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# Coping, Psychiatric Morbidity and Perceived Care in Patients with Aneurysmal Subarachnoid Haemorrhage

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ACTA  
UNIVERSITATIS  
UPSALIENSIS  
UPPSALA  
2009

ISSN 1651-6206  
ISBN 978-91-554-7653-3  
urn:nbn:se:uu:diva-109761

Dissertation presented at Uppsala University to be publicly examined in Enghoffsalen, Entrance 50, Akademiska sjukhuset, 751 85, Uppsala, Saturday, December 12, 2009 at 09:15 for the degree of Doctor of Philosophy in Medicine. The examination will be conducted in Swedish.

### **Abstract**

Hedlund, M. 2009. Coping, Psychiatric Morbidity and Perceived Care in Patients with Aneurysmal Subarachnoid Haemorrhage. Acta Universitatis Upsaliensis. *Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine* 496. 53 pp. Uppsala. ISBN 978-91-554-7653-3.

Many patients with an aneurysmal subarachnoid haemorrhage (SAH) exhibit difficulties in rehabilitation, even in cases of a good prognosis. The present project investigates this using qualitative methods and standardised outcome measures.

Patients with SAH treated at Uppsala University Hospital between 2002 and 2005 with an expected good prognosis were consecutively included. In addition, nurses working with such patients were interviewed.

Outcome was assessed in terms of perception of care, psychiatric health, coping and health related quality of life (HRQoL).

Qualitative content analyses revealed eight categories, which were divided into two patterns, *Confident or Pessimistic perception of recovery*, largely on the basis of the presence or absence of depression.

Eighty-three patients were assessed by The Structured Clinical Interview for DSM-IV, Axis I (SCID-I). Forty-one percent fulfilled criteria for any psychiatric disorder seven months after SAH and 45 % presented with a history of lifetime psychiatric morbidity. Logistic regressions indicated that a psychiatric history was related to a higher risk of psychiatric problems seven months after SAH, as well as a lower return to work.

SAH patients had lower HRQoL than the general Swedish population; almost entirely in the subgroup with a psychiatric history prior to the SAH. Those with a psychiatric history used more evasive, fatalistic, emotive and palliative coping strategies associated with inability to handle illness. Multiple regressions revealed that a psychiatric history and use of coping were independently associated with HRQoL, albeit more in the mental than the physical domains.

Qualitative content analyses revealed that nurses viewed patients' support needs as a process ranging from technological to emotional care. Shortcomings in the communication between nurses in acute and rehabilitation settings on the subject of support were acknowledged.

The results underline the importance of early diagnosis of coexisting psychiatric illness and the need for an intact health care chain.

*Keywords:* subarachnoid haemorrhage, health related quality of life, depression, nursing care, post traumatic stress disorder, psychiatric disorders, coping

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ISSN 1651-6206

ISBN 978-91-554-7653-3

urn:nbn:se:uu:diva-109761 (<http://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-109761>)

# List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Hedlund, M., Zetterling, M., Ronne-Engstrom, E., Ekselius, L., Carlsson, M. (2009) Perceived recovery after aneurysmal subarachnoid haemorrhage in individuals with or without depression. *Journal of Clinical Nursing*. In press.
- II Hedlund, M., Zetterling, M., Ronne-Engstrom, E., Carlsson, M., Ekselius, L. (2009) Depression and posttraumatic stress disorders after aneurysmal subarachnoid hemorrhage in relation to lifetime psychiatric morbidity. Submitted for publication.
- III Hedlund, M., Ronne-Engstrom, E., Carlsson, M., Ekselius, L. (2009) Coping strategies, health-related quality of life and psychiatric history in patients with aneurysmal subarachnoid haemorrhage. Manuscript.
- IV Hedlund, M., Ronne-Engstrom, E., Ekselius, L., Carlsson, M. (2008) From monitoring physiological functions to using psychological strategies. Nurses view of caring for the aneurysmal subarachnoid haemorrhage patient. *Journal of Clinical Nursing*, 17(3):403-11.

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# Abbreviations

DSM	Diagnostic and Statistical Manual of Mental Disorders
HRQoL	Health Related Quality of Life
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
JCS	The Jalowiec Coping Scale
PTSD	Posttraumatic stress disorder
RN	Registered Nurse
RLS85	Reaction Level Scale
SAH	Aneurysmal subarachnoid haemorrhage
SCID-I	Structured Clinical Interview for DSM-IV, Axis I Disorders
SF-36	The Short-Form 36 Health Survey
WFNS	World Federation of Neurosurgical Societies



# Introduction

Experiencing an aneurysmal subarachnoid haemorrhage (SAH) is a devastating event and outcome, with respect to both life and function is depending on several factors. For the immediate survival neurosurgery and highly advanced neurointensive care are crucial and undisputed. Long term recovery is related to the cerebral injury, but also to less well characterized individual factors. Many research groups are currently evaluating the contribution of such factors in order to enable the most successful recovery possible for the individual concerned. The present thesis is a part of this exploration.

The onset of SAH is often perceived as very traumatic, as illustrated by the following quotation from one of the participants.

“I remember being at work; suddenly I heard what sounded like a gunshot inside my head. I started to vomit and a terrible headache hit me, for an instant I thought that I had been shot, but there was no blood. Then I became horrified! What had happened to me? It was unlike anything I’d ever experienced before. I was sure that I was going to die. Who would take care of my children if I died?”

*Woman, 50 years old, living with two teenage children*

## Epidemiology of SAH

Stroke is one of the leading causes of death and disability in the adult population worldwide (73). The overall annual incidence of stroke in western countries is around 300-500/100 000 (112) and SAH comprises approximately 5% of all cases (120), i.e. about 15-25/100 000. There are, however large variations in the annual worldwide incidence of SAH. Finland, e.g., has a high rate of 22.5/100 000, while Beijing in China exhibits a much lower rate of 2.0/100 000 (46).

SAH mainly occurs in adults, but those afflicted are generally younger, i.e. in their fifties, than patients with stroke of other aetiologies (51), who are mainly in their seventies (129). A meta-analysis, however, revealed that the mean age at SAH onset has increased from 52 to 62 years between 1970 and 2002 (81). SAH is more common in women than men (5). Known risk factors are high blood pressure, heavy alcohol use and cigarette smoking (26).

Moreover, a positive family history of SAH represents a higher risk (100), first-degree relatives having a 3 to 7 fold increased risk (121).

The onset of SAH is often dramatic with a sudden severe headache (71). The case-fatality rate varies between approximately 8 % and 67 % in population based studies (81), 15 % die before hospital admission (41) and 10 - 20% of survivors are left disabled with reduced ability to care for themselves (41). The case-fatality rate has decreased in recent decades, probably due to improved diagnostic techniques and management including neurointensive care (13, 41).

## Neurointensive care of patients with SAH

### General

The onset of dramatic symptoms related to the SAH forces the affected to seek medical attention. CT (computed tomography) is often the first line examination and if the brain imaging is negative but the suspicion remains lumbar puncture is commonly used as a second investigation (121). By far the most common cause of SAH is a spontaneous rupture of an intracranial arterial aneurysm, which results in an abrupt increase in intracranial pressure (ICP), sometimes leading to a period of global ischemia (121). There is a risk for repeated bleeding, which is related to poor prognosis. Consequently, the aneurysm must be eliminated rapidly, which is done either surgically or by endovascular technique (120).

To minimize brain damage due to intracranial processes that sometimes occur after SAH, so-called secondary-insults, patients are admitted to neuro-intensive care units (86). Besides the risk of repeated bleeding there is a risk to develop local vasospasm close to the bleeding aneurysm a few days after the onset, which can lead to ischemic stroke symptoms of varying severity (61). Another complication is hydrocephalus, which often leads to changes in mental status and level of consciousness and is managed by means of ventricular drainage (120).

### Nursing

As mentioned above, preventive measures and continuous observation in order to avoid secondary insults are the main features of neurointensive care and constitute crucial nursing tasks (86).

Among other important intensive care nursing tasks is to provide emotional support and information about the care to patients and their family members (15, 125). Basic nursing care includes pressure sore prophylaxis and management of patients' daily hygiene. Furthermore, much of the life saving management of patients with SAH takes place within the nursing

discipline and some key features are continuous observation, nutrition management, pain management, prevention of vein thrombosis and pulmonary embolism as well as pharmaceutical administration (121). A sudden increase in intracranial pressure enhances the risk for ischemia (110), motivating the need for continuous monitoring of neurological functions as well as physiological parameters, such as level of consciousness and blood pressure (14). Swift detection of ‘warning signs’ of secondary insults is vital (86) and a multidisciplinary approach by skilled nurses is needed in order to correctly interpret such changes and alert physicians (17). Patients in neurointensive care units following an SAH also need nurse administered drugs, e.g. calcium antagonists, which protect against cerebral vasospasm (61). Moreover, nurses play an important role in hydration and fluid management in acute SAH patients (16).

## Rehabilitation of patients with SAH

### General

The rehabilitation of patients with SAH is similar to that of patients with other forms of stroke. The organisation of stroke rehabilitation differs between countries and regions. In some regions stroke rehabilitation is generally performed by a multidisciplinary team comprising e.g. physicians, nurses and physical therapists. This is carried out at specialized stroke units providing care exclusively for stroke survivors (58).

It has been suggested that in order to provide the best possible care, it would be desirable for patients need of stroke rehabilitation to be estimated within 24 to 48 hours of admission and thereafter on an ongoing basis for as long as necessary (89).

### Nursing

Kirkevold (1997) used a theoretical approach to describe two perspectives on acute stroke rehabilitation nursing, namely a ‘*coordinating role*’ comprising the dissemination of vital information to other health professionals (experts) as well as coordinating therapeutic management and a ‘*unique role*’ involving patient centred care such as helping with getting dressed and personal hygiene. In the ‘coordinating role’ the nurse is considered an assistant who continues therapeutic management when the experts, such as physical therapists, are unavailable. Furthermore, nurses have an overview of the patients’ various forms of treatment which makes them important contributors at patient conferences (58). Nurses in multidisciplinary stroke rehabilitation may have both a patient-centred and a co-ordinating role (72).

There are few studies on nursing that explore the long-term rehabilitation of SAH patients. Jarvis and Talbot (2004) suggested that optimal nursing aimed at promoting rehabilitation following SAH continues after discharge and involves a specialized SAH nurse who undertakes home visits to patients over a 12 month period in order to prevent psychological sequels and facilitate recovery (50).

## Psychiatric disorders

Members of the World Health Organization (WHO) are obliged to use the International Classification of Diseases (ICD) for reporting morbidity and mortality statistics (133). The Diagnostic and Statistical Manual of Mental Disorders (DSM) was developed to further enhance the ability to describe psychiatric morbidity in accordance with homogeneous categories (2, 3). Moreover, the development of structured diagnostic interviews, such as the Structured Clinical Interview for DSM-IV, Axis I (SCID-I), based on the DSM-IV classification system, has facilitated the diagnostic procedure and improved the accuracy of the identification of mental illnesses (28). SAH patients' history of mental health has, so far, not been subject to investigation by means of the SCID-I.

Psychiatric disorders are common in the general population and a severe burden for those affected. In two population based epidemiological surveys from Norway and the US, the lifetime prevalence of all psychiatric disorders was 52.4% and 46.4% respectively (56, 62). An epidemiological survey based on a Norwegian population in a rural setting had a somewhat lower prevalence rate of 30.9% for lifetime psychiatric disorders (63).

Furthermore, psychiatric morbidity such as depression in the aftermath of various medical conditions seems to have a negative effect on recovery.

## Psychopathology after subarachnoid haemorrhage

Several studies have suggested that in the aftermath of an SAH, patients have a considerable psychopathological burden, including depression, anxiety and posttraumatic stress disorder (PTSD) (7, 78, 91). Astheno-emotional disorder, which is characterised by symptoms such as fatigue, concentration difficulties and memory dysfunction (96), and emotional-motivation blunting disorder with symptoms of emotional and motivational reduction (95) have also been described.

## Depression after stroke and SAH

The DSM-IV criteria for a major depressive episode state that there should be five or more symptoms over a 2 week period (criterion A), including de-

pressed mood or loss of interest. The symptoms should not meet the criteria for a mixed episode (criterion B), but demand functional impairment or significant distress (criterion C). The symptoms should not be a physiological effect caused by a substance or a medical condition (criterion D). The final criterion (E) states that the symptoms should not be better explained by bereavement (3). Symptoms of minor depression are also associated with suffering and functional impairment (3). Depression constitutes a substantial burden for the individual, his/her family and society (52). Furthermore, recent literature suggests that a previous history of depression implies an increased risk of mental health problems in relation to stressful events (8).

A systematic review of 53 observational studies revealed that approximately one third of patients with stroke, irrespective of the aetiology involved, reported depression (35). Although the prevalence rates for depression vary in line with the time from stroke onset, there seems to be a peak at three to six months after the stroke event and continuously high rates for up to three years (128).

Up to 20 % of patients with SAH experience persistent symptoms that can be classified as depression 16 months after the onset (78). There are, however, substantial differences in the prevalence of the reported occurrence of depression after SAH, varying from 5 % after two years (38), 9 % after nine months (91), 10 % after 18 months (92) to 20 % after 16 months (78).

## Posttraumatic Stress Disorder

In the 1970's two types of responses to terrifying events, *intrusion* and *avoidance* were described (42). In 1980 posttraumatic stress disorder was included as a category in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) by the American Psychiatric Association (131). In addition to the symptoms of intrusion (criterion B) and avoidance (criterion C), the DSM-III criteria for PTSD also contained hyperarousal symptoms (criterion D). Furthermore, an exposure requirement (criterion A) and a duration of six months (criterion E) were added (2). In the revised fourth version of the DSM (DSM-IV), criteria A and E were amended. Criterion A was widened and duration was reduced to one month. In addition, a new criterion, F, was introduced that required functional impairment or significant distress (3).

Criticism of the PTSD concept can be found in recent literature, both due to the definition of PTSD as a single disorder and the assumption that it is caused by a terrifying event (9, 77). The critics suggested that the symptoms can be considered non-specific and associated with other symptoms such as depression, personality traits (9, 77) or pre-existing forms of vulnerability such as genetic components (37).

Once PTSD has developed it remains in up to 40 % of affected individuals (76). Furthermore, in the majority of patients, PTSD is accompanied by

another disorder, such as depression or substance use disorder. Individuals with PTSD experience the symptoms for approximately 20 years and miss four days of work per month as a result (55). Moreover, a majority of those affected do not seek care for their persistent PTSD symptoms (55) but tend to seek help for somatic problems instead (18). The reason for this may be found in the avoidance cluster (55).

It was not until the late 1990s that the first assessment of PTSD symptoms was performed in SAH patients, when Berry (1998) used the DSM-III criteria to assess PTSD in patients with good physical recovery who had been referred from a neurosurgical department for psychological evaluation (7). Out of 28 patients, nine (32%) met the diagnostic criteria for PTSD. Reports demonstrate that the prevalence of PTSD after SAH exhibits great variation from 6 % after eighteen months (92), 19 % after three months (103), 32 % after six months (7) to 60 % after three months (91).

## Coping

Research that contributes to the understanding of psychological distress following stroke has been performed within the theoretical model of stress and coping predated by Lazarus and Folkman (66) and Lazarus (67). According to this model, the cognitive process of *appraisal* is a key concept and there are differences in stimulus responses to similar situations over time inside and between individuals. *Primary appraisal* is the individual's judgment of the potential threat; *secondary appraisal* is his/her thoughts about how to respond to it (67). Coping can be defined as 'constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of a person' (66).

Coping strategies refer to an individual's thoughts and actions aimed at managing perceived stress and may facilitate or hinder an individual's adaptation to stressful events such as SAH. Coping strategies are often divided into two categories; *problem-focused coping*, aimed at doing something to change the situation, and *emotion-focused coping*, aimed at regulation of the emotional distress caused by the situation (66). Individuals tend to use more problem-focused coping in situations appraised as controllable, while those appraised as uncontrollable are associated with emotion-focused coping (30). It has been suggested that some coping strategies are more beneficial than others for improving the health outcome, and problem-focused coping has been associated with success (85). Other coping strategies, such as emotive, evasive and palliative, have been linked to inability to handle illness (69).

## Coping and SAH

The use of coping strategies after stroke may have an impact on recovery (20). It has been suggested that SAH patients use less social supportive coping strategies and more emotion-focused coping compared to controls (119). Passive coping seems to be associated with reduced HRQoL two to four years after the onset of the SAH (132). Furthermore, maladaptive coping strategies have been linked to PTSD following SAH (82). It has been suggested that the effectiveness of different coping strategies changes over time, where avoidant coping strategies prove beneficial in the initial period after a stressful event, while non-avoidant coping strategies are more suitable for long term adaptation (114).

## Health and health related quality of life (HRQoL)

### General

The World Health Organization (WHO) defines health as ‘...a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (118). The International Classification of Functioning, Disability and Health (ICF) complements the WHO’s International Classification of Diseases – 10<sup>th</sup> Revision (ICD), which contains information on diagnosis and health conditions, but not on functional status. The ICF is structured around three broad components; body functions and structure, activities, i.e. related to tasks and actions by an individual, and participation, i.e. involvement in a life situation, and also contains information on severity and environmental factors. Functioning and disability can be viewed as complex interactions between a health condition of the individual and a contextual factor in the environment as well as personal factors (135).

Health related quality of life (HRQoL) is a multidimensional concept comprising the individuals perception of the quality of his/her physical, psychological, social and existential well-being (4) and is an important indicator of outcome in many medical conditions.

There are several instruments for assessing HRQoL, of which some are generic. Among the most common instruments are the Short Form 36 Health Survey (SF-36) (113) and the EQ-5D (1). SF-36 is frequently used to measure HRQoL in SAH patients (19, 101). Other instruments are disease specific. The Stroke-Specific Quality of Life scale (SS-QOL) is an example of an instrument that focuses on deficits after brain injury (130).

### Health Related Quality of Life (HRQoL) after SAH

Many patients quality of life seems to be negatively affected after SAH (10, 101). One study reported a substantial decrease in quality of life four months

after the onset of SAH (53). However, male sex and the absence of disability seem to be protective features. Cognitive deficits after SAH are related to poorer HRQoL (75), as are sleep disturbances (102) and psychiatric sequelae (82, 132). Studies have revealed that a drop in HRQoL after SAH can be a long term problem (44) and that factors such as the severity of the initial bleeding and neurological status on admission may influence this decrease (45). However, there is evidence of a considerable decrease in HRQoL also in a subgroup of patients with good prognosis (10, 126). A study of 610 SAH patients who regained independence during their hospital stay revealed that 50 % were affected in terms of their ability to work, where one out of four had ceased working and an equal number worked shorter hours per day with less responsibility. Furthermore, several patients experienced social difficulties related to the SAH for up to ten years after onset (126). In another study, one third of the patients had not return to fulltime work five years after the onset of SAH (12). Finally, in a Swedish longitudinal study of 14 patients with a good neurological outcome after SAH or traumatic brain injury, 80 % reported that life was satisfactory and 60 % had returned to work five years after the onset (106).

Mood disturbances (132) and PTSD following an SAH seem to be negatively associated with HRQoL (82).

## Aims of the present study

This thesis is part of a multidisciplinary project on different aspects of recovery from SAH conducted at Uppsala University Hospital Neurointensive Care Unit, which is one of six national units and covers the central part of Sweden and the Finnish province of Åland, representing a total catchment area of approximately 1.900.000 inhabitants. The annual incidence of ruptured aneurysm is 5.5/100 000 (97).

A substantial group of patients with a good prognosis reported problems during the recovery process. The focus of the present project was to assess this phenomenon from different perspectives.

The project is based on the concept that recovery from SAH may be influenced both by factors related to the SAH itself and by non-SAH related factors such as perception of care, psychopathology prior to the SAH and coping resources.

Few researchers have addressed the relationship between a lifetime history of psychiatric disorders and mental health in the aftermath of SAH. Furthermore, previous observations that SAH is associated with great psychological distress and poorer HRQoL, have not been fully explored, which is also true of SAH patients' ability to handle stress. Moreover, patient's view on care and recovery needs to be further illuminated, as well as nurses' views on the care of SAH patients.

To deepen the understanding of the aneurysmal SAH experience and seek answers to the research questions the author of this thesis used both qualitative methods, and standardized outcome measures.

The specific aims were

1. to describe what participants with no or only minor neurological deficits perceived as consequences of their SAH and what they considered important for recovery,
2. to assess lifetime psychiatric disorders in patients with SAH using strict DSM-IV criteria and evaluate the incidence of PTSD and depression seven months after the onset of SAH,
3. to assess HRQoL seven months after SAH in patients with and without a psychiatric history and to evaluate the use of different coping in these patients, and finally
4. to describe nurses' views of the physical and supportive needs of patients with SAH, as well as of changes in their social circumstances and mental conditions.

# Methodology

## Design, participants and procedures

Papers I and IV had a qualitative descriptive design approach, and papers II and III a prospective, longitudinal design.

Papers I – III are based on one sample of 93 SAH patients treated at the Neurointensive Care Unit at Uppsala University Hospital between September 2002 and October 2005.

All interviews in this thesis were performed by the author, who is not a member of the regular staff at the Uppsala University Hospital Neurointensive Care Unit.

## Papers I-III, patients with SAH

The patients were consecutively approached as soon as their medical condition allowed. Inclusion criteria were: Swedish speaking, aged between 18 and 75 years, treated by clipping or coiling after a first time aneurysmal SAH, and awake, Reaction Level Scale 85 (RLS85) 1 or 2, i.e. devoid of apparent cognitive dysfunction, i.e. at the very most drowsy but not confused.

Of 129 eligible patients who met the inclusion criteria, 36 were not approached for administrative reasons or declined participation (Figure 1). These 36 not included patients did not differ from those included in terms of sex, age, SAH characteristics, RLS85 on admission and discharge, World Federation of Neurosurgical Societies (WFNS) scores, Fisher grade, mode of treatment or location of aneurysms.

The first interview was performed at the Neurointensive Care Unit within the first ten days after admission and concerned sociodemographic data.

A second interview was conducted seven months later and concerned lifetime and ongoing psychiatric disorders. Ten patients dropped out between the first and the second interview, leaving 83 respondents. The ten drop-outs were older but did not differ from the remaining participants in terms of sex or SAH characteristics. The psychiatric interviews took place at a setting chosen by each patient, consequently 53 were performed at

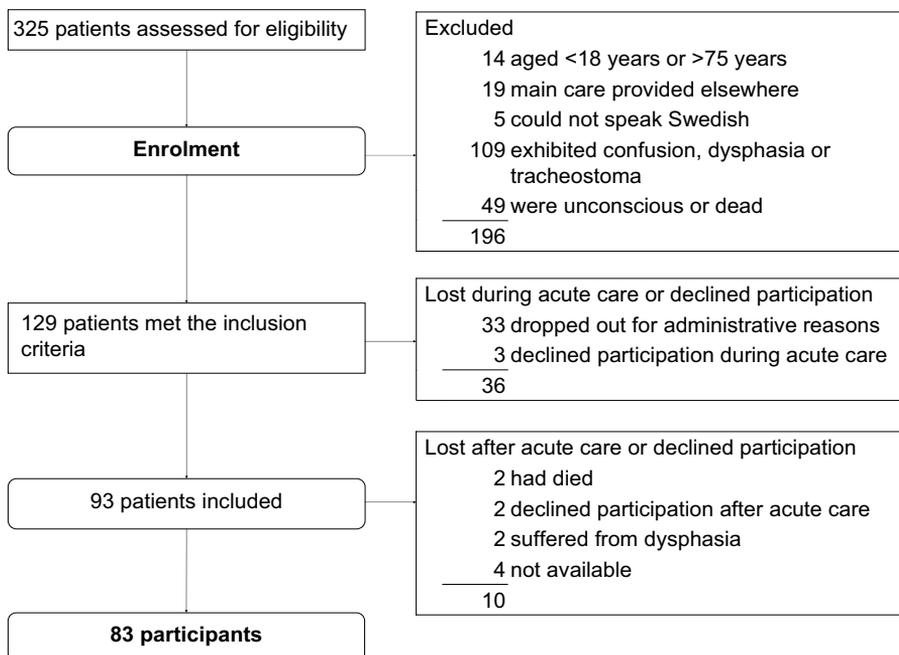


Figure 1. Flow chart of patients through each stage of the study presented according to the CONSORT statement ([www.consort-statement.org/](http://www.consort-statement.org/)).

Uppsala University Hospital. Twenty-four in the patient's home, 2 at Orebro University Hospital, and 4 patients opted for a telephone interview.

In paper III, all 93 participants were approached approximately three weeks before the second interview by means of postal questionnaires. Reminder letters and the same questionnaires were sent three weeks later. Fifty-nine of the eligible 93 patients returned questionnaires. The characteristics of the participants in paper II and III are presented in Table 1.

Paper I is based on an investigation conducted approximately 12 months after the onset of SAH in a purposefully selected sample of 20 individuals from the eligible 93 patients, based on the following criteria: men and women of different ages from different locations within the catchment area who had undergone clipping or coiling for SAH. The reason for choosing a purposeful sample was to gain a rich understanding of the research topic (84).

Table 1. Characteristics of participants in papers II and III

Paper	N	Age at onset	M/F	RLS85 at admission	RLS85 at discharge	Fisher grade score	WFNS scale score	Surgery / Coiling	Working or student / Not working
II	83	52 (9)	30/53	1 = 63	1 = 73	I or II = 22	1 = 63	29/54	67/16
				2 = 14	2 = 9	III or IV = 61	2 = 14		
				≥3 = 6	≥3 = 1		≥3 = 6		
III	59	52 (8)	16/43	1 = 43	1 = 53	I-II=15	1 = 46	21/38	47/12
				2 = 12	2 = 5	III-IV=44	2 = 8		
				≥3 = 4	≥3 = 1		≥3 = 5		

Values are means (SD), N is the size of actual investigated sample, M/F = males/females, RLS85, Fisher grade and WFNS scale are described in the text.

## Paper IV, nursing staff

Paper IV is based on an investigation conducted in a purposefully selected sample of 18 nurses from neurointensive care and rehabilitation settings. Head nurses assisted in selecting participants thought to have different experiences. All were registered nurses (RN) with between five months and 31 years' (median 5.5 years) experience of working in neurointensive or rehabilitation care. Six RNs had obtained the Graduate Diploma in Nursing Care; intensive care (2) psychiatric care (2), and medical/surgical care (2). Two held a Master's Degree. The seventeen women and one man were aged between 27 and 61 years of age (median 42.5 years).

## Semi-structured interview guide

Semi-structured interview guides with open-ended questions were constructed and used in papers I and IV to gather data about the question areas (84). The contextual questions served to initiate the dialogue. In order to probe more deeply into the participants' responses, the interviewer posed follow-up questions as proposed by Patton 2002 (84). All interviews were audio-taped.

## Psychiatric interview

The Structured Clinical Interview for DSM-IV, Axis I (SCID-I) (28) was employed in paper II. The SCID-I is a semi structured interview designed to be administered by a trained mental health professional and usually takes one to two hours to complete, depending on the density of psychiatric history and the respondent's ability to clearly describe past and current psychiatric morbidity.

In the present study, the SCID-I was modified to assess diagnosis for three time periods. "Lifetime" prevalence is the proportion of patients who fulfilled criteria for a diagnosis at any time up to and including SAH onset. The "12-month" prevalence is the proportion of patients who met criteria for a diagnosis at some time during the 12 months up to and including SAH onset. The "seven months after SAH" prevalence is the proportion of patients who fulfilled criteria for a diagnosis at the time of the interview.

Furthermore, the DSM-IV criteria for minor depression were applied, i.e. presence of either depressed mood or loss of interest as well as two to four depressive symptoms and an indicator of functional impairment. In post stroke patients, the DSM-IV diagnostic criteria for depressive symptoms have been found to have good specificity (98 %), sensitivity (100 %) and a positive predictive value of 80 % compared to gold standard diagnostics six months post stroke (94).

The criteria suggested by Mylle and Maes for subsyndromal PTSD, requiring the presence of the re-experiencing symptom cluster and at least one symptom from the avoidance and the arousal symptom clusters, in addition to an indicator of functional impairment, were also applied (80). For a thorough description of the psychiatric disorders in papers II and III, see the table section in the respective paper.

## Socio-demographic data and SAH specific data

In papers II and III socio-demographic data were gathered by means of a structured interview, while in papers I - III, SAH specific data were collected from medical records.

## Health Related Quality of Life (HRQoL)

The Short-Form 36 Health Survey (SF-36) was used to measure HRQoL in paper III. The SF-36 is a reliable and valid generic instrument measuring HRQoL on eight scales: physical functioning, role limitations - physical, bodily pain, general health, vitality, social functioning, role limitations - emotional, and mental health (113). The raw scores from the eight subscales are transformed and range from 0 (poor health) to 100 (full health) (123). The Swedish version of the SF-36 has been found to have satisfactory construct validity and internal consistency, with Cronbach's alpha values ranging from 0.79 to 0.93 (87, 113). The SF-36 is commonly used for measuring HRQoL in stroke patients (39).

## Coping

In paper III coping was assessed using the Jalowiec Coping Scale (JCS), which is a reliable and valid generic instrument (47). The Cronbach's alpha values for each coping strategy were tested in a random sample of the Swedish population and ranged from 0.60 (fatalistic) to 0.88 (confrontative) (70). JCS tap coping in the process perspective (47). Evaluation of concurrent validity has been conducted using associated items in the Sickness Impact Profile and Ferran's quality of Life Index with satisfactory results (48). The JCS contains two parts, A= use, B= effectiveness, each containing 60 items. Due to a strong positive correlation ( $r=0.85$  to  $0.95$ ), which may indicate that parts A and B reflect the same aspects of coping (69), only part A was included in the study. The use of coping strategies is measured on eight scales *problem-focused*; confrontative - constructive problem solving and supportive - using support, *emotion-focused*; evasive - avoiding facing the problem, optimistic - positive thinking, fatalistic - pessimistic thinking, emotive - expressing emotion, palliative - modulating tension without direct problem confrontation, and self-reliant - depending on oneself (49).

## Measurements of consciousness and SAH severity

The Reaction Level Scale (RLS85) is a rating scale for assessment of reaction levels in patients with suspected nervous system disturbances and is designed to be performed by trained physicians, nurses or assistant nurses in clinical practice (109). The RLS85 has demonstrated satisfactory reliability when tested in adult patients with SAH (107). The construct validity of the RLS85 is satisfactory, relates to motor response of Glasgow Coma Scale (117) and ranges from 1 (*alert, no delay in response*) to 8 (*unconscious, no response to pain stimulation*) (109).

The Fisher grade classifies manifestation of CT-visualized subarachnoid haemorrhages (29). The Fisher grade was initially developed to determine criteria for the amount and distribution of subarachnoid haemorrhage in order to predict development of vasospasm (29). The Fisher grade has been validated prospectively (59) and ranges from 1 (*none evident*) to 4 (*any thickness with intravascular haemorrhage or parenchymal extension*) (29).

The World Federation of Neurosurgical Societies (WFNS) Committee scale represents the consensus of an expert committee for grading the severity of patients with subarachnoid haemorrhage (116). It is based on the Glasgow Coma Scale (GCS), with the addition of focal motor deficits (116). The WFNS scale ranges from 1 (*GCS 15, no motor deficit*) to 5 (*GCS 3 to 6, with or without motor deficit*) (99, 116). Several studies have revealed that high WFNS scale scores increase the likelihood of poor outcome (83, 98).

The RLS85, Fisher grade and WFNS scale scores presented in paper I - III were collected from medical records.

## Data analysis

### Content analysis

In papers I and IV a qualitative manifest content analysis inspired by Graneheim and Lundman (33) was conducted. The audio-taped interviews were transcribed *verbatim* by the first author and the interview text was read through several times in order to become familiar with the data. The content of the text was discussed in relation to the aim of each research question in order to reach consensus. Meaning units (related by their context and content) were identified, condensed (shortened while still preserving the core), abstracted and labelled with a code. Only text pertaining to the focus of the study was included in the analysis. All codes were compared and sorted into categories (manifest content) based on shared similarities and labelled to reflect their content. In paper IV the latent content of the categories were formulated into themes.

In the analysis process of paper I it became evident that the text contained information that was coloured by depressive views. A decision was therefore

made to use information from the previously performed SCID-I interviews in order to confirm the presence or absence of depression in each participant.

## Statistical analyses

All statistical analyses were performed using SPSS 17.0. An overview of the statistics used is shown in Table 2. In papers II and III clinical parameters were considered independent covariates if providing a p-value <0.25 in bivariate regressions (43). For a thorough description of the statistical analyses in papers II and III, please see the statistics section of the respective paper.

Table 2. Statistics used in papers II and III.

Paper	Statistical method
II	Mann-Whitney U-test
	Chi-square
	Logistic regression analyses
III	Mann-Whitney U-test
	Chi-square
	One sample t-test
	Independent sample t-tests
	Spearman's rho
	Multiple regression analyses

## Ethics

All studies were performed in accordance with the principles of the Helsinki declaration (134) and approved by the Regional Ethical Review Board at Uppsala University. Approaching vulnerable subjects in neurointensive care settings requires an attentive interviewer, who can recognise signs of exhaustion in the participants. At some occasions, the interviews were postponed until the participants felt stronger.

# Results

## Perceived recovery after SAH (Paper I)

The aim of paper I was to describe what participants with no or minor neurological deficits after an SAH perceived as consequences of their SAH, and as being important for recovery,

The initial content analysis resulted in eight categories. These categories were differently distributed between participants with and without a diagnosis of depression after their SAH (Figure 2). For examples of quotations see paper I. There were two categories that were shared between those with and without a previously diagnosed depression; *Informal and formal caregivers' reactions* and *Individual consequences and reactions*. In the category *Informal and formal caregivers reactions* the participants articulated the value of informal support, such as friends and family. However, those suffering from depression expressed a perceived lack of such support. Furthermore, depressed participants expressed that their family members were anxious and worried concerning the participants health, and in some cases even expressed fear.

In this category inadequate follow-up by the referral hospital was mentioned and more information of SAH and of time spent at the neurointensive care unit was wanted. Furthermore, job-related support to promote a return to work was lacking.

In the category *Individual consequences and reactions*, the participants emphasised 'hidden handicaps' such as fatigue and sensitivity to light and noise but also strengthened relationships. Those who were depressed, however, described weakening relationships and sexual impairment. Financial difficulties due to the SAH were also described, as were emotional reactions and fear of a new SAH onset were also acknowledged.

Three categories were found exclusively in those without a previously diagnosed depression; *Back to normal life*, *Positive meaning* and *Own belief system*. The category *Back to normal life* constituted the ability to return to a normal life by adjusting to the situation. The category *Positive meaning* constituted positive lifestyle changes and the ability to see the SAH as a meaningful experience. The category *Own belief system* reflected the participants' ability to draw strength from religious faith.

The categories found exclusively in those with a previously diagnosed depression were *Sense of loss*, *Dependence and uncertainty* and *Wishing for*

*improvement*. In the category *Sense of loss* the participants acknowledge perceived loss of ability to achieve goals in life. In the category *Dependence and uncertainty* the participants expressed increased dependence on others and less confidence in decision making. Finally the category *Wishing for improvement* constitutes the participants passive longing to return to former life.

Based on the occurrence of depression the categories could be sorted into two patterns (Figure 2). The two patterns were labelled *Confident perception of recovery* and *Pessimistic perception of recovery*.

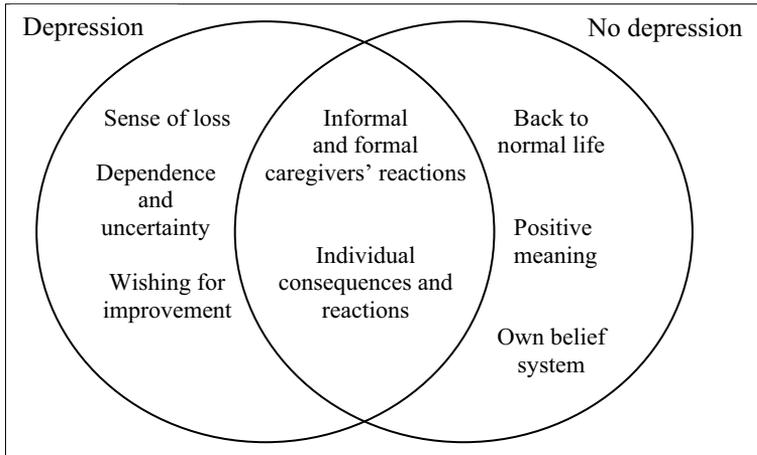


Figure 2. The patterns for recovery after subarachnoid haemorrhage.

## Depression and posttraumatic stress disorders after SAH (Paper II)

In paper II the aims were to assess lifetime psychiatric disorders in patients with SAH using strict DSM-IV criteria and to assess the incidence of PTSD and depression seven months after SAH onset.

Out of the 93 eligible patients, 83 were assessed by means of the SCID-I interview. The lifetime prevalence of psychiatric disorders in these patients, as well as their prevalence 12 months prior to and seven months after SAH onset, is presented in Table 3.

Out of the 83 patients, 37 (45 %) reported at least one lifetime psychiatric disorder. The most common disorders were major depression and alcohol abuse or dependence. Psychiatric co-morbidity was present

Table 3. Prevalence rates of psychiatric disorders in the 83 patients admitted to the Neurointensive Care Unit.

	Lifetime		12 months prior to SAH onset		7 months follow-up	
	N	%	N	%	N	%
Any affective disorder	22	27	4	5	17	21 <sup>2</sup>
Major depressive episode	22	27	3	4	17	21
Minor depressive episode	na <sup>1</sup>	na	na	na	4 <sup>3</sup>	5
Manic or hypomanic episode	1	1	1	1	0	0
Dysthymia	2	2	0	0	0	0
Any anxiety disorder	22	27	11	13	26	31 <sup>2</sup>
PTSD	7	8	1	1	15	18
Subsyndromal PTSD	na	na	na	na	10 <sup>4</sup>	12
Panic disorder	6	7	1	1	2	2
Social phobia	6	7	6	7	6	7
Simple phobia	6	7	6	7	6	7
Psychosis UNS	1	1	0	0	0	0
Any substance use disorder	11	13	3	4	3	4
Alcohol abuse/dependency	10	12	2	2	2	2
Drug abuse/dependency	4	5	1	1	1	1
Eating disorder	1	1	1	1	1	1
At least one disorder	37	45	16	19	34 <sup>2</sup>	41 <sup>2</sup>

<sup>1</sup> not assessed,

<sup>2</sup> minor depression and subsyndromal PTSD not accounted for,

<sup>3</sup> of whom two had another disorder and one had subsyndromal PTSD,

<sup>4</sup> of whom three had another disorder and one had minor depression.

in 17 out of the 37 patients with at least one lifetime disorder. Sixteen (19 %) patients fulfilled criteria for at least one diagnosis in the year prior to SAH onset. The prevalence of at least one psychiatric disorder was 41 % seven months after the SAH onset. Major depression was present in 17 (21 %) patients, while four suffered from minor depression. SAH related PTSD was present in 15 patients (18 %) and another 10 experienced subsyndromal PTSD. In total, 34 (41 %) experienced symptoms of depression and/or PTSD while 49 did not. Of the 34 with symptoms of depression and/or PTSD, 24 had at least one lifetime psychiatric disorder prior to SAH onset compared to 13 out of the 49 (p=0.001). Patients with an affective disorder or who had

been treated with antidepressants before the SAH had a lower return to work than those who had no such disorder or had not been prescribed antidepressants ( $p=0.019$  and  $p=0.031$ , respectively). This was also true for those with symptoms of depression and/or PTSD, or with antidepressant treatment after SAH.

Logistic regression analyses revealed that a depressive disorder at seven months after SAH onset was related to the presence of a lifetime affective disorder, a lifetime anxiety disorder, a lifetime substance use disorder and lifetime psychiatric co-morbidity (Table 4). Full or subsyndromal PTSD seven months after SAH onset was related to a lifetime affective disorder.

Table 4. Logistic regression analyses with the presence of minor and major depression, as well as subsyndromal and full PTSD at the seven month follow-up after SAH as dependent variables and the presence of lifetime psychiatric disorders before SAH as independent variables.

Lifetime disorders	Minor or Major Depression <sup>1</sup>			Subsyndromal or Full PTSD <sup>2</sup>		
	OR <sup>3</sup>	95% CI <sup>4</sup>	<i>p</i>	OR	95% CI	<i>p</i>
Lifetime affective disorder	11.9	3.0-46	0.001	7.5	2.3-24	0.001
Lifetime anxiety disorder	6.5	1.6-26	0.008	2.0	0.6-6.0	ns
Lifetime substance use disorder	9.8	1.5-66	0.019	2.0	0.5-8.0	ns
Any psychiatric disorder lifetime	14.1	3.0-66	0.001	4.4	1.5-13	0.007
Psychiatric comorbidity	10.1	2.2-47	0.003	2.1	0.6-7.1	ns

<sup>1</sup> Adjusted for Fisher grade, WFNS scale, ventricular drainage, vasospasm and female sex

<sup>2</sup> Adjusted for WFNS scale and female sex

<sup>3</sup> Odds Ratio

<sup>4</sup> Confidence interval

## Psychiatric morbidity, coping and HRQoL after SAH (Paper III)

The aims of paper III were to assess HRQoL seven months after SAH in patients with and without a psychiatric history and to assess the use of different coping strategies in these patients.

Out of 93 patients, 59 returned completed SF-36 questionnaires, and 53 JCS questionnaires. The drop-outs did not differ with respect to sex, age, WFNS scale or Fisher grade compared to the responders. Fifty-one percent of the patients had a psychiatric history before and/or after SAH. SAH patients had a significantly lower HRQoL in all eight SF-36 domains compared to the general Swedish population. However, the lower HRQoL was almost

entirely in the subgroup of patients with a psychiatric history (Figure 3). Those without a psychiatric history had a significantly lower HRQoL in only one SF-36 domain; Role- physical.

HRQoL was strongly, but differently correlated with the use of coping. The physical domains were less affected by the use of coping than the mental domains. The emotional coping styles *evasive*, *emotive* and *palliative* affected SF-36 domains more than other coping styles. The most used coping styles were the problem solving style *confrontative* and the emotional styles *optimistic* and *self-reliant*. Those with a psychiatric history used more coping compared to patients without such history but this did not apply to problem solving coping styles. This difference was most evident for the *evasive*, *fatalistic*, *emotive* and *palliative* coping styles.

Finally, multiple regression analyses were used to investigate the extent to which the use of coping and psychiatric history prior to SAH was independently associated with HRQoL domains. The findings indicated that the explained variance was higher for the mental than for the physical domains (Table 5). The clinical covariate included in the final model was a high RLS85 at intake.

Table 5. Final models used in backward multiple regression analyses with the domain scores in SF-36 as dependent variables, and use of coping, the presence of a psychiatric history and clinical predictors as independent variables.

SF-36 domain	Included covariates	B-coefficient	p-value	Adjusted R <sup>2</sup>
Physical Functioning	Evasive	-12.3	0.012	0.10
Role-Physical	Evasive	-30.6	0.001	0.18
Bodily Pain	Evasive	-20.0	<0.001	0.21
General Health	Evasive	-16.5	<0.001	0.21
Vitality	Evasive	-18.2	<0.001	0.47
	Psychiatric history	-20.3	0.003	
Social Functioning	Emotive	-18.6	0.001	0.34
	Psychiatric history	-16.5	0.015	
Role-Emotional	Psychiatric history	-39.2	0.001	0.34
	Emotive	-19.4	0.034	
Mental Health	Evasive	-33.9	<0.001	0.71
	Psychiatric history	-18.6	<0.001	
	RLS85 <sup>1</sup>	-10.1	0.025	
	Optimistic	13.2	<0.001	

<sup>1</sup> dichotomized RLS85=1 vs. RLS85>1.

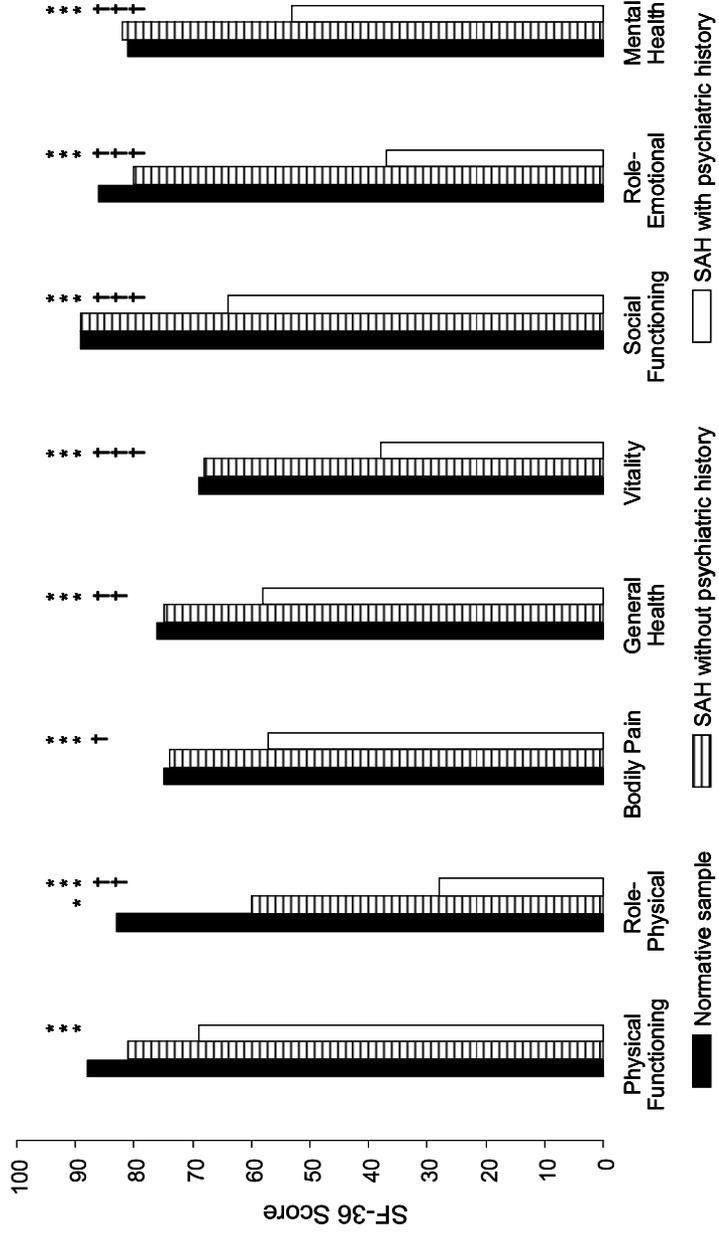


Figure 3. Health related quality of life in patients with aneurysmal subarachnoid haemorrhage presented for each domain divided into those with and without a psychiatric history at any time. Mean values are shown. Normative sample is from Sullivan M, Karlsson R-A, Ware JE Jr, 1994, SF-36 Hälsoenkät (Swedish manual and interpretation guide) .

\*, p<0.05; \*\*, p<0.01 and \*\*\*, p<0.001 denote a significant difference vs. normative population based data. Similarly †, ††, and †††, denote differences between those with and those without a psychiatric history.

## Nurses view of caring for the SAH patient (Paper IV)

The aim of paper IV was to describe nurses' views of the physical and supportive needs, as well as nurses' views of changes in social circumstances and changes in mental condition of patients after SAH.

Two themes emerged from the content analysis. First, support of patients suffering from SAH was stipulated in the theme '*Support, ranging from highly advanced technological care to emotional care*' and contained four categories (Table 6). In the category *Monitoring*, the participating nurses emphasized the importance of monitoring physiological parameters. The category *Active treatment* constituted nurses' view that drug administration was important. In the category *Collaboration*, the participants articulated the importance of collaboration with other health care professionals to promote patients recovery. The final category *Relationship with the patient* contained supportive strategies carried out in a relationship with the patient. However, nurses in the neurointensive care settings found it difficult to imagine patients' future support needs. In addition, rehabilitation nurses acknowledge that assurances of total recovery from neurointensive care staff made it harder for them to support patients, especially those with a reduced ability to reach complete recovery.

Second, the combined analysis of the questions pertaining to changes in social circumstances and mental health resulted in the theme: '*SAH outcomes as obstacles and advantages regarding a return to everyday life*', which contained six categories. In the category *Weakened relationships* separation as a result of problems in the aftermath of SAH was featured. This could be due to e.g. sexual impairment and overprotection.

Table 6. Nurses' views of patients' physical and supportive needs. Main results, themes and categories

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**Support, ranging from highly advanced technological care to emotional care**

- Monitoring
- Active treatment
- Collaboration
- Relationship with the patient

---

**SAH outcomes as obstacles and advantages regarding a return to everyday life**

- Weakened relationships
- Strengthened relationships
- Loss of normality
- Adaptation to reality
- Changes due to the event
- Reaction to the event

---

The category *Strengthened relationships* comprised nurses' view that family members rallied closer together due to the SAH event. In the category *Loss of normality* nurses emphasised their view that patients lost their job, driving licence and normal appearance. The category *Adaptation to reality* contained the nurses' view that patients need to adapt to their altered reality. *Changes due to the event* category constituted nurses' view that patients may suffer long term cognitive deficits, as well as personality and mood changes in the aftermath of SAH. Finally, the category *Reaction to the event* contained nurses' view that patients reacted with fear.

# Discussion

This thesis focuses on aspects of psychosocial recovery after SAH, as a significant number of patients with likely good prognosis exhibit problems during the adaptation process. To expand the understanding of the experience of having SAH both qualitative methods and quantitative methods with standardized outcome measures, were used.

## Methodological considerations

### Design

The strength of the qualitative and descriptive approach used in papers I and IV is that it provides the potential for a richer understanding of stroke experiences than standardized outcome measures (93). This was deemed of importance due to the paucity of information both on how patients with SAH view different components in their recovery, paper I, and on nurses' views of caring for such patients, paper IV.

The prospective and longitudinal design of paper II and III theoretically allow for optimal assessment of all psychosocial aspects, e.g. risk factors (54). A key issue was to obtain a valid assessment of the psychiatric history, i.e. before the SAH. We therefore initially considered conducting a SCID-I interview at baseline, i.e. close to the SAH. However this approach was not used, as a SCID interview may take several hours and is thus too tiresome and impractical for patients undergoing continuous neurointensive care monitoring. The interview with respect to the entire psychiatric history was therefore undertaken in one single context and at one time seven months after the SAH. This would allow for a certain bias recall. Actually, several data suggest the possibility of significant underestimation in lifetime recall of psychiatric illness, where distant episodes of illness may be forgotten, especially in those with milder or less recurrent illness or who do not receive treatment (104).

### Sample

The core concern is whether the subgroup of patients investigated in this thesis is representative of a larger group of patients with SAH.

First, we consider the sample representative from a population based view. The sample comprised patients referred to Uppsala University Hospital Neurointensive Care Unit, which receives all SAH patients from a large catchment area covering the central part of Sweden and Åland with a total population of approximately 1.900.000 inhabitants. The structure of the Swedish Health Care system makes it unlikely that any patient from this catchment area who suffered an SAH would receive care elsewhere, unless the onset took place while they were temporarily far away from their home region. Likewise, no patient in this sample had his/her domicile in another health care region. These are strong arguments for regarding the sample as population based.

Second, only patients who were expected to make a good recovery were included. Previous studies have adequately covered the types of problems that characterise those with a moderate to bad prognosis (108). In contrast, few studies have focused on problems in those with an expected good prognosis. However those that did so underlined the fact that such patients also exhibit significant problems during adaptation and return to work. Identification of cases for the present study was based on previous literature, which suggested that, in general, patients with normal or only slightly affected consciousness on admission in general belong to a group with an expected good prognosis (83, 98, 116). Inclusion criteria were therefore an RLS85 score of 1 or 2.

The possibility of generalising the results to all patients with a good prognosis to recover could also, however, be discussed since only 93 (72%) of the eligible 129 cases were invited to take part, and another ten dropped out before the seven month follow up, thus just 83 participated. Almost all, 33 of the 46 patients that were lost before the interview were missed of administrative reasons, and not due to a patient dependent or disease specific process that were expected to affect generalizability. This is supported by the fact that there were no or only minor differences between the attrition group and the participants (Paper II).

HRQoL and coping could only be assessed in the 59 and 53 patients respectively who returned the postal questionnaires, i.e. less than 70 % of those included. Previous literature suggested that poor self-rated health is a predictor of sample attrition (6, 21, 122), thus a higher level of attrition would underestimate rather than overestimate the problems investigated. Although not desirable, the most obvious drawback of a high attrition in the present context is therefore that it diminishes the sample size and invites criticism, in the same way as earlier studies on predictors of depression in the aftermath of stroke has been criticized for their small samples (34). This is most critical for logistic regression analyses, as in paper II, where a non random attrition of "positive cases" will result in a significant loss of power.

Paper I and IV had a qualitative approach and a different sampling technique than papers II and III. The samples of patients in paper I and nurses in

paper IV were small and not randomized. The purposeful sampling technique was used in order to ensure diversity, in that a wide range of extremes with respect to defined “variations” are searched for and included in the sample. This is purposely done after definition of these “variations”. In the present study we identified patient variations with respect to sex, age, living environment, and treatment by means of either clipping or coiling for SAH. Sample variations for nurses were based on head nurses’ perceptions of individuals’ different professional experiences, including age, duration of employment in neurointensive care or rehabilitation care, and postgraduate training.

## Method

The use of self-report instruments is associated with some more or less pronounced biases, including the participants tendency to present themselves in the best possible way, sometimes called ‘*social desirability*’ (54), to tick off answers on a questionnaire one after the other without reflecting, to agree with items despite their content (54) and ‘*end-aversion bias*’, which denotes unwillingness to use the extremes of a scale (111). However, self-report measures are easy to administer and consequently save time (54). Furthermore they permit the researcher to assess several domains of multidimensional concepts such as HRQoL in a standardized way without the risk of interviewer related bias. The self-report instruments used in this thesis has been validated in previous studies and found to have satisfactory psychometric properties.

Use of the SCID-I interview is a considerable strength. It is the most widely used and scientifically scrutinised clinical psychiatric interview (124) and provides a sound basis for international comparisons. Furthermore, using DSM-IV diagnostic criteria to assess depressive disorders in the aftermath of stroke has been recommended due to their high specificity and sensitivity (94). A limitation regarding the use of SCID-I is that is that inter-rater reliability is not accounted for, since only one person, a psychiatric nurse, performed all SCID-I interviews. However, an earlier study revealed that trained nurses and psychiatrists have high diagnostic agreement for psychiatric disorders assessed by means of structured clinical interviews based on the DSM-IV criteria (36). Furthermore, before the start of the study the interviewer successfully completed a SCID-I course that required an inter-rater reliability with kappa agreement of 0.9.

The choice of qualitative content analysis in papers I and IV had an obvious strength. At that time there were few empirical studies on nursing in stroke rehabilitation in general (11) and even less on SAH rehabilitation. Content analysis is an empirically grounded method (64) which allows the researcher to start the analysis inductively and use deductive strategies half way through when the initial content analysis is operationalized on basis of

earlier information (24, 90). Furthermore, qualitative content analysis is frequently used in nursing research, perhaps due to the empirical implications which allow nurses and researchers to benefit from their clinical understanding.

The methodological considerations affecting the trustworthiness of paper I and IV could be summed up by the concepts of *credibility*, *dependability*, *transferability* (33), and *confirmability* (68, 88).

The concept *credibility* deals with how well the data and analyse process attend to the planned focus of the study (33, 88). In papers I and IV the author used a purposeful sample to enhance credibility. A heterogeneous sample contributes to a richer variation of perspectives, which has been suggested to increase credibility (33, 84). Credibility is also considered to involve choosing the most appropriate method for gathering data (33). In paper I, six participants preferred telephone interviews. However, the statements of the informants fell into the two patterns; they had no speech difficulties and felt comfortable speaking over the phone with the interviewer whom they had previously met. The amount of data is also involved in the concept of credibility (33). In paper I, one interview lasted five minutes and, in paper IV, one interview took ten minutes, but, despite the short duration these interviews were included since they contributed to the understanding. Moreover, the whole research team was involved in reaching agreement on condensing, abstracting and coding the data. The quotations were chosen in order to describe the similarities within and differences between categories.

The concept of *dependability* deals with the stability of data or design included change (33). To increase dependability in papers I and IV the interviewer used a semi-structured interview guide to ensure a similar interview structure. Moreover, all interviews were transcribed *verbatim* by the interviewer. The fact that the SCID-I interviews were performed prior to the interviews presented in paper I is a possible drawback, since it is possible that the depression could have eased at the time of the interview.

*Transferability* refers to the extent to which the results can be transferred to other settings (33, 88). The careful description of the participants in papers I and IV was undertaken to make it possible for the reader to assess transferability.

In order to minimise threats to *confirmability*, such as personal bias (68), the interviewer was not a staff member of the neurosurgical clinic.

## Perception of care

Paper I is the first qualitative analysis of what patients who suffered an SAH 12 months previously perceived to be important for recovery. Two patterns were found regarding recovery, but with some common experiences acknowledged by the participants. Expectations concerning rehabilitation were

not met. The participants described emotional reactions such as fear of relapse associated with headache and with the one-year anniversary of the SAH onset. The importance of informal support was emphasised, although those with depressive tendencies expressed lack of such support. Notable is that some of the participants perceived that they had no place outside family and friends to turn to with their questions and worry.

One of the two patterns regarding recovery after SAH found in the participants may be considered beneficial for the individual. Those without depression seemed to have had a confident perception of recovery, as they managed to focus on important issues in life and found meaning in the SAH event. The ability to direct energy towards important features in life has been described in a previous study concerning stroke survivors (31). Furthermore, the ability to find meaning in negative events has previously been acknowledged (105). In contrast, those with depression expressed more difficulties. They had a negative outlook on their recovery, with perceived loss of a whole year, and did not seem to have moved forward in the recovery process. In addition, those with depression expressed difficulties seeking help. It has been reported that depression may hamper long-term recovery after stroke (79). The finding of the present study supports the above view in relation to SAH patients.

The qualitative information about presence of depression as a key issue in perceived perception of rehabilitation after SAH is quantitatively validated by the analysis of HRQoL in paper III. Here it was shown that SAH patients had significantly lower HRQoL in all eight SF-36 domains compared to the general Swedish population. The lower HRQoL was almost entirely in the subgroup of patients with a psychiatric history, which is dominated by a history of depression.

## Psychiatric morbidity

Lifetime psychiatric morbidity as well as that after SAH was assessed by means of SCID-I interviews based on strict DSM-IV criteria. The prevalence of lifetime psychiatric morbidity in the present study, 45 %, seems to be in line with population based epidemiological surveys (56, 62). The depression prevalence in the present study appears to be in accordance with findings in stroke in general (35, 94) but somewhat higher than in previous reports in SAH samples (38, 78). This may be due to the lack of strict DSM-IV criteria in previous studies (35, 94) and/or that SAH is more common in women (5, 97), who have a higher risk for affective disorders than men (56). The seven months after SAH prevalence of PTSD in the present study is similar to (103) or lower than previously presented (91).

The present findings imply that those with a previous history of psychiatric morbidity constitute a risk group for depression and PTSD in the after-

math of SAH. This is in line with previous findings regarding the burden of psychiatric history and increased risk for psychiatric problems after a severe traumatic injury in the form of a burn (23). In the present study, those with symptoms of depression and PTSD at seven months reported lower return rate to work than those without such symptoms. Moreover, those with a history of any affective disorder had lower return to work rate than those without such history. Return to work has been associated with quality of life in stroke patients (127). Furthermore, other studies after trauma suggest that psychosocial morbidity (74), preinjury mental status (25) and personality traits (22) are related to return to work, and that return to work is associated with a higher HRQoL (22).

## Health related quality of life

Patients with SAH had a significantly lower HRQoL in all domains of the SF-36 instrument compared to the general Swedish population, which is in line with previous reports (19, 101). A very important observation was that the lower HRQoL was almost entirely found in the subgroup with a lifetime history of psychiatric disorders. This subgroup constituted slightly more than half of the individuals. It may be that a state effect of an ongoing psychiatric disorder at seven months would exclusively explain this relation. With a restricted inclusion of only those who had fulfilled criteria of a psychiatric disorder before SAH, but not at the seven months follow-up, those with a psychiatric vulnerability still had significantly worse HRQoL for the four mental domains of SF-36, but not for the remaining domains. This implicated that the vulnerability for having a psychiatric disorder in itself is related to a worse HRQoL with respect to mental domains, even if there is no ongoing disorder. It, thereby, links psychiatric vulnerability to perceived health after SAH.

In previous studies HRQoL has also been associated with individuals' capability to handle stressful events (132). The findings in paper III indicate that reduced HRQoL is correlated with the use of emotional coping.

## Coping

As a psychological concept coping is neither positive nor negative, although the literature suggests that individual ways to cope are related to more or less successful dealing with perceived problems, and that coping strategies may influence the relationship between stress and psychiatric and physical health (115). Furthermore, psychiatric disorders have been associated with insufficient coping resources to meet challenges (115). This was the basis for assessing coping in relation to psychiatric morbidity and

HRQoL after SAH. The findings of the study indicate that those with a prior psychiatric history on a group level use coping in a different way than those without such a history. SAH patients with a prior psychiatric history, thus, used more coping for all strategies, except for the problem solving strategies *supportive* and *constructive* than those without a psychiatric history. Furthermore those with a prior psychiatric history used significantly more of the coping strategies that in previous studies have been associated with an inability to handle illness than those without a psychiatric history.

Moreover, in the present study the coping strategies *evasive*, *palliative* and *emotive* were those with the strongest relation to poor HRQoL. In previous investigations and in other medical conditions these coping strategies have been associated with an inability to handle psychological, social and existential aspects of life (69) and with poor sense of coherence (60). This is in line with the observation that the use of avoidance coping strategies has been associated with post-stroke depression (57).

The relationship between coping and outcome may give an opportunity to intervene in a supportive way in order to promote individuals' adaptation after a negative event such as SAH. Nurses are suggested to hold a key position in that respect (105).

## Nurses' view

In a qualitative study, paper IV, eighteen nurses were asked about their view of the physical and supportive needs as well as of changes in social circumstances and changes in mental condition of patients after SAH. Participating nurses viewed SAH patients need of support as a process, ranging from highly advanced technological care to emotional care. They also acknowledged lack of communication between neurointensive care and rehabilitation care. The neurointensive care nurses expressed that they could not imagine patients future supportive needs, an observation that suggest a lack of continuity in care of patients with SAH. Several studies give support to the concept that a better continuity, from acute care to rehabilitation for patients with stroke / SAH will be beneficial from many aspects. Yamamoto and Lucey (2005) suggest a case management approach while the SAH patients still reside at the critical care unit (136). A greater role for the specialist nurse that stretches beyond the hospital walls, continues for a longer time (11), and includes home visits in order to support patients and carers during the first year after SAH onset has been suggested (50).

Furthermore, SAH as a medical condition seems not to be commonly known to nurses and other categories of health care personnel in rehabilitation care. This indicates a need to build a functional health care organisation with emphasis on educating health care personnel to better assist SAH patients.

## General discussion and clinical implications

The SAH is a traumatic event for the individual. In the course of the interviews performed during this work a number of extraordinary patient histories were told. Several participants described the horror they felt when they became ill. Others recalled the shock of finding themselves connected to life support equipment when they woke up in the neurointensive care unit. Some described a negative first encounter at the referral hospital or with the health-care information hotline; some were diagnosed with migraine and sent home, others were recommended to drink sugar water against nausea. Despite this, several of the participants had a positive outlook in terms of recovery and reported no - or what they perceived as manageable - SAH related problems. Some also expressed that they felt more content with life after the SAH than before. One explanation could be that those individuals had access to certain *protecting factors* in the form of support from caring family members and friends, strength from religious faith and the ability to use problem-focused coping strategies that protected them from developing emotional disorders. In addition, some may have had more specific internal *resilience factors* (40). These issues have not, however, been assessed in the present thesis.

One of the main findings of this thesis is that previous or ongoing psychiatric morbidity constitutes a considerable obstacle to recovery in SAH patients despite good prognosis. Thus, a history of psychiatric morbidity is related to a considerable risk of developing PTSD and depression, a decreased HRQoL and less likelihood to return to work. It is therefore important to identify both those with prior psychiatric morbidity and those who develop psychiatric sequels after SAH. Identification of prior psychiatric episodes should take place already during acute care in order to minimize suffering for the patients and their families and in order to make health care more effective. Adequately trained nurses are a suitable group for performing this identification.

One of the suggested targets of nursing rehabilitation is prevention of the serious complication depression (65). There are, however, findings indicating that rehabilitating interventions after SAH is foremost offered to those more physically disabled and that threats to recovery such as depression remains undetected in others (27). Only a fraction of the patients in the present study suffering psychiatric disorders seven months after the SAH onset were offered treatment. This suggests that there is room for improvement in health care. Early treatment may also promote a swift return to work which may decrease the economical burden related to long absence from work. In addition, the participants perceived that the health care provided was not attuned to their expectations and needs.

The findings in the present studies suggest an association between decreased HRQoL, prior history of psychiatric disorders and use of emotion-focused coping strategies. One might suggest that it would be beneficial if

nurses early during care could detect which coping strategies the SAH patients used in order to promote use of the problem-focused coping strategies more effectively for recovery. Earlier work suggests that positive change can be achieved in SAH patients with psychiatric sequels. In a previous case-study cognitive-behavioural therapy, thus, reduced maladaptive coping strategies related to panic symptoms following SAH (32). Irrespective of the type of support planned, the results point to the fact that it is important to identify those with a psychiatric history, irrespective if there is ongoing psychiatric morbidity, in order to provide optimal support during follow-up.

# Conclusions

The main conclusions of this thesis are

1. Participants' categorized consequences of SAH were sorted into two main patterns, *confident perception of recovery* and *pessimistic perception of recovery*, with a total of eight categories. The presence of depression greatly affected the perceived consequences of SAH.
2. Depression and PTSD are present in a substantial proportion of patients seven months after SAH. Those with a history of psychiatric morbidity any time before the SAH are more at risk, and also constitute a risk group for difficulties in returning to work.
3. Patients report decreased HRQoL after SAH, above all those with a past or ongoing psychiatric history. In addition, use of maladaptive emotional coping was related to worse HRQoL.
4. Nurses' views of the physical and supportive needs of patients with SAH could be stipulated into two themes, *support, ranging from highly advanced technological care to emotional care* and *SAH outcomes as obstacles and advantages regarding a return to everyday life*.

# Acknowledgements

First and foremost I would like to thank my three supervisors; you have really complemented each other. Thank you for always believing in my ability and for your kind support; *Professor Lisa Ekselius*, for accepting the responsibility as main supervisor and for excellent scientific guidance and for sharing your outstanding knowledge in psychiatry; *Professor Marianne Carlsson*, for generously sharing your expertise in caring sciences, valuable discussions on qualitative methods and for always taking time to answer my questions; *Associate professor Elisabeth Ronne-Engström*, for crucially contributing to my understanding of aneurysmal subarachnoid haemorrhage.

This work would not have been possible without the support of *Professor Lennart Persson*, Former Head of the Department of Neurosurgery at Uppsala University. I am also grateful to the late *Professor Per-Olov Sjärdén* for accepting me as a PhD student at the Department of Public Health and Caring Sciences.

I would also like to express my gratitude to *Professor Lars von Knorring* at the Department of Neurosciences, Psychiatry for all support during the project as well as *Ulises Penayo* and *Birgitta Lanner*, Former Heads of the Department of General Psychiatry at Uppsala University Hospital and Associate professor *Gunilla Stålenheim* for introducing me to psychiatric assessments and for your kind support. Thanks also to *Anna-Karin Oscarsson* for your comments on the draft of paper IV.

A special thanks to my co-author and fellow PhD student *Maria Zetterling* for long discussions about science and other important things in life. Thanks also to former and current fellow PhD students at the Department of Public Health and Caring Sciences: *Ingrid Demmelmaier*, *Åsa Muntlin*, *Josefin Westerberg* and especially to *Ulrika Pöder*, for sharing your knowledge of neurointensive care nursing, and to former and current members of Marianne's PhD group.

I am indebted to *Hans Arinell* for invaluable statistical advice and computer support, and to *Jane Wigertz*, *Gullvi Nilsson* and *David Grist* for excellent linguistic help. Thanks to *Lena Bohlin* for everything concerning daily administration (and for going to the movies - remember Smala Sussie :-).

I would also like to thank former and current members in Lisa's research group for all your kind support, *Mia Ramklint, Johan Dyster-Aas, Ann-Charlotte Åkerblad, Josefin Bäckström, Adriana Ramirez* and *Josefin Sveen* and to *Associate professor Mimmie Willebrand* for sharing your expertise on the subject of coping and for all the interesting conversations.

I would like to express my gratitude to *Kristina Haglund* and *Caisa Öster* for your kind support over the years.

A special thanks to all participants for making this thesis possible.

Finally I wish to thank my friends and family for your constant support.

Financial support was provided by the Swedish Research Council, the Uppsala County Council, the Uppsala University Faculty of Medicine, the Nasvell Foundation, the Stroke Foundation, the Anna-Britta Gustafsson Foundation and the Selander Foundation.

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