**ON FUNCTIONS, ABILITIES AND QUALITY OF LIFE AFTER
SUBARACHNOID HAEMORRHAGE**
Occupational Therapy Aspects

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Abstract

This investigation addresses functions/impairments, abilities/disabilities and quality of life (QoL) in a consecutive series of non-hospitalized long-term survivors (2,5-12 years) of subarachnoid haemorrhage (SAH). The investigated parameters of functions/impairments were: motor, language, perceptual and memory functions. Abilities/disabilities studied were: activities of daily living (ADL) including both personal- and instrumental ADL, working and leisure capacities. Quality of life was assessed using a double visual analogue scale. Occurrence of depression was registered using a self-rating scale.

A questionnaire focusing motor and language impairments, personal ADL, work and leisure activities was initially mailed to 324 subjects. The vast majority answered the questionnaire. Ten hospitalized subjects could not validly report their functions and abilities and were by that reason excluded.

In a follow-up investigation up to 247 long-term non-hospitalized subjects were investigated by a physician and an occupational therapist. A total of 82% had at least one impairment. The majority (73%) had memory impairment and among these subjects equal proportions (about 50%) had impairments of long- and short-term memory. Forty-five percent were perceptually impaired, while motor impairment occurred for 25% and aphasia in 10%. Only a small minority (9%) were, according to self-reports, regarded as being to some extent disabled in personal ADL. The corresponding numbers of disabled in instrumental ADL, leisure and working-capacity were 52%, 48% and 40%. Depression was found in 22% – among whom the majority had minimal or mild depression. Overall QoL was judged to be unchanged or increased in 62% and, therefore, decreased in 38%.

As expected impairments to a significant degree caused disabilities. None of the 5 different categories of impairments were associated with mood (depressed/not depressed) and QoL (decreased/not decreased). Occurrence of depression was significantly associated with different aspects of disabilities. In contrast among a series of instrumental ADL-variables, leisure and working capacity, QoL was influenced negatively only by decreased ability to act sociably and, to a minor extent, by depressed mood.

Judging from the extent of decreased quality of life, it appears that nearly 40% of all non-hospitalized former victims of SAH have not coped successfully with the impact of the SAH. A follow-up programme aiming at optimizing the coping process of SAH-victims is, therefore, outlined.

Keywords: Subarachnoid haemorrhage, impairment, disability, activities of daily living, work, leisure, depression, quality of life, rehabilitation, occupational therapy.

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Original papers

This dissertation is based on the following papers, which will be referred to in the text by their Roman numerals:

- I: Lindberg M, Ängquist K-A, Fodstad H, Fugl-Meyer K, Fugl-Meyer AR. Self-Reported Prevalence of Disability after Subarachnoid Haemorrhage, with special emphasis on return to leisure and work.
Br J Neurosurg; 6: 297-304, 1992.
- II: Larsson C, Rönnerberg J, Forsell Å, Nilsson L-G, Lindberg M, Ängquist K-A. Verbal Memory Function after Subarachnoid Haemorrhage Determined by the Localisation of the Ruptured Aneurysm.
Br J Neurosurg; 3: 549-560, 1989.
- III: Lindberg M, Fogelsjö A, Ängquist K-A, Larsson C, Fugl-Meyer AR. On Long-Term Consequences of Subarachnoid Haemorrhage:
I. Prevalence of Impairments.
Clin Rehabil, in press.
- IV: Lindberg M, Fugl-Meyer AR. On Long-Term Consequences of Subarachnoid Haemorrhage: II. Prevalence of Instrumental ADL-disabilities.
Clin Rehabil, in press.
- V: Lindberg M. Quality of Life after Subarachnoid Haemorrhage, and its relationships to impairments, disabilities and depression.
In manuscript.

Some abbreviations used in this thesis

ACoA	Anterior Communicating Artery.
ADL	Activities of Daily Living.
AVM	Arteriovenous Malformation.
FCR	Final Cued Recall.
FFR	Final Free Recall.
GOS	Glasgow Outcome Scale.
ICA	Internal Carotid Artery.
ICIDH	International Classification of Impairments, Disabilities and Handicaps.
IFR	Immediate Free Recall.
LTM	Long-Term Memory.
MCA	Middle Cerebral Artery.
QoL	Quality of Life.
SAH	Subarachnoid Haemorrhage.
STM	Short-Term Memory.
VA	Vertebrobasilar Artery.
WHO	World Health Organisation.
WM	Working Memory.

Introduction

Some comments given by long-term survivors of SAH, during interviews and examinations (II-V).

In spite of being incredibly exhausted, I went to a football match and to town the same week I came home from the hospital, no-one was going to think that I had any aftereffects from the haemorrhage. After being on sick leave for 2.5 months, I returned to my work at my own request, to prove to myself and those around me that I had come through the operation without any adverse effects. It came as a shock to me to discover that I couldn't cope with work the way I used to, and because of that I was taken off the regular staff. All through the first year I needed to sleep several times a day. Today I'm back working full-time and managing without sleep during the day. A word of advice, however: try to put the brakes on those who seem a bit too optimistic. Otherwise you suffer the setbacks and the patients are completely unprepared for them and can become depressed or stress themselves far too much as a result. (Woman, three years after SAH at age 37, no impairments, no disabilities, no depression, QoL unchanged).

I haven't experienced any problems since the haemorrhage. After a period of three months' sick leave, I returned to my work on a full-time basis. Because I no longer think about my operation or that I had a haemorrhage, I was a bit surprised about receiving the request to come to the examination today. (Man, four years after SAH at age 23, no impairments, no disabilities, no depression, QoL unchanged).

Life isn't what I'd imagined it would be, but it can still be good anyway. (Woman, eight years after SAH at age 49, perceptual impairment, disabled in IADL, work and leisure, no depression, QoL unchanged).

I only manage about a third of what I used to. But if I want to do something, I do it, even if it takes me a while to do it. (Woman, five years after SAH at age 46, impaired motor and memory function, disabled in IADL, work and leisure, no depression, QoL decreased).

I find it hard to explain to friends and acquaintances about a handicap they can't see, because they can never understand what it means. (Woman, three years after SAH at age 56, no impairments, disabled in work, depressed, QoL not assessed).

I got my early retirement pension 18 months after the haemorrhage but I'm still having problems with the Social Insurance Office, because I look so healthy. (Woman three years after SAH at age 48, impaired motor function, disabled in IADL, work and leisure, depressed, QoL decreased).

I could do everything before. Now I just glide past those things which are difficult and I am not faced with the same demands I once was. I get irritated by not being able to do those things which were so easy before. (Man, eight years after SAH at age 58, memory impairment, disabled in work, no depression, QoL not assessed).

Your circle of friends shrinks after any form of illness, the number of people with whom I still socialise is much more limited than before. I'm not as outgoing as I was before the haemorrhage and that's probably due largely to the fact that I have stopped working. I couldn't cope with the practical aspects of my work, things which had been simple before became so hard for me to manage. That's why I requested early retirement pension. (Man, seven years after SAH at age 53, memory impairment, disabled in IADL, work and leisure, depressed, QoL not assessed).

Everything goes in slow motion nowadays and I feel that I'm half the person I was before. Before I had the haemorrhage, I was a supervisor in a large company, but I couldn't manage my old job because of memory and language problems. Because of that I was transferred to a position with less responsibility. It was really hard to "step down" at work. But now, since I retired, I'm pleased to be able to continue with my leisure activities and to not be dependent on anyone else to look after me. The problems after the haemorrhage haven't actually led to any direct deterioration in my quality of life. (Man, eight years after SAH at age 53, impaired memory function, disabled in IADL and leisure, no depression, QoL unchanged).

Before the haemorrhage, I was very active and enjoyed it. I often had extra work as well as my full-time job. Since the haemorrhage, everything takes much longer and that often makes me annoyed. I can't find my way in the forest anymore and I daren't go out alone picking berries, for example. After 18 months, I was granted early retirement pension. (Woman, thirteen years after SAH at age 45, motor impairment, disabled in IADL, work and leisure, depressed, QoL not assessed).

Aims

The overriding aim of this investigation was to assess the need for rehabilitation in long-term survivors of subarachnoid haemorrhage, and occupational therapy in particular, as judged retrospectively by the prevalence of impairments and disabilities, and their impacts on quality of life, and the occurrence of depression. Perceived quality of life was used here as a measure to evaluate the successfulness of coping in these subjects.

Some facts about SAH

The onset of subarachnoid haemorrhages (SAH) is usually sudden; the patient experiences severe headache, often accompanied by nausea and vomiting. Loss of consciousness is common and occasionally cramps occur (Sahs et al, 1966, cf. Vermeulen et al 1992, Hällén et al, 1995). SAH may sometimes be preceded over a period of several weeks by "warning leaks", in the form of sudden headaches which the sufferers do not experience as sufficiently severe as to give cause to seek medical attention (cf. Vermeulen et al, 1992). It is of vital importance that those cases where SAH may be suspected be referred for neurosurgical assessment as soon as possible, in order that appropriate neurosurgical intervention can be begun as early as possible (Lund-Johansen and Wester, 1994).

Approximately three quarters of SAH are caused by a ruptured saccular aneurysm. In a further 5% of cases, the cause is an arteriovenous malformation (AVM), while for the remaining 20-25% the source of haemorrhage cannot be demonstrated (Engberg-Stabell, 1991, Pacult, 1994). Trauma, tumours, and infections can also cause SAH in certain cases. Multiple aneurysms have been demonstrated in up to 20 % of cases (Kassell et al 1990a).

Aneurysms are most often related to the anterior vessels of the Circle of Willis (cf. Vermeulen et al, 1992, Pacult, 1994). The underlying cause of the development of aneurysm is still not entirely clear. Towards the end of the last century a congenital theory was proposed (Eppinger, 1887; quoted by Sahs et al, 1966) in which aneurysm was supposed to have been caused by maldevelopment of or a hereditary weakness in the vascular wall. Others believed that acquired degenerative changes in the vascular lining could give rise to aneurysm (cf. Stehbens, 1983). Even the importance of haemodynamic stress, with or without rising blood pressure or damage to connective tissue, has been discussed as a possible contributory cause in the development of aneurysm (Stehbens, 1989). Interestingly a study in Rochester, Minnesota, showed that more effective treatment of high blood pressure had reduced the incidence of stroke in general, although the incidence of SAH had remained unchanged (Phillips et al, 1980). Similar results have been presented by Sarti et al (1991), who, in an epidemiologically based study from Finland, were unable

to demonstrate a reduction in the incidence of, or mortality from, SAH over the last 30 years, despite a decreased presence of risk factors such as hypertension and smoking.

It has not been unequivocally shown that strain, and an attendant rise in blood pressure, can lead to SAH. A Finnish survey (Nyström, 1973) investigated activity at the onset of SAH in more than one thousand SAH-patients. Slightly more than half of the individuals concerned were not being subjected to any form of strain; approximately one fourth were undergoing (some form of) hard physical strain and as many were experiencing slight physical strain while a small proportion (4%) were subject to emotional stress. Schievink et al (1989) have identified activity at onset for 500 subjects with SAH caused by ruptured aneurysm. They found that 43% of patients fell ill in conjunction with stressful activities whereas the bleeding started during non-strenuous activities in 35% of cases, and in 12% of subjects, during rest or sleep. No information regarding activity at onset of illness was available for the remaining patients. Tzementzis et al (1985) found that SAH-subjects more often fell ill in the lavatory and during sexual and sporting activities, than was the case for subjects with intracerebral haemorrhage or cerebral infarction.

Cigarette smoking alone has been described as a risk factor for SAH (Fogelholm and Murros, 1987), and in combination with high blood pressure or oral contraceptives (Bonita 1986, Sacco et al 1984, Canhrao et al 1994). Life-event stress, independent of cigarette smoking, that is perceived as out of the subject's control, or which results in negative emotions, has been described as another risk-factor by Ogden et al (1993a).

The primary brain damage is caused either by the flow of blood from the ruptured aneurysm or by a compression due to an extracerebral haematoma. Widespread brain damage occurs relatively frequently. One reason for this may be that the intra-cranial pressure often rises, which leads to extensive cerebral ischaemia. One serious complication is delayed ischaemia caused by vasospasm (Kassell et al, 1990a, cf. Vermeulen et al, 1992). It can emerge after several days and can peak about a week after bleeding. Treatment with different substances - calcium antagonists, for instance, is often used to minimise the risk of and the degree and severity of ischaemia and vasospasm (Gilsbach, 1988). While high-dose treatment with a calcium channel antagonist

can prevent the emergence of symptomatic vasospasm, it seems that hypertensive/hypervolemic therapy may be effective in reducing ischaemic deficits once they have emerged (Taylor et al, 1991, Haley et al, 1993). Transcranial Doppler-guided high-dose treatment with calcium channel antagonist appears however to have a positive effect upon cerebral dysfunction caused by delayed vasospasm (Zygmunt and Delgado-Zygmunt, 1995).

Sweden is an oblong-shaped country with a distance of approximately 2000 kilometres between its southern- and northernmost extremities. In common with other cerebrovascular diseases (Wester et al, 1992), there would seem to be geographical differences in the incidence of SAH. In southern Sweden, the incidence has been estimated as 6-8/100 000 (Sonesson, 1992); in central Sweden, the incidence appears to be 8-9/100 000 (Edner and Ronne-Engström, 1991), while in northern Sweden the incidence may be as high as about 12/100 000 (Fodstad et al, 1990). It has, however, been maintained that approximately 1/3 of those who become victim of an SAH are not adequately diagnosed in the early phase, in particular among older subjects and those with "warning leaks" (Drake, 1981, Rosenørn et al, 1987). One reason which may account for this is that many of these subjects are not referred for neurosurgery. According to Schievink et al (1995) more than ten percent of Dutch subjects with aneurysmal SAH die before reaching medical attention.

In Denmark, the incidence of SAH has been reported to run at approximately 3-4/100 000 (Rasmussen et al, 1980, Rosenørn et al, 1987); in Norway, somewhat higher: 6/100 000 (Kristiansen, 1956); and in Iceland at 8/100 000 (Gudmundsson, 1973). Finland has a considerably higher incidence of SAH, being estimated between 16-24/100 000 (Pakarinen, 1967, Waltimo et al, 1980, Fogelholm, 1981). All these calculations are, however, based on neurosurgically treated subjects.

The average age of neurosurgically treated SAH patients is slightly less than 50 (Stehbens, 1989). It is uncommon for children or young people under 20 to suffer an SAH, the most frequently occurring age of onset being between the ages of 40 and 70. (cf. Vermeulen et al, 1992).

The average proportion of SAH in relation to all registered cases of stroke in people under 65 in northern Sweden is approximately 15%. The relative

incidence of SAH in over-65s is considerably lower: about 3-4%. The northern Swedish proportion of SAH in age-groups <65/≥65 is therefore for both women and men about 3-3.5/1 (Stegmayr et al, 1994), indicating that the vast majority of SAH-victims are still in their vocationally active years at the onset of the SAH (Bamford et al 1990, Stegmayr et al 1994).

Early rebleedings are not uncommon. In an international cooperative study, Kassell et al (1990a) reported this occurring in 11 percent of aneurysmatic SAHs. Such rebleedings, secondary ischaemia and vasospasm (with delayed ischaemia) are regarded (Sacco et al, 1984, Kassell et al 1990a) as major reasons for a relatively high early mortality, which in a community-based investigation (Sarti et al, 1991) was found to be 47%. It should be noted that the level of consciousness at admission has great predictive value for the outcome. Deruty et al (1995) reported that the mortality rate was 5% for alert patients, 14% for drowsy patients and 61% for comatose patients.

Calculated Nordic rates of early mortality vary between 8 and 44% (Vapalanti et al, 1984, Ljunggren et al, 1987, Rosenørn et al 1987, Hernesniemi et al, 1993), and are quite clearly due to differences in design. Thus, some authors only discuss post-operative mortality while others only include selected groups of subjects.

Improvements in pathological-anatomical diagnosis, including advanced neuroradiology and micro-surgical operating techniques, in addition to pre- and post-operative medication have, over the last few decades, increased the chances of surviving an SAH for those subjects admitted to a department of neurosurgery (Hårdemark, 1995). The subjects with ruptured aneurysms can be operated on at different points in time: early - within 72 hours; intermediately - between days 4 and 6; and late, on day 7 or later (Säveland et al, 1992). Often surgery is performed in accordance with prevailing clinical conditions (Deruty et al, 1991). The reasons generally given for early surgery are that the risk for new bleeding is eliminated and the development of delayed ischaemia due to vasospasm is reduced, whereas the acute reaction of the brain and its vessels has subsided (Drake, 1981) if surgery takes place later, thus making operative intervention more viable. Kassell et al (1990b) have stated that the postoperative risk following early surgery is comparable with those complications which can arise while waiting for delayed surgery. Even if this

matter still seems to be unresolved, it may be noted that in Sweden early surgery is favoured (Säveland et al, 1992). Conservative treatment is given: when the patient's condition does not permit surgical intervention; if the aneurysm in question is adjudged to be inoperable because of localisation; for those who do not have an identifiable source of bleeding; and for those who refuse an operation (Nishioka et al, 1984).

Some historical notes

It is surprising how few of these haemorrhages from aneurysms on the large basal arteries are immediately fatal; the majority give sufficient warning to allow one to formulate a plan of treatment. A majority of these patients, moreover, are comparatively young, and many are perfectly healthy apart from this one small defect on a cerebral artery.

These are the words of the British neurosurgeon Dott (1933) who, to the best of my knowledge, described the first surgical treatment of a ruptured intracranial aneurysm, just ten years after Symonds (1923) in a single subjects description of five patients had pointed to the association between ruptured aneurysms and SAH. Dott had followed a series of patients, several of whom died after re-bleedings. He therefore decided that the next patient with ruptured aneurysm and reiterated SAHs, and in whom the location could be established based on clinical examination, should be operated on in order "to reinforce Nature's attempt at healing". Thus, some 64 years ago on April 22, 1931, what was possibly the first neurosurgical intervention to avoid further re-bleedings was performed on a 53 year old man who had had three SAHs due to ruptured intracranial aneurysm. Thin strips of muscle were bound around the bleeding vessel until a thick collar of muscle embedded the aneurysm and nearby arterial trunks.

The operation was successful and two years later at follow-up, Dott (1933) observed that the patient had recuperated to such an extent that he could return to the duties he had previously held, and had taken up his pre-SAH leisure activities again: namely, shooting and mountaineering. From an occupational therapist's point of view, it is interesting to note that the first neurosurgeon who carried out aneurysm surgery, did a long-term follow-up after 2 years, and based his comments regarding final outcome on the patient's ability to perform activities which she/he had been able to perform earlier.

The first operation where a (non-ruptured) aneurysm - located at Willis' circle - was operated upon using a silver clip, was performed in 1937 by Dandy (1938). The patient who was apparently "a very heavy drinker", suffered delirium tremens post-operatively, for three days, but in spite of this was able to leave the hospital two weeks later with a marked regression in the symptoms caused by the effects on the III-cranial nerve. We are unable to ascertain whether or not the patient was able to resume previous activities, the heavy drinking included. At the follow-up seven months after the operation, it was observed that all functions controlled by the III-cranial nerve had recovered.

A relatively early Scandinavian study often referred to is the long-term follow-up of conservatively treated SAH-subjects conducted by Ask-Upmark and Ingvar (1950). The patient's return to work was an essential yardstick in assessing final outcome in that follow-up study. The other extreme was mortality. The authors concluded:

Without an operation only about one case in five can be expected to make a good recovery and resume his former occupation; one case in five remains crippled and the other three cases die sooner or later from SH".

It was in the light of this conclusion that the expression "the rule of five" was later coined (Drake, 1971, Pakarinen, 1967). In an another early Swedish study, Höök (1958) used a questionnaire to follow-up a consecutive series of long-term survivors of SAH admitted to two different hospitals in Stockholm during the period 1934-1955. Höök addressed the neurological status of 64 long-term survivors and found that focal neurological signs were present in about 50%. Among these subjects slightly more than half reported that they were fully able to work, whereas 10 (16%) considered themselves wholly unable to work.

A much quoted investigation is that of Botterell and co-workers (1956) who suggested two different scales; one for characterising the early phase and the other for validation of the late outcome after SAH. The first scale describes a method for grading the operative risk from 1 to 5: Grade 1: conscious patient; Grade 2: drowsy patient without neurological deficit; Grade 3: drowsy patient with neurological deficit; Grade 4: major neurological deficit and deteriorating; Grade 5: moribund or near moribund patient. Many scales for

grading the severity of the SAH and operative risks at admission have been developed since the 1950s. One of the most frequently used is that described by Hunt and Hess (1968, for an overview see Deruty et al, 1995).

The background for the outcome scale of Botterell et al (1956) is given through a detailed description of 23 cases of aneurysms who were followed for up to ten months using this outcome "scale". This scale - or rather classification - of Botterell et al is particularly interesting for occupational therapists because it contains multiple single case illustrations with individual descriptions, including the ability to pursue pre-SAH activities in the areas of ADL, work and leisure. The results of neurosurgical intervention were graded into excellent / good / fair / bad. This classification may best be illustrated by quoting from the original description:

An excellent result: Follow-up after three months. He has returned to his work as a draughtsman and has remained well.

A good result: Postoperative course: She was paralysed, left-side. At discharge (after two months) all movements had returned in the left arm. She had spastic weakness of the left hand with loss of individual finger movements. Cortical sensory deficit persisted. She was well and doing her own housework at follow-up after ten months.

A fair result: Postoperative course: He was conscious with good power in the right arm and leg. He was not talking. A profound right hemiplegia with marked facial weakness global aphasia was present. He was fully conscious (3 days after operation). He was discharged home (after one month). Nominal aphasia was present which was severe enough to prevent him from speaking fluently but he was able to express himself using circumlocution. He had right facial weakness and right spastic hemiparesis, most marked in the leg. The power in the arm and thigh muscles was 4-5 and in the ankle 1-2. Sensory system was intact. Individual finger movements were present. At follow-up after three months a considerable improvement has occurred. Mild nominal dysphasia remains. The right spastic hemiparesis persists, most marked in the leg. There is no sensory deficit. He is doing odd jobs on a farm.

A bad result: Postoperative course: One day after the operation the left side completely hemiplegic. The left arm and leg were flaccid and there was facial weakness. He was discharged after two months to his home. He was still markedly retarded mentally. He could answer only simple questions and could feed himself if his food were cut up. There was left lower facial weakness. He could hold his left hand against gravity or raise it to his face. There was marked spastic paralysis of the left leg. He still required a catheter. At follow-up after five months he was living in a convalescent nursing home. The left leg remains spastic but he is walking unaided and there is a considerably increased usefulness of the left arm. He carries on an ordinary conversation and reads the daily paper. Urinary incontinence remains a problem. A bad result, in spite of continuing slow recovery.

Several subsequent authors have a similar outcome *terminology* when classifying outcome after SAH (see, for instance, Suzuki, 1978, Takaku et al, 1979, Sundt et al, 1982, Keogh et al, 1993). Unfortunately one cannot surmise

from these works the type and extent of disabilities and impairments that have constituted a basis for categorisation of the patients.

The outcome scale developed by Jennet and Bond (1975) bears a considerable resemblance to that developed by Botterell et al nearly twenty years earlier (discussed above). Their scale, the Glasgow Outcome Scale (GOS) had the following steps: good recovery / moderate disability / severe disability / vegetative state / death after brain damage. This scale has been quite widely used over the last ten years to characterise the outcome after SAH (see, for instance, Kassell et al 1990a,b, van Gijn et al, 1994). One possible explanation for this is that in 1988 the World Federation of Neurological Surgeons recommended the GOS for the classification of outcome in SAH patients (Drake et al, 1988). The value of the GOS has however, been called into question by several authors (DeSantis et al, 1989, Hütter and Gilsbach, 1993, Ogden et al, 1994). It has been demonstrated that in long-term survivors of SAH a good proportion of those who 6 months after the SAH had been classified according to the GOS as having good recovery had marked neuropsychological impairments (Hütter and Gilsbach, 1993). Given the very gross steps on them, these type of outcome scales with mixed impairments and disabilities appear too crude, at least for those dealing with rehabilitation and psychological adaptation after brain damage.

A literature survey

In order to obtain a general overview of the published work dealing with those questions and issues related to this dissertation, a literature search was done for the period 1965 - 1995 September (Medline) and 1974 - 1995 September (Excerpta medica). Using only the key-word "subarachnoid haemorrhage" these searches yielded more then 6500 (Medline) and about 5200 (Excerpta medica) possible references. In a subsequent search under the main caption SAH but using the additional key-words given below, 394 possible references emerged. The actual search terms were categorised as follows:

- Impairments; (key-words: impairment, aphasia, hemiplegia, perceptual disorders, memory disorders / amnesia, cognition, neuropsychology)
- Disabilities; (key-words: disability, disabled, activity of daily living, leisure, work)
- Coping/Adaptation; (key-words: coping, adaptation-psychological, life adjustment-satisfaction, quality of life)
- Rehabilitation; (key-words: rehabilitation, occupational therapy, physical therapy, social work, speech therapy)

Among these 394 titles, 114 considered stroke or other etiologies of brain damage. A further 112 particularly addressed specific treatment modalities in case reports or rather small series ($n \leq 12$). Finally, 13 references were abstracts or letters and 15 focused on research in animals. About half of these were listed at least twice - due to the fact that two searches were performed using different databases and many publications included several of the code words used. After exclusions of duplicates, 73 publications were left. Two of these are parts of this dissertation, and ten were written in languages (for instance Chinese, Finnish, Russian) not interpretable by the author, further four, all published before 1978, could not be made available to the author. In brief, only a relatively small proportion of all publications listed appear to concern impairments, disabilities and adaptation/rehabilitation. In Figure 1, the distribution of the remaining publications is shown under the captions: impairments, disabilities and adaptation/rehabilitation.

Figure 1. Distributions of 56 publications on impairments, disabilities and coping/rehabilitation in relation to SAH, during 1980 through 1995 (September) yielded from literature searches on Medline and Excerpta medica.

As shown, a total of 19 publications concerned themselves with disabilities. However, eighteen of the publications listed with disability as a key word only used the GOS and did not appear to focus in reasonable detail on disability. They are not referred to in this survey. Hence, having gone through all this "stepwise" scrutiny of the publications, it appeared that 39 publications were relevant for this dissertation.

Impairments

All publications under the "Impairments" rubric are concerned with various neuropsychological deficits. *Gade (1982)* showed that memory dysfunctions among subjects operated on for ruptured ACoA aneurysm were, to a large extent, related to the surgical technique used. An amnesic syndrome, still persisting after two years, was found in 82% of the subjects operated upon by trapping, whereas 16% of those who were operated upon by ligation of the neck of the aneurysm had amnesia. *Säveland et al (1988)*, in a two-year follow-up of SAH-patients (n: 56, all treated with early surgery), reported no significant differences in cognitive disturbances between subjects treated with a calcium antagonist and those not receiving one.

In several published articles, the results of the neuropsychological assessment were related to the location of the aneurysm. *Vilkki et al (1989)* concluded in a follow-up study at one year post-SAH that neuropsychological deficits were related to the infarction site and to diffuse brain damage verified on computed tomographic scans. They also reported motor dysfunction in ten percent of the 96 subjects. *Tidswell et al (1995)* found at follow-up, at least six months after operation for ruptured aneurysm, that 65% were cognitively impaired. They did not find any differences in neuropsychological dysfunction between ACoA and other locations. This would tend to support *Hütter and Gilsbach (1992)*, who found no significant correlation between ACoA aneurysms and the subjects' results on different cognitive tests. They observed a trend, however, in which subjects with ruptured ACoA aneurysm tended to have more memory deficits. In a long-term follow-up (at least two years post-SAH) of 20 subjects with aneurysmatic SAH, *Romner et al (1989)* noted a very high prevalence of memory impairment, with LTM dysfunction occurring independently of the location of the aneurysm.

Even after haemorrhages of unknown origin - generally very small bleedings - subjects may have neuropsychological deficits which persist (*Sonesson et al, 1989, Hütter et al, 1994*). In a long-term follow-up (12-84 months post-SAH) of 27 subjects with ruptured ACoA aneurysm, *Stenhouse et al (1991)* found that cognitive impairment occurred in 59% of cases and could be related to cerebral vasospasm. That the various types of memory are affected is dependent upon the extent of the bleeding has been demonstrated by *Larsson et al (1994)*. With the exception of those patients with ACoA aneurysm who had both LTM and STM dysfunction regardless of the size of the bleeding, large bleedings were related to both LTM and STM dysfunction whereas small bleedings were only associated with impaired STM function. In contrast to the foregoing, *Richardson (1991)*, who studied 76 subjects operated on for intracranial aneurysm, concluded after a follow-up investigation at six months that there was little evidence of any generalised cognitive deficits.

Disabilities

Rosenørn and Eskesen (1994) followed 571 subjects with ruptured intracranial aneurysm and related the size of the bleeding to the subjects' "daily functional capacity" (not further defined), occupation and mental outcome. Of the subjects with small and medium aneurysm rupture, only 55% achieved a normal daily functional capacity, with only 49% returning to their previous work, while only one third of the subjects had a normal mental outcome after two years.

Impairments and disabilities

Work as a parameter for evaluating outcome is included in all publications under this heading. *Ropper and Zervas (1984)* reported from a follow-up one year after onset that about two thirds of their SAH-subjects (n:105) could return to work, but only 44% at the same level as previously. Even functions of daily living (PADL, author's interpretation) were included, and they observed that almost half of the subjects were independent, while another 25% were independent but had emotional or psychological deficits which interfered in their daily lives, with the remaining subjects being totally dependent on help from another person in PADL.

The prevalence of reduced working capacity varies from 25% to 59% in different studies (*Shephard, 1983, Bornstein et al, 1987, Ogden et al, 1993b, Mercier et al, 1994*). In the Shephard study, only a minority (7%) of 501 long-term survivors after SAH had reduced working capacity due to hemiplegia. Bornstein et al compared neurological and neuropsychological outcome with working capacity. One interesting result presented by Ogden et al was that 39% of the SAH-subjects were working full-time as home-makers compared to the 12% who stated that they had done so prior to the SAH. No correlations between memory dysfunction and ACoA aneurysms, other aneurysm locations or SAH patients without aneurysms, were found. Mercier was unable to establish any significant differences between cognition or working capacity and treatment with Calcium antagonist when compared with subjects treated with vascular volume expansion. *Kollegger et al (1989)* have reported that organic brain syndrome (not further defined), low Barthel ADL index and focal neurological deficits at discharge are important predictors for the working capacity post-SAH.

Disabilities and coping/rehabilitation

Fogelholm et al (1993) reported that among SAH-subjects treated during the 1980s, the independence in activities of daily living (not further defined) was significantly better than for those treated during the 1970s; 82% in comparison with 64%. They concluded that the SAH-subjects' QoL is significantly increased due to an active treatment policy over the latter decade. This conclusion has in all likelihood been premised upon the ADL grading-scale, as there is no indication of it having been assessed separately.

Impairments and coping/rehabilitation

A group of SAH-patients were included as part (12%) of a larger follow-up study of stroke-patients at a neurological clinic in Helsinki (*Kotila et al, 1984*). All subjects had received rehabilitation according to individual needs. The rehabilitation team drew its members from the following disciplines: neuro-psychology, occupational therapy, physiotherapy, speech therapy. At discharge from hospital, the SAH-subjects as a group seemed to recover better with regard to PADL and work, but age-matching accounted for such differences, however.

Säveland et al (1986) found that only 33% of 49 long-term SAH-survivors had a favourable physical and psychological outcome when examined one year post-SAH. However, if only the initially good risk patients were included, the success rate was 70%. In this study, both a cognitive assessment and a comprehensive (not further defined) evaluation of the quality of life were conducted, in addition to a determination of general adjustment. QoL was not specifically examined, however.

In a follow-up of 22 subjects two years after SAH, *Hårdemark et al (1989)* reported that *all* subjects showed varying degrees of cognitive impairment. Life-adjustment was assessed using a questionnaire and a specific inventory focusing on everyday cognitive problems, as well as emotional and interpersonal problems. The results were not related to cognitive outcome but revealed that women perceived a higher degree of maladjustment in themselves following SAH. In a one year follow-up of 83 SAH-subjects, *McKenna et al (1989a)* observed that the SAH had a very small effect on cognitive function and QoL among the subjects with no neurological deficits. *Hütter and Gilsbach (1993)* emphasise that SAH-patients ought to receive neuropsychological rehabilitation with the aim of preventing secondary psychical disturbances.

Impairments, disabilities and coping/rehabilitation

In a review article from a rehabilitation department, *Clinchot et al (1994)* stressed that it is important for the rehabilitation specialist engaged in the rehabilitation of subjects who have suffered ruptured aneurysms or arteriovenous malformations, to be well acquainted with the background factors of SAH, such as its incidence, potential complications and surgical intervention. Furthermore, a thorough assessment of cognitive, behavioural and social factors is extremely important given that these factors have such great importance for the rehabilitation process.

The ascertaining of QoL, the seeking for a pattern of adjustment, and the ascertaining of incidence and degree of cognitive impairment have formed the basis for a study by *Ljunggren et al (1985)*. They found only one out of 40 long-term survivors of aneurysmal SAH to be totally devoid of signs of cognitive impairment. A reduced capacity for taking initiative, less interest in earlier activities, and a decreased work capacity were reported by almost two thirds of those who expressed changes in energy resources and energy consumption. QoL was not specifically examined. In another article from the same group of researchers (*Sonesson et al, 1987*) the outcome for subjects after late or early operation for ruptured aneurysm was compared. There was no significant difference with respect to outcome between both groups within cognition, emotional adjustment, or work.

Kostron et al (1988) found that SAH-subjects treated with a calcium antagonist had a significantly better outcome concerning neurological, intellectual and social functions when compared to a group without this medical treatment. The authors suggested on the basis of their results that the calcium antagonist improves QoL. In a long-term follow up of 144 patients operated on for an intracranial aneurysm, *DeSantis et al (1989)* compared the SAH-subjects' classification on GOS with a Disability scale (CES) and with the results from a neuropsychological investigation. They were able to show that there was a distinct lack of congruence between the two types of examination and maintained that GOS has substantial limitations when it is a question of assessing work, social habits or emotional life. *McKenna et al (1989b)* noted at a one year follow-up of 100 subjects that decrease in QoL was not related to the SAH for the majority of the patients. They compared their results with those of a control group consisting of patients with a diagnosis of myocardial infarction. *Oder et al, (1990)* describe a more detailed rehabilitation of SAH-patients on the basis of a comprehensive view of rehabilitation. The work has been led from a department of neurology, and unfortunately the majority (62%) of the SAH-subjects in this investigation had an SAH of unknown origin. At the end of the observation period (2-12 years), significant correlations were found between the presence of persisting

neurological and cognitive deficits, disability in ADL and work and the decline in familial and social functioning. The same authors *Oder et al (1991)* also described the prognostic factors for 41 patients suffering spontaneous SAH without demonstrable bleeding source. They found that the long-term prognosis (the mean observation period was eight years) for survival was excellent since there was only a minimal risk (2,5%) of a rebleed. Even the functional outcome was relatively favourable: 27% of the subjects experienced handicaps in social functioning, and only 14% were incapable of working.

Ogden et al (1990) compared the outcome at a five year follow-up for 10 patients with SAH after ruptured aneurysm and five patients with SAH of unknown etiology. All patients had cognitive impairments with no significant difference existing between the groups. The majority had emotional and psychosocial problems. In fact, the no-aneurysm sample experienced a greater decline with respect to work-capacity, fatigue and leisure activities.

Vilkki et al (1990) included 83 SAH-subjects (with a surgically treated aneurysm) who were in active employment at the onset of the SAH, in a follow-up study at one year after SAH. The investigation focused on social competence in relation to computed tomographic findings and cognitive functions; GOS was normal in 66% of cases; work and social relations were normal for 75%, and subjective mental status was normal for 43%. Using discriminant analysis, it became apparent that the outcomes of the cognitive tests were closely related to GOS, work status, social relations, and subjective or clinical status. *Stegen and Freckmann (1991)* , and later *Freckmann et al (1994)*, have followed up 108 subjects one year after SAH using questionnaires, physical and neuropsychological assessments. The authors reported almost normal results in cognitive functions among these subjects. Delay in rehabilitation was related to psychological problems, increased anxiety, personality changes and lack of social contacts. On the basis of these kinds of results, the importance of a psychologist participating in the rehabilitation of SAH-patients ought to be stressed.

Neuropsychological functions and QoL were investigated by *Hütter et al (1995)* and in another investigation, two of the same authors, *Hütter and Gilsbach (1995)* focused on capabilities with cognitive deficits after SAH. The sample consisted of 58 SAH-patients, classified as having good recovery or moderate disability on GOS. Aphasia was the least commonly occurring (11%) disturbance, followed by verbal LTM impairment in 28% of cases, dysfunction on tests of reaction time varying between 13% and 65%, and visual STM impairment in 46%. QoL was decreased according to a self-rating scale in motivation (50%), interest (47%), mental capacity (47%), leisure activities (52%), social relationships (39%) concentration (70%), fine-motor co-ordination (25%) and sleep (25%). Life-satisfaction was significantly reduced for 37% of the sample. Nearly one third of the subjects experienced negative consequences with regard to their working situation. They found only a slight correlation between the degree of cognitive impairment and self-rated impairment (and disabilities, cf. above, author's note). This was in contrast to a proxy impairments rating which correlated well with the degree of cognitive disturbances.

Problems with psychosocial adjustment and a reduced ability to continue with leisure activities have a negative effect on QoL according to *Ogden et al (1994)*. It is not apparent whether QoL has been examined separately in the investigation, however,

although an inventory which includes temperament and emotionality, activities and social behaviour and physical capabilities, was used. The authors assert that problems of psychosocial adjustment which exist for these patients can be overlooked or regarded as trivial. No matter how simple these problems may appear, they can nevertheless be of crucial importance for the individual who came precious close to losing her/his life.

From the point of view of an occupational therapist, it appears somewhat astonishing that among the thousands of publications on SAH, not a single one uses occupational therapy as a key-word, and only in one (Kotila et al, 1984) hint at the use of occupational therapy with SAH. This is true also for social work, and speech therapy, while one publication lists physical therapy as a code word. On the other hand, there has been a steep increase since the early 1980s of articles published on adaptation, disability, rehabilitation and in particular neuropsychology. The interest in describing QoL after SAH has increased during later years, but in the majority of these studies it is not the patient's own experience which has constituted the basis for assessing QoL.

A modified version of Dott's (1933) observation made over 60 years ago, could, based on the literature reviewed here, possibly read as follows:

It is surprising how few of these long-term survivors of patients with haemorrhages from aneurysms on the large basal arteries appear to be offered rehabilitation. The majority have impairments and/or disabilities and their need should allow one to formulate a plan of rehabilitation.

On principles of rehabilitation and occupational therapy

Foucault (1973) described the development of medicine in the western world, in which he considered that the human view of health was individually based rather than characterised by a generalising normative way of thinking; however, late in the 19th century, and during this century, changes have taken place which have meant that medicine and science have gradually assumed a biostatic perspective (cf. Nordenfelt, 1987). According to this view, reality is often broken down into "objectively" observable bits and interpreted through the study of these bits, rather than the psychosomatic whole. The individual is seen in bipolar terms: observably sick or healthy ("normal").

The World Health Organisation (WHO, 1980) subscribes to such a view as evidenced in the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH). The classification is based on describable consequences of illness(es). Impairments are defined here as disturbances at the organ level - "any loss or abnormality of psychological, physiological or anatomical structure or function", whereas disabilities are defined as disturbances at the individual level - "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being". Finally, in the ICIDH-context, handicap is defined as "a discordance between the individual's performance and the expectations of the environment".

Those instruments which have been used for assessing functions/impairments in rehabilitation are mainly premised on a normative way of thinking. This appears fully logical, at least concerning the degree of normalcy of psychological and anatomical functions and structures. However, the ICIDH also appears to apply a biostatic point of view in its definition of abilities/disabilities and handicaps. It operates with a concept which only to a very limited extent allows for a description of how any specific individual may experience her/his situation. From the perspective of the individual, then, such a model is not applicable when planning or evaluating rehabilitative inputs (see for instance Fugl-Meyer and Fugl-Meyer, 1988).

At the department of Rehabilitation Medicine in Umeå, we prefer to regard rehabilitation after brain damage as a coping process with high demands of adaptive skills (cf. Sjögren et al, 1982). Later (see for instance Fugl-Meyer, 1993) a model which statically describes the rehabilitation process has been developed at our department. This model is also based on the concept of coping which, many years ago was defined as adjustment under existential threat (Lazarus, 1966).

The above-mentioned model, which constitutes the conceptual background for this dissertation is shown - in a slightly modified form - in Figure 2. According to the model, a healthy person has functions (at the organ level) that enable her to reach her activity goals - through her repertoires of abilities. If she knows or believes that she can reach her goals she will feel satisfied with different domains of life; emotions which will lead her to perceive that she has

a good quality of life. Goals obviously vary from individual to individual. Hence abilities (activity repertoires) are personal, not normatively generalisable features that exist within a person's field of action. They are therefore related to the individual's social context, which includes environmental factors. In this context it is of particular interest to note that Pörn (1984) stated that a person who is healthy carries with him the intra-personal resources that are adequate to reach his goals.

Figure 2. A model of rehabilitation.

In the case of SAH a subject may (in the terminology of this model) acquire one or more impairments. Some of these disappear within a short time, while others are long-lasting or stay with the individual for the remainder of her life. Depending upon the attainability of pre-morbid goals the subject may or may not experience an aspirations/achievement gap (Michalos, 1980). If such a gap occurs she is disabled. If too little or nothing is done either to find new ways of reaching old goals or to modify old or even find new meaningful goals the disabled person is at risk to feel dissatisfied within a particular domain. If this domain is important for her, her perceived overall quality of life is likely to decrease.

The multifaceted range of impairments and disabilities usually requires teamwork within rehabilitation, teamwork that in addition to nursing staff and physicians, includes many different professionals from the areas of occupational therapy, psychology (or neuropsychology), physiotherapy, social work and speech therapy. One of the rehabilitation professions is occupational therapy which, in its modern form, stems from the moral treatment movement (for refs see Bing, 1981).

A key figure in the history of occupational therapy, often quoted in the introductions of medical dissertations by Swedish occupational therapists (see for instance Bränholm, 1992, Törnquist, 1995), is Adolf Meyer, who emphasised that humans even under difficult conditions must achieve some kind of balance between work, play, rest and sleep. The only way to achieve such a balance was "..... actual practice, a program of wholesome living in the basis of wholesome feeling and thinking and fancy and interests" (Meyer 1922, quoted by Bing 1981). Occupational therapy has, after a long period in which it has been strongly influenced by biostatic and functional approaches (cf. Kielhofner, 1992, Törnquist 1995), begun to return to those basic premises which laid the foundations of the profession. Occupation, a word which has been synonymous with activity in Sweden, is the central element in occupational therapy (cf. Henriksson, 1995). The fundamental assumptions of Adolf Meyer are incorporated as the philosophical foundation of occupational therapy in the Code of Ethics adopted by the Swedish Association of Occupational Therapy (FSA, 1993);

- People are inherently active and capable of developing.
- Peoples' experience and understanding of the world around them presupposes activity.
- The development of people depends on activity and action.
- People are autonomous beings.
- People are social beings who engage in activities in interaction with others.
- People can influence their health by means of activity and action.
- Peoples' health requires a balance of activity and rest.

The major focus of Swedish occupational therapy is now, in my opinion, to prevent disability and if indicated to support a disabled person to regain realistic and fully meaningful activities.

Subjects and methods

Through the chart files of the Department of Neurosurgery all subjects with an SAH (n:578), discharged (whether alive or dead) from that department during 1969 through 1980 were identified. At the commencement of this investigation 252 had died and two lived abroad, this left a target population of 324 subjects. Figure 1 shows the reasons for exclusion and the number of subjects participating in the different parts (I-V) of this dissertation.

Figure 3. The consecutive series of SAH-subjects and reasons for not including subjects in the present investigation (I-V).

All charts of patients with a diagnosis of SAH, were carefully checked and the following data were recorded: age, gender, date of the SAH, Botterell grade at admission (see p. 15), surgery/conservative treatment and aphasia. Additionally a neuroradiologist revised all angiographies to specify the location of the SAH and when appropriate the location of the aneurysm.

I. A questionnaire was mailed to all 324 long-term (2.5-13 years) survivors of SAH. This method was used because of the relatively great geographic area of the region. The prevalence of *self-reported motor and/or language impairments* graded into; no / slight / moderate / marked were explored. Ability to perform *Personal Activities of Daily Living* (PADL, 11 items) and *Instrumental Activities of Daily Living* (IADL, 10 items) were explored. The answering alternatives for the ADL variables were; independent / partly dependent / dependent. For simplification overall PADL and IADL competencies were post-hoc dichotomised independently by two of the authors (M.L. and A.F-M.) into dependent vs. independent. Four additional questions addressed the need for *help/personal assistance* in managing daily life and further six questions dealt with the ability to maintain pre-SAH *leisure activities*. Finally, four questions addressed the *ability to work* (if the subject was at a vocationally active age after the SAH).

The response rate among the non-hospitalised subjects was 94%. Further ten subjects (3%) had been institutionalised in long-term care facilities since shortly after their SAH. Two of these subjects did answer the questionnaire by themselves while five reports were filled in by relatives and three by a nurse. Evidently this indicates poor self-report validity. Therefore the institutionalised subjects were excluded from further detailed investigations/analyses.

Approximately one year later a follow-up investigation was performed (II-IV). The target sample was the 272 long-term survivors who had answered the questionnaire and were still living in the catchment area. A total of 260 subjects (96%) were willing to participate, these were examined and interviewed by an occupational therapist and by a physician. The interviews/examinations were performed either at the department of Neurosurgery or at the hospital nearest the subjects' domicile. Subjects who pre- or post SAH had suffered other brain damages were excluded from this

investigation. In one case the reason for exclusion was a traumatic brain injury, six subjects had had a stroke of other origin than SAH, and four subjects were treated due to mental disorder/dementia which was not clearly related to the SAH. Further two subjects had had an iterated SAH and could therefore not validly report long-term consequences at the time of the follow-up.

At the initial admission to the department, the subjects' gross neurological status was categorised using Botterell's 5-grade scale (Botterell, 1956). Using this categorisation the vast majority (94%) could be classified as "good-risk" patients (Botterell grade I-III). Angiography had been performed for all patients at the initial hospitalisation. In 201 subjects, single (79%) or multiple (21%) aneurysms were revealed. The majority (80%) of these were surgically treated during. Further six subjects had arteriovenous malformations. For the remaining 40 subjects no source of haemorrhage could be radiologically determined. Among the 260 deceased subjects 72% died within six months after their SAH, a further 10% died between 7 and 24 months post-SAH, and at the time of follow-up the remaining 18% had survived the SAH by an average of 56 months (range 27-168).

The parameters used for describing prevalence of impairments were: *Memory (II, III)*; *Language (III)*; *Motor function (III)* and *Perception (III)*. The data obtained were used for analyses of the impact of impairments on *IADL*, the prevalence of which was analysed in (IV) and on *occurrence of depression and change in quality of life (V)*.

Verbal memory function could be assessed in 219 of the subjects (II), 85% of whom had a ruptured aneurysm. The tests comprised immediate free recall (serial positions 1-8 indexing long-term memory, LTM, and serial positions 9-12 indexing short-term memory, STM), final free recall (LTM) after 10 minutes delay and final cued recall (LTM) of words after another ten minutes delay. Eight different word-lists consisting of 12 words, from three categories of words were used. In a digit-span test (an index of working memory, WM) the subject should recall digits, randomly assigned to series of different lengths (from two to nine digits). By comparison with a reference group (n:36) occurrence of dysfunction was empirically determined. In III, IV and V

dichotomies of LTM and STM (into impaired vs. not impaired memory function) were used.

Language function: A psychologist trained in aphasiology assessed the subjects (n:54) who either had been diagnosed as having aphasia at the initial hospitalisation, or had reported language problem in **I** or were judged by the examining occupational therapist to possible to have an aphasia. The instrument used for the assessment in **III** was that given by Reinvang and Engvik (1980). The grading used was marked aphasia, slightly decreased or normal language function. When comparing these data with other results, a dichotomy into impaired vs. not impaired language function was used.

Motor function: was assessed (**III**) using the method described by Fugl-Meyer et al (1975), placing subjects along a 0-100 scale of motor control, categorising motor function into: marked or moderate hemiplegia (score ≤ 84), slightly decreased motor control (score 85-99) and normal motor function (score 100). When comparing these data with other results (**III-V**), a dichotomy (impaired vs. not impaired motor function) was used.

Perceptual function: A total of 237 subjects (**III**) were completely assessed concerning perceptual function, (ten subjects declined to complete all of the perceptual items). Perception was assessed using a method originally developed in Israel (Najenson et al, 1984) and modified by Bernspång et al (1989) to suit Swedish conditions. Among the 15 items six characterise visual perception and nine visuo-motor perception. For each item, the function was dichotomised into normal vs. impaired and perceptual impairment was registered if, for any item, performance was not judged normal.

Instrumental ADL: A total of 244 subjects (three subjects were excluded due to insufficient data registration) were completely assessed concerning change in IADL (17 items) which was focused in **IV**. The items were:

Use of telephone	Make one's bed	Purchasing provisions
Handling money	House cleaning	Responsibility for house-keeping
Visits by relatives/friends	Laundry	Filling in forms
Visiting relatives/friends	Heavy house-work	Managing bank/post matters
Visiting restaurants	Write notes	Responsibility for domestic economy
Shopping	Planning purchases	

The capacity to manage each of these activities was rated by the author of this dissertation during the interview. The ordinal scale used was: decrease to complete dependency / decrease to partial dependency / no change. All items which were performed neither prior to nor after the SAH were rated as no change.

Depression (V). In 121 of those studied in **IV** prevalence of depression (using the Zung instrument, see below) and levels of perceived Quality of Life (QoL) before the SAH and at follow-up (also cf. below) were assessed. Zung's Self-Rating Depression Scale encompasses 20 statements, along a four-step (1-4) scale. Thus, individual scores range from 20-80, where scores ≥ 40 indicate depression (Zung, 1965).

Among the 121 subjects the majority 86% (n:104, 57 women and 47 men; mean age 55 ± 13 years) had been assessable concerning all parameters of impairments and disabilities. The reasons for the 14% drop-out were severe problems with assessments of memory (n:10), perception (n:3) and leisure (n:4). The n:104 sub-sample was representative for the total sample with exception for lower prevalence of language impairment and for IADL, leisure and work. The lower rate of disabilities simply reflects that for reasons of communicability during the investigation the majority of those with language impairment had to be excluded and these subjects were generally quite disabled.

Quality of Life (QoL) was measured using the double visual analogue scales given by Ahlsjö et al (1984). As shown in Figure 4, the subjects assessed their general quality of life prior to the SAH (left line) and their actual quality of life (right line). The difference between the two assessments was measured in millimetres and was categorised as follows: a difference of 5 millimetres in either direction was scored as increased or decreased QoL while differences of less than 5 mm were scored as no change. After this self-assessment the subjects were asked to comment or justify their assessments.

Figure 4. The double visual analogue scales of Ahlsjö et al, 1984, used for assessment of perceived quality of life.

In brief:

Occurrence of impairments were focused in **I** (self-reports: language and motor), in **II** (memory) and in **III** (language, motor, perceptual and memory); while disabilities (PADL, IADL, leisure and work) were addressed in **I** (self-reports) and in **IV** (IADL). Change/no change in QoL was the main focus of **V** together with occurrence of depression. The results of **I**, **II** and **III** were related to the findings in **IV**.

In **V** reported change in leisure and work (**I**) together with registered impairments (**II**, **III**) and change/no change in IADL were related to depression and change/no change in QoL.

Statistics

In the main result section simple crosstabulations (chi²-tests, 1 df or Fishers exact probability tests, when appropriate) are generally used. For multistatistics factor- and discriminant-analyses were applied. The latter were preceded by F-statistics. The chosen level of significance was $p < 0.05$.

Main results

Institutionalised subjects

Of those who returned the questionnaire, ten subjects (3%, six were women and four men) had been institutionalised in long-term care facilities since shortly after the SAH. The time that had elapsed since the SAH was, in six cases, more than ten years. All subjects had motor impairment (seven severe), seven had aphasia (five severe), and they were all PADL-dependent. As previously stated, they were not included in further data-analyses as a check showed that only two of them could validly answer the questionnaire.

Impairments and disabilities

In **I**, the self-reported prevalence of language and motor impairments were 20% and 17%, respectively. For both of these impairments the proportions of moderate/marked vs. slight were nearly 1:1. Cross-tabulations showed close positive associations between these two categories of functions/impairments ($p < 0.0001$). In apparent congruence with these results, the capacity to manage PADL and IADL was 9% and 20%, respectively. However, a further 23% among those who appeared to be PADL-independent reported that they needed help from another person for managing daily life. The prevalence of disability in leisure activities was 48% and of those who were still of a vocationally active age after the SAH, 40% never returned to any gainful employment. As might be expected, both the decrease in ability to pursue pre-SAH leisure activities and the capacity to return to work were significantly correlated to both categories of functions/impairments. Remarkably, more than 60% of those who never returned to work had no motor or language impairments. Furthermore, decreases in leisure-abilities were as common for old-age pensioners as for their younger peers.

In **II**, long-term memory (LTM), short-term memory (STM) and working memory (WM) were defined as three specific memory systems. In Figure 5 the serial positions for recall of word lists are presented. As a group, the SAH subjects performed at a significantly lower level than the control group ($p < 0.05$), except for positions 1-8 on immediate free recall.

Figure 5. LTM; Immediate free, final free and final cued recall of words for the SAH group and the control group as a function of serial position. The shadowed area shows the serial positions of short-term memory (STM).

There was no significant difference between the SAH group and the control group concerning WM, indicating that this memory system is not sensitive to brain damage caused by SAH, whereas STM, in contrast, was in fact highly sensitive. The final free recall task was the most sensitive measure of LTM while the immediate free recall task was the least sensitive. STM and WM were independent of the location of the ruptured aneurysm while subjects with LTM impairment most frequently had aneurysms on the left anterior communicating artery. Subjects without known vasospasm or mass effect (as described by the neuroradiologist) performed at a lower level than the control group only in STM. On the other hand, subjects *with* vasospasm or mass effect had LTM dysfunctions, in contrast to those *without*.

Using a simple dichotomy of long- and short-term memory-functions into impaired vs. not impaired, 73% had impairment of memory. Slightly more than half of these subjects had long-term memory deficits with a similar proportion having short-term memory deficits. The prevalence of language impairments found in **III** was lower (by 50%) than that of the self-reports (**I**). There was, however, a significant association ($p < 0.0001$) between self-reports (**I**) and objectively verified (**III**) language impairments. This was also true for

motor impairments ($p<0.0001$) when comparing the results from **I** with those of **III**, although in **III** 25% in fact were found to have at least some degree of motor impairment. Perceptual impairments (**III**) were much more common (45%) and, with the criteria applied (cf. p. 30), occurred for close to half of this series of non-institutionalised long-term SAH-survivors. Finally, motor and LTM functions/impairments were significantly associated with the three other categories of functions/impairments (Table 1).

Table 1. Correlation - matrix of five different functions/impairments. All items are dichotomised into impairment/no impairment. With one df (degree of freedom) $p\leq0.05$ for $\chi^2 \geq 3.9$, $p\leq0.01$ for $\chi^2 \geq 6.7$, $p\leq 0.001$ for $\chi^2 \geq 10.9$.

	Motor	Language	Perception	STM*
Motor (n:247)	-			
Language (n:247)	$p<0.01$	-		
Perception (n:237)	$p<0.01$	NS	-	
Short-term memory (n:219)	$p<0.05$	NS	NS	-
Long-term memory (n:219)	$p<0.05$	$p<0.001$	$p<0.001$	$p<0.01$

* Short-term memory

In all, 82% of the subjects in **III** were found to have at least one type of impairment. It should be particularly emphasised that the two most common types of impairment were in memory and perception. These categories of functions/impairments are quite often not surveyed during the early period of hospitalisation, in particular perhaps at the time when these subjects fell victim to their SAH, a time when neither occupational therapists nor neuro-psychologists are common ingredients in neurosurgical (after-)care.

Combining the findings of functions/impairments in **III** with those of abilities/disabilities in leisure and work (**I**), impairments of motor function and LTM (Table 2) influenced the ability to return to pre-SAH leisure activities and to work negatively. Return to leisure was also negatively influenced by language impairment (aphasia), while working capacity was negatively influenced by perceptual impairment.

Table 2. Relations between functions/impairments and change/no change in leisure activities and work. With one df (degree of freedom) $p \leq 0.05$ for $\chi^2 \geq 3.9$, $p \leq 0.01$ for $\chi^2 \geq 6.7$, $p \leq 0.001$ for $\chi^2 \geq 10.9$.

	Leisure	Work
Motor	$p < 0.001$	$p < 0.005$
Language	$p < 0.05$	NS
Perception	NS	$p < 0.05$
Short-term memory	NS	NS
Long-term memory	$p < 0.001$	$p < 0.01$

Using factor-analytic techniques, findings on perception from previous studies of stroke (Bernspång et al, 1987, 1989) were substantiated. After SAH perceptual function was thus characterizable as either lower- (two factors) or higher- (two factors) order perception. Moreover, higher order perception could be separated from memory function by the same statistical technique, indicating that perception and memory are separate entities.

As expected, impairment of language was the only impairment which was associated with side of brain lesion, being significantly more common with left than with right hemisphere bleedings. Using the dichotomy impaired vs. not impaired, LTM impairment was significantly more common with anterior than with posterior communicant aneurysms, and perceptual impairment was significantly more common with anterior communicant aneurysms than with aneurysms at other locations.

In IV, dependency in IADL occurred for about half of the sample, which was considerably higher than that reported in the questionnaire (I); but in I fewer items were included. Significantly more women than men were found to have decreased ability to perform home-maintenance activities. This could to a great extent be explained by gender roles, since nearly all the women identified most of the IADL items as their regular chores, while only half to two thirds of the men regarded home-maintenance IADL as part of their routine. No gender differences of this type occurred among singles. Using factor analysis, IADL could be grouped into three factors, labelled by us as: a) *domestic and social*

activities, which explained 37% of the variance and included eleven typical homemaking chore activities and sociable performance b) *administrative chores* (5 items) explained 23% of the variance and c) *handling money/telephone* (2 items) which explained 12% of the variance. Motor and perceptual functions were significantly ($p<0.001$) associated with *domestic and social activities*, whereas long- and short-term memory ($p<0.001$) and language (0.01) were significantly associated with administrative chores. No such significant correlation was found for the factor *handling money/telephone*.

Computing the occurrence of decreased ability to engage in pre-SAH activities within the domains of work, leisure and ADL (I and IV), it was found that only 35% of the non-hospitalised SAH subjects had no decreases in these activities. When one adds the ten permanently institutionalised subjects, it appears that in this consecutive series of survivors of SAH, only 34% have been able to fully regain these pre morbid goals.

Quality of life

The perceived quality of life (QoL) had, due to the SAH, increased for 14% of the sample (n:104), was unaltered for 48% and had decreased for 38% (V). Using Zung's sub-classification of mood (Zung, 1965), twenty-two percent were classified as depressed, and of these about two thirds had minimal to mild depression. Even if there was a significant correlation between the dichotomy of depression and QoL, this association was by no means unambiguous, since nearly half of the depressed sample reported no/negligible change in QoL. No significant correlation was found when comparing the dichotomised variables of function (language, motor, perceptual, long-term and short-term memory) with QoL and with depression. In contrast, both work and leisure were significantly associated with depression among the subjects who were of a vocationally active age at the onset of the SAH. This was also the case for all domestic and social activities.

In order to identify a minimum set of variables that could reasonably well predict QoL in terms of no-negligible change/increase or decrease, all functions/impairments, abilities/disabilities and also mood were introduced into a series of F-statistics. Only four of the 24 variables were significantly associated with reported QoL. These were: ability to pursue leisure activities

($p < 0.001$) being visited by or visiting relatives or friends (in both cases $p < 0.005$) and mood ($p < 0.005$). Including three of these four variables in discriminant analyses, up to 69% of the sample could be correctly classified. The absolute major predictor was leisure activities (discriminant coefficient: 0.70) followed by visits by relatives or friends (discriminant coefficient: 0.40) and mood (discriminant coefficient: 0.20). This indicates that a decreased level of leisure activities and a decreased capacity to maintain a social life are two very important factors in the development of decreased quality of life after SAH, the former in particular, while depression is a lesser, albeit somewhat important third factor.

General discussion

This investigation is based on a *consecutive* series of subjects with SAH, acutely admitted to the only Department of Neurosurgery within the catchment area. It cannot reasonably be regarded as epidemiologically based for several reasons. In addition to the reasons given on page 12, one further reason may be the considerable geographical distances within the region, perhaps in relation to the clinical conditions of some patients, resulting in a relatively low rate of admissions. Given the fairly stable population of approximately 650 000 inhabitants in the northern Swedish hospital region (at the time of investigation), the 578 subjects admitted over a twelve year period would give an average incidence of 7.4/100 000/year. This is clearly lower than that calculated by Fodstad et al (1990) but quite similar to that reported from southern and central Sweden (cf. p. 12). On the other hand, if the suggestion by Rosenørn et al (1987) is correct, viz. that about one third of all new cases of SAH are not admitted to a neurosurgery department, the present findings would mean that the total incidence would be 11.1/100 000/year, only slightly lower than that calculated by Fodstad et al (1990).

From a positive standpoint, it should be stated at the outset that although only 18% of the non-hospitalised former SAH-victims in this consecutive series had no impairment, a total of 35% had no disability and nearly two thirds (62%) of the subjects reported quite similar or even increased QoL when retrospectively assessing present and pre-SAH levels. The primary explanation may be that some subjects (good copers), do not consider that impairments and disabilities affect their overall quality of life in a negative way. However, it may also be

so that in some cases impairments, especially those of memory and perception perhaps, but conceivably even those of motor and language function, may be so slight that they have little perceived impact on activity repertoires.

Adding the ten (all impaired and disabled) institutionalised patients to the non-institutionalised persons led to only a slight increase in the total proportion of impaired (83%) and disabled (66%) survivors of SAH. It can not be stated here that the real prevalence of impairments, disabilities, depressive moods and the levels of QoL are congruent with the present findings because there is little doubt that the real incidence of SAH includes more subjects (both those who die early and those who are long-term survivors). Moreover, this investigation covered a span of time ranging between 2,5 and 12 years after the SAH, which also makes it of dubious value to generalise the findings to all who survive the SAH by at least 2,5 years. However, the interval since the SAH (calculated in 2-year interval-cohorts) did not influence impairments, depressive mood or QoL significantly.

From the occupational therapy point of view, a central finding in this investigation is the high prevalence of decreased ability to maintain pre-SAH activity repertoires within IADL, leisure and work, whereas the capacity for managing PADL was much less affected. The latter finding may be important background to the fact that, as established in the literature survey, so little attention has been paid to comprehensive rehabilitation after an SAH. It may reasonably be stated that many patients are discharged from (neuro-)surgery care in good clinical condition with few, if any, motor and language impairments, apparently able to manage all or most PADL. Having returned home, the considerably more complex activities within IADL, leisure and work can not adequately be performed due not only to obvious impairments, but also in large part to the much more common impairments to memory and perception.

Functions and abilities

The 25% prevalence of motor impairment found in this series of SAH-victims corresponds closely with that reported by Rasmussen et al (1980), Rosenørn et al (1987), Engberg-Stabell (1991), but is clearly higher than the ten percent found by Vilkkii et al (1989), one year post-SAH. On the other hand, we found no previous report on the impact of motor-dysfunction *per se* on post-SAH

activity repertoires such as that found here on the investigated parameters in PADL, IADL and leisure. While Shephard (1983) found that the reduced work capacity was due to hemiparesis/hemiplegia in only 5% of long-term survivors of ruptured aneurysm, we actually found a close correlation between motor dysfunction and work. A simple explanation of the negative effect of motor impairment on activity repertoires within this broad range is that good mobility is a prerequisite for these activities. However, the significant association of motor impairment with all other aspects of impairments investigated here would indicate that if motor impairment prevails, then other impairments are likely to be found. This, we would suggest, may be of importance for those who are in charge of the early treatment.

The objectively found prevalence of aphasia (10% - but considerably higher in the self-reports) in this sample corresponds reasonably well with that found by others (Rasmussen et al,1980, Rosenørn et al,1987, Engberg-Stabell,1991). Of the 58 SAH-subjects classified as having a good recovery or moderate disability on GOS, Hütter et al (1995) found language dysfunction in 11% at post-SAH follow-up 1-5 years afterwards. The particular effect of aphasia on administrative IADL chores appears very logical as does the negative effect of aphasia on leisure. These effects are well known from a wealth of reports on stroke patients, and imply that communication is essential for man's activity repertoires, simple as well as complex.

The relatively common occurrence of perceptual impairment (45%) appears lower than can be deduced from other reports where combined neuropsychological tests have been used (Ljunggren et al, 1985, Sonesson et al, 1987). It is much higher, however, than that reported by McKenna et al (1989b), who also used combinations of neuropsychological batteries and suggested that the cognitive function was unaffected after an uncomplicated SAH. Good motor and visuo-spatial perceptual functions are obviously prerequisites for the continued performance of domestic and social activities, and indeed work, as demonstrated by the close association between these two functions and the ability to perform domestic, social and work activities.

That 73% of the long-term SAH-survivors in this consecutive series had a memory impairment is a finding similar to that of an investigation from the southern part of Sweden (Ljunggren et al, 1985) in which about 80% of long-

term SAH-survivors with "good neurological recovery" had learning- and memory disturbances. However, the same investigators later reported an 89% prevalence of memory impairment in post-aneurysmatic SAH subjects investigated 12-103 months after the vascular incident (Sonesson et al, 1987).

While working memory was insensitive to the brain damage caused by the SAH, short-term memory was very sensitive. The latter finding appears to be supported by Moscovitch (1982), who suggested that this dysfunction might be due to diffuse cortical loss rather than to damage of specific structures. The 52% prevalence of short-term memory is identical to that reported on visual short-term memory by Hütter and Gilsbach (1993). Long-term memory dysfunction was particularly common with (left) ACoA aneurysms, but could also be found in subjects with ruptured aneurysm in other locations, suggesting that other areas of the brain are also influential for verbal long-term memory function. This would seem to support Storey (1967), who found that memory dysfunctions were more frequent in patients with aneurysms on the middle cerebral artery and Takaku (1979), who reported a high incidence of this disorder after ruptured vertebro-basilar aneurysm. In contrast to this, some authors have found no significant association between cognitive dysfunction and ACoA aneurysm (De Santis et al, 1989, Vilkki et al, 1989, Ogden et al, 1993b).

We have not located any reports on the impact of memory *per se* on ADL. It appears logical, however, that both long-term memory and short-term memory should be significantly associated with the ability to perform administrative IADL chores. Neither have we been able to locate reports pointing to the negative effect of long-term memory on leisure and work. Tentatively, it would appear reasonable to suggest that both types of activity require planning, and hence good memory.

There is some incongruence between reported PADL-independence (91%) and self-reported need (23%) for assistance from relatives and/or home-helps among those who reported PADL-independence. We are not aware of other studies which point to such differences. One explanation may be that early on after the SAH many subjects may establish a regressively dependent "sick-role" as also found in post-stroke hemiplegic subjects (Sjögren and Fugl-Meyer, 1982). Moreover, Ropper and Zervas (1984) found that 1-2 years after an

aneurysmal SAH (good-risk patients), 46% were independent in ADL, an additional 25% were independent but had psychological difficulties that "interfered" with their daily lives.

It appears that if IADL has been considered at all in the literature on long-term survivors of SAH, it has been included in a broad and often poorly defined ADL concept (see for instance; Artiola i Fortuny and Prieto-Valiente, 1981, Ropper and Zervas, 1984, Oder et al, 1990, Fogelholm et al, 1993, Rosenørn et al, 1994). It may be hypothesised that IADL involves such a degree of complexity that the prevalence of IADL disability after subarachnoid haemorrhage is considerably greater than that of PADL disability, and this was, indeed, the case. Using a modification of Matsutsuyu's (1969) interest check-list, it was recently found that home-caring (chore) activities were significantly more common, considered more important and performed more frequently by 25-55 year old women than in males of the same age (Bränholm and Fugl-Meyer, 1994). The northern Swedish sample studied here evidently conformed, to a large extent, to "classical" gender-roles (National Swedish Board for Consumer Policys, 1984) as demonstrated by the considerably greater proportion of women than men performing home-maintenance activities.

The significant associations between the majority of IADL items appear to indicate that additive (numerical) indices, and perhaps particularly such indices that merge PADL and IADL (see for instance Fugl-Meyer et al, 1980, Sarno et al, 1973) are of dubious value. This postulate is further substantiated by the factor-analytic findings of three distinct IADL-factors, which were logically explainable.

The level of disability in work agrees with Bornstein et al (1987) but is lower than the 59% reported by Ogden et al and the 55% found by Rosenørn et al (1994). The reported level of disability in leisure is close to that reported by Hütter et al (1995). However, all their subjects were classified as having good recovery or moderately disability on GOS. In this context it appears important to emphasise the fact that a 40% drop-out of previous vocational ability must be seen as a financial burden for society at large. The loss of capacity to actively engage in IADL, leisure and work taken together appear to illustrate

that a good proportion of former SAH-patients are left with an isolated lifestyle.

On mood

The present findings are in keeping with those of Storey (1967), who classified about one fourth of 261 SAH-subjects as depressed, with only a few of these having a more severe depression. Ljunggren et al (1985) reported that about one third of long-term survivors (average 3.5 years) of an SAH experienced recurring periods of depression or dysphoria. In recent years, the Beck Depression Inventory has been used in several follow-up investigations of SAH-subjects. Using this methodology Ogden et al (1993b) found nearly the same prevalence of depression as we did in 89 SAH-subjects, one year after haemorrhage. Tidswell et al (1995) found a somewhat lower prevalence (16%) at follow-up 6-45 months after SAH, whereas Hütter et al (1995) reported a somewhat higher (30%) prevalence of depression in 1-5 year post-SAH.

The close association between occurrence of depression and decreased ability concerning IADL, leisure activities and work cannot be explained unequivocally. In retrospect, it is difficult or impossible to analyse to what extent decreased functions and abilities cause depression or, on the other hand, to what extent depression – through anxiety, fatigue, and passivity, for instance – causes disabilities.

On quality of life

Ahlsjö et al (1984) used in principle the same method as that applied here when they had stroke-survivors assessing their past and present QoL two years after stroke. They found a considerably greater proportion of decreased QoL than we did. Their higher prevalence of decreased QoL may be attributable to methodological differences. It appears that they recorded all changes, however small, whereas we regarded differences of less than ± 5 millimetres as no/negligible change. Furthermore, the present group of post-SAH victims were somewhat younger than their post-stroke counterparts, and it is quite well established that younger people find it easier than older people to cope with major disabilities.

As previously observed in the literature survey several authors (Kostron et al, 1988, McKenna et al, 1989b, Fogelholm et al, 1993) have concerned

themselves with QoL after SAH. It appears that in their reports decrease in QoL is assessed by inference, however. If impairments or disabilities prevail, these authors assume that QoL is decreased. Such findings are far from substantiated by the present results. In our model of the rehabilitation process, see Figure 2, the patient's own experience of life-satisfaction or QoL is the single most important aspect of outcome. Hence the present findings indicate that following SAH, leisure and sociability are the major determinants of the experienced QoL. This is - at least partially the assumption of Ogden et al (1994), who maintain that problems of psychosocial adjustment and a reduced ability to continue with leisure activities have a negative effect on QoL. On the other hand, Hütter et al (1995) recently reported that 37% of their good recovery/moderately disabled survivors (of 1-5 years) of SAH had decreased life satisfaction. This is a proportion which is very close to the 38% decreased QoL found here. In this context it should be noted that QoL and general life satisfaction are often regarded as synonymous concepts (cf. Veenhoven, 1984).

We regard failure to cope adequately the major cause of the relatively high prevalence of decreased QoL. Both the subject who has experienced a major catastrophe and those nearest to him/her must cope with the catastrophe *per se* and with its possible sequelae, such as physical impairments and disabilities. The vast majority of our SAH-subjects and their relatives were given no or very little professional assistance in order to regain meaningfulness in life and to help them cope with the psychological impact of the SAH. Only a small minority, for instance, had been given the opportunity to participate in comprehensive rehabilitation programs. Many of the patients may have chosen maladaptive psychological defence mechanisms (Sonesson, 1992), the most common of which is that of regressive dependency with passivity (that is psychologically caused by loss of activity repertoires), and is often coupled with depression/melancholia, anxiety, and loss of self-esteem; this latter accompanied by more or less pronounced feelings of stigmatisation (cf. Sjögren, 1982).

There is an apparent need for a rehabilitation program which focuses on activity repertoires and - perhaps in particular - such activities as explore and enhance the possibilities for an SAH-subject to maintain a lifestyle in which she/he participates socially and actively with others. A good rehabilitation

program should ultimately result in the facilitation of the coping process towards an optimal QoL.

A sketch for optimal coping support (rehabilitation)

It appears reasonable to conclude that more than half of the long-term survivors of SAH are in need of rehabilitative inputs including psycho-social support. In order to identify such people, a follow-up program is needed which includes *all SAH-subjects*. A program for rehabilitation after SAH presupposes close collaboration between a department of (neuro-)surgery and a department of rehabilitation or its equivalent. The program ought, in the long-term, to aim at supporting at the coping process in patients and significant others.

Early assessment of rehabilitation needs

* During the period of neurosurgical care, the patient should be assessed by a rehabilitation physician, an occupational therapist and a physiotherapist. In the (neuro-)surgical department, certain resources for psycho-social support should be accessible. The early assessment should form the basis of an individual rehabilitation plan, which can be forwarded to the next point in the medical care process, and through it those patients who are in need of early rehabilitative inputs may be identified on the basis of pronounced cognitive-, perceptual-, motor- or language impairments, which in their turn can be expected to incur decreased ability not only in PADL, but also in IADL, leisure and work. If possible, pre-morbid activity preferences (goals) should be noted. It is of particular importance that there should be coordination between the various links in the rehabilitation chain.

* Rehabilitation plans ought to be set up even for those patients whose rehabilitation needs are not acute prior discharge to the patient's home. In this group one can include those patients who have less pronounced impairments but who are independent within PADL, and where one can expect a convalescent period to take place. The rehabilitation plan is remitted to the local rehabilitation clinic or its equivalent, where access exists to a complete rehabilitation team, together with a follow-up proposal regarding rehabilitative needs within approximately one month.

* During the period of neurosurgical treatment it is not usually relevant to assess neuropsychological functions in more detail or activity repertoires within IADL, leisure and work. A large number of the patients do not appear to need an early rehabilitation plan on the basis of the rather simple assessment methods which are applied regarding the time available during the neurosurgical care period. However, even these patients ought to be followed up after a period of convalescence.

Follow-up assessment of rehabilitation needs

* A follow-up assessment ought to take place approximately three months after discharge and should be coordinated between a department of (neuro-)surgery and a department of rehabilitation.

* The repertoire which every individual possesses within the different domain of activity varies according to the individual's interests, social situation, social network, environment, education and work situation. In rehabilitation, and particularly in the area of occupational therapy, it is important that the treatment program for SAH-subjects focuses on the vital goals in the individual's daily life. The overall aim of treatment should be that the individuals, as far as is possible, be able to maintain their life roles in different domains of life. Hence, and as stated (cf. p. 25), realistic activity repertoires and goals should be the main focus of an adequate rehabilitation program. This may mean that if too little or nothing is done either to find new ways of reaching old goals or to modify the old goals, or even to find new meaningful goals, the disabled person runs the risk of feeling dissatisfied within a particular domain. If this domain is important for her, her perceived overall quality of life is likely to decrease. From this point of view, the starting point for a program for late rehabilitation can be the individual's abilities, and here, perhaps, is the main role for occupational therapy.

* At the follow-up, the occupational therapist ought to focus on the individual's roles, habits and interests within the various spheres of activity. If the individual has a decreased ability to reach what are for her vital goals, thorough assessments of functions/impairments and abilities/disabilities are indicated. In such cases, the patient should be remitted to a rehabilitation clinic or its equivalent.

*Throughout the rehabilitation process, attention should be paid to those people in the patient's network as they often need early, adequate information and empathy. This is particularly true if relatives or significant others are likely to bear heavy burdens of responsibility in the event that roles that one has become accustomed to within the family or at the workplace can no longer be upheld.

* The rehabilitation process is one which may last for several years. Adequate long-term follow-up by recurrent visits to the rehabilitation team or by routine questionnaires can therefore be indicated.

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