Psychosocial outcomes at 18 months after good neurological recovery from aneurysmal subarachnoid haemorrhage

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Objectives: To evaluate functioning, 18 months after surgery, of 49 patients with good neurological recovery following aneurysmal subarachnoid haemorrhage (SAH), and to determine the extent of any improvements in disturbances of mood, cognitive functioning, and levels of activity and participation previously observed at 9 month follow up.

Methods: SAH patients, matched for age, gender, and occupation with healthy control participants, completed quantitative measures of mood (HADS, FIES, BDI) and activity/participation (BICRO-39), and a brief cognitive assessment battery (verbal fluency, digit span, prose recall). Controls completed the HADS and the BICRO-39.

Results: Patients showed some recovery of cognitive functioning, though impairments of prose recall persisted. Anxiety and depression symptoms were higher in patients than in controls, but fewer than the patients. Anxiety is associated with only one questionnaires except for RIES-Intrusive thoughts (22%); only three showed signs of full blown post-traumatic stress disorder. Almost half showed elevated dependence on others for domestic activities and organisation and abnormally low levels of employment. Very little variance in outcome was predicted by demographic variables, neurological or cognitive impairment, prior stress, or mood. However, levels of social activity and self-organisation were related to persisting fatigue.

Conclusions: The observed decline in intrusive thoughts and avoidance over time is consistent with that seen after life threatening illness or trauma. The persistent reductions in independence and levels of employment may in some cases reflect considered lifestyle adjustments rather than adverse and unwanted changes but in others indicate a need for focused rehabilitation.

We recently described 9 month follow-up results from a prospective study of 52 patients with good neurological recovery after surgery for aneurysmal subarachnoid haemorrhage (SAH). Participants were assessed on self-report measures of emotional symptomatology (the Hospital Anxiety and Depression Scale (HADS), the Beck Depression Inventory (BDI), the Revised Impact of Events Scale (RIES) and of activity/participation (the BICRO-39 scales), and on cognitive tests (verbal fluency, prose recall, digit span).

Rates of clinically significant HADS anxiety and depression scores (>10) were two to three times higher in the SAH group than in a closely matched healthy control group, confirming reports elsewhere of elevated psychiatric morbidity after SAH. High levels of intrusive thoughts about the illness and/or hospitalisation were reported by over 25% of patients, and 17% reported avoidance behaviour at a level commensurate with that seen in post-traumatic stress disorder (PTSD). Cognitively, although there was no evidence of impairments in digit span or verbal fluency, nearly a third of patients scored below the 10th percentile on a test of immediate prose recall. Other research groups have likewise reported neuropsychological dysfunction in some patients with apparently good neurological outcomes.

Most striking, however, were patients’ reduced levels of activity and participation; over 35% showed abnormally low levels (below the 10th percentile of the matched control group) of independence on the Mobility scale of the BICRO-39 (extended activities of daily living such as laundry, shopping, etc), whilst 50% reported similarly low levels of independence in Self-Organisation (for example, planning, structuring domestic/personal routines, managing finances). Only 44% had resumed “normal” levels of Productive Employment (that is, engagement in paid or voluntary employment, education/training, or childcare). Whilst other research groups have noted similarly low rates of resumption of former employment a year or more after surgery, and have described a high rate of subjective complaints of headaches and fatigue with associated reductions in leisure and social activities, the increased level of dependence on others of this neurologically unimpaired group for routine domestic activities has not previously been identified using quantitative measures.

There were only slight improvements on the BICRO-39 from 3 to 9 months, reaching statistical significance only for the Mobility scale. Neither independence nor employment were predicted by a set of demographic variables, indices of premorbid health, and indices of early clinical outcome (GOS scores, dysphasia), consistent with other reports. Current mood disturbance was significantly associated with only one BICRO scale (Self-Organisation).

The present paper describes the functioning of the same patient group at 18 months post-discharge.

Abbreviations: BDI, Beck Depression Inventory; BICRO-39, Brain Injury Community Rehabilitation Outcome - 39; COWAT, Controlled Oral Word Association Test; HADS, Hospital Anxiety and Depression Scale; LCS, Life Change Scale; MANOVA, multivariate analyses of variance; PTSD, post-traumatic stress disorder; RIES, Revised Impact of Events Scale; RLQ, Revised Life Changes Questionnaire; SAH, subarachnoid haemorrhage
METHODS

Design
This was a prospective study of 52 consecutive patients admitted to the neurovascular service of the National Hospital for Neurology and Neurosurgery (NHNN) for treatment of aneurysmal SAH, and making a good neurological recovery. Patients were interviewed at hospital discharge and then assessed 3, 9, and 18 months later on measures of cognitive and psychosocial functioning. The study aimed (i) to determine the prevalence of various cognitive, affective, and psychosocial problems at each follow-up point, and thus to trace the pattern of recovery over time, and (ii) to determine whether adverse outcomes could be predicted from early clinical signs or pre-injury characteristics. Ethical approval for the study was given by the hospital Ethics Committee.

For each participant a healthy control of the same gender, closely matched for age, ethnicity, and occupational status immediately prior to the SAH, completed, once only, the HADS and the BICRO-39. For these variables, the scores of the SAH participants at each follow-up point were compared with those of this reference group, which provided better matching for demographic factors than could be achieved from the limited existing normative data. Participants’ scores on the remaining measures were referenced to published norms for healthy adults of similar age.

SAH participants
All patients were aged 16 or over, had a good initial WNFS grade (1 or II, that is, no motor deficits, and Glasgow Coma Scale scores of 15 or 14, respectively), and had made a good neurological recovery at the point of hospital discharge (GOS score of 4 or 5). All participants gave informed consent to follow up by an independent assessor (JH) either at the hospital or in their own homes according to their preference.

Assessments
Fuller details of the measures described below are given in our earlier paper.1

Neurological impairment
The presence of sensorimotor symptoms possibly attributable to the SAH or surgery was assessed 3 months after discharge using the Bond Neurophysical Scale.14

Stressful life events
The Revised Life Changes Questionnaire (RLCQ)15 required respondents to indicate whether, over the 12 months preceding their SAH, they had experienced each of 74 objectively defined life events. Scores are represented as total “life change units”.

Patients also completed the 10-item Life Change Scale (LCS)16 which asked them to rate in global terms, on 0–10 scales, the subjective extent of stress in each of ten areas of their life (for example, finance, relationships, work) over the same period.

Tests of cognitive function
Digit Span,17 the Controlled Oral Word Association Test (COWAT),18 19 and a test of prose recall20 similar to the WMS Logical Memory test but with four equivalent versions, were administered using parallel forms at each assessment occasion. Verbal fluency and digit span scores were converted to age-related percentiles using published norms.17 19 For the prose recall test, immediate recall scores below 7/25 and delayed recall scores below 4/25 fall below the 10th percentile.1 20

Mood state and fatigue
Symptoms of anxiety and depression were assessed using the Hospital Anxiety and Depression Scale (HADS),21 the clinical cut off for both mood states being 10/11 (that is, scores of 11+ fall within the clinical range). The Beck Depression Inventory (BDI)22 was also used; here, scores of 19 or higher fall outside the normal range.

The Revised Impact of Events Scale (RIES)23 yielded indices of intrusive thoughts about the SAH and avoidance of reminders/emotional reactions; the scale serves as a screening (though not a diagnostic) instrument for PTSD. Cut offs of 11/12 for Intrusions and 13/14 for Avoidance have been used to categorise scores as “abnormal”.1 4

Participants also rated their current experience of fatigue, defined as physical and/or mental tiredness, using a simple three point scale (0 = none, 1 = mild to moderate, 2 = severe).

Social participation
The Brain Injury Community Rehabilitation Outcome - 39 (BICRO-39) scales24 measure the impact of brain injury on domestic, social, and psychological functioning in patients living in the community. The scales employed here were Personal Care, Mobility, Self-Organisation, Socialising, Productive Employment (including voluntary and paid work, childcare, and education/training), and Psychological Well-Being; in each case scores can range from 0 to 5, with 0 indicating good outcome (for example, independence, high level of activity) and 5 poor outcome (for example, dependence, low engagement, poor psychological state).

Statistical analyses
To test the prediction that in general SAH patients would show more severe problems than demographically matched healthy adults, two multivariate analyses of variance (MANOVAs) were used to compare the 18 month scores of the SAH group with those of the control group on (i) the two HADS subscales and (ii) the six BICRO subscales.

Repeated measures MANOVAs were used to determine whether the SAH group showed significant recovery from 9 to 18 months on: (a) the five cognitive measures; (b) four of the mood measures (HADS and RIES subscales); and (c) the six BICRO scales. For completeness, univariate statistics are also reported from these MANOVAs for the individual component measures, with Bonferroni corrections for multiple comparisons within each family of measures.

Multiple regression was used to explore the relationships between a number of predictor variables and psychosocial outcomes.

RESULTS

Participants
Both SAH and control groups comprised 35 women and 17 men. SAH participants were aged from 27 to 82 years (mean (SD) age 46.9 (10.4) years) and controls from 26 to 74 years (mean (SD) age 46.7 (10.7) years). As detailed in our earlier paper,1 the groups were very comparable for occupational status.

Of the SAH patients, 47 had their aneurysms clipped, four had them coiled or wrapped, and one was managed conservatively. A total of 44 had a discharge GOS score of 5; the remainder scored 4. Of the participants, 51 were successfully contacted and assessed 3 months after hospital discharge, 48 at 9 months, and 49 at 18 months. The 49 participants whose 18 month results are reported here comprised 33 women and 16 men, with a mean (SD) age of 46.0 (10.7) years.

At 3 months, the Bond Neurophysical Scale indicated that 23.5% of participants had impaired visual acuity (not
necessarily due to the SAH), 8% a visual field deficit, 6% diplopia, 15.7% tinnitus, 27.5% dysphasia, and 12% vertigo. None suffered from nystagmus, ataxia, or locomotory deficits. In all, 61% of the sample presented with at least one of the above symptoms, though in most cases they were mild.

Eight SAH participants reported a prior history of treatment for psychiatric or emotional problems; two of these, and another two participants, also reported prior drug or alcohol problems. Very few reported significant histories of physical ill health, though one had had a head injury necessitating hospital admission, and one had suffered a previous CVA (cerebrovascular accident).

Changes in cognitive and psychosocial dysfunction from 9 to 18 months post-SAH

Table 1 shows (i) mean scores on the measures of cognitive functioning, mood, and participation in the SAH participants at 9 and 18 months, (ii) healthy control scores on the HADS and BICRO (measured once only), and (iii) prevalence of "abnormality", operationally defined either as above clinical cut-offs (for mood measures), below the 10th percentile on delayed recall, barely more than 10th percentile: at 22%, this represented some recovery from the 34% impairment rate at 9 months but is still about twice the expected rate in neurologically intact individuals. A total of 13.6% scored below the 10th percentile on delayed recall, barely more than would be expected in the general population.

For the 43 SAH patients with complete data on all measures, MANOVA revealed significant improvement from 9 to 18 months (F1,38 = 9.0, p < 0.001). Univariate ANOVAs, with Bonferroni correction of the significance level to p < 0.01, showed significant improvements on three (verbal fluency, F1,42 = 11.7, p < 0.001; delayed recall, F1,42 = 8.0, p < 0.01; forwards digit span, F1,43 = 9.2, p < 0.005), and trends for immediate prose recall (F1,42 = 6.2, p = 0.02) and reversed digit span (F1,43 = 5.5, p < 0.03).

Mood state and fatigue

All indices were reasonably normally distributed. As shown in Table 1, only the two RIES sub-scales showed recovery from 9 to 18 months. Nevertheless, approximately 22% continued to score in the clinical range for Intrusions (down only slightly from 25.5% at 9 months) and 13% in the clinical range for avoidance (again, only a little lower than the 17% at 9 months). The proportions scoring in the clinical range on the BDI, HADS Anxiety, and HADS Depression were all marginally higher at 18 than at 9 months.

MANOVA comparing the 18 month HADS scores of the SAH patients against those of the control group showed a weak trend for elevated scores in the SAH group (F2,47 = 2.26, p < 0.11). Univariate comparisons indicated a stronger trend for SAH patients to be more anxious than controls (F1,48 = 4.44, p < 0.05) but no difference in depression.

A MANOVA on the two HADS and two RIES sub-scales revealed a trend for the SAH patients to show improvement from 9 to 18 months (F1,46 = 2.1, p = 0.10). Univariate ANOVAs, with Bonferroni correction of the significance level to p < 0.01, detected significant recovery on the RIES Intrusions subscale (F1,43 = 7.5, p < 0.01), a trend on RIES Avoidance (F1,44 = 4.2, p = 0.05), but no change on HADS Anxiety or Depression or on the BDI (F<1, NS, in all cases).

Fatigue was a common problem, being reported as moderate by 30 and severe by nine participants at 9 months; there was no significant reduction in mean scores by 18 months, with 32 still reporting it as moderate and five as severe (F1,47 = 2.4, NS).

Participation: the BICRO-39

Although scores on several of the BICRO-39 sub-scales were non-normally distributed, ANOVA is relatively robust with
with non-parametric correlations used for continuous variables. The nine predictors and each of the four outcome variables, with non-parametric correlations used for continuous variables (age, physical health, prose recall, RLCQ, and LCS) and Mann-Whitney U tests for dichotomous variables (gender, dysphasia, GOS scores, and mental health).

All nine predictor variables were entered simultaneously into separate multiple regressions on each of the four outcome variables. The sample size (up to 44 participants with complete data for each multiple regression) is a little below the recommended minimum for this technique (40+ p, where p represents the number of predictor variables) and so the results must be treated somewhat cautiously.

The nine predictors jointly accounted for less than 7% of the variance in BICRO Self-organisation (R = 0.39; adjusted R² = 0.35; F(1,40) = 14.9, p < 0.001). The only individual predictor to account for a significant unique portion of the variance (that is, after partialling out the other predictors) was prior physical health (part correlation = 0.39, that is, 16% of variance; R = 0.70; F = 14.9, p < 0.001). The relationship between emotional and functional outcomes was significant but modest (R = 0.61; adjusted R² = 0.35; F = 14.9, p < 0.001), though this did not quite achieve statistical significance (R = 0.39, that is, 16% of variance; R = 0.70; F = 14.9, p < 0.001). Two predictors made significant unique contributions to the variance: prior mental health (part correlation = 0.39, that is, 16% of variance; R = 0.70; F = 14.9, p < 0.001) and dysphasia (part correlation = 0.30, that is, 9% of variance; R = 0.70; F = 14.9, p < 0.001).

Relationships between emotional and functional outcomes
Mood (sum of HADS and RIES scores) at 18 months was not significantly correlated with 18 month scores on either BICRO Mobility, Self-organisation, or Productive Employment.
Employment (r < 0.35, p > 0.09 in every case). Subjective fatigue ratings, by contrast, were associated with functional outcomes. The 37 participants who reported fatigue as moderate or severe at 18 months showed lower independence in Self-Organisation and lower levels of Socialising than the 12 who did not (Mann-Whitney tests: Z = -3.1 and -2.4, p < 0.02, respectively). They also tended to be less independent in Mobility (Z = -1.9, p = 0.06), though their scores on Personal Care and Productive Employment did not differ from the non-fatigued participants (Z < 1, NS, in both cases).

DISCUSSION

At 9 months after these patients had made a good neurological recovery from surgery for aneurysmal SAH, about a third showed evidence of cognitive impairment which was particularly manifest on a measure of verbal recall, consistent with findings from some other empirical studies. The slight improvements in verbal recall over the ensuing 9 months fell just short of significance, with over 20% of patients continuing to score below the 10th percentile. This is approximately twice the expected (“normal”) rate. However, no impairment was evident on tests of verbal fluency, digit span, or delayed prose recall, tests selected because previous research had shown them to be sensitive to post-SAH dysfunction.

Thus, the majority of participants were functioning within normal limits on most cognitive tests 18 months after surgery. Indeed, of those who completed all five tests, only 27% scored below the 10th percentile on one or more tests and only 9% scored below this level on two or more tests. Allowing for normal measurement error in cognitive testing, an expected “abnormality” rate of 10% for each test individually, and individual variation in cognitive abilities, these patterns of abnormal performance are only slightly higher than would be found within the general population. These findings are consistent with at least two previous studies which have found little indication of cognitive dysfunction in similar patients a year after surgery.

It is striking, given the absence of marked cognitive impairment or physical disability in the majority of these patients, that 40–50% reported abnormally high dependence on others for assistance with extended activities of daily living and self-organisation, and low levels of engagement in productive employment-related activities including paid and unpaid work, education or training, and childcare. There was remarkably little improvement in psychosocial functioning from 9 to 18 months post-surgery, and neither dependence on others for organisation nor low levels of productive employment were significantly predicted by any of nine demographic, clinical/cognitive outcome, and pre-SAH stress/health-related variables. The absence of any significant predictors of independence in Self-Organisation failed to mirror the findings at 9 months, when memory impairment at 3 months and prior life stress (RLCQ scores) both emerged as independent predictors. These findings suggest that once increased levels of dependence and altered patterns of activity have been established for several months, they become entrenched and are relatively resistant to further spontaneous change. This may partly reflect the observations made by some patients that their experience of life-threatening illness had prompted them to reprioritise their life priorities and adjust their lifestyles accordingly.

The nine predictors did, however, jointly explain 35% of the variance in Mobility (independence in physical activities inside and outside the home) at 18 months compared with 20% at 9 months. Contrasting with the lack of individually significant predictors at 9 months, by 18 months 16% of the variance was attributable uniquely to pre-SAH physical health. Although it is unclear why the role of prior physical health should become apparently more influential, it might possibly be associated with the development of additional medical problems which then play a role in perpetuating dependence on others for domestic activities. This speculative explanation cannot be directly tested here, but in future research it would be of interest to record the occurrence of other health-related problems after SAH.

Mood state generally showed only a trend towards improvement from 9 to 18 months, though there was a significant reduction in intrusive thoughts relating to the illness and hospitalisation. Although over 20% of patients continued to report frequent intrusive thoughts, only three (6%) scored above clinical cut offs on the RIES for both intrusive thoughts and avoidance. This suggests that clinical diagnoses of post-traumatic stress would be uncommon at this stage post-illness. The temporal decline in the rates of patients reporting both symptoms, from 30% at 3 months to 15% at 9 and then 6% at 18 months, is similar to the pattern for post-traumatic symptomatology after other life-threatening events. Of the three patients reporting both symptoms at 18 months, two had a prior history of treatment for mental health problems; this may suggest that symptoms initially triggered by the SAH, as by other traumas, are likely to persist over the long-term primarily in people with a pre-existing vulnerability to mental health problems.

Although mean scores on the HADS and the BDI did not change significantly, remaining within normal limits, it is notable that clinical levels of HADS anxiety and depression, were respectively three times and twice as likely to be reported by the SAH patients than by the matched controls. Similarly, eight of the SAH patients (16.3%) had BDI scores over 18, consistent with at least a mildly depressive state; only three of these had a previous history of treatment for mental health problems. These rates of clinically significant mood disturbance, though elevated, are markedly lower than the 75% reported by Beristain et al or the 30–50% suggested by Politynska et al from a review of published studies. The reason for these disparities is unclear, though one possibility is that the patient groups had differential access to sources of post-discharge support. Pritchard et al have recently highlighted the hiatus in care and support which frequently occurs following hospital discharge and have linked this to major psychosocial problems for SAH patients and their carers. Our research group is currently investigating this issue experimentally via a randomised controlled evaluation of post-discharge support from a nurse specialist.

When predictors of continued mood disturbance were explored statistically, prior mental health treatment accounted for 16% of the variance in mood outcome, and the presence of dysphasic symptoms 3 months after surgery for a further 9%. None of the other variables entered into this model (age, gender, initial outcome grade (GOS 4 v 5), impaired prose recall at 3 months, pre-SAH life stress, or pre-SAH physical health problems) increased explanatory power; indeed, the total variance explained was only 20% and the overall model fell just short of significance. Thus mood disturbance seen at this duration after SAH appears to be only in relatively small part attributable to pre-existing difficulties, with post-SAH cognitive impairments possibly serving as a small additional influence.

Perhaps surprisingly, the participants’ observed elevated levels of dependence on others for activities and organisation and the low levels of productive employment were not associated with low mood. Thus, their reduced levels of activity and participation appear not either to result from or to contribute to dysphoria. This may reflect the anecdotal observations noted earlier, that for some patients, reductions in activity may in part represent positive lifestyle adjustments...
rather than a deterioration in personal autonomy. It is too simplistic for clinicians and researchers to assume that a decline in these aspects of social functioning necessarily represents a reduction in patients’ quality of life; indeed, insofar as the absence of subjective distress indicates an acceptable quality of life, these data suggest that the road to recovery need not necessarily focus on promoting resumption of prior or even “normal” patterns of activity. In future research it would be valuable to ask participants directly about their perceived reasons for changes in their lifestyles, and about their future aspirations.

Fatigue, by contrast with mood, may be an important influence on outcome in this group. When, based on spontaneous reports of problematic fatigue at earlier follow-up points, we asked them to rate the severity of their fatigue at 18 months on a simple 3 point scale, a statistical association emerged with some of the psychosocial outcomes, particularly frequency of socialising and level of independence in self-organisation. The mechanisms underlying fatigue after brain injury are far from clear, and it may be that it is as much a consequence as a cause of failure to resume an active lifestyle: that is, failures to resume premorbid levels of activity might result in reduced fitness with consequent fatigue and reduced perceptions of competence. This is an interesting area for further investigation utilising more theoretically-conceived and well-validated measures of fatigue than the simplistic and unvalidated screening tool used here.

The trajectory and predictors of recovery observed within this “good neurological outcome” sample should not automatically be extrapolated to the broader SAH population, where the presence of more severe physical, sensory, or cognitive impairments may have a more significant bearing on psychosocial outcomes. Appropriate clinical interventions must depend on not only an accurate description of what has changed but on an understanding of the immediate and secondary psychological reactions that individual patients experience to their illness, hospitalisation, and subsequent symptomatology. Where patients’ horizons become limited by health anxieties, fatigue, or a loss of confidence in their abilities, support and information from a knowledgeable professional after hospital discharge may play on its own be sufficient to dispel inaccurate beliefs and prevent avoidable problems developing. In other cases, it may be appropriate to provide access to more intensive specialist interventions—for instance from a psychologist or occupational therapist—to overcome potentially debilitating mood disturbances or directly to assist the patient in re-engaging with activities of daily living and regaining their personal autonomy.

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