Daily life after Subarachnoid Haemorrhage
Identity construction, patients’ and relatives’ statements about patients’ memory, emotional status and activities of living

Elisabeth Berggren
“Life can only be understood backwards, but it must be lived forwards”

Søren Kierkegaard
Abstract

The overall aim of this thesis was to describe patients’ experience and reconstruction regarding the onset of, and events surrounding being struck by a Subarachnoid Haemorrhage (SAH), and to describe patients’ and relatives’ views of patients’ memory ability, emotional status and activities of living, in a long-term perspective. Methods: Both inductive and deductive approaches were used. Nine open interviews were carried out in home settings, in average 1 year and 7 seven months after the patients’ onset, and discourse analysis was used to interpret the data. Eleven relatives and 11 patients, 11 years after the onset, and 15 relatives and 15 patients, 6 years after the onset, participated in two studies. Interviews using a questionnaire with structured questions and memory tests were used to collect data. Fischer’s exact test and Z-scores were used for the statistical analysis.

Results: Patients with experience of a SAH were able to judge their own memory for what happened when they became ill. The reconstruction of the illness event may be interpreted as an identity creating process. The process of meaning-making is both a matter of understanding SAH as a pathological event and a social and communicative matter, where the SAH is construed into a meaningful life history, in order to make life complete (I). Memory problems, changes in emotional status and problems with activities of living were common (II-IV). There was correspondence between relatives’ and patients’ statements regarding the patients’ memory in general and long-term memory. Patients judged their own memory ability better than relatives, compared with results on memory tests. Relatives stated that some patients had meta-memory problems (II). The episodic memory seemed to be well preserved, both concerning the onset and in the long-term perspective (I, II). There were more problems with social life than with P- and I-ADL (III), and social company habits had changed due to concentration difficulties, mental fatigue, and patients’ sensitivity to noisy environments and uncertainty (IV). Relatives rated the patients’ ability concerning activities of living and emotional status, and in a similar manner to patients’ statements (III-IV).

Conclusions: The reconstruction of the illness event can be used as a tool in nursing for understanding the patient’s identity-construction. Relatives and patients stated the patients’ memory, emotional status and activities of living in a similar manner, and therefore both patients’ and relatives’ statements can be used as a tool in nursing care, in order to support the patient. However, the results showed: meta-memory problems (relatives’ statements) and that the patients’ judged their own memory ability better than relatives in comparison with results on memory tests. Nevertheless, there was a high degree of concordance between relatives’ and patients’ evaluations concerning patients’ memory ability, emotional status, emotional problems, social company habits and activities of living. Therefore both relatives’ and patients’ statements can be considered to be reliable. However, sometimes the patients and the relatives judge the patients’ memory differently. Consequently, memory tests and formalized dialogues between the patient, the relative and a professional might be required, in order to improve the mutual family relationship in a positive way. Professionals however, must first assume that patients can judge their own memory, emotional status and ability in daily life.

Key Words: SAH, Stroke, Pain, Memory, Decisions, Meaning-making, Identity-construction, Psychological sequelae, Emotional status, Social life, P-and I-ADL, Memory tests, Interviews, Questionnaire
The thesis is based on the following papers, referred to in the text by their Roman numerals.

**Paper I.**

**Paper II.**

**Paper III.**

**Paper IV.**

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<tr>
<td>CBF</td>
<td>Cerebral blood flow</td>
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<tr>
<td>CPRS</td>
<td>Comprehensive Psychopathological Rating Scale</td>
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<tr>
<td>DA</td>
<td>Discourse Analysis</td>
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<tr>
<td>HRQoL</td>
<td>Health Related Quality of Life</td>
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<td>LTM</td>
<td>Long term memory</td>
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<td>MMT</td>
<td>Mini Mental Test</td>
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<tr>
<td>RAVLT</td>
<td>Rey Auditory Verbal Learning Test</td>
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<tr>
<td>SAB</td>
<td>Subarchnoidalblödning (In Swedish)</td>
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<td>SAB-94</td>
<td>Subarchnoidalblödning- 94 (In Swedish)</td>
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<tr>
<td>SAH</td>
<td>Subarachnoid Haemorrhage</td>
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<td>STM</td>
<td>Short term memory</td>
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Definitions

**Emotional status** can be described as the patient’s neuropsychological ability and/or neuropsychological sequelae, as a consequence of being hit by SAH (Sonesson, 1992).

**Emotional problem** is the patient’s reduced neuropsychological capacity responding to demands in daily life, viewed by patients themselves and relatives.

**Fatigue** is mental fatigue (in Swedish: uttröttbarhet/hjärntrötthet).

"**Hidden**” disability/problem, is a disability/problem that is invisible for others than patients themselves and/or their relatives.

**Identity Construction**, in this thesis is how “the self as past” is set against “the self as present” (Goffman, 1959) in the reconstruction (Hydén, 1997a) of the illness event (SAH) in communicative interaction (Linell, 2004).

**Meaning Making** is how an illness event is construed into a meaningful life history (Candlin, 2000).

**Memory** is described as Short term memory (STM), Long term memory (LTM); Episodic memory, Semantic Memory, Procedural Memory, Recent Memory, Remote Memory, and as memory in general (STM and/or LTM) and meta-memory.

**Memory ability** is the patient’s capacity to remember and store new information.

**Memory problem** means the patient’s reduced capacity to remember and store new information, according to patients’ and/or relatives’ statements and/or from results on memory tests.

**Nurse**, in this thesis is a RN (registered nurse), and sometimes a specialist RN.

**Personal identity**, in this thesis is what a person experiences her/himself to be as a person, what makes someone the very person who he/she is. This problem area includes, according to Charmaz (1997) such questions as: “Who am I? When did I begin to be that very person (changed) and what will happen to me in the future”.

**Recent Memory** is memory being new in time, near to the present (belonging to LTM).

**Remote Memory** is memory for what happened far away from the present point in time (belonging to LTM).

**Sense Making** (Gwen, 2002) is in this thesis to understand from a cognitive perspective.
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INTRODUCTION
A Subarachnoid haemorrhage (SAH) is a life threatening event, that occurs dramatically and spontaneously, with the sudden appearance of a severe headache, nausea, attacks of vomiting and is sometimes followed by immediate unconsciousness (Norving et al., 2006). Neuro intensive care and clinical surveillance of the patient’s neurological condition (Persson & Enblad, 1999) is necessary in the acute stage. When a person is hit by a severe illness as SAH (belonging to the state of illness referred to as Stroke), it has implications for both the patient and the relative in short- and long-term. Wallengren Gustavsson (2009) reported that relatives of persons affected by stroke experience chaos, and Forsberg Wärleby et al. (2001) reported that in the first weeks of the patient’s stroke, spouses’ psychological well-being was low compared with norm values. Patients being hit by a life threatening event, has a special need to create meaning (Candlin, 2000) for the illness event and the time following it, in order to make sense (Gwyn, 2002) of what happened to them. This, letting patients create meaning (Candlin, 2000) for the onset of and events surrounding the SAH in communicative interaction (Linell, 2004) is described in this thesis.

It is known from earlier research that a SAH has impact on patients’ daily life (Lindberg et al., 1992; Lindberg & Fugl-Meyer et al. 1996; Hedlund, 2010a), and that patients after a SAH can experience memory and emotional problems. Such cognitive sequelae are common both in a short- (Passier et al., 2012) and in a long-term after patients’ SAH (Visser-Meily, 2009). However, problems after a stroke do not just affect the person stricken by the stroke, it also has implications for the wellbeing of people close to them (Forsberg-Wärleby et al, 2001; 2004a). One year after the patients onset of a stroke, the spouses of patients who had cognitive impairments judged their satisfaction with life as a whole, as being lower compared to spouses of patients who had only sensory motor disorders (Forsberg-Wärleby et al. 2004b; Forsberg-Wärleby, 2002). Patients’ memory and emotional problems after a SAH might affect patients’ and relatives’ mutual life negatively. Consequently, it is urgent to support patients and relatives before discharge from the hospital, preparing them for their mutual life together. To be able to do this, requires knowledge concerning patients’ memory ability, emotional status and ability in activities of living in home context, emerged from patients’ experience and both patients’ and relatives’ views.

Patients who outwardly show signs of being neurologically recovered after their SAH, fairly soon after their onset, will be discharged from the hospital. These patients probably have memory and emotional problems, which might affect patients’ and relatives’ mutual life. Nevertheless, cognitive dysfunction (memory and emotional problems) concerning physically independent survivors after SAH was missed in routine follow-up examinations (Fertl et al., 1999). Many patients, who outwardly show signs of being neurologically recovered, classified as having good recovery on Glasgow Outcome Scale (GOS; Jennett & Bond, 1975; Jennett et al., 1981; Jennett, 2005) after being struck by a SAH, had cognitive and/or emotional problems according to Passier et al. (2012). It might be a problem for both patients and relatives in their mutual life together, that memory and emotional problems were/are missed in follow-up examinations. Forsberg-Wärleby (2002) showed that patients’ cognitive and asteno-emotional problems after a stroke can affect spouses’ wellbeing, partner relation and family life, and that spouses’ and patients’ emotional health were related to each other. This might be an extra burden to relatives, while supporting a person suffering from SAH. According to Buchanan et al. (2000) relatives reported moderate or high levels of family burden, although the patients had been considered to have good recovery (outwardly
neurologically recovered) or to have moderate disability (minor physical disability), 19 months after patients SAH. Consequently, relatives and patients might need support from a professional focusing on factors that contribute to health.

Supporting patients and relatives in their daily life together in home settings, is suggested in this thesis to take place in formalized dialogues before patients’ discharge from the hospital, and also in follow-up dialogues with a specialized nurse in home settings. It is urgent to develop formalized dialogues between the patient, the relative and a nurse in nursing care, as survival rates will increase due to new diagnostic and treatment strategies (Hütter et al., 1999; Nieuwkamp et al., 2009). However, patients still are expected to suffer from cognitive impairments after the SAH (Hütter et al., 1999). That means that more persons living in home settings might suffer from memory and emotional problems due to SAH, in the future.

Patients will probably, due to increasing survival rates, be discharged from the hospital even earlier than today. That could mean that the persons struck by SAH might be dependent on relatives (support), even earlier after the onset than today. This is vital to take into account, when developing nursing care strategies and nursing interventions, in order to support both patients and relatives. To do this, it first requires knowledge emerged from patients’ experience of the onset of the SAH, and patients’ and relatives’ view of patients’ cognitive ability and daily life following a SAH, in long-term in a home context. Therefore, this thesis concerns patients’ experiences of the onset and events surrounding a SAH. This thesis also deals with patients’ memory ability, emotional status and ability in activities of living, from patients’ and relatives’ views, and from results on memory tests in a long-term perspective after SAH.
BACKGROUND

The experiences of cognitive and/or emotional problems (Visser-Meily, 2009; Passier et al., 2012), due to unconsciousness (Jakobsen et al. 1990) and/or cognitive impairments (Jakobsen, 1992), leading to memory and emotional problems (Rödholm, 2003) after being hit by a SAH might be noticeable. It is an unexpected and a new situation being cared for in a neuro intensive and/or neurosurgical care unit in a hospital context due to a life threatening event as a SAH. Therefore the patient suffering from a SAH has a special need to create meaning for the illness event (Candlin, 2000), in order to make sense (Gwyn, 2002) for what happened at the onset of and events surrounding the SAH.

Meaning-making in communicative interaction

It is important to encourage patients in their meaning-making (Candlin, 2002), letting them talk about their experience of the onset and events surrounding the SAH, in communicative interaction (Linell, 2004) with a professional/and or a relative after being struck by the SAH. This can be done reconstructing (Hydén, 1997a) the onset and events surrounding the patient’s SAH, in communicative interaction (Linell, 2004) with a nurse and/or a relative, in order that the patient might be able go further in his/her life.

According to Linell (2004) action, language and meaning is socially constructed, shared and confirmed (social constructionism) in interaction, such as happens when patients from experience talk about the onset of a SAH, in interaction with the researcher, based on a dialogic approach. The dialogical approach proposes a theoretical framework for understanding cognition, conversation and communication (Linell, 2004). The essence of the dialogic approach is interactionism, contextualism, social constructionism and double dialogism (Hellström Mühl, 2003).

Interactionism means that meaning arises in interactions between individuals and between individuals and contexts (Linell, 2004). Our actions are part of context and the actions create and recreate context (Säljö, 2000). At the same time there is a motive behind human actions triggered by the situation. There are also situations cross socio-cultural motives over time (double dialogism) underlying the behaviour, such as traditions of how to express themselves verbally and act in different contexts (Linell & Thunquist, 2003). Contextualism means that cognition and communication always includes contexts of various kinds (Linell, 2004). In this thesis, the context is the informants’ (patients’) homes and the onset of and the events surrounding their SAH are presented as facts and constructions of interest (Wetherell et al., 2003).

To “use” meaning-making (Candlin, 2000) as a nursing intervention (suggested in this thesis), in order to help a patient who suffers from a SAH to make sense (Gwyn, 2002) for what happened at the onset of and events surrounding the SAH, first requires knowledge concerning SAH, neuro intensive care, treatment and clinical surveillance.

Subarachnoid haemorrhage

SAH belongs to the state of illnesses referred to as stroke and the incidence of stroke in Sweden is about 30 000 persons per year, and approximately twenty thousand persons fall ill for the first time each year. Nearly 85% of the strokes diagnosed are caused by brain infarctions, 10% are caused by intra cerebral haemorrhage, and 5% by SAH (Norrving et al., 2006). There are however large world wide variations concerning the incidence of SAH. The
incidence of SAH is stated as 6-9 per 100,000 persons a year in most communities/populations (Linn et al., 1996; van Gijn et al., 2007; de Rooij et al., 2007; Le Roux et al., 2010; Zacharia et al., 2010). In Finland and Japan SAH is more common; approximately 20-22 per 100,000 persons a year (de Rooij et al., 2007) compared with China that reports 2 per 100,000 persons (Ingall et al., 2000). South and Central America report low incidences, 2 per /100,000 persons a year (de Rooij et al., 2007; Le Roux et al., 2010). The incidence of a SAH increases with age (de Rooij et al., 2007) and there is a peak among people between 50 and 60 years of age (Ingall et al., 2000; Le Roux et al., 2010). However, children and young people also suffer from SAH, but it is more unusual. AVM (Arteriovenous malformations) occur in 1 per 100,000 children per year, and AVM are four times more common than aneurysms (Getzoff & Goldstein, 1999). SAH is somewhat more common in women than in men (the incidence is approximately 24% higher, but not in all countries according to Ingall et al., 2000), and it tends to start in the sixth decade. The decline in incidence of SAH is relatively low compared with stroke in general (de Rooij et al., 2007). The SAH is usually located in the subarachnoid space, and the causes can vary over time in the patients studied. Approximately 60% of the SAH diagnosis are caused by ruptured aneurysms, 20% are caused by ruptured AVM, high blood pressure and/or arteriosclerosis. In 20% of the cases no reasons are found (non-aneurysmal bleeding), Norrving et al. (2006). Classically, aneurysms have been attributed to congenital week areas, but hypertension, smoking, alcohol, cocaine, amphetamine and ecstasy use are some of the risk factors for subarachnoid haemorrhage (Wilson et al., 2005).

Computed tomography (CT) scan is required and additionally, if there is an intracranial haemorrhage in a vascular area, then a SAH is suspected, and then a catheter angiogram is required to identify the presence of an aneurysm. Lumber punctures are important in a small minority of patients (about 3%) who display normal CT head scans. Within 12 h the cerebrospinal fluid may show metabolites of haemoglobin and then an angiography can subsequently confirm a ruptured aneurysm (van Gijn et al., 2007).

About 8-25% of the patients die before they reach the hospital (Phillips et al., 1980; Bonita & Thomson, 1985; Fogelholm et al., 1993; Broderick et al., 1994; Cook, 2008), and the post-operative mortality is approximately 8-26% (Säveland et al., 1992). In the acute stage the mortality is high, approximately 30% (Norrving et al., 2006). However, if patients are properly looked after in the acute stage, with early diagnosis, surgery and/or medical treatment and treatment against vasospasm, nearly 50% of the persons will survive without any visible physical neurological disability (Norrving et al., 2006) and approximately 20% will suffer some morbidity (Säveland et al., 1992).

The pathophysiology when suffering a SAH differs from haemorrhage strokes in general. According to Norrving et al. (2006) a SAH, at the onset of the haemorrhage, causes a high intracranial pressure and is assumed to contribute to a stop to the haemorrhage. The adverse effect of the high intracranial pressure, at the onset, is that it leads to a reduction in the cerebral blood flow (CBF). Patients who are unconscious at the acute stage present a more severe global reduction in the CBF than patients who are conscious at the onset (Jakobsen et al., 1990; Rödholm, 2003). The reduction in CBF at the onset of a SAH can cause ischemic damage (Jakobsen, 1992; Rödholm, 2003) in the cells and that can lead to cognitive impairments, causing memory and emotional problems, which might affect the person’s activity of living in daily life. Therefore, patients who have experienced a SAH need to be transferred to a neurosurgical unit immediately or at least as Cook (2008) states, within 24
hours. Neuro intensive care in the acute stage of the illness is necessary to prevent ischemic damage caused by secondary injuries post SAH (Norving et al., 2006).

**Neuro intensive care, treatment and clinical surveillance**

Neuro intensive care is offered after SAH in order to identify, prevent and treat secondary injuries after SAH, such as re-bleeding, acute hydrocephalus, seizures, arterial hypotension and arterial vasospasm, that may give cerebral ischemia (Persson & Enblad, 1999) and the treatment varies according to the source of the bleeding (Norving et al., 2006). Early surgery (within 72 hours) was reintroduced at the end of 1970, because of re-rupture risk during the time of waiting, which were the leading causes of severe morbidity (Hütter et al., 1999). Cook (2008) states that clipping or coiling is used when it is aneurysmal in origin. When clipping is used (a surgical procedure) a craniotomy is performed. The aneurysm is located and a clip is placed across the neck of the aneurism to restore the integrity of the vessel. When endovascular coiling is used the aneurysm is located with the use of a conventional angiogram, with a catheter fed to the site and then coils are placed inside the aneurysm. The coils initiate a thrombotic reaction which forms a clot. The modern microsurgical techniques with clip ligation during the 1970s have reduced the surgical trauma and endovascular treatment with coils was introduced during the early 1990s (Brilstra et al., 1999). The cognitive outcome is shown to be better using endovascular treatment compared with surgery, even if cognitive outcomes seem to be dictated by complications due to SAH (Hadjivassiliou et al., 2001). To reduce the risk of complications such as relapse bleeding and spasm in the vessels, early intervention concerning the aneurysm (within 48-72 hours) is necessary (Norving et al., 2006). Pharmacological treatment with calcium antagonists (e.g. Nimodipine) is used to reduce the risk of ischemic damage, due to vasospasm (Norving et al., 2006). Persson and Enblad (1999) stated that in life-threatening situations, hyperventilation, mannitol, barbiturates, induced hypothermia, and surgical decompression with removal of extensive cerebral tissue is warranted.

**Nursing care and nursing interventions**

Clinical surveillance of the patient’s neurological condition, such as control of the patient’s consciousness, orientation to time, space and person, control of: pupillary respond, breathing, blood pressure, pulse, body temperature, blood-glucose level and rise of paresis/paralysis are important assessments when caring for a patient with SAH in the acute stage (Cook, 2008). Crimlisk & Grande (2004) stated that changes in mental status may be the earliest indication of a neurological event and the change in a patient’s mental status requires immediate attention and intervention from acute care nurses. According to Cook (2008), pain management is vital in managing the care of patients with SAH. Pain increases ICP (intra cranial pressure) and respiratory quotients. Assessment for pain and discomfort in those who are unresponsive is necessary in nursing care. According to Persson and Enblad, (1999) continuous registrations of body temperature, arterial blood pressure, central venous pressure, oxygen saturation and frequent checks of arterial blood gases are important to check in most patients. In the acute stage, it is vital to obtain good ventilation and keep the ICP down, sometimes using respiratory therapy. This is done in order to reduce cerebral impairments due to SAH, which might reduce the patient’s disability in daily life post SAH.

In neurosurgical and neurological care units, in the acute stage clinical surveillance, nursing interventions related to the patient’s neurological status and the patient’s personal body daily care are carried out. However nursing care also includes, as Gwyn (2002) states, ordinary discourse (talk) in the nursing care situation: What you talk about and what you try to understand. This ordinary discourse could be important in clinical surveillance in order to see
if: (i) the patient’s neurological status, caused by the SAH affects the patient’s physical and/or mental resources and (ii) the patient shows signs of pathological deterioration, shown as headache, memory disorientation and confusion, followed by unconsciousness.

In this thesis there is focus on patients’ internal resources (Carnevali, 1984; 1990), after being hit by a SAH, in the sense of: (i) memory ability, (ii) emotional status and (iii) ability in activities if living in long term, from the perspective of patients and relatives. There is also a focus on patients’ memory and language resources in talk interaction (Hydén, 1997a; Gergen, 2001; Hall et al., 2006), in the accounts concerning the onset of and the events surrounding patients’ SAH.

There is also focus on patients’ need for ordinary discourse in interaction with a nurse and/or a relative, in order for the person to be able to talk about (meaning-making; Candlin, 2000) and make sense (Gwyn, 2002) of what really happened at the onset and in events surrounding being struck by SAH. Consequently, nursing care is a communication issue, what you talk about and tries to understand in ordinary discourse, in interaction with each other, and which has long-term consequences for how people (patients) will experience daily life when they suffer from severe illness (Gwyn, 2002). It might be of importance that patients are offered ordinary discourse in interaction with a professional and/or a relative after being stricken by a SAH, and when a person experiences memory and emotional problems due to a SAH.

Relatives are important recourses for the patients both in the acute phase, in short- and long-term in home settings. Key principles in nursing care of patients with stroke in Sweden are information/education and training of patients and relatives, and ensuring that relatives are able to participate in the care of the patient at an early stage after the onset (National Guidelines for stroke care, 2009). Rehabilitation should be planned in close collaboration with the patient and family members. Patients and their carers should be provided with “medical and nursing information”, at all levels and for all phases of rehabilitation (Helsingborg Declaration on European Stroke Strategies, 2006). As memory problems (Larsson et al., 1989; Lindberg et al., 1996; Rödholm et al., 2001) and emotional problems (Hellawell & Pentland, 2001; Rödholm et al., 2001) are common after SAH there is, in order to support relatives and patients, a need to acquire knowledge of how patients’ and relatives’ view patients’ memory ability, emotional status and patients’ activities of living in home settings. However, few studies describe how daily life turns out to be in relation to existential issues and from the perspective of patients’ memory and emotional abilities after SAH, in a home context. Being able to support patients and relatives before patients’ discharge from the hospital therefore requires knowledge from research studies concerning patients’ experience of the onset of and events surrounding the event. It also requires knowledge about patients’ memory abilities, emotional status, and patients’ abilities in activities of living, from both patients’ and relatives’ in long-term perspectives. Paying attention to the patient’s experience of the onset of the SAH, and the patient’s memory ability and emotional status before the patient is discharged from the hospital is necessary, in order to support the patients and the relatives for the time in their home context. It is also important to pay attention to patients’ and relatives’ experiences, in order to improve individual nursing care and nursing interventions in hospital context, for patients suffering from a SAH. This is vital as cognitive dysfunction concerning physically independent survivors after SAH was missed in medical routine follow-up examinations (Fertl et al., 1999), and memory and emotional problems probably will remain. The patients in this thesis are physically independent persons, however many of them suffering from cognitive sequelae (memory and emotional problems) due to their SAH.
Outcomes post SAH

Cognitive sequelae after SAH

Cognitive sequelae, such as memory and emotional problems, have been described as common both in short-term (Brandt et al., 1987; Säveland et al., 1986 Rödholm, 2003; Hedlund et al., 2007; Hedlund et al., 2010a; 2010b; 2011) and in long-term after patients’ SAH (Ljunggren et al., 1985; Sonesson et al., 1987;1989; Romner et al. 1989; Sonesson, 1992; Lindberg et al. ,1996; Hellwell & Pentland, 2001; Morris et al., 2004; Visser-Meily, 2009). This is according to post-SAH test results, patients’, proxies’, relatives’ and nurses’ statements (Ljunggren et al., 1985; Säveland et al.,1986; Sonesson et al., 1987;1989; Brandt et al., 1987; Larsson et al., 1989; Romner et al., 1989; Hütter et al.; 1995; Lindberg et al.,1996; Hellawell & Pentland., 2001; Morris et al., 2004; Visser-Meily, 2009; Hedlund et al., 2007; Hedlund et al., 2010a; Hedlund et al., 2011).

The independent outcome predictor for late neuro behavioral sequelae after SAH is the patient’s clinical status on admission to the hospital. The five grade scale of Hunt and Hess (1968) is used to classify the severity of a SAH on patients’ admission to the hospital. The scale is also used by surgeons, in relation to the outcome after surgery (Säveland et al., 1992). The Glasgow Outcome Scale is used as an overall outcome scale (Jennett & Bond, 1975; Jennett et al., 1981; Jennett, 2005) after SAH. Cognitive sequelae (memory and emotional problems), psychosocial problems and neurobehavioral changes were found among patients, who were classified as having a good recovery on GOS in medical follow-up examinations after surgery (Säveland et al., 1986; Ogden et al., 1990; Stegan & Freckmann, 1991; Buchanan et al., 2000; Passier et al., 2012). “Having good recovery” has been defined as patients without neurological deficits, with exception of cranial nerve palsies (Säveland et al., 1992). According to Säveland et al. (1986), five out of 26 patients classified as they had “good neurological recovery” a year after their SAH, showed severe psycho social and cognitive difficulties. Ogden et al. (1990) showed that all patients who rated as they had “good recovery” at a 5-year follow-up study, had memory impairments. Seventy % of the patients classified as they made “good recovery” or “moderate recovery” viewed by a neurosurgeon 19 months after surgery, experienced behavioral changes, according to Buchanan et al. (2000). Passier et al. (2012) reported that 64% of 113 patient based on GOS had “good recovery” after SAH. However, 54% of them were anxious, 41% had depressive symptoms, 83% had cognitive and 96% had emotional complaints three months after their SAH. The classifications on GOS is used as on overall outcome scale (Jennett & Bond, 1975; Jennett et al., 1981; Jennett, 2005) and categories on both 3-, 5- and 8- grade scale, that listen specific and/or nonspecific disabilities have been/are used. There has according to Jennett (2005) over the years been a development of the GOS. It is important to be aware of the purpose with the scale and those personnel using the GOS have adequate training (Jennett, 2005). However, the GOS does not say anything about the patient’s and/or the relative’s view concerning the patient’s memory ability, emotional status and ability in activities of living after a SAH. Nevertheless, cognitive sequelae (memory and emotional problems) due to SAH are common, and this is often a larger handicap than physical neurological impairments (Soneson, 1992). The high intracranial pressure at the onset can lead to memory problems (Larsson et al., 1989; Lindberg et al., 1996; Rödholm et al., 2001), and emotional problems, such as psychological tiredness (mental fatigue) and concentration difficulties (Rödholm, 2003).
Memory problems

Memory problems are common after SAH, according to both test results and patients’ statements. Ljunggren et al. (1985) reported that 83% of the patients stated that they had memory problems, 14 months to seven years after their SAH. Sonesson (1987) reported that 55% of the patients stated that they had memory problems, one to eight years after the patients SAH. Larsson et al. (1989) found, from results on memory tests (3 to 14 years after the SAH), that Short term memory (STM) problems were common and closely connected to brain damage caused by SAH. Lindberg et al. (1996) demonstrated that among long-term consequences, seven years (range 2.5-14) after the onset of a SAH, 52% of the patients had STM problems and that 53% of the patients had Long term memory (LTM) problems, according to memory test results. Larsson et al. (1989) stated that LTM dysfunction found from memory test results was often caused by ruptured aneurysms on the left ACoA (Arteria Communicans Anterior), and among patients who had suffered from vasospasm.

Memory and memory tests

Memory can be described as primary memory (short-term memory, STM) and secondary memory (long-term memory, LTM), meaning stored information (Baddely, 1984). In relation to STM, incoming information is available for a very short period of time, about 30 seconds, and the information in STM can be lost after 20 seconds if the person is distracted by subsidiary information or tasks (Peterson & Peterson, 1959). STM is purported to consist of passive and active processes (Working memory, WM). In WM, decisions are made, according to whether or not the incoming information will be stored in LTM, or be forgotten (Baddely, 1984; Anderson, 1995). Cantor et al. (1991) state that there is an exchange between STM and LTM and that there is a need to be able to shift attention between different parts of a problem. This means, to be able to utilise and bring up information from LTM, in order to store the new information, from STM, in LTM. To have a large capacity in STM can be interpreted as the person retaining a large amount of information for a short time. This facilitates the active part of the STM (WM) in exchanging and bringing up information from LTM. A complementary classification of memory is; (i) Episodic memory, which can be described as personal events, connected to time and space, (ii) Semantic memory which is the memory for facts, and (iii) Procedural memory, can for example be, how to ride a bicycle. This (procedural memory) is implicit memory, that is, memory without a conscious element (Baddely, 1984; 1999; Anderson, 1995; Egidius, 2008), and which belongs to LTM (Egidius, 2008). Meta-memory is described as the capacity to correctly evaluate one’s own memory functioning (Rönnberg & Larsson, 1989; Egidius, 2008). Memory ability can be measured in different ways; (i) lists of words (ii) digits, and (iii) content of pictures to be related (Bingley, 1958, Folstein et al., 1975; Hindfelt, 1995; Schmidt, 2004).

In Sweden there are no routinely offered memory tests to all patients affected by SAH before discharge from the hospital. Neither are there routine follow-up examinations concerning all patients’ memory in long-term, even though memory problems are common after SAH, according to results from research studies (Larsson et al., 1989; Lindberg et al., 1996; Rödholm et al., 2001). Memory problems seem to be secondary to emotional problems, such as concentration problems, which can reduce patients’ ability of maintaining attention (Rödholm, 2003).

Emotional problems

Concentration problems (Hütter et al., 1995; Hellawell et al., 1999; Rödholm, 2003) and fatigue (Ljunggren et al., 1985; Hellawell et al., 1999; Visser-Meily, 2009) are common after SAH. Hellawell et al. (1999) stated that 42% of the patients reported and 43% of the relatives
reported that patients had concentration problems six months after the onset of the SAH. Hüttter et al. (1995) reported that 71% of the patients on self-rating and on proxy-rating 46% of the patients (1-5 years after the onset) had concentration problems. Hellawell et al. (1999) reported that 68% of the patients had self-reported symptoms of fatigue two years after the onset and Ljunggren et al. (1985) reported, 14 months to 7 years after the onset that 82% of the patients, who were interviewed stated that they had problems with fatigue. According to Visser-Meily (2009), 67% of the patients reported fatigue, two to four years after the onset of a SAH.

Overly sensitive to noise (Hellawell et al., 1999; Rödholm, 2001), emotional instability (as tearfullness; Rödholm, 2001) were also common. Rödholm et al. (2001) reported that 43% of patients with mild Astheno emotional disorder (AED) and 67% of the patients with moderate AED (1 to 6 months after the onset) were overly sensitive to sounds. Hellawell et al. (1999) reported that 58% of the patients (2 years after the onset) were overly sensitive to noise. Rödholm et al. (2001) stated that 46% of patients with mild and moderate AED showed emotional instability, one to six months after the onset of a SAH.

Patients also had problems with irritability, anxiety and depression. Rödholm et al. (2001) reported that 33% of the patients had problems with irritability one to six months after the SAH, and Sonesson et al. (1987) reported that 30% of the patients had problems with irritability one to eight years after the SAH. Hellawell et al. (1999) reported that patients themselves stated that 23% of them were anxious whilst their relatives reported that 36% of the patients were anxious, 12 months after the onset of a SAH. Morris et al. (2004) reported that moderate to severe levels of anxiety were present in approximately 40% of the patients, and mild levels of anxiety were present in 16% of the patients, 16 months after a SAH. Thirty-two % of the patients reported anxiety and 23% reported depression, two to four years after the onset according to Visser-Meily et al. (2009). On a self-report, three months after their SAH, 54% of the patients stated that they were anxious, and 41% had depressive symptoms (Passier et al., 2012). Stegan and Freckmann (1991) reported that only 7% of the patients, 12 months after surgery, suffered from physical deficits, and that the delay in rehabilitation was caused by increased anxiety and personality changes (depression or aggression) and lack of social contact.

Memory problems and emotional problems, can affect patients’ adjustment to daily living (activities of living) following a SAH (Sonesson, 1992).

Problems with activities of living

Activities of living in this thesis is described as; (i) social life, in the sense of social company, recreational activities, watching television and reading, (ii), Personal and Instrumental Activities of Daily Living (P- and I-ADL) according to Katz (1963) and Hulter Åsberg (1984). There are few studies addressing activities of living of patients suffering from SAH. Lindberg et al. (1992) reported that 48% of the patients who participated in a study 2-14 years after the onset of a SAH reported cessation and/or decrease in leisure activities. Passier et al. (2011) reported that 66% of the patients (n=141), participating in a study 2,5-3,5 years after their SAH, were satisfied with their leisure situation (34% were not satisfied), and 75% of them were satisfied (25% were not satisfied) with contact with friends. Lindberg and Fugl-Meyer (1996) stated that 26% of the patients had a decreased ability for visits from relatives and friends, and that 27% had decreased ability to visit relatives and friends, 7 years after the onset of the SAH.
Lindberg et al. (1992) reported that 9% of the patients had problems with personal activities of daily living (P-ADL), and 20% of the patients had problems with instrumental activities of daily living (I-ADL), according to patients’ reports 2–14 years after the onset of the SAH. Passier et al. (2011) reported that more than 88% out of 141 patients (28-44 months after the patients’ SAH) were satisfied with their self-care ability, but one-third of the subjects were not satisfied with their life as a whole. Sixty four patients out of the 141 patients in Passier et al. (2011) had a score of V on the GOS (good recovery), and approximately 72% of these patients were satisfied with their life as a whole. A patient not being able to cope with activities of living, and/or not being satisfied with her/his life probably will affect relatives’ quality of life. Therefore it is vital to attend to how both patients and relatives experience or view the patients’ SAH, to be able to support patients and relatives after patients’ SAH.

Patients’ and relatives’ views of SAH

Patients who suffered from a SAH, stated that they had lower Health Related Quality of Life (HRQoL) than the general Swedish population seven months after the onset, and physical domains were less affected than mental domains, according to Hedlund et al. (2010b). Passier et al. (2012) reported that patients one year after their SAH, experienced lower psychosocial than physical HRQoL. The lowest score on HRQoL was for the domain thinking, and the highest for domain self-care. The problems after a SAH/stroke however, do not just affect the person struck by SAH/stroke. The problems also have implications for the wellbeing of people close to them (Forsberg-Wärleby, 2002), and the mutual family relationships in daily life. The association between the spouses’ view of stroke, their personal consequences for the future and for their psychological well-being (10 days after patients’ stroke) was strong, stronger than the association of psychological well-being and the patient’s objective symptoms (Forsberg-Wärleby et al., 2001; Forsberg-Wärleby, 2002).

Spouses of patients, who could not cope with personal care and who had cognitive impairments, often had a pessimistic view of the future, in the first weeks after the patients’ onset (Forsberg-Wärleby et al., 2002). The spouses’ psychological well-being compared with norms, was lower in the first weeks after their partners’ stroke. However, the spouses’ psychological wellbeing was more associated with the patient’s visible sensorimotor impairment, than with “hidden” cognitive impairments in the first phase (Forsberg-Wärleby et al., 2001; Forsberg-Wärleby, 2002). Four months after the patients’ stroke the spouses’ well-being had increased, but their life satisfaction was lower compared with life prior to stroke (Forsberg-Wärleby 2002). At four months the spouses’ psychological wellbeing was related to the patients’ cognitive impairment and patients’ ability in self-care (Forsberg-Wärleby et al., 2004a). The consequences of cognitive impairments became more evident in daily life in their homes (Forsberg-Wärleby, 2002), and spouses’ psychological well-being, one year after patients’ stroke was related to patients’ sensorimotor and cognitive impairments (Forsberg-Wärleby et al., 2004a).

Larsson (2005) stated that spousal caregivers of patients suffering from strokes have a complex life situation, and that there are negative effects on the spouses’ quality of life and psychosocial well-being. According to Buchanen et al. (2000), relatives 19 months after patients’ SAH reported moderate or high levels of family burden concerning patients who were classified, by a neurosurgeon as having good recovery or moderate disability. According to Forsberg-Wärleby et al. (2004a) spouses of patients with emotional difficulties, such as depression and astheno-emotional syndrome, had worse psychological wellbeing one year after the patients’ stroke, than spouses of patients who did not suffer from depression and/or astheno-emotional syndrome.
One year after the patients’ strokes, spouses of stroke patients with only sensorimotor function disorders had a more optimistic view of the future, than spouses of patients who also had cognitive function disorders (Forsberg-Wärleby, 2002). The spouses of patients who had cognitive functioning disorders and/or astheno-emotional syndrome one year after the patients’ stroke, judged their satisfaction with life as a whole, as being lower than before the patients’ stroke. Spouses of patients with cognitive function disorders and astheno-emotional function disorders were also less satisfied in their relationships with their partners, both at four months and one year after the patients’ strokes, compared with the spouses of patients who had only sensorimotor disorders. (Forsberg-Wärleby et al. 2004b; Forsberg-Wärleby, 2002).

Anderson et al. (1995) reported that almost all non-professional caregivers (n=84), mostly a family member, reported adverse effects on their emotional health, social activities, leisure time, when caring (in patients’ homes) for one-year stroke survivors with residual mental and physical handicap. Forty six caregivers (55%) showed emotional distress and more than half of the caregivers reported adverse effects on family relationships. From this study it was also concluded that many caregivers may have unmet needs. However, Grant et al. (2002) showed (in an intervention group) that family caregivers who participated in a social problem-solving telephone partnership, who met a trained nurse within a week after the patients onset of a stroke had; (i) less depression, (ii) improvement in measures of vitality, social functioning, mental health and role limitation, related to emotional problems, compared with control groups.

Personal internal and external resources (Carnevali, 1984; 1990) might influence how both patients and relatives solve problems, and manage to cope with their lives after a family member is hit by a life threatening event such as SAH. It is therefore important in nursing care to support patients and relatives in problem-solving, and also to support patients’ wellbeing after SAH, in order that patients might experience health, although memory and emotional problems, due to impairments caused by SAH might be life-long. In nursing care, to adopt a salutogenic model which means focusing on factors that contribute to health (Antonovsky, 2003) might help patients and relatives to cope with their lives after patients’ SAH. Sense of coherence (SOC) can be seen as an “individual based coping resource” and is the central concept in the salutogenic model. The model explains why a person is able to move towards health on a health-disease continuum. There are three core components in SOC: (i) comprehensibility, (ii) manageability and (iii) meaningfulness. Comprehensibility means to what extent a person experience inner and utter stimuli (demands and life events) to be understandable. Manageability means to what extent a person has resources of his/her own, and/or have external resources to meet and cope with demands and events in life. Meaningfulness means if a person is motivated to cope with demands and events, and if coping make sense (Antonovsky, 2003). To be able to support patients focusing on factors that might contribute to health (Antonovsky, 2003) means that the nurse must have knowledge concerning how both the patient and the relative experience their situation when a family member is hit by a SAH. Patients in this thesis, who suffered from a life threatening event as SAH, were motivated to talk about the onset and events surrounding the SAH.
RATIONAL FOR THIS THESIS

A SAH is a life threatening and a complex pathophysiological event that causes a high intracranial pressure at the onset (Norrving et al., 2006), and that can lead to cognitive sequelae (memory and emotional problems), both in a short-term (Rödholm, 2003; Hedlund, 2011; Passier et al., 2012) and in a long-term after patients’ SAH (Sonesson, 1992; Lindberg et al., 1992; Hellawell et al., 2001; Morris, 2004; Visser-Meily, 2009). It is known that a SAH can affect patients’ daily life (Sonesson, 1992; Lindberg et al., 1992; Lindberg & Fugl-Meyer, al. 1996; Hedlund, 2010a; Passier et al., 2011), and patients also showed low HRQoL (Hedlund et al., 2010b; Passier et al. 2012) after SAH. Relatives reported family burden concerning patients, who outwardly showed signs of being neurologically recovered after SAH (Buchanen et al. 2000). Patients, who outwardly showed signs of being neurologically recovered, had cognitive and/or emotional problems according to Passier et al. (2012). Nevertheless, cognitive dysfunction (memory and emotional problems) concerning physically independent survivors after SAH (patients who outwardly showed signs of being neurologically recovered) was missed in routine follow-up examinations (Fertl et al., 1999; Passier et al., 2012).

The decline in incidence of SAH is relatively low compared with stroke in general (de Rooij et al., 2007), and survival rates will increase due to new diagnostic and treatment strategies (Hütter et al., 1999; Nieuwkamp et al., 2009). Patients might therefore be discharged from the hospital earlier than today being dependent on relatives support, probably because of memory and emotional problems. This might influence patients’ and relatives’ mutual life together. Consequently relatives and patients need support from a professional (as a suggestion a specialised nurse) focusing on factors that may contribute to health (Antonovsky, 2003). It is therefore urgent to develop nursing care strategies and evidence based nursing care for patients suffering from SAH, in order to support both patients and relatives to cope with patients’ memory and emotional problems in daily life. This will probably improve relationships in families of people who have had a SAH, and patients and relatives might be able to feel they have good or fairly good quality in their mutual life together, despite memory and/or emotional problems probably will remain. To support patients and relatives in families of people who have had a SAH requires developing nursing interventions and a concise questionnaire, focusing on memory ability, emotional status and activities of living after a SAH. A questionnaire could be developed from questions used in this thesis, and from results in this thesis. However, a questionnaire and nursing care interventions must first be evaluated in a large group of patients suffering from SAH. This requires knowledge emerged from: (i) patients’ experience of the onset and events surrounding the SAH, and (ii) patients’ and relatives’ views of patients’ memory ability, emotional status and activities of living following a SAH. Such knowledge has relevance for the care strategies at the time for the onset of the SAH, before patients discharge from the hospital, and also for later rehabilitation and adjustment to family life.
AIM

The overall aim of this thesis was to describe patients’ experience and reconstruction regarding the onset of, and events surrounding being struck by a SAH, and to describe patients’ and relatives’ views of patients’ memory ability, emotional status and activities of living, in a long-term perspective.

Specific aims

STUDY 1 (I)
The aim was to analyse people’s accounts of Subarachnoid Haemorrhage and to describe how they initiate and create meaning for the onset and events surrounding the SAH.

The specific questions were:
(i) What is highlighted in the accounts of SAH?
(ii) How is the illness reconstructed?
(iii) How is meaning created through communicative interaction with others about SAH?

STUDY 2 (II)
The aim of this study was to describe patients’ memory after an SAH from the perspective of relatives and patients in two cohorts. In this study, the researchers also aimed to evaluate the application of relatives’ statements as a tool in nursing care and rehabilitation in order to support patients. This was achieved by comparing:
(i) Relatives’ statements with patients’ statements
(ii) Relatives’ and patients’ statements with the patients’ memory test results.

STUDY 3 (III)
The aim of this study was to describe activities of living in relation to memory ability following SAH with regard to social life and Personal and Instrumental Activities of Daily Living (P- and I-ADL), from the perspective of relatives and patients in two cohorts. The aim was also to evaluate the application of relatives’ statements, as a tool in nursing care in order to support the patient.

This was achieved by comparing:
(i) Relatives’ statements regarding the activities of living with patients’ statements
(ii) Relatives’ and patients’ statements on activities of living with the patients’ results from memory tests
(iii) Relatives’ and patients’ statements on activities of living with relatives’ and patients’ statements about the patients’ memory.

STUDY 4 (IV)
The aims of this study were to describe patients’ emotional status and social company habits, from the perspective of relatives’ and patients’ statements in long-term perspective using two
cohorts and to evaluate the application of relatives’ statements as a possible tool in nursing care to support the patient. This was achieved by comparing relatives’ statements regarding patients’ emotional status, and patients’ social company habits with patients’ own statements.
METHODS

Design
All the studies (I-IV) in this thesis had a descriptive design, and the interviews took place in a naturalistic setting (Polit & Hungler, 1995; Polit & Beck, 2007; 2012). An inductive (I) as well as a deductive approach (I-IV) has been used in this thesis, a pragmatic way of answering the research question. The patient’s perspective (I) and the researcher’s professional perspective (I-IV) are benchmarks in this thesis, meaning that knowledge can be: (i) created from the patient’s lived experience and (ii) obtained from the researcher’s scientific and experienced knowledge (I-IV; von Post & Eriksson, 1999).

STUDY I
In study I, the focus was on patients’ experience from a communicative perspective, which means that it is through the language in discourse interaction, that people create and recreate meaning and confirm social relations, social orders and how social realities are constructed (Gergen, 2001; Hall et al., 2006; Hydén, 1997a). The study (I) has both an inductive (patient’s perspective; patients’ experiences) and a deductive approach (professional pre-understanding; researcher’s scientific and experienced knowledge). The data collection had an inductive approach (patients reconstruction) and the accounts were first analysed by elucidating patterns and grouping the data (induction), but then the patients’ accounts concerning the onset of, and events surrounding being struck by a SAH were analysed from knowledge concerning the language.

STUDY II, III AND IV
In study II-IV the focus was on patients’ and relatives’ views of patients’ memory ability, emotional status and activities of living, and on results from memory tests, in relation to patients’ and relatives’ statements. Professional pre-understanding (von Post & Erikson, 1999) were used constructing and analysing the questions about patients’ memory ability, activities of living, emotional status and social company habits.

The data collection was based on questions designed by the author of this thesis and results from memory tests. The questions were constructed from the author’s professional pre-understanding as a former nurse within neurosurgery nursing and based on scientific knowledge regarding memory subdivisions and classification (Baddely, 1984; Cantor et al., 1991; Anderson, 1995; Egidius, 2008). The questions were prepared in agreement with a medical expert in neuropsychiatry. The questions used in Study II-IV were first tested in a pilot study, where only relatives (n=17) participated in a study 3 years after the patients’ onset of a SAH, selection 1 (Figure 1b). All the questions were found to be valid for the purpose, when they were used in the pilot study. The questions which were designed to suit home living circumstances were then compared with questions in The Comprehensive Psychopathological Rating scale (CPRS; Starmark, 1990), the Assessment protocol mental fatigue, SAH 94-95, Version 5 (Rödholm & Starmark, 1994), Subarachnoid Haemorrhage-94 (SAH-94; Sonn et al., 1994), Personal and Instrumental Activities of Daily Living according to Katz (1963) and Hulter Åsberg (1984), Mini Mental Test (MMT; Folstein et al., 1975). The questions used in study II-IV (Appendix 1-3) cover the parts of interest well, when compared with the above-mentioned questionnaires. Examples showing the overlapping coverage concerning the questions designed by the first author of this thesis and the Assessment protocol mental fatigue, SAH 94-95, Version 5 (Rödholm & Starmark, 1994), The
Subarachnoid Haemorrhage-94 (SAB-94; Sonn et al., 1994) and the Mini Mental Test (MMT; Folstein et al., 1975) are presented in Appendix 4, in this thesis.

Using a questionnaire with structured questions and specific response categories, designed from the first author’s professional pre-understanding, adjusted to suit home living context captured the relatives’ and the patients’ views (experiences) in a natural manner. Well known valid memory test instruments such as Bingley “12- object test” (Bingley, 1958), MMT (Folstein et al., 1975) and Rey Auditory Verbal Learning Test (Schmidt, 2004) were used when testing the patients’ memory in this thesis. To use well known valid memory tests, testing the patients’ memory will give reliable results regarding the patients’ memory ability. The results from the patient’s memory tests are useful when comparing whether or not the relative and patient view (experiences) the patient’s memory in a similar manner to results from patient’s memory test.

Participants
In this thesis 35 patients and 26 relatives participated (Table 1). The patients were former patients, persons living in their own homes, and they had been treated for a SAH at a university hospital in Sweden.

Table 1. Participants, data collections and data analysis in Study I, II, II and IV

<table>
<thead>
<tr>
<th></th>
<th>STUDY I</th>
<th>STUDY II, III and IV (two groups)</th>
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<tr>
<td><strong>Groups</strong></td>
<td></td>
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<tr>
<td><strong>Participants</strong></td>
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<td>11 patients</td>
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<tr>
<td><strong>Data collection</strong></td>
<td>Open interviews</td>
<td>Interviews using a questionnaire (Study II)</td>
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<tr>
<td><strong>Data analysis</strong></td>
<td>Discourse analysis</td>
<td>Fischer’s exact test Z-scores</td>
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**STUDY I**
Nine patients, who had experienced a SAH were interviewed in their homes in average 1 year and 7 months (ranging 14-24 months) after the event, concerning the onset of and events surrounding a SAH (Figure 1a). The question was “Describe what happened when you suddenly became ill”. Support statements/questions, such as for example “tell me more”, humming and “what happened than, were used in the interaction. Six of the patients were women aged between 35-54 years and three were men aged 33-67 years. The patients, who were contactable and native language-speaking at the time of their discharge from the University hospital, were selected from the hospital’s patient records system over the course of a year. Patients with dementia or brain damage from causes other than SAH were excluded, as were patients with noted substance misuse according to medical records, so too were patients who were unconscious, according to the Reaction Level Scale (RLS), Starmark et al. (1988), when discharged from the University hospital and those who were under-aged (< 18 years) at admission to the University hospital.
Ten patients, who had been treated for SAH at a University hospital over a course of a year, were recruited to participate in the study. Female and males, patients living both in large and small town environments, patients falling ill within different point of time of the year, alternating from the bottom and the top of the hospital’s patient records system list were elected before reading the patients’ medical records. Patient who did not fulfil the inclusion criteria (due to the exclusion criteria) were excluded. External attrition rate comprised two patients, who declined to participate. Another two patients were recruited, according to the selection procedure mentioned, and they were contacted and asked permission about their participation in the study. One of them could not participate in the study due to family matters. Nine patients (informed consent), living in their own homes, participated (Figure 1a) and both patients working outside their homes and patients retired from work participated. Three of the patients were males with an average age of 55 years (33-67), and six patients were females with an average age of 47 years (35-54). They had different educational background and blue collar workers (manual workers), white collar workers and academics were represented. The patients suffered from ruptures that supply the front area (A. Communicans anterior, n=1), the middle area, (A. C. Media dexter, n=4,) and the back area (Pica aneurysm, n=4). Four patients suffered from complications (hydrocephalus) due to SAH.
Table 2. Patients’ occupation before and after the onset of the SAH, profession and education

<table>
<thead>
<tr>
<th>STUDY I</th>
<th>STUDY II-IV</th>
<th>Cohort 1</th>
<th>Cohort 2</th>
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<td>Males</td>
<td>Females</td>
<td>Males</td>
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<td></td>
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<td>n=10</td>
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<td>AVERAGE AGE</td>
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<td>(35-54)</td>
<td>(48-85)</td>
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<td>OCCUPATION AFTER THE ONSET</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Working in the home</td>
<td></td>
<td>-</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Blue collar (Manual worker)</td>
<td></td>
<td>-</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>White collar</td>
<td></td>
<td>1</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Academic</td>
<td></td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>EDUCATION</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary school</td>
<td></td>
<td>-</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Upper secondary school</td>
<td></td>
<td>1</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>Vocational school</td>
<td></td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>University studies</td>
<td></td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

STUDY II, III AND IV

In study II-IV 26 relatives and 26 patients, who had experienced a SAH (2 cohorts) were interviewed and 26 patients (2 cohorts) in study II underwent memory tests in their homes, 11 (Cohort 1) and 6 (Cohort 2) years respectively after the event (Table 1). Cohort 1 (Figure 1b; comprised 10 females and one male (ranging in age between 48-85 years, mean age 67 years) and Cohort 2 (Figure 1b) comprised nine females and six males (ranging in age between 41-75 years, mean age 60 years). Haemorrhage origin, status at the onset and complications in the acute phase are presented in Table 3.

Table 3. Demographic data, status at the onset and complications in the acute phase of the SAH. The demographic data presented in Table 3 has also been presented in Berggren et al., 2010 (Study II; Table 1).

<table>
<thead>
<tr>
<th>Haemorrhage origin</th>
<th>Supply areas of the brain</th>
<th>Age at interview</th>
<th>Unconsciousness at the onset, according to statements</th>
<th>Complications</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Spasm in the vessels</td>
</tr>
<tr>
<td>A. communicans anterior (ACOA)</td>
<td>Fronto-occipital lobe</td>
<td>38</td>
<td>70 (62-77)</td>
<td>&gt; 10 minutes n=1</td>
</tr>
<tr>
<td>A. carotis dexter</td>
<td>Fronto-occipital lobe</td>
<td>1</td>
<td>65</td>
<td>---</td>
</tr>
<tr>
<td>A. c. media dexter</td>
<td>Parietal and Temporal lobes</td>
<td>2</td>
<td>2</td>
<td>56 (48-64)</td>
</tr>
<tr>
<td>Vermis haemangioma</td>
<td>Cerebellum</td>
<td>1</td>
<td>68</td>
<td>---</td>
</tr>
<tr>
<td>Pica aneurysm</td>
<td>Cerebellum</td>
<td>1</td>
<td>73</td>
<td>&gt; 10 minutes n=1</td>
</tr>
<tr>
<td>A. basilaris</td>
<td>Ocipital lobe</td>
<td>1</td>
<td>81</td>
<td>---</td>
</tr>
<tr>
<td>SAH (unknown origin)</td>
<td>Unknown area</td>
<td>3</td>
<td>70 (61-85)</td>
<td>&gt; 10 minutes n=1</td>
</tr>
</tbody>
</table>
The participants (relatives and patients) in Cohort 1 and 2, in study II-IV were recruited from two different groups of patients diagnosed with SAH (selection 1 and 2) and from two separate earlier studies (Figure 1b), where only relatives participated three years after the patients’ onset of the SAH. In selection one and two the patients were recruited from the hospital’s patient records system over the course of a year. The exclusion criteria were: Relatives of patients with presence of dementia or brain damage from causes other than SAH; with noted substance misuse; who were unconscious according to the Reaction Level Scale (RLS; Starmark et al. (1988)) while leaving the University hospital; who had died and those who were under-aged (< 18 years) at admittance to the University hospital. The patients (three years after the patients onset) were first asked permission (by the author of this thesis) to contact a relative, and the relative was asked to participate (informed consent) in the study (selection 1 and 2), at a separate occasion. The relatives were spouses of the patients and two of the relatives were sons, and two were daughters, who lived close to the patients’ home, having daily contact, both before and after the patients’ onset of the SAH.

Eleven years (Cohort 1) respectively 6 years (Cohort 2) after the patients SAH, patients and relatives were asked to participate in study II-IV.

In Cohort 1, 16 out of 17 patients were asked permission (one patient had died) about their own and their relatives’ participation, 11 years after the onset. The external attrition rate comprised five patients; one declined to participate and four patients did not answer reminder letters. Eleven patients gave their consent to participate in the study and they also gave consent to contact the relatives. Eleven relatives and 11 patients (informed consent) participated in the study, 11 years after the patients’ onset of the SAH (Figure 1b).

In Cohort 2, 20 out of 22 patients were asked permission (two patients had died) about their own and their relatives’ participation, 6 years after the onset. The external attrition rate comprised five patients; three declined to participate and two patients did not answer the reminder letters. Fifteen patients gave their consent to participate in the study and also gave consent to contact the relatives. Fifteen relatives and 15 patients (informed consent) participated in the study, six years after the onset of the patients’ SAH (Figure 1b).

The patients and the relatives who participated in study II-IV (Cohort 1 and 2) were persons both working outside their homes and persons retired from work. The patients had different educational background and blue collar workers (manual workers), white collar workers and academics were represented (Table 2). The relatives were spouses of the patients, who lived together with the former patients in their common homes, both before the patients’ SAH onset and at the time of the interviews (study II-IV), with four exceptions: Two of the relatives were sons and two were daughters, who lived close to the patients’ home, having daily contact, both before and after the patients’ onset of the SAH.

Data collections

STUDY I

The interviews which varied between 60 and 90 minutes took place in the informants’ homes, and the interviews were recorded on tape and transcribed verbatim. Forty pages of text in relation to the question “Describe what happened when you suddenly became ill” were analysed.

The patients made accounts concerning the onset of, and events surrounding their SAH, which involved studying social life and human actions and meaning-making in
communication. This process also identifies contexts, such as the situation for the SAH incident, as well as the interview situation. This means that the accounts are situated and context-related (Sarangi & Coulthard 2000; Linell & Thunkvist 2003). The method is based upon the notion that the individual’s thoughts are internalised dialogue (Linell, 2004). The interactional aspect and the language (the how) are just as important as the topics (the what) in the accounts (Riessman, 1997).

In focusing on language there was a two-fold focus (Riessman, 1997; Linell & Thunkvist, 2003) to find out:

- what were the lived experiences of people suffering from SAH and
- how did people initiate accounts of their becoming acutely ill, and how did they initiate accounts when attending to aspects of sense-making practices (Gwyn, 2002) in the discourse interaction (Linell, 2004) with the researcher.

**STUDY II, III AND IV**

A questionnaire with structured interview questions and specific response categories concerning patient’s memory (II), activities of living (III), emotional status and social company habits (IV), and memory tests (II) were used as instruments to collect data. The questions in study II-IV were designed from the author’s professional pre-understanding, and based on scientific knowledge regarding memory subdivisions and classification. This is described in the design of this thesis.

**The interviews (II -IV) and the memory tests (II)**

The interviews (relatives and patients) concerning study II-IV, using a questionnaire with specific response categories took place in the informants’ homes and varied between 60-90 minutes and the respondents had access to a personal copy of the questionnaire form during the whole interview, with the intention that they could both listen to and read the questions themselves during the interview. The memory tests (II), which altogether took between 60-70 minutes to perform, took place in the patients’ homes at the same occasion as the interviews. The patient and the relative were interviewed on separate occasions on the same day (except for two relatives who were interviewed by telephone at work (the patient was not present), and they were not able to talk with each other about the questions before answering them.

**The questions in Study II** focused on STM and LTM; (i) episodic memory, (ii) semantic memory, (iii) procedural memory, (iv) recent memory, (v) remote memory and (vi) meta-memory, and memory test were performed. The questions concerning patients’ memory are presented in Appendix 1 (Questions to patients) and 2 (Questions to relatives), and in appendix 3 (Grouped Questions) in this thesis. The memory tests in Study II were carried out in order to examine the patients’ memory ability and to compare the test results with the statements of relatives and patients, concerning memory ability, after the SAH. Mini Mental Tests (MMT; Folstein et al., 1975); Bingley “12-objects test” (Bingley, 1958) and Rey Auditory Verbal Memory Test; (Schmidt, 2004) were used to evaluate the patients’ STM and LTM.

**MMT examination** (Folstein et al., 1975) measures STM and LTM, and the total scores at the test. The total scores were taken into account in the present study. The patients’ scores were compared with reference values (mean, standard deviation) according to age and education level (Hellström, 2004), using Z-scores (Altman, 1999).
The Bingley “12-object test” (Bingley, 1958) was used to evaluate the patients’ STM and LTM. Twelve ordinary objects, on a card, were shown to each patient for 30 seconds. During these 30 seconds the patient was asked to read the name of each object aloud, in order to memorize them. Immediately after that, the patient was asked to reproduce what had been shown on the card (STM). After 30 minutes (delayed recall), the patients were again asked to reproduce the objects shown earlier (LTM). The level for passing the test was set, by the first author, to a minimum of six pictures for the STM (reproduced after 30 seconds) and to a minimum of four pictures for the LTM (reproduced after 30 minutes), irrespective of age or education background/level. The level was set from experience in clinical practice, in agreement with a researcher in neuropsychiatry.

The Rey Auditory Verbal Learning Test (Schmidt, 2004) was performed by reading 15 unrelated words from a list and the patient was immediately (STM) asked to loudly reproduce the words (immediate recall) in any order. This was done five times and then a new list (No 2) with 15 new words was read to the person, and the person was immediately asked to reproduce the words, in any order (STM). Then the person was immediately asked, from his/her memory to reproduce the words from the first list again, in any order. Thirty minutes (delayed recall) after the first list was read, the patient was asked from his/her memory to recall the words from the first list again in any order (LTM). The Rey-test was finished with a digit span memory rehearsal test, (digits forward and backwards). The patients’ scores were compared with reference values (mean, standard deviation) due to age (Ivnik, 1990; Schmidt, 2004), using Z-scores. The author of this thesis performed and analyzed all memory tests.

The questions in Study III focused on social life and personal and instrumental activities of daily living (P- and I-ADL). The questions concerning patients’ social life and personal and instrumental activities of daily living (P- and I-ADL) are presented in Appendix 1 (Questions to patients) and 2 (Questions to relatives), and in appendix 3 (Grouped Questions) in this thesis.

The questions in Study IV focused on patients’ emotional status and social company habits. The questions concerning patients’ emotional status and social company habits are presented in Appendix 1 (Questions to patients) and 2 (Questions to relatives), and in appendix 3 (Grouped Questions) in this thesis.

Data analysis

STUDY I

Discourse analysis was used to describe meaning-making in the accounts (Buttny, 1993; Horton-Salway, 2003; Taylor, 2003; Potter & Wetherell, 2007) of the experience of the onset of a SAH. Discourse analysis consists of two parts: a part close to the data (fine-grained) and a more general analysis (context-related). The text was read several times in order to acquire a full appreciation of the data and to elucidate patterns. Both the information (what), and the interaction (how) were studied according to Linell and Thunkvist’s methodology (2003). Interesting content and statements which occurred together were grouped jointly in content and topics whereupon Discourse Analysis was carried out (Wetherell et al., 2003). Sequences and episodes were then analysed with support of data extracts, which are presented descriptively. The accounts were rich in fact and interest constructions (Wetherell et al., 2003). The extracts were translated from Swedish to English by a native English speaker, in order that the subtleties and meaning from the original language were not lost. According to Taylor (2003) the principal difference between DA and other data analyses is not the initial analysis process, rather it is the analytical concept’s theoretical tradition. The researcher refers
back in the analysis to the assumptions which result from the language, the accounts, the interactions, the context and the interactions between all of these, which are applied in Study I. It is the theoretical basis rather than the classification system which characterises DA (Taylor, 2003).

The author of this thesis performed all interviews, which were recorded on tape, and then transcribed verbatim. The text was read several times separately by the author of this thesis and another researcher, and the data (accounts) were then analysed both separately and together by the author and another researcher. A third researcher read the findings after the analyses were performed, to see if there was relevance in the analysis.

STUDY II, III AND IV

Cognitive sequelae such as memory and emotional problems, and problems with the ability in activities of living after a SAH can affect daily life. A patient and a relative can judge the patient’s memory, emotional status and ability in activities of living (P-and I-ADL and social life) differently, which may have negative effects on the patient’s future mutual family relationship.

The main interest was therefore to evaluate the application of relatives’ statements, by comparing the relatives’ statements with: (i) patients’ statements (II-IV) and (ii) the results of memory tests (II), in order to investigate whether the relatives’ and patients’ statements differs or are similar. Therefore the cohorts (1 and 2) were analysed both separately (as the mean age in cohort 2 were lower than in cohort 1) and together in these studies. This was done to see if there were any differences concerning the statements about patients’ memory, activities of living and emotional status and social company habits in relation to age in the cohorts. As the prevalence of residual impairments are stable after two and a half years (Lindberg et al., 1996) the outcomes at six, compared with 11 years, after the onset of the SAH, may have a negligible influence on the outcome of the relatives’ and patients’ statements.

Fischer’s exact test (Altman, 1999) was used for the statistical analysis of paired proportions: from relatives’ and patients’ statements (II-IV), from relatives’ statements and the results from patients’ memory tests (II), and from patient’s statements and the results from patient’s memory tests (II). The significance level was set to \( p < 0.05 \), \( p < 0.01 \) and \( p < 0.001 \). Z-scores (Schmidt, 2004), corrected for age and education concerning MMT (Folstein et al., 1975; Hellström, 2004), corrected for age concerning Rey Auditory Verbal Learning Test (Hellström, 2004; Ivnik et al., 1990; Schmidt, 2004) were used to analyse the results from memory tests (MMT and Rey Auditory Verbal Learning Test) in Study II. The results were then compared with previously reported evaluations from memory tests, based on populations with no reported memory problems (Ivnik et al., 1990, Schmidt, 2004). Individual test results with a Z-value of -1 or less were considered to be statistically different from the reference value estimated from population means (Schmidt, 2004).

The author was responsible for collecting the data, performing the interviews and the memory tests and undertook the data analysis. The author and one of the researchers in study II-IV undertook the statistical analysis. A third researcher (II and III) and three researchers (IV) read the findings after the analysis were made, to see if the analyses were conducted in a proper manner.
Ethical considerations

Ethical guidelines and rules are aimed to protect people in all kinds of research. It is especially important when appealing to vulnerable data of patients, such as that concerning memory ability and emotional status. When planning, performing and presenting the results, the four ethical principles: Autonomy, doing good and not harming (beneficence) and justice were taken into consideration. The principle of autonomy (The Belmont Report, 1979; Northern Nurses’ Federation, 2003) was respected in the following way: Letters of inquiry concerning participation in the studies were sent by the researcher to the patients’ home addresses. The patients received information concerning the aim of the current study. They were also informed regarding the implementation, the voluntariness to participate, that the information given would be treated confidentially and that the results should be presented in such a way that no single person and/or family could be identified. The approached patients were asked to sign and send a written informed consent to the author, stating if they were willing to participate in the study. Information was also provided stating that the interview could be stopped at any time, without any influence on any continued nursing care and/or medical treatment. The patients also received information that there should be an additional contact, if the patient had interest to participate in the study, with the aim to decide time and place were the interview should take place. In those studies were relatives participated, the patients were contacted before the relatives. Both patients and relatives received the same information and written informed consent was given by both but separately.

Informed consent pre supposes understandable information and that voluntary participation is ensured (The Belmont Report, 1979; Northern Nurses’ Federation, 2003). Further, it was possible to contact the author of this thesis by telephone, to get more information or clarification. Written consent was awaited before contact was taken to determine time and place of the interview. The questions concerning participation made were asked at separate occasions, and there were time for reflection for both patients and relatives. There were also opportunities to change the participate decision and to suspend participation during or after the interview. Autonomy was thus taken into account and also free will.

Doing good and not harming

In this thesis, bringing up not noted problems such as memory and emotional problems has been carefully considered. By participating in studies patients and their relatives would become more aware of the patient's memory capacity and emotional status. The benefits (doing good) of being aware of the problems are considering the risks (of injury), when many elements of daily life can be dangerous if there are memory problems, and are even worse if the patient and relatives are unaware of the problems. The author gave assurance before the interview that contact with health care providers were established for the patient. This was done to ensure that the patient had some professional to turn to, if the patient had questions about his/her memory and/or emotional status. All participants in the studies were in contact with a medical centre. When both the patient and the relative were interviewed, the interview took place individually and the information obtained during the interviews was not reported to the patient or the relative. The patient's performance on memory tests was not presented to the relative, due to the patients’ privacy, if the patient did not ask for it. Consideration has therefore been given to privacy, even from a relational perspective (not to harm). All former patients were interested in participating in memory tests and those patients who performed less well on the tests were satisfied with their results. According to the patients, the results confirmed their own experience of how their memory functioned in daily life. When interviewing the relatives (this was done after the patients’ interview and memory tests) it emerged that the relatives were aware of the memory difficulties of those patients who
performed less well on the memory tests. Even the relatives were asked if the patients had any ordinary contact with a medical centre, physician or hospital of any kind. Therefore it is to be considered that there were no risks in not presenting the patients’ results from memory tests to the relative.

**In study I** the project was approved by the Research Ethic Committee at University of Umeå (Registration no 98-138) in Sweden. In addition to written information verbal information about the study was also provided at the time of the interviews. Written informed consent was obtained at the time of the interviews.

**In study II-IV** in addition to written information, verbal information about the study was also provided at the time of the interviews. Written informed consent was obtained at the time of the interviews. The project was approved by the Research Ethics committee of medicine at Sahlgrenska University Hospital, Sweden (Registration number: S 234-03).
RESULTS

People stricken by SAH interviewed seem, though there were memory gaps, to be able to judge their memory for when they were becoming ill (informants’ accounts). The process of meaning-making is both a matter of understanding SAH as a pathological event, and a social and communicative matter, where the SAH is construed into a meaningful life history, in order to make life complete. The informants positioned themselves as cognitive alert persons and the accounts can be interpreted as an identity construction (I).

Memory problems, changes in emotional status and problems with activities of living were common according to relatives’ and patients’ statements (II-IV). Memory problems were also common from memory test results (II). There were memory problems both in the acute stage, (informants’ accounts; I) and in a long-term perspective (patients’ and relatives’ statements, and test results; II). The episodic memory seemed to be well preserved both concerning the onset of the SAH and events surrounding the onset (informants’ accounts; I) and in a long-term perspective after the SAH, regarding relatives’ and patients’ statements (II).

Patients’ statements concerning their memory in a long-term perspective corresponded to a higher degree with memory test results, in comparison with relatives’ statements. Patients’ statements concerning memory ability in general (STM and/or LTM) and Long-term memory (LTM) corresponded with memory test results. There was correspondence between relatives’ and patients’ statements regarding the patients’ memory in general and long-term memory. Both relatives and patients underestimated older patients’ memory ability and underrated younger patients’ memory problems, when compared with results on memory tests. Some patients had meta-memory problems according to relatives’ statements (II). Relatives described the patients’ daily life ability (problems or not) in a similar manner to the patients’ statements. Patients’ statements about problems with activities of living corresponded to the results from memory tests and patients’ statements. Patients had more problems with their social lives than with personal and instrumental activities (P- and I-ADL). Relatives’ and patients’ statements concerning P-and I-ADL and patients ability to read and assimilate a book (social life) corresponded (III). Changes in emotional status were more common (IV), than memory problems (II). Relatives rated patients’ emotional status (having problems or not) in a similar manner to patients’ statements. Patients had changed their company habits because of changes in in their emotional status; concentration difficulties, fatigue, patients’ sensitivity to noisy environments and uncertainty. Patients’ and relatives’ statements about social company habits corresponded (IV). The results showed that there was a high degree of concordance between relatives’ and patients’ evaluations concerning patients’ memory ability, emotional status and patients’ ability in activities of living in studies II-IV.

Study I

The person’s reconstruction of the illness event in interaction with the researcher was interpreted as an identity-creating process. The informants positioned themselves and wanted to show that they were cognitively alert people. The analysis emphasised topics and content from the informants’ experiences (inner world) of SAH and how these were woven together in the talk interaction and in the accounts (outer world). The findings were arranged into three

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1 When presenting the results in study I, the researcher refers back (in the analyses) to the assumptions which results from the language, the accounts, the interactions, the context and the interactions between all of these. According to Taylor (2003), the principal difference between discourse analysis and other forms of data analysis is the theoretical tradition which shaped the practice of discourse analysis, rather than the process of initial analysis. It is the theoretical basis rather than the classification system which characterizes discourse analysis.
topics: (i) Sensations, (ii) Actions and (iii) Cognitions. Sensations were described as physical and mental sensations and as physical pain, using metaphors. Actions were expressed as conscious irrational and rational actions, and cognitions were interpreted as memory and memory problems (Table 4). Deeper analyses identified critical events related to SAH: (i) Existential threats and existential insights, (ii) Time as ‘waiting’ and time as ‘structuring meaning’.

Table 4. Summary of topics and content from the informants’ experience and accounts of SAH in Study I. The informants experience and accounts of SAH presented in Table 3 has also been presented in Berggren et al., 2010 (Study I; Table 1).

<table>
<thead>
<tr>
<th>Topics</th>
<th>Sensations</th>
<th>Actions</th>
<th>Cognitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Content</td>
<td>Physical</td>
<td>Mental</td>
<td>Pain</td>
</tr>
<tr>
<td>Example</td>
<td>Reducing feeling</td>
<td>Unsteadiness</td>
<td>Paralysis</td>
</tr>
</tbody>
</table>

**FINDINGS FROM TOPICS**

**Pain as metaphors**
The pain was often described with the use of metaphors, for example, like being ‘‘thought my eyes were shooting out of my head’’ (Data extract 2) and as ‘kicked in the head by a horse’ (data extract 1). Metaphors were used by the informants in order to make the incomprehensible (the intensity of the pain and being stricken by a SAH) comprehensible by other people. The metaphors worked as a tool to verbalise and to make concrete an experience like pain. The pain, which is a subjective sensation, has been verbalised and made more concrete and objectified, so that the listener can get a concrete impression of what the pain was like. In spite of the pain the informants continued with their actions.

**Irrational and rational actions**
It emerged that the informants’ accounts about actions were conscious expressions described as being either irrational or rational actions. The following data extract (Data extract 2) ‘then I thought, I suppose, yes I suppose we better get the boat into the lake’ showed that the person continued with his activities as though the haemorrhage had not happened. This was in spite of the pain being described as intense: ‘thought my eyes were shooting out of my head’’. Nevertheless, the informant was acting rationally when he said ‘I better get myself somewhere else’, that is, he actually understands that he must get himself to hospital. The later action in the form of a decision to get help was driven by the developing symptoms as the experience of physical sensations: ‘I couldn’t walk, began to limp’ and mental sensation ‘I got really weird’. Acting rationally, such as seeking help, was delayed. The informant nevertheless showed that he quickly understood what was happening - that something serious had
happened - when he said: ‘then I understood that I better get myself somewhere else’. The man was talking from two perspectives.

Talking from two perspectives
During the communication interaction informants were speaking from two different perspectives: Partly with the ‘healthy’ voice (something that has happened) and partly with the ‘sick’ voice (to be in the situation). This is also described by Hydén (1997b). The latter, both speaking with the sick and the healthy voice was described as: “then I thought I suppose we better get the boat into the lake” followed by “I better get myself somewhere else” and with the sick voice “began to limp and my right leg was dragging’ and ‘it was dragging and I got really weird’ and then with the ‘healthy’ voice when he described something in the emotional life, as he understood it: “then I understood...” (Data extract 2). In the informant’s description with the ‘healthy’ voice he made more concrete something which was diffuse, that is, his emotional life, and at the same time he positioned himself, according to Davies and Harré, (2007), Van Dijk, (2007), as a healthy, cognitively alert and credible person.

Episodic memory and memory gaps
Both memory and memory gaps for the onset of the illness and events closely after it were reported. The informants even described memories of when their memory returned. In relation to memory function, detailed descriptions were even given of the time and place, including the context of the illness events. Memory for the acute phase of the illness, so called episodic memory, seemed to be well preserved in the sense that the experience of becoming ill were related to time, place and activity. This was described in data extract 3 as: ‘Sunday evening on the 18th of December, 1996’ (time) and the place (room) were described as: ‘a restaurant up there’ and the activity as: ‘were invited to Christmas dinner’. In spite of gaps in the memory: ‘then I don’t remember so very much more’, it is clear from the data extract when the informant says: ‘we were invited to Christmas dinner’, that there was memory for personal events. This allows us to understand that more complex memory as episodic memory, derived from secondary memory (long-term memory) can be well preserved after a SAH. The informant’s accounts are also examples that show that the informants were able to correctly evaluate their own memory (meta-memory).

Perceived meta-memory
The informant (data extract 3), continues to say: ‘I don’t remember so very much more’ that can be explained in terms that the encoding and storage of sensory impressions were impeded with the reduction of consciousness. The fact that the informant was aware of what is and is not remembered, and was aware of when memory returned: ‘it took several months before I really realised that I was in hospital’ showed that the informant was able to correctly evaluate and judge her own memory abilities (meta-memory). The informant positioned herself in the interaction with the researcher.

Positioning oneself
One interesting aspect was the informant’s way of dealing with the report of the exact time of becoming ill and the described contextual relationship, including that the time before the event was described as: ‘I can begin on that day first’, ‘we were invited to a Christmas dinner’ (data extract 3). In addition to this construction of facts, it is also clear that there is also construction of interests (Horton-Salway, 2003) where the informant describes herself as being believable (in spite of some memory gaps), by her convincing the interviewer: ‘I remember it exactly’. The informant in data extract 4 said: ‘I have been told’ –that ‘I have
answered both what my name is and how old the boy is'. The informant was aware that there were periods during the acute phase when she was not aware of her own world, which led to being dependent upon others, but at the same time she wanted to appear as having functioned reasonably well: ‘I kind of functioned’, using the healthy voice. The informant seems to need to position herself (Davies & Harré, 2007; van Dijk, 2007) as cognitively alert in the communicative interaction. This can be described as an identity creating process.

Identity creating process and sense making

It seems that the former informant (data extract 4) was aware of the fact that cognitive functions might have been damaged during the SAH, but in spite of this wanted to portray herself as believable by giving a richly-detailed report of the course of events at the time she became sick. In addition, a chronological account is given of what her husband - who looked after her when she became ill - did and thought: ‘then he understood that it was something serious’, ‘he tried to get me back to bed so that I wouldn’t fall’ and ‘he rang for an ambulance’ (data extract 4). The reconstruction during the communication interaction of becoming ill can therefore be seen as an identity-creating process (Davies and Harré, 2007), where the informant positioned herself as being cognitively alert, not just during the acute phase of the illness, but also when she presented herself as being cognitively intact when she speaks with the ‘healthy’ voice during the dialogue with the interviewer. The illness event is an experience and realisation of both how vulnerable the body is and of what it is like to be reliant upon somebody else’s memory, ‘So I have been told’ (data extract 4). Both these experiences influenced the construction of the individual identity. By speaking with a retrospective perspective, the self-identity was constructed (Goffman, 1959; Gwyn, 2002) as well as it was a way of making sense (meaning-making) of the disruption of life related to the SAH.

The critical events represent the crux of the meaning which is enmeshed in the lived experiences of having been stricken with a SAH. The critical moments were (i) “existential threat and existential insight”, and (ii) “time as waiting and time as structure”.

CRITICAL MOMENTS

Existential threat and existential insight

SAH is a pathophysiological event which was verbalised and ascribed an existential meaning. The informants seem to be incapable of influencing what is happening. In relation to the threat against the biological existence, this was described: ’now I am disappearing’ (data extract 5). It provides an existential insight into the vulnerability of life, in which the person stricken by a SAH had no control over in the course of events. Instead of acting, a detached observation of what is happening in the body arises - what others said and did, and what was happening to the person’s life.

Although the person in extract 5 had no control over his biological existence, the observation was described by the repetition of phrases such as: ‘so when I lay there I got such pain’, ‘then I felt’, ‘when I was lying there’, ‘it was dreadfully painful I didn’t actually get any’ and ‘then I said’. From the extract it is clear how pain as a sensation is described in an objectified form as ‘it’, separated from the person’s Self by stating it as: ‘then it came back again’. This expresses the understanding of the pain as being exogenous, that is, something which comes from the outside. At the same time, the pain is personified with qualities associated with himself personally: ‘so when I lay there I got such pain’, that is, it was something
endogenous. This way of expressing pain as both personified and de personified indicates two different ontological perspectives of pain, as it being both real and true and as a subjective experience of having pain (Gwyn, 2002). Therefore, in order to create meaning and understanding of being stricken by a SAH, linguistic (lexical items) and contextual resources are employed (Linell, 2006). The man said, when feeling that his existence was threatened: 'it was so dreadfully painful’. The statements created the man’s identity on two levels.

**Identity construction on two levels**

The pain threatened his existence, which can be interpreted to be the reason for the man saying to his pal: ‘you can go home now’ (data extract 5). The statement created identity for the man on two levels; partly in the account and partly in the interaction. In the account a picture developed of a man who in spite of a life-threatening situation, manages to keep himself calm and even requested his pal to go home. He showed that he could control the situation cognitively and verbally, in spite of the fact that he has lost control over what the illness is doing to his body. In the interaction the man created a dramatic account in which he uses time as an intensifying factor: ‘it wasn’t really a long time I was lying there’.

**Time as waiting and time as structure**

In addition to the pain which was described as dreadful in Data Extract 5, the informant also mentions in the ‘here and now’ of the course of events (historical present) of how he was losing consciousness. Apart from this, the man places himself in past time, that is, the time during which he lay and waited to be dealt with: ‘it wasn’t really a long time I was lying there’. The informant described how he suddenly became aware that he as a person was starting to disappear: ‘now I am disappearing quickly’. In spite of this he expresses hope - quite apart from what the course of events might turn out to be - when he says to his pal: ‘it will be alright’. The time is used as a resource for working out what his illness is and for coming to understand what is happening (Hydén, 1997a; 1997b).

**Meaning making through interaction**

The event, (data extract 5) was placed in a time frame according to the following: (1) He is admitted to hospital, (2) he gets a lot of pain, (3) he waits for help, (4) he does not get any pain relief, (5) he feels he is disappearing quickly, (6) he tells his friend to go home. This ordering of events over time highlights the fact that time was used as a structuring mechanism for the informant to come to terms with the significance of the illness, and with how his condition changed over time. The man’s condition changed from seeming to be not particularly dangerous to being life-threatening when the man feels that he is starting to lose consciousness. This is described by the man as being related in some way to the fact that he is not getting any pain relief: ‘but then I felt that now I am disappearing quickly because it was so dreadfully painful I didn’t actually get any painkillers’. This manner of describing events in sequence is called ‘minimal narration’ and consists of at least two events in sequence (Labov, 1972). This description is also an example of a retrospective online description, which gave an insight into to what happens when someone is stricken with a SAH and which was seen from a lived experience. It also showed how an event is construed and reconstructed in dialogue in order to create meaning through the interaction.

The accounts concerning the critical events should be seen as a retrospective distancing from the illness event, and to put it in a coherent life context and within an identity construction which makes life complete or whole.
**Study II**

Problems with memory, including meta-memory problems (relatives’ statements), were common in a long-term perspective. Relatives and patients stated patients’ memory in a similar manner. However, patients’ statements concerning their memory corresponded in higher degree with memory test results, in comparison with relatives’ statements. Both relatives and patients had difficulties judging the patients’ STM. However, relatives’ and the patients’ statements concerning the patients’ LTM and memory in general (STM/ and or LTM) corresponded.

**RELATIVES’ AND PATIENTS’ STATEMENTS CONCERNING PATIENTS’ MEMORY ABILITY**

Both relatives and patients stated the patients’ memory ability in general (STM and/or LTM), in a similar manner in Cohort 1 and 2 judged together (p<0.05) and in Cohort 1 (p<0.05), figure 2. Concerning STM, no correspondence was found in Cohort 1 and Cohort 2, or in Cohort 1 and 2 judged together. There was, however, correspondence between the relatives’ and the patients’ statements regarding the patients’ LTM in cohort 1 (p<0.05) and in Cohort 1 and 2 judged together (p<0.05), Figure 2.

Nineteen patients (Cohort 1 and 2 together) had memory problems in general, according to relatives’ statements and 20 patients had memory problems in relation to the patients’ own statements (Table 5).

**Figure 2.** A comparison between relatives’ and patients’ statements concerning 26 patients’ memory problems/ability, six (Cohort 2: patients n = 15, relatives n = 15) and 11 (Cohort 1: patients n = 11, relatives n=11) years after the patients’ onset of a SAH. A represents statements concerning STM, B represents statements concerning LTM and C represents statements concerning memory from a general point of view (STM and LTM). I represents relatives and patients who do experience memory problems, II represents relatives who are not aware of any memory problems, patients who do experience memory problems, III represents relatives who do experience memory problems, patients who are not aware of any memory problems, and IV represents relatives and patients who do not experience any memory problems. Fisher’s Exact Test was used for the statistical analysis of paired proportions from relatives’ and patients’ statements. ‘*’ represents a correspondence concerning relatives’ and patients’ statements at a significance level of p < 0.05. The data presented in Figure 2 has also been presented in Berggren et al., 2010 (Study II; Figure 2).
Eleven years after the onset of the SAH (Cohort 1), relatives reported that eight patients had memory problems and patients themselves reported that nine of them had memory problems. Six years after the onset of the SAH (Cohort 2), relatives reported that 11 patients had memory problems and patients reported that 11 of them had memory problems. Both STM and LTM problems and several types of LTM problem were represented in both Cohort 1 and 2 after the onset: (i) Episodic memory, (ii) Semantic memory, (iii) Recent memory, (iv) Remote memory, except for problems with Procedural memory, which were expressed by only one patient in Cohort 1 (Table 5).

Relatives stated that five patients (Cohort 1 and 2 together) had meta-memory problems (Table 4). The patients also showed concentration problems, according to both the patients (n=17, 65 %) and the relatives (n=16, 62%), in Cohort 1 and 2 judged together.

**Table 5.** Memory problems in relation to relatives’ and patients’ statements about memory, and results on memory tests in Cohort 1 and Cohort 2, eleven years and six years after the onset of the SAH. The statements and memory problems presented in Table 5 have also been presented in Berggren *et al.*, 2010 (Study II; Table 2).

<table>
<thead>
<tr>
<th>Cohort</th>
<th>Statements</th>
<th>Memory tests</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Participants</td>
<td>Relatives n=11</td>
<td>Patients n=11</td>
</tr>
<tr>
<td>Type of problem</td>
<td>Numbers of relatives and patients who made statements concerning memory problems and numbers of patients with memory problems according to memory tests</td>
<td></td>
</tr>
<tr>
<td>Problem with memory ability in general (STM and/or LTM)</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Problems with both STM and LTM</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>STM (short-term memory, primary memory)</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>LTM (long term memory, secondary memory)</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Episodic memory</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Semantic memory</td>
<td>6</td>
<td>7</td>
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<tr>
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<td>1</td>
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<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Meta-memory</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

**RESULTS FROM MEMORY TESTS**

Twenty patients, (seven patients in Cohort 1 and 13 patients in Cohort 2), had memory problems in general (STM/ and or/LTM) according to the results from one, several, or all the memory tests (Table 5; 6). Four patients (Cohort 1), and 12 patients (Cohort 2), were found to have problems with STM. Five patients (Cohort 1), and nine patients (Cohort 2), had LTM
problems (*Table 5; 6*). Two patients (Cohort 1), and eight patients (Cohort 2), had both STM and LTM problems (*Table 5*).

There were no differences concerning the outcome of memory problems from the memory test results, between the 13 patients (n=6, Cohort 1; n=7, Cohort 2) who had complications (hydrocephalus and spasm in the vessels) after the SAH, and the 13 patients (Cohort 1, n=5 and Cohort 2, n=8) who did not suffer from complications in the acute phase. In the group with complications (n =13), three patients in Cohort 1 and seven patients in Cohort 2, had memory problems, according to results from the memory tests.

*Table 6. Memory test results among 20 patients with memory problems in general (STM and/or LTM), in Cohort 1, n=7 and cohort 2, n= 13, according to test results (Bingley, Rey and MMT)*

<table>
<thead>
<tr>
<th>COHORT</th>
<th>PATIENTS WITH MEMORY PROBLEMS ACCORDING TO MEMORY TESTS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Patients with memory problems in general (STM and/or LTM) according to one, several, or all tests</td>
<td>7</td>
</tr>
<tr>
<td>Problems according to MMT</td>
<td>0</td>
</tr>
<tr>
<td>MEMORY PROBLEMS according to:</td>
<td>STM</td>
</tr>
<tr>
<td>MMT and/or Bingley and/or Rey</td>
<td>4</td>
</tr>
<tr>
<td>Bingley 12-object test</td>
<td>0</td>
</tr>
<tr>
<td>Rey Auditory Verbal Learning Test</td>
<td>4</td>
</tr>
</tbody>
</table>

In the group without (n=13) complications (Cohort 1; n=5, Cohort 2, n=8), four patients in Cohort 1 and six patients in Cohort 2 had memory problems, according to the results from the memory tests. However, in the group with complications, three out of (Cohort 1 and 2 together) the seven patients in Cohort 2 (with complications) had memory problems, according to the results from MMS examination (MMT).

**PATIENTS’ AND RELATIVES’ STATEMENTS COMPARED WITH MEMORY TEST RESULTS**

Patients judged their own memory ability, in comparison with results from memory tests, better than relatives judged the patients’ memory ability. Patients’ statements, in Cohort 1 and 2 together, concerning memory ability in general (STM and/or LTM) corresponded with results from the memory tests (p<0.01). Relatives’ statements, in Cohort 1 and 2 together, concerning memory ability in general did not correspond with memory tests (p<0.29).
was no correspondence between the patients’ (p<0.10) or the relatives’ (p<0.68) statements concerning STM and the results from the memory tests, in Cohort 1 and 2 judged together (Figure 3).

Patients did, however, judge even their LTM (p<0.01; Cohort 1 and 2 together) better than relatives did (p=0.66, Cohort 1 and 2 together). There was a significant correspondence between the patients’ judgement of LTM and the results from the memory tests (p<0.01) in Cohort 2 (Figure 3).

Relatives did not judge the patients’ memory in accordance with the results from the memory tests. However, 21 of the 26 pairs’ statements (relatives’ and patients’) were equal. In those five pairs, where the statements did not correlate, one patient’s statement and four relatives’ statements did not correlate with results from the memory tests.

The memory tests gave a partly different result than the statements (relatives and patients) about memory ability. The results from the memory tests showed that both relatives and patients in Cohort 1 underestimated the patients’ memory ability (reported more problems), whilst both relatives and patients in Cohort 2, underrated the patients’ memory problems in comparison with the outcome on memory test results. In Cohort 1, relatives stated that eight patients had memory problems. The patients themselves stated that nine of them had memory problems. In Cohort 2, 11 relatives and 11 patients stated there were memory problems. However, memory tests demonstrated that seven patients (Cohort 1) and 13 patients (Cohort 2) had memory problems (Table 5).

All patients who had meta-memory problems (n=1, Cohort 1; n=4, Cohort 2), regarding relatives’ statements (Table 5), also had memory problems, according to the results from the memory tests, and the results were in correspondence with relatives’ statements. The patients suffered from complications surrounding the onset of the SAH. Three of the patients had post-operative hydrocephalus and two of them were unconscious at the onset of the SAH.

The eight patients (Cohort 1, n=2, Cohort 2, n=6), who suffered from post-operative hydrocephalus (Table 3), had memory problems according to the memory test results. Six of them had memory problems according to both the relatives’ and the patients’ own statements.

**Study III**

Problems with activities of living were common and patients reported more problems with their social lives, than with personal and instrumental activities of daily living (P- and I-ADL), according to patients’ and relatives’ statements.

The relatives rated the patients’ daily life ability (problems or not) in a similar manner to the patients’ statements; (i) 13 of 15 patients (Cohort 2), (ii) nine of 11 patients (Cohort 1) and (iii) 22 of 26 patients (Cohort 1 and 2 together) were similar. According to the relatives’ statements 23 patients (Cohort 1, n=9, Cohort 2, n=14) and according to the patients’ statements, 23 patients (Cohort 1, n=11; Cohort 2, n=12), had some kind of problem with activities of living in daily life (Figure 2; and Table 1, III; Table 7).
Figure 3. Relatives’ and patients’ statements concerning memory problems/ability among 26 patients, six (Cohort 2: patients n = 15, relatives n = 15) and 11 (Cohort 1: patients n = 11, relatives n=11) years after the patient’s onset of a SAH, in comparison with results on memory tests (MMT, Bingley 12-object test, Rey Auditory Verbal Learning Test) on the same occasion. A and B represent statements concerning STM and results on STM memory tests, C and D represent statements concerning LTM and results on LTM memory tests, E and F represents statements concerning memory problem/ability and results on memory tests from a general point of view (STM and/or LTM), for relatives and patients respectively. I represents statements (memory problem) that corresponded with results from memory tests (memory problem), II represents statements (no problem) that did not correspond with results from memory tests (memory problem), III represents statements (memory problem) that did not correspond with results on memory tests (no problem), and IV represents statements (no problem) that corresponded with results on memory tests (no problem). Fischer’s Exact Test was used for the statistical analysis of paired proportions from relatives’ statements and the results from patients’ memory tests, and paired proportions from patients’ statements and the results from patients’ memory tests. ‘***’ represents a correspondence concerning patients’ statements and results from memory tests at a significance level of p < 0.01. The data presented in Figure 3 has also been presented in Berggren et al., 2010 (Study II; Figure 3).

Many patients with problems in activities of living, had memory problems in general (short- and/or long-term memory), according to the results from memory tests (Table 7), and/or patients’ and/or relatives’ statements (Figure 2, III).
STATEMENTS ABOUT ACTIVITIES OF LIVING AND MEMORY TEST RESULTS

With reference to relatives’ statements about activities of living and memory test results, 19 (Cohort 1, n=6; cohort 2, n=13) out of 23 patients with problems in daily life also had memory problems according to the memory test results. With reference to patients’ statements, 19 (Cohort 1, n=7; cohort 2, n=12) out of the 23 patients with problems in daily life also had memory problems according to the memory test results (Table 7; Table 1, III). In cohort 2, memory ability in general from patients results on memory tests corresponded to patients’ statements on activities of daily life ability (p<0.05). There was no correlation between memory test results (memory in general) and relatives’ statements on daily life ability (Cohort 2, p<0.13).

STATEMENTS ABOUT ACTIVITIES OF LIVING AND STATEMENTS ABOUT MEMORY

In statements about activities of living and memory: relatives stated that 18 (Cohort 1, n=8; Cohort 2, n=10) out of 23 patients who had daily life problems according to relatives, also had memory problems. According to the patients 20 (Cohort 1, n=9; Cohort 2, n=11) out of 23 patients, who had daily life problems regarding patients, also had memory problems. Five patients, according to relatives’ statements and three patients, according to patients’ own statements (Figure 2, III), had problems with activities of living, but no memory problems. In Cohort 2 (p<0.01), and in Cohort 1 and 2 together (p<0.01), there was correspondence between patients’ statements about memory ability (memory in general) and their statements on daily life ability. Relatives’ statements on memory ability in general did not correspond with statements regarding daily life ability (in Cohort 2, p<0.73; in Cohort 1 and 2 together, p<0.16). However, in Cohort 1 there was a correspondence between relatives’ statements regarding memory ability (memory in general) and statements on daily life ability (p<0.05).

Problems with activities of living

The patients had problems with Personal and Instrumental activities of daily living and social life; social company, recreational activities, reading and assimilating the content of a book, and problems with emotions in daily life (Table 7; Figure 2 and Table 1, III).

Personal and instrumental activities of daily living

Before the onset of the SAH, all patients and relatives (Cohort 1 and 2) reported that the patients were independent concerning P-and I-ADL. Relatives’ and patients’ statements concerning whether or not the patients had full or reduced capacity concerning P- and I-ADL after the SAH corresponded (Cohort 1, p<0.01; Cohort 2, p<0.01; Cohort 1 and 2 together p<0.001).

After the onset of the SAH, three relatives and three patients (Cohort 1) and three relatives and three patients (Cohort 2) stated that the same patients had reduced ability in coping with P- and I-ADL. Four out of the six patients (Cohort 1 and 2) suffered from complications at the time of the SAH onset. Five of six patients (Cohort 1 and 2) had memory problems according to both the relatives’ and the patients’ statements, and four of them had memory problems according to the results of the memory tests.

In Cohort 1 and 2 together, relatives stated that four patients had problems with P-ADL (two couples had the same opinion) and that six patients had problems with I-ADL (in agreement with patients’ statements). Patients stated that two patients had problems with P-ADL (in
agreement with relatives’ statements) and six patients had problems with I-ADL (in agreement with relatives’ statements).

**Social life**

**Social company**

Both relatives and patients stated that established social company habits were changed after the SAH (Table 7; Figure 2 and Table 1, III). The statements on social company habits corresponded in Cohort 2 (p<0.001) and in Cohort 1 and 2 together (p<0.01), but not in cohort 1 (p<0.5). In Cohort 1, six relatives and four patients and in Cohort 2, six relatives and six patients stated that the social company habits were changed due to the patient’s status after SAH (Table 7; Table 1, III).

According to relatives’ statements, 10 of 12 patients (Cohort 1 and 2 together) with changed social company habits also had memory problems (Figure 2, III), and 10 of the patients also had self-reported memory problems (not presented). Ten patients (Cohort 1 and 2 together) had problems as shown by results from the memory tests (Table 7; Table 1, III). Patients stated that six of the 10 (Cohort 1 and 2 together) patients with changed social company habits had memory problems (Figure 2, III). According to relatives’ statements, five patients had memory problems (not presented), and six of them had problems as shown by results from the memory tests (Cohort 1 and 2 together), Table 7; Table 1, III.

**Recreational activities**

Both relatives and patients (Cohort 1 and 2) stated that patients could no longer practice the recreational activities they undertook before SAH (Table 7; Figure 2 and Table 1, III). The recreational activities mentioned varied, for example shopping, needlework, walks, reading, skiing, bicycling, picnicking, boating and home improvements.

According to relatives’ statements, (Cohort 1 and 2 together) 12 patients had problems with former recreational activities and their recreational activities had changed. Relatives stated that 10 of the 12 patients had memory problems (Figure 2, III) and according to patients’ statements, 11 had memory problems (not presented). Memory problems were present in 11 of the 12 patients with changed recreational activity, according to results from the memory tests (Table 7; Table 1, III).

According to the patients’ statements, (Cohort 1 and 2 judged together) all eight patients with recreational activity problems had memory problems (Figure 2, III). Relatives also stated that the eight patients had memory problems (not presented), and this was also shown on results from the patients’ memory tests (Table 7; Table 1, III).

Relatives’ and patients’ statements concerning patients’ recreational activities did not correspond.

**Watching television, reading a newspaper and reading a book**

All patients (Cohort 1 and 2) could follow television programs and assimilate the content of a television program (Table 7; Figure 2 and Table 1, III), according to the relatives’ and the patients’ statements.

**Reading a daily newspaper**

All patients in Cohort 1 (n=11) were able to read and assimilate the content of a newspaper according to the relatives’ and the patients’ statements. In Cohort 2 (n=15), two patients, according to relatives’ statements, and one patient according to the patient’s statement, had
problems in assimilating the content of a newspaper (*Table 1 and Figure 2, III*; *Table 7*). All three patients had memory problems according to both the relatives’ and the patients’ statements (*Figure 2, III*), and as shown by the results from the memory tests (*Table 7; Table 1, III*).

*Table 7*. Problems with activities of living regarding relatives’ (n=23) and patients’ (n=23) statements, among all patients (n=26) and concerning patients without (n=6) and patients with memory problems (n=20) regarding results from memory tests, in Cohort 1 and Cohort 2 together, eleven and six years after the onset of the SAH.

<table>
<thead>
<tr>
<th>Cohort</th>
<th>All patients</th>
<th>Patients</th>
<th>Patients</th>
<th>Patients</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>without</td>
<td>memory</td>
</tr>
<tr>
<td>Participants</td>
<td>Relatives n=11</td>
<td>Patients n=15</td>
<td>Relatives n=4</td>
<td>Patients n=2</td>
</tr>
<tr>
<td>1</td>
<td>9</td>
<td>11</td>
<td>14</td>
<td>12</td>
</tr>
</tbody>
</table>

**Problem with situations that are hard to cope with**

<table>
<thead>
<tr>
<th>Numbers of relatives and patients who made statements concerning patients’ various problems in activities of living</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>P-ADL</strong></td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td><strong>I-ADL</strong></td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td><strong>Social company with relatives and friends</strong></td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td><strong>Old social company habits (changed)</strong></td>
</tr>
<tr>
<td>6</td>
</tr>
<tr>
<td><strong>Recreational activity (changed)</strong></td>
</tr>
<tr>
<td>6</td>
</tr>
<tr>
<td><strong>Watching television</strong></td>
</tr>
<tr>
<td>0</td>
</tr>
<tr>
<td><strong>Reading a daily paper</strong></td>
</tr>
<tr>
<td>0</td>
</tr>
<tr>
<td><strong>Reading a book</strong></td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td><strong>Emotions in daily life</strong></td>
</tr>
<tr>
<td>8</td>
</tr>
<tr>
<td><strong>TOTAL NUMBERS OF PROBLEMS MENTIONED</strong></td>
</tr>
<tr>
<td>28</td>
</tr>
</tbody>
</table>
**Reading a book**

The statements concerning the ability to read and assimilate a book were similar among relatives and patients (p<0.05, Cohort 1 and 2 together).

Two relatives in Cohort 1 and four relatives in Cohort 2 stated that the patients had problems in assimilating the content when reading a book. Five patients in Cohort 1 and three patients in Cohort 2 stated that they had problems in assimilating the content, when reading a book (*Table 7; Figure 2 and Table 1, III*).

All patients in Cohort 1 (n=5) and in Cohort 2 (n=5), who had problems reading and assimilating a book according to the relatives’ and/or the patients’ statements, also had memory problems, according to both relatives’ and patients’ statements (not presented). Four out of the five patients in Cohort 1 and all five patients in Cohort 2 who had problems reading and assimilating a book according to the relatives’ and/or the patients’ statements, had memory problems, as shown by the results from the memory tests (not presented).

**Emotional problems**

The most common problem in daily life were problems with emotions according, to both relatives’ (Cohort 1 and 2 together, n=22) and patients’ statements (Cohort 1 and 2 together, n=23), *Table 7; Figure 2 and Table 1, III*.

**Study IV**

Changes in emotional status were common both 11 (Cohort 1) and 6 (Cohort 2) years after the patients’ onset of a SAH, according to relatives’ and patients’ statements. Twenty three patients and 22 relatives (Cohort 1 and 2) stated that patients had emotional problems for example:

- Fatigue
- Concentration difficulties
- Restlessness
- Sleep difficulties
- Feeling more emotional
- Lacking initiative
- Uncertainty
- Low degree of empathy
- Orienting self in new environments
- Crowded noisy environments (loud sounds; *Table 2 and Figure 2, IV*).

Relatives and patients rated patients’ emotional status in a similar manner to patients’ statements (8 of 11 patients in Cohort 1, 13 of 15 patients in Cohort 2, and 21 of 26 patients in Cohort 1 and 2 judged together).

All patients in Cohort 1 and 2, according to relatives’ statements and most patients, (except one of the patients in Cohort 2), according to the patient ’s own statement, socialized with relatives and friends. However, 12 patients according to relatives’ and 10 patients according to patients´ own statements (Cohort 1 and 2) had changed company habits because of changes in emotional status due to:

- Patients being oversensitive to loud sounds in crowded noisy environments
- Concentration difficulties
• Fatigue
• Uncertainty (Table 3, IV).

Ten out of 12 patients, who had changed company habits according to relatives’ statements, had memory problems (memory in general) according to memory test results. Six out of 10 patients, who had changed social company habits according to patients’ statements, had memory problems (memory in general) according to memory test results. Relatives’ and patients’ statements about social company habits corresponded in Cohort 2 (p<0.001) and Cohort 1 and 2 judged together (p<0.01; data not shown).

CHANGES IN EMOTIONAL STATUS AND SOCIAL COMPANY HABITS

Fatigue
Nineteen relatives and 20 patients (Cohort 1 and 2) stated that patients had problems with fatigue (Table 2, IV).

- Were more tired than before the SAH
- Had low mental stamina, became tired more quickly
- Showed irritability, low tolerance when tired
- Were tired, unable to socialize as before
- Could only manage to socialize with fewer people than before (Table 2, IV).

Relatives’ and patients’ statements concerning patients, who had problems with fatigue corresponded in Cohort 1 (p<0.05) and in Cohort 1 and 2 judged together (p<0.05; Figure 2, IV).

The following statements made by relatives and patients corresponded: Had low mental stamina in the sense of becoming tired more quickly (Cohort 2, p<0.05; Cohort 1 and 2 judged together, p<0.05; data not shown), were tired, unable to socialize as before (Cohort 1, p<0.001; Cohort 2, p<0.001; Cohort 1 and 2 judged together, p<0.001) and could only manage to socialize with fewer people than before (Cohort 2 p<0.01; Cohort 1 and 2 judged together, p<0.01), Figure 3, IV.

Seven out of 19 patients according to relatives’ statements and six out of 20 patients according to patients’ own statements (Cohort 1 and 2), who had problems with fatigue, could not socialize as before because they; were tired, unable to socialize as before and/or were tired, could only socialize with fewer people than before (Table 3; Figure 3, IV).

Concentration difficulties
Sixteen relatives and 17 patients (Cohort 1 and 2) stated that the patients had problems with concentration (Table 2, IV).

- Was hard to concentrate (Table 2, IV)
- Became tired, quickly losing concentration
- Could only concentrate with one person at time (Table 2 and 3, IV)

The following statements made by relatives and patients corresponded: Was hard to concentrate (Cohort 1, p<0.01; Cohort 2, p<0.01; Cohort 1 and 2 judged together, p<0.001; data not shown), became tired quickly and lost concentration (Cohort 1 and 2 together (p<0.05; Figure 3, IV) and could only concentrate with one person at time (Cohort 2, p<0.01; Cohort 1 and 2 judged together, p<0.01; Figure 3, IV).
Nine out of 16 patients according to relatives’ and seven out of 17 patients according to patients’ own statements (Cohort 1 and 2) with concentration difficulties could not socialize as before because of concentration difficulties; became tired quickly and lost concentration and/or could only concentrate with one person at the time (Table 3; Figure 3, IV).

Sleep difficulties
Twelve patients, according to relatives’ statements, and nine patients according to patients’ statements (Cohort 1 and 2) had some kind of sleep difficulties; Increased need of sleep and/or disturbed sleep/poor sleep quality (Table 2, IV). Relatives’ and patients’ statements concerning sleep difficulties corresponded in Cohort 2 (p<0.01) and in Cohort 1 and 2 judged together (p<0.01; Figure 2, IV). Seven relatives and four patients (Cohort 1 and 2) stated that patients had increased need for sleep (Table 2, IV) and according to relatives’ statements seven patients, and according to patients’ statements eight patients (Cohort 1 and 2) had disturbed sleep/poor sleep quality (Table 2, IV). Relatives’ and patients’ statements regarding disturbed sleep/poor sleep quality corresponded in Cohort 1 (p<0.05), Cohort 2 (p<0.001) and Cohort 1 and 2 judged together (p<0.001; data not shown).

Uncertainty
Five relatives and three patients (Cohort 1 and 2) stated that the patients experienced uncertainty after the SAH; anxiety about how other people would treat them and/or scared that their memory would let them down (Table 2, IV) and relatives’ and patients’ statements corresponded in Cohort 2 (p<0.01; Figure 2, IV).

Three patients, according to relatives and 2 patients (Cohort 1 and 2) stated that patients were anxious about how other people would treat them (Table 2 and 3, IV). Relatives’ and patients’ statements corresponded in Cohort 1 (p<0.001), in Cohort 2 (p<0.01) and in Cohort 1 and 2 judged together (p<0.01; Figure 3, IV). Three relatives and three patients (Cohort 1 and 2) stated that patients were scared their memory would let them down (Table 2 and 3, IV).

All five patients according to relatives’ statements and all three patients according to patients’ own statements (Cohort 1 and 2), who were uncertain, could not socialize as before due to uncertainty; anxiety about how other people would treat them and/or being scared that their memory would let them down (Table 2 and 3, IV).

Oversensitive to crowded noisy environments (loud sounds)
Ten relatives and eight patients (Cohort 1 and 2) stated patients were oversensitive to loud sounds in crowded environments (Table 2 and 3, IV). Relatives’ and patients’ statements corresponded in Cohort 2 (p<0.01) and Cohort 1 and 2 judged together (p<0.05; Figure 2 and 3, IV).

All ten patients according to relatives’ statements and all eight patients according to patients’ own statements (Cohort 1 and 2), who were oversensitive to crowded noisy environments could not socialize as before (Table 2 and 3, IV).
DISCUSSION

Methodological discussion

Using both an inductive and a deductive approach is an advantage when answering the research question regarding patients’ experience of a SAH and relatives’ and patients’ experience concerning patients’ memory, emotional status and activities of living post SAH. The general aim of this research was to study patients’ experience and reconstruction regarding the onset of and events surrounding a SAH (I) and to study patients’ and relatives’ experience of patients’ memory ability (II), activities of living (III), emotional status and social company habits (IV) in a long-term perspective.

In study I an open interview question was used, and in study II-IV a questionnaire with structured interview questions (patients and relatives), and in Study II memory tests (patients) were used. There were memory problems both in the acute stage, (patients’ accounts) and also in a long-term perspective (patients’ and relatives’ statements, and memory test results), but the episodic memory was well preserved both concerning the onset of the SAH and in a long-term perspective after the SAH, according to relatives’ and patients’ statements. Using both an inductive (I) as well as a deductive approach (II), was a pragmatic way of getting knowledge about patients’ memory after a SAH.

When assessing trustworthiness in qualitative data (I), credibility, dependability, conformability, transferability and authenticity are taken into account (Polit & Hungler 1999; Polit & Beck, 2007; 2012). The informants experience and reconstruction of the onset of a SAH was investigated in study I in interaction between the informant and the author. The results which emerged from study I can be considered to be credible (trustworthiness) as the data (accounts) were analysed by two researchers, both separately and together (investigator triangulation). According to Denzin (1989), it is possible to have two or more researchers, independently analysing the same qualitative data and then comparing the data analyses. A third researcher read the findings after the analysis were made, to see if there was relevance in the analysis, a process called peer debriefing (Lincoln & Guba, 1985). The interviews were recorded on tape and transcribed verbatim, and the results of the analysis were shown with illustrations of data extracts. This shows the authenticity and the results in study I might therefore be considered to be credible.

When collecting data as in study I, it was important to have an engagement and deep understanding for the context (suffering from a SAH), so that there would be no misunderstanding during the interviews. Another aspect of credibility, according to the latter mentioned is researcher credibility; meaning that the researcher is an instrument when collecting the data, as well as a creator of the analytic process (Patton, 1990). It is therefore a strength in this thesis that the researchers in study I had different professional backgrounds. There were both non- and pre-understanding for the context of the patients’ experiences of a SAH, and for the context of nursing in the acute phase of a SAH. It is both an advantage and a disadvantage, that the author of this thesis had pre-understanding concerning neurosurgical nursing. It is a disadvantage, as the best way of ensuring reliable results (dependability) in qualitative studies is to have an open mind. However, to put aside one’s own pre-understanding means to control it. It does not mean to be completely free from one’s pre-understanding (Speziale & Carpenter, 2007), as a complete reduction never may be possible. It could however also be a benefit having pre-understanding for the context of neurosurgery nursing, when analysing accounts concerning the onset of a SAH using discourse analysis.
Von Post and Erikson (1999), states that professional pre-understanding is useful in scientific research. In study I the researchers had different skills, competence and pre-understanding when analysing the data, which may be considered as the results being confirmed. According to Polit and Beck (2007, 2012) *conformability* refers to the objectivity or neutrality of the data, meaning that there is agreement between people concerning the relevance or meaning of the data. To ensure the *trustworthiness* in qualitative data it is necessary to include participants with different age, sex and experiences (Dahlberg et al., 2008). This was done in study I, since both (i) female and males, (ii) patients living in large and small town environments, (iii) patients of different age, and (iv) patients falling ill within different point of time of the year, alternating from the bottom and the top of the hospital’s patient records system list were elected before reading the patients’ medical records, with regard to exclusion criteria’s.

The results of study I can be considered to be *reliable* (*dependability*), meaning stable over time, as the data were analysed by two researchers separately and together and then evaluated by third researcher. However, to ensure the scrutiny of the data, an external review with two independent scientists took place (*double blind reviewed*).

In the communication interactions in study I the patients positioned themselves as being cognitively alert people through their use of different linguistic strategies and detailed accounts. Their positioning can be interpreted as a firm impression that the patients wanted to give, that they could evaluate their memory for when they became ill and for the time immediately following it - an identity creating process in the communication interaction. Similar findings in relation to identity creation were observed by Davis and Harré (2007) and described by Charmaz (1997), concerning people with long-term illness. However, the transferability of the results from study I may be investigated in other studies and from clinical praxis.

In study II well known valid memory test instruments were used to test patients’ memory and the patients’ results on memory tests were compared with patients’ and relatives’ statements, using a questionnaire with structured interview questions concerning their views of the patients’ memory. Using well known memory tests (valid instruments) should give reliable results regarding the patients’ memory function, and can be used to investigate if patients’ and/or relatives’ statements, differs or are similar to results from memory test results. The interview questions in study II-IV, were designed from the author’s professional pre-understanding as a former nurse within neurosurgery nursing, in mutual agreement with a medical expert as well a qualified researcher in neuropsychiatry, and they were first tested in a pilot study. The questions were than compared with questions in well-known questionnaires and based on scientific knowledge concerning memory subdivisions and classification. Therefore the questions might be considered to be valid and the results may be reliable.

The findings in this thesis, constructed from the author’s professional pre-understanding, to suit in home context captured the relatives’ and the patients’ views in a natural manner. The results in study II-IV match results in previous studies based on the patients’ perspectives and test results. Therefore the results concerning memory, emotional status and activities of living from the small samples, emerged from questions designed by the author of in this thesis to suit home context, might be considered to be reliable.

The findings in study I, was also confirmed in study II; meaning that there were memory problems, not just in the acute stage (I), but also in a longer perspective (II), and that the
episodic memory was well preserved not just in the acute stage (I), but also in a longer perspective (II).

In many clinical long-term studies it is hard to include enough patients, which were the case in study II-IV. However, the numbers of participants in the studies were within the range for the statistical method used (Fisher’s exact test, Altman, 1999; Z-scores, Schmidt, 2004) and thus the results were considered to be reliable. Considering that the patients and the relatives were interviewed over a long time (6 and 11 years) after the patients’ onset of a SAH, the numbers of participants were considered to be satisfying.

A strength in study II-IV is that the patients and the relatives were asked the same questions, but without the opportunity to discuss the questions and answers with each other. It is also strength that the patients’ memory tests in study II took place on the same occasion as when the patients were interviewed. Fischer’s exact test (Altman, 1999) was used for the statistical analysis of paired proportions: from relatives’ and patients’ statements, from relatives’ statements and the results from patients’ memory tests, and from patient’s statements and the results from patient’s memory tests. For the purpose (a small sample) the choice of statistical analysis method was relevant. Z-scores (Schmidt, 2004) were used to analyse the results from memory tests (MMT and Rey Auditory Verbal Learning Test) and the results were then compared with previously reported evaluations from memory tests, based on populations with no reported memory problems (Ivnik et al., 1990; Schmidt, 2004). Using well known statistical methods as in study II-IV, can be considered to give answers to the research questions, and therefore the results may be considered to be reliable.

THE BENEFIT OF A QUESTIONNAIRE FOR FOLLOW UP INTERVIEWS OF HEALTH STATUS AFTER AN SAH

The questions designed by the author of this thesis (II-IV), may later be developed into a short and concise questionnaire. Questions in a concise questionnaire with a focus on daily life and answered by a patient and a relative/significant other can be used to prepare a dialogue between the patient, the relative and a specialist nurse before the patient’s discharge from hospital and in follow-up dialogues, in order to be able to create a conversion about how both the patient and the relative/significant other experience/view the patients, memory ability and emotional status after the SAH, and how it also might affect their mutual life. Considering that the patient’s problems also have implications for the wellbeing/emotional health/social activities/leisure time of people close to them (Forsberg-Wärleby, 2002; Wallengren Gustavsson, 2009; Larsson, 2005; Anderson et al., 1995), and that the consequences of cognitive impairments became more evident for spouses in daily life in their homes (Forsberg-Wärleby, 2000), there is a need to have a dialogue, first using a concise questionnaire. According to Forsberg-Wärleby (2002), relatives/significant others need tools to handle their daily life together with the patient. Since nursing also, as Gwyn (2002) states, includes ordinary discourse in the care situation; what you talk about and what you try to understand, there is an opportunity for both the patient and relative/significant other to discuss the patient’s problems in dialogue with a specialist nurse. Letting all patients suffering from SAH take part of a concise questionnaire, with a focus on daily life as a preparation before a formalized dialogue, before the patient’s discharge from the hospital could be: (i) a document for follow-up dialogues between the patient, the relative and the nurse, both in a short and long perspective, (ii) an evaluation to see if the patient has a special need to see a medical doctor and/or a psychologist (from the nurse’s recommendation) and get their attention before discharge from the hospital, and perhaps in a longer perspective. This, using a concise
questionnaire before a dialogue; (i) before the patient’s discharge from the hospital, (ii) in short-term and (iii) long-term after a patient’s SAH will give the nurse, the patient and the relative the opportunity to follow the patient’s health status over time. However, the questionnaire must first be tested in large groups of persons, who suffer from SAH, and their relatives. Since cognitive dysfunction (memory and emotional problems) concerning physically independent survivors (GOS V) after SAH was missed in routine follow-up examinations (Fertl et al., 1999) and patients, who outwardly showed signs of being neurologically recovered, had cognitive and/or emotional problems according to Passier et al. (2012), there is a need developing a questionnaire that focus on memory ability and emotional status from a daily life perspective. This is confirmed by Jennett (2005), who stated that the most important disabilities are often mental deficits or personality changes, and such mental problems can only be revealed by questioning both patients and his/her family, and that it easy to underestimate the degree of disability on GOS, if the surgeon is busy meeting on outpatient. Therefore using a concise questionnaire, with a focus on daily life as a preparation before a formalized dialogue with a nurse, in advance of the patient’s discharge from the hospital and in a follow-up dialogue would be an advantage.

Result discussion

Studies of SAH with focus on cognitive sequelae (memory and emotional problems) are well documented (Sonesson, 1992; Rödholm, 2003; Hedlund, 2009). However, there were no studies concerning patients’ experiences of the onset of, and events surrounding the onset of a SAH from a communicative perspective. Furthermore, there were few studies from both the relative’s and the patient’s perspectives concerning the patient’s memory ability, emotional status and activities of living in a long-term perspective. The results in this thesis showed that patients’ accounts of SAH can be interpreted as an identity creating process (I). Patients were able to judge their own memory for what happened when they became ill (I) and in the long-term perspective (II). The patients judged their own memory ability better than relatives, compared with results from memory tests (II). Memory problems, changes in emotional status and problems with activities of living were common, and there was a high degree of concordance between relatives’ and patients’ statements (II-IV). Both relatives and patients underestimated older patients’ memory ability and underrated younger patients’ memory problems (II), and there were also age differentials concerning statements about emotional status (IV) and activities of living (III). There were more problems with social life than with P- and I-ADL (III), and social company habits had changed due to concentration difficulties, fatigue, and sensitivity to noisy environments and uncertainty (IV).

IDENTITY CONSTRUCTION

The patients who had experienced a SAH were able to assess their own memory (meta-memory) for what had happened to them at the time of the illness event. Initiating accounts of SAH in a long-term perspective is a question of making meaning and it is created and recreated in interactions between people, in this case between the interviewer and the interviewee. The results show that understanding the SAH is not only a matter of a pathological event but it is also a social, relational and communicative matter. It is in communication with others that identity is construed, and in this construal that the identity of ‘Self as past’ is set against the identity of ‘Self as present’. The reconstruction of events surrounding being stricken with a SAH vacillates between speaking with the 'sick voice' and the 'healthy voice' can be seen (I). Using both the healthy and the sick voice can be seen in Hydén (1997b). According to Phillips and Winter Jørgensen (2002), this can be seen as a transition from one position in the dialogue to another, with the help of linguistic resources. This is also observed in Kvarnström and Cedersund (2006) study where the pronoun ‘we’ is
used in different ways in relation to different constellations of personnel groups in healthcare - a kind of positioning in the communication interaction of who one is in different contexts. Positioning and the associated identity construction (Davies & Harré, 2007) after a SAH is concerned with (i) facing the ‘Me as I am now’, (ii) a comparison of the self with the ‘Me as I was before’, (iii) and wondering what will happen to the ‘Me in the future’ (I). Similar results are discussed in Charmaz (1997) in relation to the identity construction in people with long-term illness. By speaking with a retrospective perspective (I), the self-identity was constructed (Goffman, 1959; Gwyn, 2002). Charmaz (1997) explains that the illness operates as both the foundation and the focal point for how it is possible for one to understand identity from the experiences of illness.

The findings support the theoretical implication of accounts of SAH and meaning-making as structured in three positions:

- The position as a mentally autonomous and thinking subject.
- The transformation to the position as a physical object, which is, handing over the physical self to experts at the hospital. The time as a physical object lasts from being admitted, and up to the point of reawakening.
- Finally the transformation back to the position as a thinking subject then occurs.

The structure represents the basis for how a SAH is construed into a meaningful life history (I), according to Candlin (2000), in order to make life complete (I).

Thus, in light of study I and earlier studies, the author suggests that staff should support patients in their identity creation by letting them, through communicative interaction, talk about memories and memory gaps reconstructing the process of their becoming ill as soon as possible.

**STATEMENTS ABOUT MEMORY, EMOTIONAL STATUS AND ACTIVITIES OF LIVING**

**Memory**

Relatives and patients stated patients’ memory in a similar manner. Seventy three percent of the patients (Cohort 1 and 2 together) had memory problems in general, according to relatives’ statements and 76% of the patients had memory problems according to the patients’ own statements (I). This is in accordance to the report of Ljunggren et al. (1985), who reported that 83% of the patients stated that they had memory problems, 14 months to seven years after their SAH. However, Sonesson (1987) reported that 55% of the patients, one to eight years after the patients SAH, had memory problems.

The results demonstrated both similarities and differences concerning relatives’ and patients’ statements about the patients’ memory ability and regarding the statements in relation to results from memory tests (II).

There was correspondence between relatives’ and patients’ statements regarding the patients’ memory ability in general and the patients’ LTM. However, there was no correspondence concerning STM and no correspondence between the patients’ and the relatives’ statements concerning STM, in comparison with the results from the memory tests. Based on the data it seems, that both relatives and patients had difficulties judging the patients’ STM. According to Peterson and Peterson (1959), information in STM can be lost after as little as 20 seconds. This means that it is not easy to judge one’s own or somebody else’s STM, and from the
authors opinion it is no reason to ask patients and relatives about patients’ short-term memory. Using memory test concerning short-term memory is more useful.

According to results from the memory tests in study II, 62% of the patients in Cohort 1 and 2 judged together were found to have problems with STM. Larsson et al. (1989) also found, from results of memory tests, that STM problems were common and closely connected to brain damage caused by SAH. Lindberg et al. (1996) demonstrated that among long-term consequences, seven years (range 2.5-14) after the onset of a SAH (median age 55 years), 52% of the patients had STM problems, according to results from memory tests. The results differed somewhat from the results in Study II. The differences regarding the median age, 55 years in Lindberg et al. (1996) and in Study II (median 64 years, Cohort 1 and 2 together) may have influenced the outcome of the memory test results. Bäckman (1987) stated that it is hard for older adults to learn and/or retrieve contemporary information, which was the type used in the memory tests in this thesis. The memory test results (II) concerning LTM were more in correspondence with the results in Lindberg et al. (1996). The memory tests demonstrated that 54% of the patients in Cohort 1 and 2 judged together, had LTM memory problems. Lindberg et al. (1996) demonstrated that 53% of the patients had LTM memory problems according to memory test results.

Meta-memory problems

In a previous study (Rönnberg & Larsson 1989) it was proposed that meta-memory can operate well after SAH, but that gaps in meta-memory can occur. This was confirmed by the results in study II, where relatives (Cohort 1 and 2 together) stated that five patients had meta-memory problems. Rönnberg and Larsson (1989) demonstrated that if a patient does not have the ability to judge and evaluate his/her own memory (meta-memory problems), there are no conditions to permit belief that this patient will be able to repair his memory disturbance by memory training. Consequently, it is important that the relative is aware of the problem mentioned by Rönnberg and Larsson (1989), when a patient has a meta-memory problem, so that the relative does not demand too much from the patient and not expect too much concerning the patients’ memory progress in the future. It is of course important to show empathy, helping patients, with meta-memory problems, to remember and maintain their dignity, by acting correctly and showing respect.

It is urgent that professionals, especially that nurses pay extra attention to patients that suffers from complications surrounding the onset of the SAH. All patient with meta-memory problems according to the relatives’ statements (n=5; Cohort 1 and 2 together) in this thesis suffered from complications surrounding the onset. Three of them had postoperative hydrocephalus and two of them were unconscious at the onset of the SAH, and all five had memory problems according to the results from the memory tests (II). All five had emotional problems (III, IV) affecting social life in four patients (III).From this point of view, memory test and formalized dialogues are required in order to prevent complications in future family relationship.

Emotional status

Relatives and patients also rated patients’ emotional status (having problems or not) in a similar manner to patients’ statements (8 of 11 patients in Cohort 1, 13 of 15 patients in Cohort 2, and 21 of 26 patients in Cohort 1 and 2 judged together). Results from relatives’ and patients’ statements showed that fatigue and concentration difficulties were the most common problems associated with changed emotional status, according to both relatives’ and patients’ statements in Cohort 1 and 2 (IV). Patients also suffered from sleep difficulties.
Rödholm et al. (2001) reported that fatigue, concentration difficulties and memory problems were the most frequent astheno-emotional symptoms. Additionally the results in Study II (concerning the same cohorts), showed that nineteen (73%) of the patients according to relatives’ statements, 20 (76%) of the patients according to patients’ statements, and 20 (76%) patients according to the results of memory tests in Cohort 1 and 2 judged together, had memory problems in general (STM and/or LTM memory problems). The results from Study IV and the results in Study II are in accordance with and support the previous report by Rödholm et al. (2001).

**Fatigue**

In study IV, relatives in both Cohort 1 and in Cohort 2 stated that 73% of the patients suffered from fatigue. According to patients’ own statements, more patients in Cohort 1 (82%) suffered from fatigue, than in Cohort 2 (73%). Ljunggren et al. (1985) reported that 14 months to 7 years after the onset 82% of the patients who were interviewed stated they had problems with fatigue. This is in accordance with patients’ own statements in Cohort 1. Hellawell et al. (1999) reported that 68% of the patients had self-reported symptoms of fatigue two years after the onset. According to Visser-Meily (2009), 67% of the patients reported fatigue, two to four years after the onset of a SAH. The results from Hellawell et al. (1999) and Visser-Meily et al. (2009) are in accordance with the results from relatives’ statements (73 %) in Cohort 1 and 2, and patients’ own statements in Cohort 2 (73 %), IV.

Fatigue seems to endure over time as shown from patients’ statements in Cohort 1 (IV). These findings are similar to those of Ljunggren et al. (1985), who reported that sequelae due to SAH may be permanent and that the degree of impairment appeared to correlate with the patients’ age. According to Visser-Meily (2009) fatigue were strongly related to decreased Health Related Quality of Life and therefore there is a need to develop nursing strategies how to help patients to coop with and minimize the effects of fatigue in order to improve health.

The results from study IV showed that irritability, low tolerance was common when patients became tired. Relatives stated that 58% of the patients, and patients themselves stated that 54% of them (Cohort 1 and 2) had problems with irritability and low tolerance when tired. Rödholm et al. (2001) reported that 33% of the patients had problems with irritability one to six months after the SAH and Sonesson et al. (1987) reported that 30% of the patients had problems with irritability one to eight years after the SAH. Thus, from the results in this thesis irritability seems to increase over the years. To be irritated, having low tolerance when tired can be considered to have negative effects on the relationships and on the social lives in families of individuals who have had a SAH. Although relatives’ and patients’ statements corresponded in study IV, it is vital that relatives and patients have the opportunity to discuss mood changes of patients together with a professional, early after the patients’ SAH, in order to help improve subsequent relationships in families and social lives, and to prevent misunderstandings.

**Sleep difficulties**

Relatives’ and patients’ statements regarding disturbed sleep/poor sleep quality corresponded in Cohort 1 (p<0.05), Cohort 2 (p<0.001) and Cohort 1 and 2 judged together (p<0.001). According to relatives’ statements 26% and according to patients’ statements 30% of the patients (Cohort 1 and 2) had disturbed sleep/poor sleep quality (IV). This is in accordance with patients’ statements (1-8 years after the SAH) reported by Sonesson et al. (1987): 29% of the patients who had late surgery treatment and 24% of patients who had early surgery treatment after the onset had sleep difficulties. Since many patients suffer from fatigue that
seems to be enduring over time (IV), it is important that nurses discuss and give advises to both patients and relatives how the patient can improve her/his sleep quality in order to lower the effects of fatigue.

**Concentration difficulties**

Relatives’ and patients’ statements on concentration difficulties corresponded and 62% of the patients according to relatives’ statements and 65% of the patients from patients’ own statements (Cohort 1 and 2) had concentration difficulties (IV). According to Hellawell *et al.* (1999), 42% of the patients reported concentration problems six months after the onset of the SAH. Relatives reported that 43% of the patients had concentration problems. However, Hütter *et al.* (1995) reported that 71% of the patients in self-rating measures had concentration difficulties, whilst in the case of proxy-rating 46% of the patients (1-5 years after the onset) had concentration difficulties, 1-5 years after the onset. The report of Hütter *et al.* (1995) on self-rating is in accordance to the results in Cohort 1 and 2 (IV). Thus, concentration difficulties can persist or even increase over time. The latter is according to the results of Hellawell *et al.* (1999). Rödholm (2003) stated that concentration difficulties reduce the ability of maintaining good attention and that memory difficulty seem to be largely secondary to problems with attention. It was common that patients in this thesis both had memory problems (II), and concentration problems (IV), according to both the patients (n=17, 65%) and the relatives (n=16, 62%), in Cohort 1 and 2 judged together (IV). This shows that it is important to evaluate relatives’ and patients’ experiences concerning patients’ concentration ability, both in a short-term and long-term perspective. Furthermore, it would aid the development of care strategies to support relatives and patients in their mutual family life and would help support patients to cope with their activities of living, as problems with social life, because of memory problems (III, IV), and social company habits had changed (III, IV) due to emotional problems (IV).

**Activities of living**

Twenty three % of the patients and the relatives, in Cohort 1 and 2 together judged together stated that patients had reduced ability to coop with I-ADL (III). This is in accordance to Lindberg *et al.* (1992), who stated that 20% of the patients had problems with I-ADL, according to patients’ reports 2–14 years after the onset of the SAH. In study 1 and 2 together patients themselves stated that 8 % of them had problems with P-ADL (III). This is also in accordance with Lindberg *et al.* (1992) who reported that 9% of the patients had problems with P-ADL. However, there were more problems with social life than with P-and I-ADL in this thesis. This is in accordance with Passier *et al.* (2011) who reported that more than 88 % were satisfied with their self-care ability, two to four years after their SAH.

**Social life**

There were problems with former *recreational activities*, even though the patients had no physical impairments, after the onset of the SAH. In Cohort 1 and 2 together, 46% of the patients had problems with former recreational activities, according to relatives, and 31% patients had problems according to their own statements. The findings from the relatives’ statements (III), is in line with Lindberg *et al.* (1992) who reported that 48% patients who participated in a study 2–14 years after the onset of a SAH reported cessation and/or decrease in leisure activities. The findings from patients’ statements (III) is in line with Passier *et al.* (2011), who reported that 34 % of the patients, participating in a study 2,5-3,5 years after their SAH, were not satisfied with their leisure situation. Patients also had *problems reading and assimilating the content of a book* due to memory problems, and the statements concerning reading and assimilating the content of a book corresponded in Cohort 1 and 2 together (III).
Not being able to read and assimilate the content of a book and not being able to practice former leisure activities, even though the patients had no physical impairments (III), may lead to patients needing other activities, and requiring to be with relatives more. This may have implications both for the wellbeing of patients and relations and for their future mutual relationships in daily life. Forsberg-Wärleby (2002) reported that spouses of stroke patients who had persisting dependency, showed less life-satisfaction, especially when dependent patients had cognitive and emotional impairments. The latter, also having cognitive problems (II), is in line with the results in Study III.

**Changed social company habits**

Relatives’ and patients’ statements concerning changed social company habits corresponded in Cohort 2, and in Cohort 1 and 2 together. The change of the social company habits, stated by the relatives and the patients (III, IV) were related to experiences of emotional sequelae (being oversensitive to loud sounds in crowded noisy environments, concentration difficulties and fatigue), IV. This is in accordance with previous studies (Sonesson, 1992; Hellawell & Pentland, 2001; Rödholm, 2003), which demonstrated that emotional problems are common after a SAH. In cohort 1 and 2 together, 12 relatives (46%) and ten patients (38%) stated that social company habits had changed post SAH (III, IV). Lindberg and Fugl-Meyer (1996) stated that 26% of the patients had a decreased ability for visits from relatives and friends and that 27% had decreased ability to visit relatives and friends, 7 years (median interval, range 2.5–14 years) after the onset of the SAH. This is in correspondence with the results from the patients’ statements in Study III and IV.

Relatives’ and patients’ statements concerning patients being oversensitive to crowded noisy environments (loud sounds) corresponded and all patients who were oversensitive to loud sounds, according to relatives’ (38%) and patients’ (31%) statements (Cohort 1 and 2), had changed their social company habits (IV). Rödholm et al. (2001) reported that 43% of patients with mild AED and 67% of the patients with moderate AED (1 to 6 months after the onset) were overly sensitive to sounds. Hellawell et al. (1999) reported that 58% of the patients (2 years after the onset) were overly sensitive to noise. The results in Study IV show that sensitivity to loud sounds may decrease in a long-term perspective. Nevertheless the patients, who remained oversensitive to loud sounds in Study IV, felt forced to change their social company habits in order to be able to socialize.

Relatives’ and patients’ statements concerning anxiety corresponded and all patients who were uncertain (anxiety about how other people would treat them and/or being scared that their memory would let them down) according to relatives’ (19%) and according to patients’ (12%) statements (Cohort 1 and 2), had changed their social company habits (IV). Passier et al. (2012) reported that 54% of the patients on self-reports, stated that they were anxious three months after their SAH, and two to four years after the onset, 32% of the patients reported anxiety (Visser-Meily et al., 2009). Hellawell et al. (1999) reported that patients themselves stated that 23% of them were anxious whilst their relatives reported that 36% of the patients were anxious, 12 months after the onset of a SAH. Morris et al. (2004) reported that moderate to severe levels of anxiety were present in approximately 40% of the patients, and mild levels of anxiety were present in 16% of the patients, 16 months after a SAH. From the results in Study IV, anxiety seems to decrease in a long-term perspective. However, persistent anxiety will affect social company habits in a long-term perspective according to results in this thesis, and Visser-Meily (2009) showed that decreased HRQoL was strongly related to anxiety.

Therefore professionals (as a suggestion specialised nurses) must listen to patients and give patients and relatives advice how to coop with patients’ problems being oversensitive to
crowded noisy environments (loud sounds) and patients’ uncertainty, in order that the patients will be able to socialize with relatives and friends.

Age differentials concerning memory, emotional status and daily life

The results from the memory tests (II) showed that both relatives and patients in Cohort 1 underestimated the patients’ memory ability in general (reported more problems), whilst both relatives and patients in Cohort 2 underrated the patients memory problems in comparison with the outcome from the memory test results. From the author’s experience, older people often refer to old age, when they make statements about their own or others’ memory ability, and younger people may be more concerned, because of societal expectations, to show that there is no decline in the memory ability. According to Levy and Banaji (2002) the negative ageing stereotypes in society may influence older people to think they have memory loss. Bäckman (1987) stated that it is easier for older adults to learn items in an episodic memory experiment and to pick up dated information from the semantic memory, than to learn and/or retrieve contemporary information. From results in this thesis, the episodic memory was well preserved. Anderson (1995) stated that verbal intelligence, which involves language comprehension, perseveres over the years, but there is a decrease in problem-solving. The latter is in line with Bäckman (1987), who states that there is a decline in storing and picking up contemporary information from LTM, when people get older. The awareness, and the experiences of, that it can sometimes be difficult to remember new stored information and contemporary information may have influenced the patients and relatives in Cohort 1, to answer as they did, underestimating the patients’ memory ability.

In study IV in Cohort 1, the data demonstrated that all patients (100%) according to patients’ own statements, had changed emotional status and relatives stated that fewer patients (73%) had changed emotional status. However, in Cohort 2 more relatives reported that patients had changed emotional status (93%) in comparison with patients’ reports (80%). The reason why the patients in Cohort 1, also in study IV, answered as they did could be that concentration (changes in emotional status; IV) and memory ability (II) are closely connected (Rödholm, 2003) and that patients might have been influenced by negative ageing stereotypes in society (Levy & Banaji, 2002). Younger persons (as the patients in Cohort 2; Study IV), might be more concerned, because of social expectations, to show there are no changes in emotional status. However, it could also mean that the patients in Cohort 2 had less self-awareness, as a result of the SAH, as they reported less changes in emotional status compared with relatives’ reports. Hellawell and Pentland (2001) showed that 72% of the patients, in a long-term perspective had emotional symptoms according to relatives’ reports, in comparison with relatives’ statements in Cohort 2 reported in this thesis, where 93% of the patients were rated to have changes in emotional status (IV). The patients included in Hellawell and Pentland (2001) were younger (mean ages 49 and 51 years, five and seven years after the onset) than the patients in Cohort 2 in this thesis (mean age 60 years) and this may help explain the differences. The informants in Hellawell and Pentland (2001) were both relatives and friends. Living together with the patients in their homes, or close to the patients, as in Cohort 2 (IV) in this thesis, could make it easier to judge the patients’ emotional status, and that may also help explain the differences.

The results from study III showed that in Cohort 1, all patients reported problems with their daily life (100%). Relatives stated that 82% of the patients had problems with their daily life. However, in Cohort 2, relatives reported that more patients had problems with daily life (93%), in comparison with the patients’ own reports (80%). It might be easier for older patients (Cohort 1; mean age 67 years, range 48–85) to express or admit, that they have difficulties managing their daily life, compared with younger patients (Cohort 2; mean age 60
Patients’ statements about their own memory ability and emotional status in Cohort 1 and Cohort 2 might also be explained by haemorrhage origin (vessels). Patients in Cohort 1 underestimated their: (i) memory ability, in comparison with the outcome from memory test results (II) and (ii) emotional status compared to relatives’ statements (IV). Patients’ in Cohort 2 underrated their: (i) memory problems in comparison with the outcome from memory test results (II), and (ii) changes in their emotional status in comparison with relatives’ statements (IV). This thesis indicate that negative ageing stereotypes in society may have influenced the patients’ and the relatives’ statements, concerning patients’ memory ability in Cohort 1. Moreover, there is a tendency that negative ageing stereotypes in society may have influenced the patients’ statements concerning their emotional status and their ability in activities of living, in Cohort 1. However the patients’ statements in Cohort 1 and 2 might also be explained by the location of the haemorrhage origin (vessels).

Haemorrhage origin (vessel ruptures)

With reference to only the patients’ statements concerning memory ability (study II) and emotional status (IV), in Cohort 1 and 2: The patients in Cohort 1 suffered from fewer ruptures of vessels, which supply the frontal lobe of the brain, in comparison with the patients in Cohort 2 (Table 2). According to Rönngberg and Larsson (1989) patients who had an intact frontal lobe, for example patients suffering from Arteria cerebri media (MCA) ruptures, underestimated their own memory ability, in comparison with patients who had Arteria communicans anterior (ACOA) ruptures. Patients with ACOA ruptures showed impaired performance compared with patients with MCA ruptures, according to memory recall tests. Rönngberg and Larsson (1989) stated that patients with MCA ruptures were able to make correct judgements of a declined memory function, which led to the patients underestimating their memory ability. However, patients with a damaged frontal lobe (patients with ACOA ruptures), overrated their memory abilities. There were dissimilarities between the results from the memory tests and the experienced memory problems reported by Rönngberg and Larsson (1989), and this could be in line with the results concerning patients’ statements about memory ability in comparison with results on memory tests in the thesis. As memory ability (II) is closely connected with attention and concentration (IV; Rödholm, 2003) haemorrhage origin also might be the reason why patients in Cohort 1 and 2 judged their emotional status differently from relatives’ statements.

Meta-memory

In spite of patients’ memory problems and being dependent on those close to them, the patient who had experienced a SAH were able to assess their own memory (meta-memory) for what had happened to them at the time of the illness event (I) and in the time after it, episodic memory (I, II). The latter was described by Baddeley (1984; 1999) and Egidius (2008) as correct memory for personal events coupled with time and space. Being able to correctly evaluate the capacity of one’ s own memory (about what happened at the time of becoming ill) is termed meta-memory (Rönngberg & Larsson, 1989). The results from study II also showed that most patients were able to judge their own memory. In comparison with memory
tests results, the patients judged their own memory ability better than relatives judged the patients’ memory ability. There was correspondence between patients’ judgement of the memory in general (Cohort 1 and/or 2 together) and LTM (Cohort 2, and Cohort 1 and 2 together) and results from the memory tests. Based on results from study II and earlier studies, it could be hard for a relative to judge whether the patient is paying attention to, and/or is concentrating, when the relative tries to convey a message, and which the relative expects the patient to remember. According to Rödholm (2003) memory difficulties seem to be largely secondary to problems with attention. It was common that patients in study II had concentration problems, according to both the patients (n=17, 65%) and the relatives (n=16, 62%), in Cohort 1 and 2 judged together (III, IV). Rödholm (2003) stated that concentration difficulties reduce the ability of maintaining good attention. The reason why relatives, in Cohort 1 in Study II, judged the patients’ memory differently compared with the memory test results could be that the relatives did not take the attention problems in to account, when they made statements regarding the patients’ memory ability.

CONCLUSIONS
The patients could in spite of gaps in their memory, assess their memory of events in relation to their becoming ill, and the reconstruction of the illness event is vital in nursing care for understanding the patient’s identity-construction. The episodic memory seemed to be well preserved, both concerning the onset, and in the long-term perspective. However, memory problems were common in a long-term perspective, according to relatives’ and patients’ statements and from memory test results. Relatives and patients rated patients’ memory ability in a similar manner to patients’ statements, and relatives and patients statements regarding the patients’ memory ability in general and the patients’ LTM corresponded. Patients’ judgement of their own memory in general and LTM and the results from the memory tests corresponded. Changes in emotional status following SAH were common. Relatives and patients rated patients’ emotional status in a similar manner to patients’ statements, and relatives’ and patients’ statements about patients’ social company habits corresponded. Social company habits had changed. Problems with activities of living were common and patients had more problems with social life than, with personal and instrumental activities of daily living (P- and I-ADL). The relatives stated the patients’ daily life ability (problems or not) in a similar manner to the patients’ statements. The relatives’ and the patients’ statements regarding the patients’ personal and instrumental activities of daily living, social company habits and the patients’ ability to read and assimilate a book corresponded.

However the results from this thesis showed:
- that some patients demonstrated meta-memory problems (relatives’ statements)
- that patients’ judged their own memory ability better than relatives in comparison with results from patients’ memory tests
- that there was no correspondence between the patients’ and the relatives’ statements concerning STM, and no correspondence between the patients’ and the relatives’ statements concerning STM, in comparison with the results from the memory tests.

Nevertheless, there was a high degree of concordance between relatives’ and patients’ evaluations concerning patients’ memory ability, emotional status, emotional problems, social company habits and activities of living, and patients, who had meta-memory problems regarding relatives’ statements had memory problems according to memory test results. Therefore both relatives’ and patients’ statements can be considered to be reliable. However, sometimes the patients and the relatives judge the patients’ memory differently. Consequently, memory tests and formalized dialogues between the patient, the relative and a
professional might be required, in order to improve the mutual family relationship in a positive way. Professionals however, must first assume that patients can judge their own memory, emotional status and ability in daily life.
WHAT IS ALREADY KNOWN ABOUT THIS TOPIC

- Being stricken with a SAH is described as dramatic with the sudden debut of headache, often followed by unconsciousness.
- Emotional and memory problems are common in short- and in long-term after a SAH.
- The problems after a SAH affect the health, wellbeing and life satisfaction of not only the patient, but also of them close to them.

WHAT THIS THESIS ADDS

- People with experience of a SAH showed that they were capable to judge their own memory for what happened at the time they became ill.
- The reconstruction of the acute phase of the illness in a communicative interaction is a tool for understanding the patient’s perspective of self-positioning, and creating a new identity.
- Relatives and patients judged the patients’ memory ability similarly, but both relatives and patients’ had difficulties judging the patients’ short-term memory.
- Patients judged their own memory ability better than their relatives did, according to the statements compared with results from memory tests.
- Changes in emotional status were common and relatives and patients rated patients’ emotional status in a similar manner.
- Old social company habits had changed due to patients’ sensitivity to noisy environments, tiredness and concentration difficulties, and the relatives’ and patients’ statements about social company habits corresponded.
- Problems with activities of living were common and relatives stated patients’ ability in a similar manner to patients’ statements.
- There were more problems with social life than with Personal and Instrumental Activities of Daily Living.
- Negative ageing stereotypes in society, and brain damage due to the location of the haemorrhage origin might be two factors that influenced how patients’ experiences (view) their memory ability, emotional status and activities of living after a SAH.
- There was a high degree of concordance between relatives’ and patients’ evaluations concerning patients’ memory, emotional status and ability in activities of living. Therefore both relatives’ and patients’ statements can be considered to be reliable and might be used as tools in nursing care.
IMPLICATIONS FOR PRACTICE

- Staff and significant others can support patients’ autonomy by listening to the patients’ experience of the illness event, letting the patient talk about memories, memory gaps and when the memory returned.

- It is vital to encourage patients in their meaning-making, letting them talk about their experiences of the onset in interaction with a professional/and or a relative as soon as possible after the illness event. Doing so should help patients to make sense of the traumatic event and to put it in a coherent life context within an identity construction, in order to make life complete. This will help patients to prepare for their new identity in daily life.

- Relatives’ and patients’ statements concerning patients’ memory and emotional status can be used as tools in nursing care, and when nurses prepare for patients discharge from the hospital, in order to support patients how to coop with daily life, with respect to patients’ memory ability and emotional status.

- Memory tests are required in order to evaluate if the patients’ have short-term memory and/or meta-memory problems. This is because memory problems may have implications for the mutual family relationships in daily life. However, professionals must first assume that patients can judge their own memory.

- Formalised dialogues between the patient, the relative and a professional (as a suggestion a specialist nurse), before patients discharge from the hospital and also, two years after the onset of a SAH is a suggestion. This since the patient and the relative sometimes judge the patient’s memory ability, emotional status and ability in activities of living differently, and that the expectations in daily life are set in relation to memory ability (especially if patients have meta-memory problems) and emotional status.

- The implementation of memory tests and formalized dialogues in nursing clinics would probably improve relationships in families of people who have had a SAH. The focus of the consultation suggested, should be on how to manage difficulties and facilitate the interaction in daily and social life, arising from possible memory and emotional problems.

- Offering patients and relatives to meet a registered specialist nurse in a consultation, focusing on factors that may contribute to health would most likely improve the wellbeing of both patients and their relatives. This is important in order to improve patients’ and relatives’ mutual family life, in spite of patients’ putative residual impairments, and that memory and/or emotional problems probably will remain.
SVENSK SAMMANFATTNING (SUMMARY IN SWEDISH)

Titel: **Dagligt liv efter Subarachnoidalblödning**

Identitetskonstruktion, patienters och anhörigas yttranden om patienters minne, emotionella status och aktiviteter i dagligt liv

Bakgrund

Subarachnoidalblödning (SAB; pulsåderblödning i hjärnan) är en komplicerad sjukdom och en dramatisk händelse. Insjuknandet sker ofta spontant med åtföljande medvetenslöshet, och minnesproblem och förändringar i emotionellt status till följd av SAB kan påverka anpassningen i dagliga livet. För att kunna stödja patienter och anhöriga på ett professionellt sätt i omvårdnaden, så krävs kunskap om patienters upplevelse av insjuknandet i SAB och kunskap om patienters minnesfunktion, emotionella status och förmåga i dagliga livet efter SAB, både från patienters och anhörigas perspektiv.

Övergripande syfte

Det övergripande syftet med avhandlingen var att beskriva patienters upplevelse av och rekonstruktion av insjuknandet i Subarachnoidalblödning (SAB) och händelser i nära anslutning till insjuknandet, och att beskriva patienters och anhörigas erfarenhet av patienters minne, emotionella status och aktiviteter i dagliga livet i ett längre perspektiv.

Specifica syften

(I) Syftet var att analysera personers framställningar om SAB, och beskriva hur de initierar och skapar mening för insjuknandet och händelser i nära anslutning till insjuknandet i SAB. De specifika frågorna var: (i) vad lyfts fram i framställningarna om SAB? (ii) hur är insjuknandet rekonstruerat, och (iii) hur skapas mening om insjuknandet i SAB genom kommunikativ interaktion med andra personer?

(II) Syftet med denna studie var att beskriva patienters minne efter en SAB, från anhörigas och patienters perspektiv i två grupper. I denna studie var syftet också att utvärdera användbarheten av närståendes yttranden, som redskap i omvårdnad och rehabilitering, för att kunna stödja patienter. Detta gjordes genom att jämföra: (i) anhörigas yttranden med patienters yttranden, och (ii) anhörigas och patienters yttranden med patienternas resultat på minnestest.

(III) Syftet med denna studie var att beskriva aktiviteter i dagliga livet (socialt liv och personligt - och instrumentellt ADL; P- and I-ADL) utifrån anhörigas och patienters perspektiv i två grupper, i relation till patientens minnesförmåga efter SAB. Syftet var också att utvärdera användbarheten av anhörigas yttranden som ett redskap i omvårdnad för att stödja patienten. Detta gjordes genom att jämföra: (i) anhörigas yttranden om patienters aktiviteter i dagliga livet med patienters yttranden, (ii) anhörigas och patienters yttranden om patienters aktiviteter i dagliga livet med patienternas resultat på minnestest, och (iii) anhörigas och patienters yttranden om patienters aktiviteter i dagliga livet med anhörigas och patienters yttranden om patientens minne.
Syftet med denna studie var att beskriva anhörigas och patienters yttranden om patienters emotionella status och sociala omgångesvanor, utifrån anhörigas och patienters perspektiv, i ett långtidsperspektiv i två grupper, och att utvärdera användbarheten av anhörigas yttranden, som ett möjligt redskap i omvårdnad för att stödja patienten. Detta gjordes genom att jämföra anhörigas yttranden om patienters emotionella status och patienters sociala omgångesvanor, med patienters egna yttranden.

Metoder

Både inductive och en deduktive ansats användes. Nio öppna intervjuer genomfördes i hemmiljö i genomsnitt 1 år och 7 månader (14-24 månader) efter patientens insjuknande, och diskursanalys användes för att analysera patienternas framställningar om insjuknandet i SAB (I). Elva anhöriga och 11 patienter, 11 år efter patienternas insjuknande och 15 anhöriga och 15 patienter, 6 år efter patienternas insjuknande i SAB deltog i två studier avseende patients minne, emotionella status och aktiviteter i dagliga livet. Ett frågeformulär med strukturerade intervjufrågor med fasta svarsalternativ, och minnestest användes för att samla data. Frågorna var designade utifrån författarens professionella förförståelse, och baserad på vetenskaplig kunskap om minnesklassifikation. Fischers exakta test, och Z-värden användes för statistisk analys av insamlade data (II-IV).

Resultat

Patienterna kunde bedöma sitt eget minne för vad som hände när de insjuknade. Både medvetna irrationella och rationella handlingar förekom, utifrån de sinnesförnimmelser, som patienterna upplevde. Kritiska moment såsom ”existentiell insikt” och ”tid som väntande, och tid som strukturerad mening” identifierades vid analyser av patienternas framställningar. Återberättandet av insjuknandet och händelser i anslutning till insjuknandet i SAB kan tolkas som en identitetskapande process. Meningsskapandet är både en fråga om att förstå SAB som en sjukdomshändelse och en social och kommunikativ fråga, där SAB konstruerades till en meningsfull livshistoria, för att kunna förstå vad som hände och för att göra livet helt (I). Minnesproblem, emotionella problem och problem med dagliga livet var vanliga enligt både anhörigas och patienters erfarenhet (II-IV), och minnesproblem var också vanliga utifrån resultat på minnestest (II). Det fanns överensstämmelse mellan anhörigas och patienters yttranden om patientens minne, och avseende långtidsminnet. Patienterna bedömde sitt eget minne bättre, än vad anhöriga gjorde, i jämförelse med patienternas resultat på minnestest (II). Det episodiska minnet var väl bevarat både avseende insjuknandet i SAB (I), och i ett långtidsperspektiv (II). Patienterna hade mer problem med sociala livet än med P- och I-ADL (III), och de sociala omgångesvanorna hade ändrats (III, IV) på grund av koncentrationssvårigheter, uttröttbarhet, patienternas känslighet för höga ljud och osäkerhet (IV).

Konklusion

Rekonstruktionen (återberättandet) av sjukdomshändelsen kan användas som ett redskap i omvårdnaden för att förstå patientens identitetskonsstruktion. Anhöriga och patienter bedömde patienters minne, emotionella status och aktiviteter i dagliga livet på liknande sätt, och därför kan både patienters och anhörigas yttranden användas som ett redskap i omvårdnaden, för att stödja patienter. Resultaten visade utifrån anhörigas yttranden att det fanns patienter, som inte kunde bedöma sitt eget minne (metaminnesproblem), och att patienterna bedömde sin minnesförmåga bättre än vad anhöriga gjorde, vid jämförelse med patienternas resultat på minnestest. Resultaten visar ändå hög grad av samstämmighet mellan anhörigas och patienters

Nyckelord: SAB, Stroke, Smärta, Minne, Beslut, Meningsskapande, Identitetskonstruktion, Psykiska följdstillstånd, Emotionellt status, Socialt liv, P-and I-ADL, Minnestest test, Intervjuer, Frågeformulär
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Appendix I
QUESTIONS TO PATIENTS

1. SEX
   Male □ Female □

2. What is your age?
   ________ Years

3. When were you treated for your stroke (Subarachnoid haemorrhage)?
   Year ________ Month ________

4. Where were you when you became ill?

5a. Was your next of kin/relative with you when you had your stroke (Subarachnoid haemorrhage)?
   Yes □ No □
   If you answered Yes, go to question 5c
   If you answered No, go to question 5b

5b. Was any other person present, who has been able to describe what happened to you?
   Yes □ No □
   If you answered Yes, go to question 5c
   If you answered No, go to question 5e.

5c. Were you and your next of kin/relative able to talk to each other just after you became ill?
   Yes □ No □
   We had contact other than verbal contact
   (eg nodding or hand-squeezing). □
   If you answered that you had contact other than verbal contact, describe how you communicated with each other.
   ____________________________
   If you answered No, go to question 5d.
   If you answered Yes, go further.

5d. How much time had you both without communicating with each other (verbally or non-verbally)?

   Less than 5 mins □
   Between 5 and 10 mins □

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14a. Is your next of kin/relative male or female?

Male □ Female □

14b. How old is your next of kin/relative?

_____ years.

14c. What is your relationship with your next of kin/relative?

Spouse/partner □
Brother/sister □
Child □
Good friend □
Grandchild □
Other relation □

If other relationship: Please state relationship __________________________

----------------------------------------------------------------------------------------------------------------------

20. Which description(s) apply to you?
You can choose more than one!

Am less psychologically resilient, become tired much more quickly than before. □

Sleep is restless and irregular.

Have less endurance in relation to activities around the house which I was uninterested in before I became ill. □

I pay less attention to what is going on around me than was the case before my stroke (Subarachnoid haemorrhage). □

I have an increased need for sleep, for no obvious explanation. □

I have an increased need for sleep, together with a sense of powerlessness and depression, because I no longer have the same mental (psychological) strength as before the illness. □

I lack initiative (unable to get going with everyday things). □

I am apathetic (indifferent to what is going on). □

I need a longer break at the end of the working day in order to be able to get on with activities around the house. □
I need constant breaks (after about 30 mins) in order to be able to manage my basic personal needs (for example, hygiene, dressing).

I have difficulties concentrating on just one work task.

I have difficulties concentrating in conversations with more than one person.

I have difficulties finding my way around in new environments.

I lose the thread in conversation because of memory problems.

I can only socialise in the company of 1-2 people at the same time, with the condition that only one person talks to me at a time.

I am more tearful and emotional than before my stroke (Subarachnoid haemorrhage).

I am more easily irritated (grouchy) when I get tired, than was the case before the stroke (Subarachnoid haemorrhage).

I am restless (unsettled).

I don’t have the same sensitivity for other people as I did before my stroke (Subarachnoid haemorrhage).

None of the descriptions apply to me.

22a. Do you think your memory has become worse since your stroke (Subarachnoid haemorrhage)?

Yes ☐ No ☐ Can not judge ☐

If you answered Yes, go to questions 22b to 22e.
If you answered No, or cannot judge, go to question 23.

22b. Try to describe how your memory has worsened.

__________________________________________________________________________________
__________________________________________________________________________________

22c. Have you problems in learning new things?

Yes ☐ No ☐

If you answered Yes, go to question 22d.
If you answered No, go to question 22f.

22d. Under what circumstances or situations is it hard for you to take in new information?

__________________________________________________________________________________

22e. Under what circumstances or situations is it easiest for you to take in new information?

__________________________________________________________________________________

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23. Does your next of kin-relative find that you forget things, even though you think your memory is unchanged compared with how it was before your stroke (Subarachnoid haemorrhage)

Yes ☐ No ☐

24. Do you think that you forget things more than was the case before, whilst your next of kin-relative thinks that your memory is just the same as before your stroke (Subarachnoid haemorrhage)?

Yes ☐ No ☐

26a. Have you noticed gaps in your memory for things that happened earlier in your life, even before your stroke (Subarachnoid haemorrhage)?

Yes ☐ No ☐

If you answered Yes, go to question 26b.
If you answered No, go to question 26c

26b. Can you say if you think that your stroke (Subarachnoid haemorrhage) has worsened the gaps in your memory?

Yes ☐ No ☐

26c. Have you gaps in your memory for things that happened earlier in your life, after your stroke (Subarachnoid haemorrhage)?

Yes ☐ No ☐

27. Everybody forgets things! We forget both things that happened a long time ago in life and things that we have recently seen or heard. What is your experience of these things?

The statements refer to both spontaneous memories and memories after being reminded.

Memory loss for something which happened 1-2 years ago. ☐
Memory loss for something which happened 4-5 years ago. ☐
Memory loss for something which happened a long time ago (more than 20 years ago). ☐
Memory loss for something that happened a very long time ago (more than 40 years ago). ☐
Memory loss for something that happened a few days ago. ☐
Memory loss for something that happened in the last 24 hours. ☐
Forgetting what I have just heard (a minute or a few minutes ago). ☐
Difficulties with learning new digit combinations (eg telephone numbers). ☐
Difficulties with using the telephone. ☐

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Difficulties with remembering names (names of people, places).

Difficulties in learning new names

Memory loss for different procedures (for example how to make coffee, how to get dressed, how to ride a bike, how to tie laces etc.)

Memory loss for different events (e.g., where and when you first met, the first Christmas you celebrated together, the birthdays of any children etc.).

Memory loss for factual knowledge I had. (e.g. that a percentage is the same as a hundredth, that it takes about 20-25 min to boil potatoes).

I have not noticed that I forget things.

28 a. Have you any physical handicap (for example paralysis or sensory loss) which means that you have not yet started back to work?

   Yes ☐  No ☐

If you answered Yes – go to question 28b

28 b. Can you describe your physical handicap(s).

_____________________________________________________
____________________________________

33a Did you read the daily papers before your stroke (Subarachnoid haemorrhage)?

   Yes ☐  No ☐

33b. Do you read newspapers today (after your stroke)?

   Yes ☐  No ☐

   If you answered Yes, go to question 33c
   If you answered No, go to question 34a

33c. What use (pleasure) do you make of the content today?

   A lot of use (pleasure). ☐
   More use (pleasure) than before my stroke (Subarachnoid haemorrhage). ☐
   Less use (pleasure) than before my stroke (Subarachnoid haemorrhage). ☐
   I seldom remember what I have read ☐
   Don’t know. ☐

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34a Did you watch TV before your stroke (Subarachnoid haemorrhage)?
Yes ☐ No ☐ Don’t remember ☐

34b. Do you watch TV today -after your stroke (Subarachnoid haemorrhage)?
Yes ☐ No ☐

If you answered Yes, go to questions 34c and 34d.
If you answered No, go to question 35a.

34c What is the reason that you watch TV today?
___________________________________________________________________________________
__________________________

34d. What enjoyment do you have with the content today?
A lot of enjoyment. ☐
Greater enjoyment than before my stroke (Subarachnoid haemorrhage). ☐
Less enjoyment than before my stroke (Subarachnoid haemorrhage). ☐
I seldom remember what I have seen or heard. ☐
Don’t know. ☐

35a Did you read books before your stroke (Subarachnoid haemorrhage)?
Yes ☐ No ☐ Don’t remember ☐

35b. Do you read books today?
Yes ☐ No ☐

If you answered No, go to question 36.
If you answered Yes, go to question 37.

36 Why do you not read books today?
I can’t manage it. ☐
I lose the thread when I am reading. ☐
I don’t remember the content from one moment to the next. ☐
I have not got around to reading yet. ☐
My next of kin/relative has warned me not to strain myself with reading. ☐
Don’t know. ☐

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37 Is there any free time activity or hobby that you did before your stroke (Subarchnoid haemorrhage), that you cannot manage today?

_______________________________________________________
_______________________________________________________

39a. Are you more mentally tired than before your stroke (Subarachnoid haemorrhage)?

Yes ☐ No ☐

*If you answered Yes, go to question 39b.*
*If you answered No, go to question 40.*

39b. What do you think is the reason for the tiredness?

After-effects from the stroke (Subarachnoid haemorrhage). ☐

I have become older. ☐

Both age and after-effects from the stroke (Subarachnoid haemorrhage). ☐

Other reason. ☐

What? ______________________________

39c. How does the tiredness show itself with you?

Irritation. ☐

Quietness. ☐

Aggression. ☐

I withdraw (e.g. go to bed) ☐

Crying. ☐

Reduced attention. ☐

Lower psychological endurance. ☐

Some other way. ☐

Please indicate how: __________________________________________

42. Imagine an ordinary day, what we need to be able to do and what needs to be done around the house. Answer the questions both according to what you did before your stroke (Subarachnoid haemorrhage) and what you manage to do today.

<table>
<thead>
<tr>
<th></th>
<th>Before the haemorrhage</th>
<th>After the haemorrhage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manage to feed myself.</td>
<td>Ja ☐ Nej</td>
<td>Ja ☐ Nej</td>
</tr>
<tr>
<td>Manage to slice meat and open food packages myself.</td>
<td>Ja ☐ Nej</td>
<td>Ja ☐ Nej</td>
</tr>
<tr>
<td>Can control my bladder and bowel.</td>
<td>Ja ☐ Nej</td>
<td>Ja ☐ Nej</td>
</tr>
<tr>
<td></td>
<td>Ja</td>
<td>Nej</td>
</tr>
<tr>
<td>-----------------------------------------------------------------</td>
<td>----</td>
<td>-----</td>
</tr>
<tr>
<td>Always manage to reach the toilet on time?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manage moving around (eg from bed to a chair) myself with or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>without aids (eg a walking stick).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manage to move around with help of another person.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manage going to the toilet completely by myself.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Task</td>
<td>Before the Subarachnoid haemorrhage</td>
<td>After the Subarachnoid haemorrhage</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>--------------------------------------</td>
<td>-------------------------------------</td>
</tr>
<tr>
<td>Manage going to the toilet myself but need some help (eg drying myself of, getting my clothes back on).</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can make coffee.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can make breakfast.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can prepare food (meals).</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can go by myself using public transport (eg to the shops or to friends and relatives).</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can plan food purchases.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can take care of my own hygiene and dressing.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can buy food.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can do my own shopping for clothes.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can do the dishes.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can make my bed.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can do the washing</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can do the ironing.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can clean the house.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can pay the household bills.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can plan the household budget.</td>
<td>Yes [ ] No [ ]</td>
<td>Yes [ ] No [ ]</td>
</tr>
</tbody>
</table>
44. Do you socialise with relatives and friends in the same way as you did before you became ill?
Yes ☐ No ☐

45. Have your socialising habits changed since you had your stroke (Subarachnoid haemorrhage)?
Yes ☐ No ☐

*If you answered No go to question 44 and/or Yes to question 45, please go to question 46.*

46. Our socialising habits and/or our company has changed because:

*You can choose more than one response!*

- I don’t manage to socialise with friends or relatives. ☐
- I only manage to keep contact with a smaller number of people. ☐
- I feel insecure because I am afraid my memory will let me down. ☐
- I can only concentrate on one person at a time. ☐
- I am sensitive to rowdy environments, ie too many people chatting away together. ☐
- I tire quickly and lose concentration. ☐
- I am still anxious about how people will react to or judge me after the stroke (Subarachnoid haemorrhage). ☐
Appendix II
QUESTIONS TO RELATIVES

1. What sex is your next of kin/relative?
   Male ☐  Female ☐

2. How old is your next of kin/relative today?
   _______ years.

3. When were your next of kin/relative treated for the stroke (Subarachnoid haemorrhage)?
   Year __________ Month ___________

4. Where was your next of kin/relative when he/she became ill?
   ______________________________________

5a. Were you present when your next of kin/relative had her/his stroke (Subarachnoid haemorrhage)?
   Yes ☐  No ☐
   If you answered Yes, to go question 5c.
   If you answered No, go to question 5b.

5b. Was anybody else present, who has been able to talk about what happened?
   Yes ☐  No ☐
   If you answered Yes, go to question 5c.
   If you answered No, go to question 5e.

5c. Were you and your next of kin/relative able to talk with each other just after your next of
kin/relative became ill?
   Yes ☐  No ☐
   We/they had contact other than verbal contact (for example, nodding or hand-squeezing) ☐
   If you answered that you had contact other than verbal contact, describe how you communicated with
   each another.
   __________________________________________________________________________
   If you answered No, go to question 5d.
   If you answered Yes, go further.

5d. How much time had you without contact with each other?
   Less than 5 mins. ☐
   Between 5 and 10 mins. ☐

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More than 10 mins. □
Don’t remember. □

14a. Are you male or female?
Male □ Female □

14b. How old are you? □

14c. What relationship are you to your next of kin/relative?
Spouse/partner. □
Brother/sister. □
Child. □
Good friend. □
Grandchild. □
Other. □
If other, please state relationship_________________

20. Which description(s) apply to your next of kin/relative?

You can choose more than one!

Is less psychologically resilient, becomes tired much more quickly than before. □

Sleep is restless and irregular. □

Has less endurance in relation to activities around the house which he/she was uninterested in before the stroke (Subarachnoid haemorrhage). □

Pays less attention to what is going on around him/her than was the case before the stroke (Subarachnoid haemorrhage). □

Has an increased need for sleep, for no obvious explanation. □

Has an increased need for sleep, together with a sense of powerlessness and depression, because he/she no longer has the same mental (psychological) strength as before the illness. □

Lacks initiative (unable to get going with everyday things). □

Is apathetic (indifferent to what is going on). □

Needs a longer break at the end of the working day in order to be able to get on with activities around the house. □

Needs constant breaks (after about 30 mins) in order to able to manage his/her basic personal needs (for example, hygiene, dressing). □
Has difficulties concentrating on just one work task. □

Has concentration difficulties when conversing with more than one person. □

Has difficulties finding his/her way around in new environments. □

Loses the thread of conversations because of memory problems. □

Can only socialise in the company of 1-2 people at the same time, with the condition that only one person talks to him/her at a time. □

My next of kin/relative is more tearful and emotional than before the stroke (Subarachnoid haemorrhage). □

My next of kin/relative is more easily irritated (grouchy) when he/she gets tired, than was the case before the stroke (Subarachnoid haemorrhage). □

Is restless (unsettled) □

Doesn’t have the same sensitivity for other people as before the stroke (Subarachnoid haemorrhage). □

None of the descriptions apply to my next of kin/relative. □

22a. Do you think that your next of kin/relative’s memory has got worse since his/her stroke (Subarachnoid haemorrhage)?

Yes □ No □ Can not judge □

*If you answered Yes, go to questions 22b to 22e.*

*If you answered No or Cannot judge, go to question 23.*

22b. Try to describe in what way your next of kin/relative’s memory has become worse.

_____________________________________________________________________

22c. Has your next of kin/relative problems in learning new things?

Yes □ No □

*If you answered Yes, go to question 22d.*

*If you answered No, go to question 22f.*

22d. Under what circumstances or situations is it hard for your next of kin/relative to take in new information?

_____________________________________________________________________

22e. Under what circumstances or situations is it easiest for you next of kin/relative to take in new information?

_____________________________________________________________________

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23. Do you find that your next of kin/relative forgets things, even though he/she thinks that their memory is no different compared with what it was like before the stroke (Subarachnoid haemorrhage)?

Yes ☐ No ☐

24. Does your next of kin/relative think that he/she forgets things more than was the case before, whilst you think that it is just the same as before the stroke (Subarachnoid haemorrhage)?

Yes ☐ No ☐

26a. Have you noticed if your next of kin/relative has had gaps in his/her memory for things which happened earlier in his/her life, even before the stroke (Subarachnoid haemorrhage)?

Yes ☐ No ☐ Don’t know ☐

*If you answered Yes, go to question 26b.
*If you answered No, go to question 26c*

26b. Would you say that you think that the stroke (Subarachnoid haemorrhage) has worsened your next of kin’s/relative’s memory?

Yes ☐ No ☐

26c. Has your next of kin/relative gaps in his/her memory for things which happened earlier in their life, after the stroke (Subarachnoid haemorrhage)?

Yes ☐ No ☐

27. Everybody forgets things! We forget both things that happened a long time ago in life and things that we have recently seen or heard. What do you think has been the case with your next of kin/relative?

*These statements can refer to both spontaneous memories and memories after being reminded.*

Memory loss for something which happened 1-2 years ago ☐

Memory loss for something which happened 4-5 years ago ☐

Memory loss for something which happened a long time ago (more than 20 years ago). ☐

Memory loss for something that happened a very long time ago (more than 40 years ago). ☐

Memory loss for something that happened a few days ago. ☐

Memory loss for something that happened in the last 24 hours. ☐

Forgetting what he/she has just heard (a minute or a few minutes ago). ☐

Difficulties with learning new digit combinations (eg telephone numbers) ☐

Difficulties with using the telephone. ☐
Difficulties with remembering names. (names of people, places)

Difficulties in learning new names

Memory loss for different procedures (for example how to make coffee, how to get dressed, how to ride a bike, how to tie laces etc.)

Memory loss for different events (eg where and when we first met, the first Christmas we celebrated together, the birthdays of any children etc).

Memory loss for factual knowledge he/she had. (eg that a percentage is the same as a hundredth, that it takes about 20-25 mins to boil potatoes).

I have not noticed that he/she forgets things.

28 a. Has your next of kin/relative any physical handicaps (eg paralysis or sensory impairment which means that he/she has not yet started working again?)

Yes ☐ No ☐

If you answered Yes - go to question 28 b

28 b. Please describe your next of kin/relative’s physical handicap(s).

________________________________________________________
________________________________________________________

33a. Did your next of kin/relative read daily papers before his/her stroke (Subarachnoid haemorrhage)?

Yes ☐ No ☐

33b. Does your next of kin/relative read newspapers today (after the stroke, Subarachnoid haemorrhage)?

Yes ☐ No ☐

If you answered Yes, go to question 33c
If you answered No, go to question 34a.

33c. What use (pleasure) do you think that your next of kin/relative has concerning the content of the newspaper today?

A lot of use (pleasure) ☐

More use than before the stroke (Subarachnoid haemorrhage). ☐

Less use (pleasure) than before his/her stroke (Subarachnoid haemorrhage) ☐

He/she seldom remembers what he/she reads. ☐

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Don’t know. □

34a. Did your next of kin/relative watch TV before his/her stroke (Subarachnoid haemorrhage)?
Yes □ No □ Don’t remember □

34b. Does your next of kin/relative watch TV today - after his/her stroke (Subarachnoid haemorrhage)?
Yes □ No □

If you answered Yes, go to question 34c and 34d.
If you answered No, go to question 35a.

34c. For what reason does your next of kin/relative watch TV today?
_____________________________________________________________________________
_____________________________________________________________________________

34d. What use (enjoyment) do you think that you next of kin/relative has with the content today?
A lot of enjoyment □
More enjoyment than before the stroke (Subarachnoid haemorrhage) □
Less enjoyment than before the stroke (Subarachnoid haemorrhage) □
He/she seldom remembers what he/she has seen or heard □
Don’t know. □

35a. Did your next of kin/relative read books before the stroke (Subarachnoid haemorrhage)?
Yes □ No □ Don’t remember □

35b. Does your next of kin/relative read books today?
Yes □ No □

If you answered No, go to question 36.
If you answered Yes, go to question 37

36. Why does your next of kin/relative not read books today?
Can’t manage it □
Loses the thread when he/she is reading □
He/she can’t remember the content from one moment to the next □
He/she has not got around to reading yet. □
As next of kin/relative I have advised him/her not to strain themselves with reading □
Don’t know □

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37 Is there any leisure activity or hobby that your next of kin/relative did before his/her stroke (Subarachnoid haematoma) which he/she cannot do today?
__________________________________________________________________________________

39a. Is your next of kin/relative more mentally tired now than before the stroke (Subarachnoid haemorrhage)?

Yes ☐   No ☐

*If you answered Yes, go to question 39b.*
*If you answered No, go to question 40.*

39b. What do you think is the reason for the tiredness?

- After-effects from the stroke (Subarachnoid Haemorrhage) ☐
- He/she has become older ☐
- Both age and after-effects from the stroke (sub-arachnoid haemorrhage) ☐
- Other reason ☐

What_____________________________

39c. How does your next of kin/relative’s tiredness show itself?

- Irritation ☐
- Quietness ☐
- Aggression ☐
- He/she withdraws (eg, goes to bed) ☐
- Crying ☐
- Reduced attention ☐
- Lower psychological endurance ☐
- Some other way ☐

Please state how:_______________________________________________________________
42. Imagine an ordinary day, what we need to be able to do and what has to be done around the house. Answer the questions according to what your next of kin/relative did before the Stroke (Subarachnoid Haemorrhage), and what he/she manages to today.

<table>
<thead>
<tr>
<th>Before the Subarachnoid haemorrhage</th>
<th>After the Subarachnoid haemorrhage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manages to cope feeding her-/himself (eating).</td>
<td>Yes</td>
</tr>
<tr>
<td>Manages to slice meat and open packages of food by him-/herselves.</td>
<td>Yes</td>
</tr>
<tr>
<td>Has bladder and bowel control?</td>
<td>Yes</td>
</tr>
<tr>
<td>Always manages to reach the toilet on time.</td>
<td>Yes</td>
</tr>
<tr>
<td>Manages moving around (eg from bed to a chair), with or without aids (eg a walking stick)?</td>
<td>Yes</td>
</tr>
<tr>
<td>Manages moving around with help of another person?</td>
<td>Yes</td>
</tr>
<tr>
<td>Manages going to the toilet him/herself?</td>
<td>Yes</td>
</tr>
<tr>
<td>Before the Subarachnoid haemorrhage</td>
<td>After the Subarachnoid haemorrhage</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>-------------------------------------</td>
</tr>
<tr>
<td>Manages going to the toilet him/herself but needs some help (eg drying him/herself or putting clothes back on).</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can make coffee</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can make breakfast</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can prepare food (meals)</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can go independently on general transport (eg to shops or to friends and relatives).</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can plan food purchasing</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can manage his/her own hygiene and dressing</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can buy food</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can manage buying his/her own clothes</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can do the dishes</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can make his/her bed</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can do the washing</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can do the ironing</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can clean the house.</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can pay household bills.</td>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>Can plan the household budget</td>
<td>Yes [ ] No [ ]</td>
</tr>
</tbody>
</table>

44. Do you both socialise with friends and relatives in the same way that you did before your next of kin/relative became ill?

Yes [ ] No [ ]

45. Have your socialising habits changed since your next of kin/relative’s stroke (Subarachnoid haemorrhage)?

Yes [ ] No [ ]

*If you answered No to question 44 and/or Yes to question 45, please go to question 46.*

46. Our socialising habits and/or company have changed because:

*You can choose more than one response!*

- My next of kin/relative cannot manage socialising with friends or relatives. [ ]
- My next of kin/relative only manages to keep in contact with a smaller number of people. [ ]

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My next of kin/relative feels insecure because he/she is scared that his/her memory will let him/her down.

My next of kin/relative can only concentrate on one person at a time.

My next of kin/relative is sensitive to rowdy environments, ie too many people chatting away together.

My next of kin/relative suddenly gets tired and loses concentration.

My next of kin/relative is still anxious about how people will react to or judge him/her after the stroke (Subarachnoid haemorrhage).
GROUPED QUESTIONS IN THIS THESIS

Patients and relatives answered 46 questions (111 part questions) during the interviews. Twenty three questions (43 part questions) is the foundation for the results in this thesis. The questions not presented in this thesis will compose foundation for results in other studies. The questions presented in this appendix, are questions grouped together, which compose the foundation for the results in Study II-IV, in this thesis.

GENERAL QUESTIONS
1-4
5a-5d
14a-14c
28a-b

QUESTIONS CONCERNING MEMORY ABILITY
22a-22e
23
24
26a-26c
27
33c (statement 4)
34d (statement 4)
36 (statement 3)

QUESTIONS CONCERNING EMOTIONAL STATUS AND SOCIAL COMPANY HABITS
20
39a-c
36 (statement 1-2)
44
45
46

QUESTIONS CONCERNING ACTIVITIES OF LIVING
27 (statement 9)
33a-c
34a-d
35a-b
36
37
42
44
45
Appendix IV
Verification of questions in this thesis

The questions in this thesis (Appendix 1 and 2) are verified against questions in the Mini Mental State, (Folstein MF et al 1975), in the SAB (SAH) 94-95, Version 5 (Rödholm, M., Starmark, J-E, 1994) and in the SAB-94 (SAH-94; Sonn U., Starmark, J-E., Svensson, E., von Essen, C. 1994). Examples are shown in Appendix 4.
Questions concerning concentration and social company habits

CPRS

4. Koncentrationssvårigheter CPRS 16

Ledfrågor enl. CPRS 16:
- Har Du svårt att koncentrera Dig, att hålla tankarna samlade?
- Har Du svårt att följa med i samtal med flera personer?
- Får Du svårt att t.ex. läsa eller se på TV?
- Klarar Du hela Rapport eller hela Aktuellt?
- Klarar Du följa med texten på en utländsk film och samtidigt följa med bilden?
- Hur ofta är det så och hur besvärande är det för Din?

Källa: Rödholm, M. & Starmark, J-E., 1994

4. Koncentrationssvårigheter CPRS 16

Questions concerning P-ADL

P-ADL, SAB-94

BADNING: tar sig till tvättplatsen, tvättar hela kroppen i badkar, dusch eller vid handfat. Oberoende/beroende

PÅ/AVKLÄDNING: tar sig till skåp/låda, tar fram kläderna, tar på/av kläder. Oberoende/beroende

TOALETTBESÖK: tar sig till toaletten, kommer på/av toalettstolen, torkar sig, tvättar sig, ordnar kläderna. Oberoende/beroende

ÖVER-FLYTTNING: tar sig ur sängen till stol, alternativt mellan två stolar = överflyttning av kroppen. Oberoende/beroende

KONTINENS: inkontinens= ofrivillig urin- eller faecesavgång, (hygien, toalettbesök, förstoppning bedöms ej). Oberoende/beroende

FÖDOINTAG: för mat från tallrik in i munnen. Hygien och bordsskick bedöms ej. Oberoende/beroende


Questions in Appendix 1 and 2 in Berggren, E., 2012
Explanation: 39c(6) is question 39c, statement six

Questions in Appendix 1 and 2 in Berggren, E., 2012
Explanation: 42(14) is question 42, statement fourteen