than in the reference group, which introduces a bias towards less dysfunction in the series of patients. By contrast, the older age in the patient group introduces a bias towards more dysfunction in the series of patients, because the level of physical dysfunction increases with age. Another factor that may explain the better quality of life score in patients compared with the reference group is that patients may appreciate life more after a stay on an intensive care unit.

Two patients reported dysfunction caused by disease. Their age and period of follow up approximate to the median age and period of follow up of the study group. We think that their reduction in quality of life can probably be explained by the comorbidity they reported, although we cannot be certain that it is not related to the perimesencephalic haemorrhage.

The patients scored better than the reference population in all domains and, despite the small sample size, significantly better in the domains body care and movement and household management. The data do therefore strongly suggest that patients with a perimesencephalic haemorrhage have no reduction in quality of life.

Most consequences of the perimesencephalic haemorrhage are found in the psychosocial domains, although even in this subset most patients had less dysfunction than the reference population. Reported problems with short term memory, sleeping, fears, irritability, and nervousness might be related to the haemorrhage itself but also to the experience of sudden illness leading to admission to an intensive care unit.

There are currently no data available on quality of life after aneurysmal subarachnoid haemorrhage. Thus far, only neuropsychological tests and semistructured interviews have been used to assess dysfunction in patients without physical disability after aneurysmal subarachnoid haemorrhage. Some studies found neuropsychological dysfunction in this subset, whereas others did not. Neuropsychological dysfunction does not invariably interfere with quality of life and conversely the absence of neuropsychological dysfunction does not mean that quality of life is unimpaired. At present, we cannot, therefore, compare quality of life in patients after perimesencephalic haemorrhage with that of the minority of patients who have no physical disability after aneurysmal rupture.

We conclude that a perimesencephalic haemorrhage does not reduce quality of life or capacity to work. Physicians, and in particular medical advisors of insurance companies, should refrain from imposing restrictions on these patients.

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