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# Understanding Life After Stroke

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### **Abstract**

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Stroke is an acute, neurological dysfunction of vascular origin with sudden occurrence and it influences physical, cognitive and psychological functions. Initial treatment aims at eliminating or reducing the brain damage. Soon, however, the influence of the stroke on the entire life of stroke survivors has to be considered.

This thesis explores the meaning of life after stroke to 19 elderly stroke survivors during the first year post stroke. Survivors were interviewed twice and the interviews were analysed through qualitative methods.

Study I was about four survivors who delayed hospital arrival far beyond time limits for thrombolytic treatment. The survivors had a strong need for control of body, autonomy and integrity and they demanded to be encountered in consultations as a person by a person. To make them search for emergency evaluation in time might demand an emergency care treating them according to these needs.

In Study II the voice of an aphasic survivor was heard. Because of the damaged language his rehabilitation unilaterally focussed on language training and his need for comprehensive support and planning for the future was not observed. Implementation of a qualitative research method for text analysis adapted to practical use in dialogues with aphasic persons might ensure these survivors an adequate rehabilitation.

Study III showed how time models in narratives helped stroke survivors to overcome uncertainty and recreate narrative coherence in their lives. Professionals can support survivors through revealing and reinforcing the meaning of these models.

Study IV found that the meaning of rehabilitation to stroke survivors was social reintegration. Many probably did not socially reintegrate because their own strategies and subjectively experienced disabilities were unacknowledged in their rehabilitation. Through integrating illness-as-lived perspectives with biomedical perspectives, subjective dysfunctions and rehabilitation strategies of survivors could be acknowledged in stroke rehabilitation.

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# List of papers

This thesis is based on the following four studies, which will be referred to in the text by their respective Roman numerals.

- I. Stroke patients' delay of emergency treatment**  
Hjelmlink F, Holmström I, Kjeldmand D  
*Submitted*
- II. Understanding the meaning of rehabilitation to an aphasic patient through phenomenological analysis – a case study**  
Hjelmlink F, Bernsten BB, Uvhagen H, Kunkel S, Holmström I  
*International Journal of Qualitative Studies on Health and Well-being.* 2007; 2; 93-100
- III. To cope with uncertainty: stroke patients' use of temporal models in narratives**  
Hjelmlink F, Holmström I  
*Scandinavian Journal of Caring Sciences.* 2006; 20; 367-374
- IV. The path to social reintegration after stroke**  
Hjelmlink F, Holmström I, Sanner MA  
*Submitted*

**Motto**

“Il y a deux choses, qui jamais cessent de menacer le monde: l’ordre et le desordre” [There are two things that never cease threatening the world: the order and the disorder] (Paul Valéry) [1].

Cover picture by the artist Kinn Lykke Hjelmblink.

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# Abbreviations

ADL = Activities of Daily Living

BI = Barthel Index

EPP method = Empirical, Phenomenological, Psychological method

GT = Grounded Theory

MMSE = Mini-Mental State Examination

ICF = International Classification of Functioning, Disability and Health

ICIDH = International Classification of Impairments, Disabilities, and Handicaps

PSD = Post Stroke Depression

PSA = Post Stroke Anxiety

QoL = Quality of Life

SSS = Scandinavian Stroke Scale

WHO = World Health Organization



# 1 Preamble

My mother told me my first story about stroke: Her grandmother had had a stroke and had after that been bedridden in a dark and dull room on mother's aunt's farm. She had bedsores and contractures and was profoundly distressed, distressed so heartbreakingly, that my grandmother did not manage to visit her but sent my mother to call on her. For many years, this story was the meaning of stroke for me.

My father read fairy tales aloud to me and taught me to love stories to the degree of a bookworm intending to study literature. It was by chance that I began studying medicine instead of literature, became a physician, and eventually a geriatrician.

However, geriatricians listen to life stories along winding tracks leading to the interruptive story of the disease of a patient. Their task among other tasks is to help their patients to recreate coherence in the life stories. Good geriatricians understand their patients' stories; they do not only interfere through medical diagnoses and pills. So, perhaps after all it might be through understanding of the unreal world of fiction that geriatricians achieve an understanding of how to understand their patients. My geriatric team came to this realization and we often read passages from literature during our clinical conferences.

Then I met the works of Alexander Lurija (1902 – 1977), the Russian scientist, who had performed his bedside studies on brain-damaged soldiers in World War II. In his books about 'the higher cortical functions of man' and 'the man with a shattered world', the stories of brain damaged people became understandable in a cognitive and emotional context [2,3]. The world of biology became interwoven with associations to human perception, thinking and action.

The works of Luria represented a turning point in my professional life and led to six months of practicing at the Centre of Brain Damage at the University of Copenhagen [4]. For a physician to observe neuropsychologists at work was peeping into a world where stories were differently interpreted and responded to than in the world of medicine. The private stories of the patients and the staff members were exchanged. The patients' stories were accessible to all and influenced each other. The old distressing narratives

about sufferers in this way were re-enacted as new tales about efficient individuals.

However, in order to give the reader an understanding of how stroke is experienced, a patient's story might be helpful. A stroke patient, who was an author, wrote a short story about his experiences of an infarction in the cerebellum. His story gives the reader an impression of what it means to be damaged to the brain. I therefore, with his permission, begin my introduction with a shortened version of what he wrote.

## 2 Introduction and aim

### 2.1 Falling ill

“I laid the book on my pillow, let my hand glide to and fro on the cover from which the author was watching me...walked out of the bedroom into the hall, stopped on the top step, grasped firmly the white wooden handrail. The polished wood suddenly felt ice-cold. It somehow warned me from taking the next step. Then it happened! By instinct I pushed with my arm to avoid diving down the steep staircase. I collapsed backwards. At first I felt no pain, although I felt as if the bones of my skull had burst at their seams through a noiseless explosion opening like a flower, the brain pulsating out. I turned around on my belly. Suddenly I had no holding ground. The world was no longer where it previously had been in a firm structure. Everything turned around in a whirling vertigo, sliding away from my groping hands. Creeping I managed to return to bed. My wife now woke and called an ambulance. I started vomiting. From the ride to the hospital I don’t remember anything...

...In a turbulent event, one of the first days in the hospital, I suddenly discovered how everything had got a duplicated shape. At first it was a little disturbing with staff of that large size around me. “Am I so ill?” I thought. Yet, eventually, I understood that half of the persons at my bed existed in only my head. My wife was sitting at my bed with a copy of her at her side. They were dressed alike. They had the same hair and the same eyes. To decide who was who, who was the real one and who was the unreal one, I stretched out my left arm believing that I could achieve some clarity. But which of my two out stretched left arms should I trust? Which was the real one and which was only a representation of the outstretched hand?

...All of a sudden, when his working situation allowed, he entered the room and sat down at my bed. “Only to talk”, he said. But I saw how his eyes went watching over me, observing my behaviour. What we talked about was literature. Nothing could be more healing for me. So I felt. This he un-

derstood – the doctor on a visit with, among other things, literature as a medication...

...Then, after some time, I managed to take a few shuffling steps supported by a woman's arm. My legs were infirm, felt emptied of strength as if their skeleton had been removed. But I managed half a round at the left side of my bed. From my humble and injured perspective I experienced it as an honorary round. Tired, heavily breathing, I was helped back to bed filled with the happiness of my success...

...The trees had begun to burst into leaves. From my bed I saw the tiny verdure, following its growth. Everything suddenly was so strange to me; nearby, although unattainable. It was as if I had passed through a never-ending vacuum to reach the reality outside of me. Find my presence in it. Of reality, which had been so well-known to me, I was now only a spectator...

...At the discharge I had some remaining balance-difficulties to fight and something that appeared a few weeks after my discharge: My head was all of a sudden filled with an intensive smell of perfume. Wherever I was, everything was perfume all day long. Even at the moments when the world around me smelled otherwise. "Perfume!" my family doctor exclaimed when I visited him. He looked at me with a smile and quietly added: "Well, well R, you are a lucky dog, you!" [5].

Yet, R was only a lucky dog on the face of it. The smell of perfume, although perhaps agreeable, was a symptom of a damaged brain. His balance was disturbed. It had become more difficult for him to write. The arteriosclerosis of the cerebral vessels which had caused the stroke was still there and caused him further ischemic attacks and small cerebral infarctions. People who become lucky dogs because of a stroke are few. However, to tell the short story had helped R and me to understand in the same way as the patient stories at the centre for brain damage had helped the patients and their psychologists.

Influenced by these insights two psychologists and I did an intervention study with support groups in the rehabilitation of elderly stroke survivors [6]. We revealed that even though the participants performed socially better at the end of the intervention, several were - in line with other research - distressed and struggled with anxiety of the future and fear of another stroke [7-12]. Medical treatment cannot offer stroke patients risk elimination, only risk reduction [13]. Consequently more than 50% of stroke survivors live in a fear of recurrence and lack of sense of control. Their fears are more associated with personal beliefs and experiences than factual information about risk factors delivered by professionals [14].

Thus stroke survivors' anxiety, distress and fear of the future were probably insufficiently met by medical professionals. Further knowledge seemed to be needed about the meaning of stroke for survivors at the crossing point between stroke as a disease, i.e. stroke as a biomedical problem, and stroke as an illness, i.e. as an experience interwoven in the survivors' lives. To get

this knowledge I found it was necessary to listen to what stroke survivors recounted about their experiences. I chose, at last, a qualitative approach.

## 2.2 Overall aim

The overall aim of the thesis is to explore the meaning of life after stroke to elderly stroke survivors.

## 2.3 Outline of the thesis

In Chapter 1 and 2, I have recounted the background of my professional adventure, the experiences of a stroke victim and the unmet psychological problems of participants in support groups. The chapters end with the overall aim of the thesis. In Chapter 3 is presented a survey of the disease stroke: its definition, epidemiology, symptomatology and treatment. A damaged brain is a disrupting experience for a human being and causes a decreased quality of life (QoL) which introduces the illness perspective. The secondary aims finish Chapter 3. In Chapter 4 my theoretical, methodological framework around the syndromes of disease and the narratives of illness are described in the subsections about phenomenology, time, narrative and grounded theory (GT). After life disrupting damage human beings want to recuperate: they claim cure and rehabilitation. The concepts of disability and rehabilitation are therefore discussed in Chapter 4. In Chapter 5 the analytical methods founded on phenomenology, narratology and GT are described and the ethical considerations of the study are presented. In Chapter 6 the findings are summarized. Chapter 7 contains the discussions of overall findings and methods. The thesis ends with a short summary, proposals for future research and a Swedish summary.

### 3 Background

In the following passages I describe stroke: first as a disease and second as an illness. The question is where in fact the *peripeteia*, the change of fortune or circumstances, takes place in the disease and illness story of a stroke patient. Is it when she or he is struck by the stroke damage to the brain or is it when she or he eventually understands the meaning of the stroke in her or his lived life? However, first I have to take stance in a small, yet important, question of terminology: how should I name the participants in a research project about stroke?

#### *Participants, informants, patients, victims and survivors*

I write about persons called by many nouns. The nouns chosen mirror a development during the last two generations in the relationships between health professionals and the people they serve [15]. Two generations ago receivers of health care under the name of patients were subordinate to the professionals in a paternalistic system. In today's health care a more equal relationship is evolving. The word "patient" is still loaded with its history of paternalistic subordination and efforts have been made to find neutral substitutes. Terms such as consumer, customer, client, partner and survivor have been proposed [16]. Deber et al. assessed what Canadians with breast cancer, prostate cancer, fracture or HIV/AIDS preferred to be called. The word "patient" was moderately favoured by those who in fact were receiving care. "Survivor" was liked by some HIV groups. The proposed alternatives consumer, customer, client and partner were rejected [16].

In my interviews the informants described themselves in different roles. I therefore chose to name them according to the parts I think they wanted to play in the actual situation. The human beings in the studies will therefore be called patients, informants, victims, survivors, people, individuals and human beings corresponding to what might be appropriate in the actual passage [15].

## 3.1 Disease

“Disease” according to a dictionary definition is “a disorder of structure or function in a human... especially a disorder that produces specific symptoms or affects a specific location” [17]. Hence, the “disease stroke” means “the physiological or bodily damage and its attachments of malfunctions” [18]. From this perspective the biological damage is in focus.

### 3.1.1 Definition

Stroke is “an acute neurological dysfunction of vascular origin with sudden, i.e. within seconds, or at least rapid, i.e. within hours, occurrence of symptoms and signs corresponding to the involvement of focal areas in the brain”. The symptoms last for more than 24 hours [19].

### 3.1.2 Epidemiology

Of the 30,000 people in Sweden who every year have a stroke, 20,000 have their first stroke [20]. The fatality during the first 28 days after a stroke is between 12 and 19%, which makes stroke the third most common cause of death in Sweden, after myocardial infarction and cancer [20,21].

The estimated incidence is about 300 per 100,000 inhabitants and year and increases with increasing age. The prevalence is 1000 per 100,000 inhabitants and year. Eighty percent of stroke patients are above 65 years old which makes stroke an important disease of the elderly although 20% are below 65 years, which is the pensionable age of Sweden. The prevalence is therefore, because of a changing population structure calculated to increase between 1990 and 2025 in spite of an unchanged incidence and a decreasing fatality [22].

Stroke is a disease that strikes women and men equally, but the mean age when diseased is 78.3 years for women and 73.5 years for men. In the age group below 65 the number of men is twice that of women, and in the age group above 85 the number of women is twice that of men [20].

To have a stroke at a certain age means for a person that her life expectancy is reduced compared to the general population of the same age. A woman in Sweden who has her first stroke at 80 gets life expectation reduced from 8.8 to 5.4 years. For a man who has a stroke at the age of 75 the reduction is from 9.5 to 6.0 years [13].

### 3.1.3 Symptomatology

The symptoms of stroke are numerous and affect different parts of the body.

### *Function*

The functional syndromes after stroke are related to the damaged area of the brain. Usual functional damages may, briefly summarized, involve: muscles of hand, arm, leg, face, throat or bladder; sensory perception from skin and muscles; field of vision and correct interpretation of visual perception; balance and intentional movements [23]. The functional damages interfere with a survivor's physical activities in her or his environment.

### *Cognition*

Cognitive deficits are detected in 63.5% of non-drowsy stroke survivors. 25.2% have aphasia, i.e. damage of language functions like expression of speech, understanding of speech, writing or calculation. 14.5% are apraxic, i.e. are unable to perform practical activities, although the necessary motor and sensory functions are preserved. 11.6% have memory disturbance. 9.2% have symptoms related to the functions of the frontal lobes, which include the ability to make plans and to perform, adequately adapted to the demands of the environment [24]. The described damages of language, performance and planning ability interfere with the survivors' ability to interact socially in their environment.

### *Severity*

In the Copenhagen stroke study the functional decrease of 33% of acute stroke victims was very severe and severe, 26% moderate, and 41% mild according to the Scandinavian Stroke Scale (SSS), which estimates state of consciousness and neurological function; and the Barthel Index (BI), which estimates activities of daily life (ADL). After rehabilitation the neurological deficits in 11 % were severe or very severe, in 11% moderate and in 78% mild to none. 31% had achieved normal neurological function. In ADL 46% had no disability, 26% were mildly disabled and 8% moderately disabled, and 20% were severely or very severely disabled [25].

### *Post stroke depression*

Reports about the prevalence of post stroke depression (PSD) vary between about 25% and about 60% [7-12].

Robinson et al. found 1982 that about 33% of stroke survivors were depressed early after the stroke. Depression was continuously diagnosed during the first two years after the stroke [26]. Åström et al. revealed that PSD occurred with 25% of stroke victims during the acute stage and remained at the same level (31%) after 3 months. There was a decrease to 16% at 12 months and 19% at 2 years. At three years the number again had increased to 29% [27]. In an Italian multicentre stroke study the prevalence of PSD was 36%. The depression generally developed during the first three months. The depressed stroke survivors had a decreased QoL compared to the non depressed [28]. Recently Linden et al. found 20 months after stroke that 34%

of elderly survivors were depressed compared to 13% in population controls [29]. According to Löfgren et al. still three years after a stroke depression negatively influenced survivors' QoL and needed to be diagnosed and treated [30].

Finally Hackett et al. found that the prevalence of PSD seemed to be about 33% of the stroke survivors, and that although early depression often was resolved, new cases might occur at any time after the stroke [31]. Hence, continuous screening for PSD on all stroke patients is important. A depression negatively impacts both the QoL of its victim and her or his functional recovery as well. If, however, the depression is treated and resolved the QoL of the stroke survivor may increase [32]

#### *Fatigue, irritability, apathy and anxiety*

10% of non-depressed stroke patients always feel tired, and 29.2% are often tired. Fatigue is a predictor of dependency in primary ADL functions and three years after stroke, patients with fatigue have a higher case fatality rate [33].

About 33% of survivors suffer from irritability and 28% from agitation. 27% have apathy and 23% have anxiety [8]. Åström et al. studied 80 elderly stroke survivors over three years with assessment for general anxiety disorder and depression. 31% had a general anxiety disorder three months post stroke, often comorbid with depression. The prevalence of general anxiety in the general population of the same age group was 1.9%. The stroke survivors with general anxiety had fewer social contacts than those without anxiety. After one year 60% of the survivors with depression had recovered. Yet, still after three years almost two-thirds of the general anxiety patients suffered from their affliction and those who had comorbid depression did not recover from the depression to the same degree as persons with pure depression [9]. These findings were confirmed by Morrison et al., who also found that anxiety was predictive for depression and a lower life satisfaction after three years [10]. That anxiety may be more common than depression has recently been confirmed in a Norwegian study. Of the Norwegian stroke survivors 26.4% had anxiety whereas only 14% were depressed [34].

The studies stress that anxiety negatively influences the stroke survivors' QoL; a fact already observed more than 20 years ago [7].

So, how then has this complex disease to be treated?

### **3.1.4 Treatment**

In Stockholm, where the catchment area of the present studies was situated, during the years 1999 – 2000, 26% of stroke patients were treated in a neurological clinic, 34% in a medical clinic supervised by a neurologist, 24% in medical clinics alone and 14% in geriatric clinics [35]. Almost all patients had the brain examined through a computed tomography. A computed tomo-

graphy is considered mandatory because it shows whether the stroke is caused by an infarction or a haemorrhage as well as the location of the lesion. A very important step forward in stroke treatment is that some brain infarctions within a time limit of three hours from the onset of symptoms can be treated with a trombolytic agent, i.e. a remedy that may resolve the obstructing clot in a brain infarction. Some patients with a cerebral haemorrhage may have their prognosis improved through neuro-surgical removal of the haemorrhage [36]. Unfortunately too many stroke victims have a delayed arrival at the emergency department. They are for this reason unable to receive trombolytic treatment and delay of treatment is therefore considered a main issue in contemporary stroke care [37].

The basic physiological functions of a stroke victim have to be monitored and supported. Assessments are done of mobility, cognition and primary activities of daily living in order to start rehabilitation as soon as possible. Three-fourths of the stroke victims have their in-hospital treatment completed at the unit for acute care and are directly discharged home. One-fourth receives further in-hospital rehabilitation in geriatric clinics, neurological rehabilitation units or clinics for rehabilitation medicine.

It is an important goal for health service that stroke patients have their emergency treatment in a dedicated stroke unit. There is convincing evidence for a better outcome of treatment for stroke patients who are treated in a specialized stroke unit compared with those who get treatment in general units. Patients treated in stroke units have a lower mortality rate and rate of dependency [38]. Their QoL is higher and their risk for institutionalization lower; a positive effect that remains five years after the stroke [39-41].

The treatment in a dedicated stroke unit is delivered by a multidisciplinary team consisting of a neurologist, specialist nurses and assistant nurses, physiotherapist, occupational therapist, speech therapist, social worker and, to some extent, a neuropsychologist [42]. Some clinics have stroke treatment integrated in a general medicine unit with the multidisciplinary stroke team adapted to the specialty of the clinic. There is good evidence that it is the multidisciplinary nature of the team and the specialization of the team members that explain the better outcome achieved by stroke units [43].

A minority of stroke patients have further rehabilitation in neurological rehabilitation departments or geriatric units. An increasing majority, with medium or mild damage, is discharged to early treatment at home supported by outreach rehabilitation teams [44-46]. The rehabilitation results for early treatment at home seem similar to those of inpatient treatment. In early rehabilitation at home it seems easier for patients to express their own goals. Besides, the home environment may be more stimulating to the survivor than the environment of a hospital [47,48].

In the Copenhagen stroke study the group with moderate and severe disability after rehabilitation decreased from 50% to 25%, and the group with mild or no disability increased from 50% to 75% [49]. Functional recovery

generally was completed within 3 months of stroke onset. Patients with mild stroke, however, recovered within 2 months [50].

In sum: It is mandatory for the prognosis of acute stroke victims to have emergency treatment at a dedicated stroke unit. They should arrive at the emergency department within a time limit that allows them to be ready for thrombolytic treatment within three hours. It is also evident that many stroke victims in spite of treatment survive with sequels that impact their future life. Disease may therefore be given a more extended definition than those mentioned in the beginning of this chapter. Disease can also be defined as “a bodily or mental process which is such that it tends to cause an illness” [51].

## 3.2 Illness

To have an illness is according to the dictionary definition “to be in a state of not being well” [17]. Thus a state of illness is founded on an experience of an unwell person which makes a state of illness more comprehensive than a biologically defined state of disease. The entire consequences of a disease in the life of a diseased person can be contained in her or his illness experiences of unwellness [18]. From this perspective illness therefore in this thesis has been given the meaning: illness-as-lived by individuals who have had a stroke (Toombs 1993 p. xvi) [52]. This leads to a further specification of the concept. Illness can be defined as a condition in which a person is unable to ‘given standard circumstances, reach all his or her vital goals. A person’s vital goals are his or her essential goals in life’ [51,53]. Illness comprises the well-being, the QoL, the entire health of a person.

### 3.2.1 Quality of Life

Assessment of a decreased QoL of stroke survivors is related to lost functions, anxiety, post stroke depression and worries about the risk of another stroke. In spite of improved function Swedish stroke survivors did not accordingly improve in QoL over a period of three years post stroke [7]. The strong impact of stroke on QoL was confirmed by a Finnish study [54]. The QoL of survivors four years post stroke was below pre stroke level although they were young, had regained lost functions, and had returned to work. Several years after stroke Italian survivors still needed to have emotional symptoms and QoL considered. This consideration seemed to be of same importance as treatment of physical disability [55].

Northern American stroke survivors’ decreased QoL was negatively influenced by depression. Living with someone else and having social support were on the other hand factors which positively impacted QoL [56,57]. This social integration process has been followed up to two years after stroke in interviews with Canadian community dwelling survivors and healthy indi-

viduals of the same age. Seventy-two per cent of the survivors had no meaningful activity to carry out during the course of their day, which made them experience a lower quality of life compared with other people of the same age [58]. Still several years after the incident a stroke strongly impacts QoL, even though it has been found that 15 years post stroke elderly victims may have a QoL similar to the normal population [59,60].

Therefore it is mandatory to treat the lost functions of the stroke patients. Yet, it seems to be just as important to focus on how they experience their QoL and their psychosocial situation. In other words: how the stroke is experienced as a lived illness and what the stroke means to the survivors in their entire life situation are crucial issues [61].

### **3.2.2 Lived illness**

Human beings have narratives about their life as they experience it; but when they fall ill their body is disturbed and because of this disturbance their life narrative is disturbed. A narrative about the biology and the symptoms of a disease is incorporated in the life narrative. Why? Because, said Merleau-Ponty, we are our body and we are present in the world through our body, not as a something existing in the body [62]. Without the body we cannot exist in the world and experience the world. This makes our body into our home in the world and disease into a threat against this home. When we fall ill the body becomes ‘uncanny’ [63-65]. Because our body, according to Heidegger, is the tool of the brain extended into the equipment totalities in which we are living and acting, the disease also makes the body ‘a broken tool’. The body’s equipment totalities are damaged or threatened [66,67]. The existential anxiety in which we are attuned emerges. The narrative of a disease thus exists in the entire, complex world of an illness and cannot be experienced as a separate phenomenon outside the lived body of the diseased person.

According to Toombs, an ill person describes an illness as “illness-as-lived”. A professional on the other hand describes a disease as a complex of biological damage and symptoms [52]. From a phenomenological point of view the patient has a “natural” attitude in her experience of the illness as lived and the professional has a naturalistic attitude that excludes the perspectives of the patient. Mishler talks about the voice of life world and the world of medicine represented in the discourse between the ill person and the professional [68]. According to the philosophy of Gadamer, the ill person and the professional have different points of view of knowledge bordered by different meaning horizons. Professional and patient have the option to find a mutual understanding where their horizons of meaning fuse [52,69,70].

### 3.2.3 Trajectory model

A trajectory model of a chronic illness describes its characteristic, sequential phases [71]. For a stroke survivor the trajectory during the first year after the stroke usually develops over four phases. In the first phase the acute onset of symptoms strikes the victim with surprise and throws her or him into a state of suspense. The acute phase is followed by a period of the initial rehabilitation's hard physical work. The focus is fixed on regaining lost functions and the survivor claims training. The survivor begins little by little to realize that recovery takes time. Next, during the phase after discharge, the rehabilitation continues with psychosocial and practical adjustment to the home environment. This phase is during the second half-year after the stroke gradually followed by a long semi-stable phase where the survivor tries to find a new meaning in a life which has become different from pre stroke life. During each phase the survivor has a need for comprehensive information and psychological support which is easily overshadowed by many short-term treatment perspectives and a number of practical factors that belongs to the phase.

A trajectory model expresses the need of having a prospective perspective in the rehabilitation of a stroke survivor during the entire trajectory. Each phase has its problem in which both the stroke survivor and the carer can be absorbed. The trajectory model helps the carer to preserve a prospective focus in her or his task [72,73].

Therefore, as I see it, the trajectory model is a practical aid for research and clinical work with stroke survivors. One may object that the model is constructed over a linear time model. Survivors' experiences along the trajectory are influenced by individual aspects as for instance spirituality, religion, concurrent illness experiences and the elements of individual profiles in daily living. These aspects are embedded in the "ordinary" life narratives of the stroke survivors and make them follow other tracks than the one described in the trajectory model [74].

Furthermore, stroke survivors and professionals may have different conceptions of what is to be considered the core of the problems along the trajectory. Professionals may see neurological deficits which probably to some degree will remain. They are aware of the uncertainty of prognosis of stroke survivors and to them recovery means adequate function in the activities of daily living in spite of remaining neurological damages. Hence, the patients do not get the needed reconciliation in their state of prognostic uncertainty because recovery to them means absence of neurological damage. They believe the trajectory is open to manipulation if they train hard enough, i.e. training leads to getting rid of the effects of the stroke [75]. Survivors may assume shifting perspectives at different points of time along the trajectory and change periods of illness-in-the-foreground with periods of wellness-in-the-foreground. When they put illness in the foreground, they focus on treatment in a biomedical meaning; when they put wellness in the foreground,

they acknowledge the lived life's priority to disease. Professionals ought to listen to these different meanings of chronic illness to stroke survivors in order to be able to give them adequate support [76].

In sum: In the encounters between stroke survivors and professionals an aspect of time will be present and a trajectory model may offer a point of support in spite of its linearity. In fact, a trajectory model is somehow a part of a professional's pre-understanding and experience. On this fundamental stroke survivors and professionals are offered the option to create narratives that make use of individual temporal models related to the trajectory.

### **3.2.4 Meaning to the survivor**

Within the first week after a stroke the survivor may have a sense of unreality. She or he feels that a personal catastrophe has taken place, but is confused about what has happened and what the consequences might be [77]. The relation with the body is changed from the reliable body of before stroke to an unreliable body that has been separated from the self in a self-body split [78]. She or he has an 'uncanny' body [64]. The survivor struggles with an existential crisis. She or he has become helpless and uncertain of her or his self-picture and her or his whole life has become uncertain [79].

One patient group, the aphasic, are communicatively damaged stroke patients who experience predicaments not found among stroke patients with normal communication [80]. Aphasia has a specific, negative influence on survivors' QoL. They have individual, complex and changing experiences which they are unable to share in normal dialogues [81].

Three months after the stroke the survivor is still suffering from unaccustomed restrictions and losses, hopes for endurance mingle with dreams of possibilities; she or he endeavours to shift perspectives towards appreciating the ordinary things in life and searches for consoling relationships [82].

One year after the stroke the stroke survivors have learned from their experiences the importance of preserving identity and integrity. They then need to be met as subjects in a social community. They live with anxiety of a next stroke and they have learned that future post stroke life will never be as pre stroke life [83]. Their rehabilitation has been both progression and periods when recovery is halted, which has precipitated negative feelings. The negative feelings have not been predictive in a linear sequence. Rather, emotional recovery from uncertainty, loss of control and anger/frustration has been reactive and unpredictable [73].

Even stroke survivors with a mild stroke may experience a life turned upside down. They have a feeling of a harmed or threatened self because of apparent and hidden dysfunctions and an unpredictable future [84]. They want to be perceived from an aspect of individuality, where also the independent seemingly unhurt stroke survivor may experience the stroke as a disastrous event [85]. Although stroke survivors from a disease perspective

have escaped with a mild stroke, they may become dependent and limited in social participation [86]. These experiences are difficult for the stroke survivors to grasp and appear almost impossible to make fully understandable to others. After a year of a changed post stroke life, conflicting opinions between stroke patients and health care providers may emerge. The patients may want to continue rehabilitation towards goals considered unrealistic by care providers, who interpret the situation of their patients from a perspective of bereavement over losses. The patients are not prepared to give up their goals and engage in a bereavement process.

Four to 20 years post stroke (average nine years) survivors who are asked about the meaning and experience of being a survivor of stroke find that the stroke has significantly impacted their embodied capabilities [87]. Psychological barriers preclude them from daily activities. Emotional difficulties prevail; yet, these difficulties are, because of their invisibility, compounded by other people. The stroke survivors' behaviour might seem ambiguous to others, and social interaction is decreased.

Nevertheless, after nine months stroke survivors, who find a meaning in their experiences instead of considering themselves as victims of contingency, are better adjusted to the stroke event [88].

To sum up: for an uncertain period of time after a stroke, stroke victims have to struggle with a conglomerate of changes of brain, body, emotion, and relations. In a long-term perspective it seems important that they are able to handle psychological problems and give the stroke an individual meaning that helps them to go on in life. However, their first, very logical response after the accident is limited: They wish to get back their lost abilities [89].

The survivor group with aphasia has a significant problem because they are excluded from normal communication about their experiences and wishes. Their need for psychological support cannot be dealt with in normal dialogues. This problem is shed light upon in Study II.

In the next section I go through the meaning of having lost ability and the meaning of having treatment because of a lost ability, in other words the meaning of disability and rehabilitation.

## 3.3 Disability and rehabilitation

### 3.3.1 Two changing concepts

Rehabilitation means according to the etymological, Latin sense of the word, 'to be restored to former privileges' or according to the contemporary conception of the word, 'to restore someone to health or normal life by training and therapy after imprisonment, addiction or illness' [17]. Rehabilitation

according to these definitions is a comprehensive concept, which allows for persons with very different losses to raise the claim that they deserve rehabilitation. However, when rehabilitation is related to disabling illness, the United Nations' Convention on the Rights of Persons with Disabilities of 2006 has this description of the concept: 'rehabilitation is measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life' [90]. Now, in this important document the presupposition for a person to qualify for rehabilitation measures is that she or he can be called a disabled person. So, to define and delimit rehabilitation 'disability' has to be defined; a concept that during the last decade has been submitted to a change from being a quality of certain individuals to being more a question of the accessibility and the attitudes of their environment [91].

### **3.3.2 Disability**

To further the development of rehabilitation and of rehabilitation research the World Health Organization 1980 edited an International Classification of Impairments, Disabilities and Handicaps (ICIDH) [92]. The classification had its point of departure from a thorough categorization of impairments which were 'any loss or abnormality of psychological, physiological or anatomical structure or function'. In principle, impairments reflected disturbances at the level of a human organ. An impairment could cause a disability, which was any restriction or lack - resulting from impairment - of ability to perform an activity in the manner or within the range considered normal [92]. Disability as a concept thus was built on a difference between an accepted, functional normality of the majority of human beings in a society and the dissimilarities of certain kinds of people. A disability might result in a handicap if it limited or prevented the fulfilment of a role that was considered normal - depending on age, sex, and social and cultural factors - for an individual. Different handicaps, including a social integration handicap, were defined and scales for assessment of the severity of the handicaps were proposed. The reasons for exclusion from participation of persons according to ICIDH were set within a medico-diagnostic frame.

However, as early as 1982 The United Nations adopted the World Program of Action Concerning Disabled Persons. Based on the definitions of impairment and disability mentioned above a person with a disability was handicapped as a function of the relationship between her or him and the environment. This happened when she or he encountered cultural, physical or social barriers which prevented her or his access to the various systems of society that were available to other citizens [93]. The focus thus began to turn from the properties of individuals towards the construction of society.

The society could contain barriers which excluded people for more reasons than those which could be founded on medical diagnoses.

In 2006 the United Nations General Assembly took a further step on the issue of disability and adopted the Convention of the Rights of People with Disability. The convention recalled in its first paragraph the Charter of the United Nations which “recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family” [90]. These rights reaffirm the right of persons with disabilities to be guaranteed their full enjoyment in society without discrimination.

In the revised edition of the ICIDH classification, the International Classification of Functioning, Disability and Health (ICF) 2001 [91] the concept of disability was changed to areas of functions, activities and participation, and environmental factors. Functions were described instead of impairments. Activities and participation, i.e. abilities, were listed instead of disability. Instead of the concept ‘handicap’ the ICF described environmental factors. However, contextual personal factors were omitted. Therefore, the ICF is turned into an instrument for describing the ability and activity of any person and the focus is turned from her or his individual properties to her or his participation in society. The classification is no longer an instrument for describing disabled people; ICF is an instrument for describing reasons for peoples’ restricted activities in society and the multiplicity of barriers society has risen against the participation of certain of its members. The ICF is translated into the languages of a majority of the member states of the UN [91]. The Swedish version appeared in 2003 [94].

In his thesis, Grönvik highlighted that five definitions of disability, commonly applied in Sweden, are in use: The *functional definition* is based on impaired body function and is used in rehabilitation planning. In the *relative or environmental definition* the relation between impairment and an inaccessible environment is considered. The *social definition* questions the properties of a society inaccessible for certain individuals. The *administrative definition*, often quite alike the functional, is used for health care planning by the welfare authorities. The *subjective definition* reflects people’s own perceptions of whether they consider themselves as disabled [95]. Depending on the definition used Grönvik found that the number of disabled people in Sweden varied between 50,000 and 1,300,000 individuals. Therefore, there is apparently not a clear distinction between the abilities of ‘normal’ persons and ‘disabled’ persons in Sweden. This is important because ‘disability’ still entitle some people to receive rehabilitation. It seems difficult to construct a normative ability criterion in a population, based on activity and replacing an impairment diagnosis.

Several examples from clinical research illustrate these difficulties. Young stroke survivors and their carers both had an understanding of the stroke survivors’ needs that were discordant with their normative picture of a disabled person, i.e. a physical and observable condition. Because of that the

survivors were prevented from getting adequate rehabilitation for a participating life in their communities [96-98]. When the social participation of elderly stroke survivors was compared with the participation of a group of “normal” individuals of similar age both groups had decreased participation compared to what was normal for a group of younger people. The normality for optimal participation for elderly stroke survivors was therefore proposed to be adapted to lower participation levels with increasing age [99].

What does this mean in the present studies?

The research question includes a functional definition: the participants in the studies have experienced a biological disturbance, the stroke. It is this accident which has qualified them for the research project of a researcher who is a geriatrician rooted in his biomedical pre-understanding of clinical rehabilitation. However, the problems of many of the stroke survivors are related to contextual factors including attitudes of people in their environment, which makes their disability a construct that has both qualified and disqualified them for rehabilitation. In this respect they are treated according to a functional or an administrative definition. Finally, because the present research was performed to shed light on the meaning of illness and rehabilitation in post stroke life, one has to listen to the survivors’ voices without prejudice. Consequently, the door is opened to subjective definitions of disability related to the informants’ conceptions of a normal life before and after a stroke.

### **3.3.3 Rehabilitation**

In the ‘World Programme of Action Concerning Disabled Persons’ from 1982, rehabilitation was defined as “a goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing her or him with the tools to change her or his own life”. It could involve measures intended to compensate for a loss of function or a functional limitation (for example by technical aids) and other measures intended to facilitate social adjustment or readjustment [93]. The example that illustrated a rehabilitation measure in the programme was a technical aid. The rehabilitation goal was to facilitate social readjustment. Ideologically the individual possessed the problem of being disabled, i.e. not having the competence to participate in the society the way it is. The world of rehabilitation mirrored the ICIDH. Disability and handicap was related to a disease or injury related disturbance. Measures in rehabilitation therefore addressed these attributes of the individual. Criticism was raised towards ICIDH because it implied a unilateral rehabilitation model that insufficiently took environmental factors into account as responsible for the situation of the individual [100].

The ideological turn towards the importance of environmental factors in rehabilitation influenced Gutenbrunner's short, yet comprehensive, definition of rehabilitation from the late 1980s: Rehabilitation "is the use of all means aimed at reducing the impact of disabling and handicapping conditions and at enabling people with disabilities to achieve optimal social integration" [101]. In the ICF this attitudinal turn was developed to focus on activities and social participation involving environmental facilitating and obstructing factors. This made rehabilitation a comprehensive concept which also depended on interactions between the impaired persons and the physical and attitudinal barriers that predominated in their environment. A rehabilitation process raises the question of accessibility to the environment through adaptation and support that includes all people who claim access to social participation [100].

### **3.3.4 Stroke rehabilitation**

In Europe the member states of the Regional Office for Europe of the World Health Organization (WHO) between 1995 and 2006 have edited consensus documents on European stroke strategies, the Helsingborg Declarations [102,103]. In these documents the principles for rehabilitation are described through the organization required for its performance and the importance of the individual goals of the stroke patients.

- Rehabilitation is an activity performed by a multidisciplinary team comprising physician, nurse, physiotherapist, occupational therapist and a speech therapist.
- A social worker, a neuropsychologist, a dietitian and an orthoptician should be available when necessary.
- Interventions should be relevant to the patient's own goals.
- Achievement of independency of daily living is a main objective of rehabilitation. The focus should be on social reintegration.

The lack of evidence based research (randomized controlled trials) about the effects of interventions makes the document rather vague and its most distinct parts are the lists of proposals of future research [104]. However, the meaning of stroke rehabilitation is indirectly expressed through the competence of the involved professionals. This might explain the relevance of the discussion about the definition of multidisciplinary rehabilitation team rather than the idea of rehabilitation in itself [105]. A significant observation is that the ordinary, multidisciplinary team does not include a neuropsychologist. This might surprise considering that stroke often damages the cognitive and emotional functions of its victims.

Recently the European organizations for physical and rehabilitation medicine have published a white paper in which rehabilitation is considered 'a process of active change by which a person, who has become disabled, according to her human rights acquires the knowledge and skills needed for

optimal physical, psychological and social function' [101]. This definition makes rehabilitation take the step into being a learning process demanding pedagogical competence of the involved professionals. The idea of rehabilitation in the document is focused on functions, activities and participation. Personal factors such as health behaviour, coping strategies, age and gender, which were excluded from the ICF, are included.

A working definition has been proposed by Wade of rehabilitation as “an educational, problem-solving process that focuses on activity limitations and aims to optimize patient social participation and well-being”. In this way rehabilitation also reduces stress felt by carer and family [106]. The definition relates to two theoretical models: 1) An illness model, inspired by the ICF, which especially decides what to target in the rehabilitation and sets the principles for the intervention and 2) A process model that includes the needed resources for rehabilitation. The general definition combined with the models intends to allow further definition of each of the topics, structure, process and outcome of rehabilitation [107].

Rehabilitation seems to have the properties of an essentially contested concept as described by Connolly [108]. It is appraisive through its concern with valued achievements. It is internally complex and its rules are open to interpretations.

Thus, rehabilitation is a discipline in search for a unifying theory [109]. The phenomenon of interest for the theory is according to Siegert et al. the recovery and adaptation of individuals after a traumatic injury or the onset of a chronic illness. The units for discussion in rehabilitation theory are not the patients and the professionals, but rather their properties and not actual disorders but the attributes of the disorders such as disturbed ability or QoL [109].

Research in rehabilitation outcomes within the different professional disciplines may need the limitation of an intervention taxonomy developed from a unifying theory [110]. To develop such a taxonomy within physical therapy Dejong et al. described a taxonomy for stroke rehabilitation comprising 59 items [110]. Such painstaking work is important as a support to observational studies performed by professionals [109].

However, rehabilitation is a discipline with difficulties in finding a satisfactory comprehensive theory that penetrates all involved professional disciplines [109]. Illness-as-lived by stroke survivors who claim rehabilitation might be needed in taxonomies for stroke rehabilitation.

### **Background in sum**

Stroke is an acute and chronic illness, which, because it damages the human brain, has a comprehensive impact on its victims' life.

In the acute phase active treatment against its pathogenetic cause - thrombosis or haemorrhage - has emerged during the last decade. Somewhat sur-

prisingly, however, a considerable number of stroke victims delay their arrival time to the emergency department, which excludes them from active treatment against the thrombosis or the haemorrhage.

Among a variety of functional deficits the aphasic, communicatively damaged stroke patients experience predicaments which are not found among survivors with normal communication [80].

Many survivors suffer from anxiety. The anxiety is often related to the risk of another - maybe fatal - stroke and an uncertain future.

Definitions and taxonomies of rehabilitation often focus functionally evident damages more than the psychosocial. Research about these topics is often performed from professional perspectives.

These aspects are considered in the secondary aims.

### 3.4 Secondary aims

- To explore the meaning of stroke symptoms and treatment to victims who delayed hospital arrival.
- To explore the meaning of rehabilitation to an aphasic stroke survivor.
- To elucidate the use of time models in stroke patients' narratives about fear of relapse and death.
- To reveal the meaning of rehabilitation to elderly, Swedish stroke survivors.

The methods of research for answering the research questions are described in the following chapter: The Empirical Phenomenological Psychological method, Narrativity, and GT. I also go through the ethical considerations which were raised in the project.

## 4 Theoretical framework

To reveal experiences and meanings of phenomena to human beings, an approach with for example interviews and analysis of what people recount in the interviews - a so-called qualitative research method - is often used. Qualitative research methods “enable health science researchers to delve into questions of meaning, examine institutional and social practices and processes, identify barriers and facilitators to change, and discover the reasons for the success or failure of interventions” [111]. In the present thesis three approaches were chosen. In Study I and II the meaning of the lived experience of the stroke survivors was searched. The method chosen was inspired by phenomenological philosophy. In Study III the intention was to reveal how survivors handled the temporal aspect of uncertainty in their narratives about stroke and a narrative model was used. Study IV addressed the meaning of rehabilitation to stroke patients. A GT approach in the analysis was found suitable to construct a theory about the meaning of rehabilitation to the survivors and how they acted. Thus, all four studies addressed the life world of human beings. Next comes therefore a section about the theoretical framework of the thesis, i.e. ‘my way of thinking about and studying the social reality of the informants in the studies’ [112]. The section headings are Phenomenology, Time, Narrativity and GT. After the methodological part follow sections about stroke as a lived illness, disability and rehabilitation. The entire background chapter ends with the secondary aims of the thesis.

### 4.1 Phenomenology

The research philosophy behind the research of the thesis is life world approach, the way it is adapted in studies on the meaning of human experiences. Phenomenology, which was introduced by the German philosopher Edmund Husserl, is a philosophy about how we, as human beings, are related to the world we try to understand [113,114]. We are ‘immersed’ in the life world; unable to separate ourselves from being a part of the world which we try to observe. We are in the world as perceiving ‘Beings’ and our con-

consciousness is intentionally directed towards the phenomena that surround us. The phenomena are experienced in a 'natural', un-reflected attitude; yet the perceived phenomena have a meaning to us and it is through this meaning they are present in our human world. Anything else is transcendental. Hence, it is through the perceived, un-reflected, lived experience of a phenomenon that the researcher should begin the research of a phenomenon that is present in the human world. To perform phenomenological research the researcher should omit pre-existing theories and models of the phenomenon in a process of 'bracketing'. The collected complex of experiences of the phenomenon can then be described in a comprehensive structure and, by means of imaginative variation, eventually be presented in an essential structure of the meaning of the phenomenon. Hence, we cannot be 'objective' observers of the world, because we are a part of the world; however, through bracketing we can minimize the influence of our pre-understanding in our research.

Husserl only described in theory how to reveal the meaning of a phenomenon. He did not give the detailed description of how to perform the research.

The thesis explores the life world of individuals with damaged brains. The French philosopher Maurice Merleau-Ponty described in his book about the phenomenology of the body and the perceived world how we as human beings are only able to be in the world as 'Beings' in our bodies; not as bodies in the world but intertwined in the world in our bodies [62]. We communicate with the world through our bodies in interactional togetherness within the world. Through being involved in togetherness, not by being observers, we can have an understanding of the reciprocal experiences of each other.

Hence, the philosophy of Merleau-Ponty bridges the gap between the research-philosophical and the analytical problem in the present studies: brain damaged persons, like other humans, are to find in their own bodies, and their thoughts are to find in the way they express themselves in constructions of words. When the brain damaged persons move they perhaps cannot make the smooth movement of a healthy person because the damage force them to move in fragmented, misdirected steps. However, in a shared world, another human being can still see the intended direction and the goal of the entire movement, the meaning of the movement. Likewise, as partakers in their world we can in a similar way as researchers reveal the intention of their speech and thus to a varying extent what they express.

In sum: In phenomenology the world wherein we live is comprehended through embodied experience. The researcher seeks to capture the meaning and common features, the essence, of an experience [111]. The studies of the present thesis are all inspired by phenomenological theory.

## 4.2 Time models

The temporality of human beings was salient to the stroke survivors in the thesis. They spoke about their experiences of being threatened by death, and in their narratives there were always aspects of time related to their past, their present or their future. Philosophy about time was therefore significant for the studies. The aspect of temporality is especially present in Study II about coping with uncertainty and Study IV about the meaning of rehabilitation.

Time in the present studies meant human time in the lived world of human beings. In phenomenological philosophy the German philosopher Martin Heidegger positioned mankind in temporality [66]. We, as human beings are, he said, at birth ‘thrown’ (geworfen) into the world. We have no choice or influence on the preconditions. We are ‘being’ in the world as ‘Beings’ (Dasein) towards death and in every moment living towards death. To give our lives a meaning, to be ‘authentic’, we must achieve an awareness of this and understand that it is between those two points of time, birth and death that we can search for the meaning of our lives. However, we, the Beings cannot live our lives in a state of constant search. In our everyday life we are in a worldhood of un-authenticity in an un-awareness of death. In this state of un-authenticity we are ‘being-with’ in togetherness with other Beings through care (Sorge) in a totality of equipment ‘ready-to-hand’ (Zuhandenheit) and ‘present-at-hand’ (Vorhandenheit). To us, the Beings, the equipment is bestowed with comprehensive meanings connected to their use which together constitute an equipment totality. Through being in the world we live and experience the world always being existentially ‘tuned’ (stimmt); the existential attunement connected to the awareness of temporality being anxiety (Angst). Thus Heidegger has placed the Beings socially in togetherness, acting in an equipment totality and being in time.

In the Western World, in which the informants in this study live, time has a meaning specific to Western individuals [115]. Human beings react to temporality and finitude by *tempering*, accepting inevitable death, or through *transcendence* into a metaphysical world of immortality. As a social reaction they also try to control time through *tracking* or *naming time*, which gives time order and makes it manageable, and they *transform time* to controllable entities. Time has by these means of tracking and transformation in modern western tradition become a socially integrated entity with the components: *time commodification*, making time into an object for trade; *time compression*, resulting in more events contained in the same amount of time; *time colonization*, with western time-concepts used globally; and *time control*, turning time into an entity that can be controlled by a machine (the clock). When an individual constructs her or his autobiography, time therefore also becomes a culturally immanent means that can be found in her or his autobiographical narratives [116]. In the narratives people construct on different models of time: *linear time* in a diachronic structure from a beginning to an

end; *circular time* where something that existed or happened at the beginning of a life story explains a certain outcome; *cyclical time* with a constant repetition that gives predictability, and *spiral time* where loops of time means evolution. Thus time becomes a resource that helps people place an illness in a life perspective not limited solely to what in fact has happened. Through the time models, narratives can help people to reconstruct their expectations for the future and explain their past [117,118].

In sum: The way people use time models in their narratives may reveal how they handle a problem in their lives.

### 4.3 Narrativity

When the stroke survivors in the present thesis were asked questions about their experiences they answered by telling narratives. A narrative can be defined as a sequence of two or more narrative clauses, that is, a sequence of clauses separated by one or more temporal junctures [119]. The composition of a narrative is often preceded with an abstract that gives a short summary. The narrative begins with some orientating information about time, place and participants. It continues with a central part of evolutions of the story or the development of the plot. It may end with a resolution that states the conclusions that can be drawn. Study II is an analysis of narratives as such; yet also the other studies are, strictly spoken, containing stories about human experiences knitted together in a dialogue.

Probably the ‘historicity’ of human experiences contains elements of a true story and a fictional story [120]. Stories people tell perhaps more intend to convey the meaning of events than the exact effectivity of events. This leads to an alternative definition of a narrative as a coherent text with a clear-cut beginning and an explanatory end, which frames a story about the meaning of the narrator’s actions in the past [120,121]. In order to express the meaning a narrative is given an ‘emplotment’, i.e. sequential, progressing, coherent events. In his way narratives can be *life narratives*, i.e. constructions of a person seen in a life perspective, and *eventual*, i.e. recounting the meaning of a single episode. A web of narratives, however, can also extend the present and say something about how the narrator intends to act in the future [122].

The *life narrative* of a person can be fractioned through a disastrous event, as for instance a stroke, that works as a turning point in the person’s sequence of narratives. A fractioned life story may mean the loss of meaning of life for this person [123]. Yet, later new narratives can help an individual in the reconstruction of coherence of life and stretch into a future that has regained its meaning [124,125]. Hence, narrative reconstruction is an attempt to reconstruct and repair ruptures between body, self and world by linking up and interpreting different aspects of biography in order to realign present and past, and self with society [126].

Ultimately, the meaning of a narrative is always intended to catch the ear of an audience. Knowledge about the context in which a narrative is told is therefore necessary to understand the meaning of the story [127].

In sum: In narratives that patients tell about symptoms, “not only diagnosis is encoded, but deep and therapeutically consequential understandings of the persons who bear the symptoms” [128].

#### **4.4 Grounded theory**

GT was first described as a research method by Glaser and Strauss 1967 and further developed by Strauss and Corbin [112]. The latter version is used for the analysis in study IV of the present thesis. The aim of GT research is to build a theory which “explains a social, psychological, educational, nursing, or other phenomenon and gives a guide for action”. Thus a theory in GT is defined as “a set of well-developed categories that are systematically interrelated through statements of relationship to form a theoretical framework that explains some relevant social, psychological, educational, nursing, or other phenomenon” [111, p. 22]. The statements of relationship explain who, what, where, why, how and with what consequences events occur. Characteristics of GT have been described as the following: in-depth interview data are collected in an ‘open sampling’. The data collection and the analysis are performed simultaneously. The researcher writes ‘memos’, i.e. ‘records of analysis, thoughts, interpretations, questions, and direction for further data collection’, from the beginning of the analysis and throughout the entire analytical procedure [111, p. 110]. Emerging concepts and categories (a category is a concept that stands for the studied phenomenon) direct later in the process the researcher into a ‘theoretical sampling’. In the theoretical sampling important findings are further explored through changed interview questions or inclusion of new informants. The sampling is continued until the researcher finds that ‘saturation’ is achieved. Saturation means that new data do not add further information about the studied phenomenon [111, p. 136]. Through a hierarchical coding process concepts and categories and their properties are generated from the data in a constant, comparative process. First a line by line coding is performed. Later the coding is more focused and it ends in an axial coding, which specifies the relationships between the categories and their subcategories [111, p. 123]. The categories and their subcategories are arranged in diagrams to support and illustrate the analysis. Eventually, a core category essential for the integration of the concepts into a theoretical framework is identified [129].

In sum: GT is an inquiry about how social structures and processes influence how things are accomplished [111]. Fundamentals of GT are the constant comparative method and the identification of a core category [129].

## 5 Methods

The design of the thesis is qualitative, inductive, empirical, explorative and cross-sectional.

For the studies, I – IV, a data set consisting of 2 x 19 interviews has been used. Below I will describe the process of data collection and analysis.

### 5.1 Data collection

#### 5.1.1 Participants

Ninety-four stroke survivors discharged from a stroke unit in Sweden had successively got a written invitation followed by a telephone call to participate in an intervention project about autonomous support groups for survivors. The purpose of the project was that the participants should exchange experiences about life after stroke. Those who accepted the invitation to support groups might be expected to have experiences and opinions about different ways of understanding post stroke life. At this point of time the aim was to evaluate the support groups from both a quantitative and a qualitative perspective.

Fifty-six of the invited stroke survivors declined participation: thirty-one were or felt too damaged to be able to participate. Thirteen did not experience a need for additional support. Twelve gave no reason. Thirteen could not be found. Four had died.

A sample of 11 women and 8 men accepted to be included in the project. Of these, 11 were randomized to group participation. One of these left the group after two meetings but remained in the interview study. Eight were randomized to a reference group.

The mean age of the women was 79 years (range 56 – 89) and of the men 71 years (range 58 – 80).

According to Barthel Index (BI) 13 were functionally independent; 3 needed some assistance, and 3 needed personal help (BI 50 to 55) [130].

None were demented according to Mini-Mental-State-Examination (MMSE) [131].

Ten had damage in the right cerebral hemisphere and eight in the left hemisphere. One person had a damage of unknown location. Extremely simplified right hemisphere damaged persons may have disability in imaging the complexity of their own person and their body in relation to the complexity of their context in space and time. This dysfunction negatively influences their ability to plan for actions and perform actions. Left hemisphere damaged persons may have dysfunction of understanding and expressing language. This dysfunction affects communication and actions that are based on the use of language.

Table 1 Background factors of the stroke survivors

<i>Gender</i>	<i>Age</i>	<i>Partner/ Single</i>	<i>Damaged Hemisphere Right/Left</i>	<i>Barthel Index 1)</i>
Female	56	Partner	Left	100
Male	58	Partner	Left	100
Male	68	Partner	Right	100
Male	68	Partner	?	100
Male	68	Partner	Right	100
Male	69	Partner	Right	100
Female	72	Single	Left	100
Male	76	Single	Right	50
Female	77	Single	Right	100
Female	78	Single	Left	100
Female	78	Single	Left	100
Female	80	Single	Right	80
Male	80	Partner	Left	100
Female	80	Partner	Right	55
Male	81	Partner	Right	100
Female	84	Single	Left	95
Female	85	Single	Left	75
Female	88	Single	Right	80
Female	89	Single	Right	55

1) The Barthel Index is an instrument for estimation of basic activities of daily living on a scale from 0 = totally dependent to 100 = totally independent

After the sampling it was decided to interrupt the quantitative part of the study due to the limited sample size. The qualitative part was continued.

## **5.1.2 Interviews**

The stroke survivors were interviewed twice, 1.5 - 3 and 8 - 14 months after the stroke by the author of this thesis. The first interview took place as early as possible after the acute and sub-acute disease phase when the survivors had a fresh memory of their experiences. It took place before the group interventions had started. The second interview took place when the group intervention and the individual rehabilitation had ended. The interviews took place in the common room at a community rehabilitation centre and lasted from 35 to 60 minutes with a mean duration of 45 minutes. The interview questions focused on what the interviewees experienced had happened to them when they fell ill and what they thought was needed to achieve a future life as they wanted it to be. They were encouraged to talk freely and comprehensively although main questions were followed up by probing questions when necessary [132]. In the first interview the focus was on what had happened at the start of the stroke and how the interviewees intended to achieve rehabilitation goals. The second interview contained more questions about how the survivors had experienced their rehabilitation and how they planned in order to achieve a good enough future. The interviews were tape recorded and transcribed verbatim; 4 by FH and 15 by a secretary experienced in transcription of research interviews.

The interviews were analyzed according to the research questions. The analysis of Study I and II followed phenomenological principles; Study III narratology and Study IV GT. The methods are described below in the mentioned order.

## **5.2 Analysis**

### **5.2.1 Phenomenological analysis**

The aim of Study I was to explore the meaning of stroke to a group of stroke victims who had delayed their emergency treatment for more than 24 hours. The participants were selected from all 19 survivors in the study. The group of victims who had delayed their treatment consisted of two women and two men. Their age ranged from 58 to 84 years.

The aim of Study II was to explore the meaning of rehabilitation to an aphasic stroke survivor. He was a 58-year-old man, who had a position as an expert in an international company and an international organization for a hobby activity. Both his vocation and his hobby activities necessitated perfect language skills in English and Swedish and an impeccable health certificate. Three months before the first interview, he had had a cerebral infarction with aphasia (i.e. injured speech, and perception of words and numbers). Physically he was left almost untouched. He had not participated in a support group.

Study I and II addressed the meaning of experiences to survivors the way they were lived. A phenomenological approach therefore was chosen. The phenomenological analysis followed the principles of Karlsson, influenced by the thoughts of Giorgi, the Empirical Phenomenological Psychological method [133-135].

First, the transcripts were read several times until the researchers got a good and empathetic grasp of the text as a whole. Parts of the transcripts that concerned the studied phenomenon were chosen for further research. The principle of “bracketing” the pre-understanding of the researchers in the first steps of the analysis was practiced. The empathetic, psychological focus in the analysis was on the other hand not bracketed. This analytical attitude might also be described as a “bridling” rather than a “bracketing” of pre-understanding [136].

Second, the texts were divided into meaning units. A meaning unit could be a whole paragraph or one single word. The text was marked every time a shift in meaning occurred.

Third, the informants’ personal language was transformed to the researchers’ language and discussed meaning unit by meaning unit. When different interpretations occurred, the researchers returned to the interview text and discussed in a free, imaginative way until a negotiated consensus was reached. The researchers left in this step the principles of bridling and her or his pre-understanding and professional knowledge were allowed to influence the analysis. Yet, theory-laden language was avoided.

Fourth, the text was gone through in a search for comprehensive themes. The text was interpreted in an interchange between the original data, the transformed units and the researchers’ theoretical pre-understanding. The meaning units were assorted under appropriate themes and thus made up the situated structure of what the phenomenon was and how it was lived.

Fifth, a general or typological structure, an essence of the phenomenon, was revealed.

### **5.2.2 Narrative analysis**

The aim of Study III was to elucidate the use of time models in stroke patients’ narratives about fear of relapse and death. The informants were the entire sample of 19 persons.

The analysis followed the principles for narrative analysis described by Riessman [127,137]. The analysis was done by the author of the thesis.

First, the transcribed texts were read through to get a good grasp of them as a whole.

Second, narratives about time were extracted from the texts. Narratives were defined as a coherent part of the text with a clear cut beginning that placed the interviewee in place and time. They had a story with a plot which set the storyteller as a protagonist among other people or in events [121].

The narratives were mostly finished by an explanation of why things had happened or the consequences they were expected to have [119,137].

Third, the sentences of the narratives were parsed into clauses, i.e. the parts of sentences comprising a subject and a predicate stating something about the subject. This brought into relief what the text said. Clauses with temporal experiences were underlined.

The clauses were collected sequentially in stanzas that focused on single topics. These parts were labelled according to themes or models of time. How different models lead to resolutions that created coherence between past, present and future was analysed. Thus the time models were defined according to their function in the stroke survivors' autobiographical constructions.

### **5.2.3 Grounded theory analysis**

In Study IV the researchers intended to explore the meaning of rehabilitation to elderly, Swedish stroke survivors.

The analysis was inspired by the method of GT according to Strauss and Corbin and according to Charmaz [112,138]. The analysis was performed by the author of this thesis with MS as co-analysers.

First, the researchers began with reading the transcribed texts to get a good grasp of their content.

Second, a step-wise procedure followed which began with line-by-line reading of the texts. Segments were coded in an open coding according to the concepts with which they dealt.

Third, the text was thoroughly gone through and the coding discussed by the researchers. Similarities and differences between codes were negotiated and the coding was reappraised until a negotiated consensus was achieved. The coded data were in this way successively assembled under categories according to their conceptual interrelationships into a framework.

Fourth, main categories and their sub categories were assembled in an axial coding.

Fifth, all categories were evaluated until a core category was identified. The core category subsumed all concepts and was central to the meaning of rehabilitation to the survivors.

Essential throughout the entire analysis was a constant comparison between the original interview text and the categories and a parallel annotation of comments and memos [129].

### **5.3 Ethical considerations**

Interviews with persons, who have been exposed to a life disruptive event, may have an impact on their well-being, way of thinking and acting. Therefore, they are vulnerable and precautions are needed to ensure that ethical issues are dealt with in a thoughtful manner. The interviewer (FH)

was a physician and the informants might experience themselves as patients confronting a doctor.

Before the interview the informants were told that they were allowed to raise questions after the interview concerning medical aspects of their stroke and their experiences during the interview. They could interrupt and end the interview whenever they wanted. It was stressed that the interviewer was performing research and not in a position to influence the survivors' treatment.

After the interviews the dialogue was continued until the interviewees expressed that they were satisfied.

The research project was submitted to ethical examination and approved by the ethics committee at Karolinska University Hospital in Solna (§ 00-359).

# 6 Findings

## 6.1 Stroke patients' delay of emergency treatment

Study I explored the meaning of stroke and stroke treatment to four stroke victims, who delayed emergency treatment for more than 24 hours. An essence was found which was constituted by four themes.

### **Essence: Threatened control of bodily functions, autonomy and integrity**

The essence of the meaning of stroke symptoms and treatment to these patients was 'threatened control of bodily functions, autonomy and integrity'. They let their stroke damaged body, like a defect device, continue ongoing activities. In health care consultations they did not accept a provider unless she or he encountered them as a person by a person. Near ones were expected to confirm, not to contradict, their decisions.

"... and I think it is important that I decide... That is the most important. I must never let someone else make decisions over me. I have to lead the business myself."

### **Theme one: Acting as if nothing has happened**

The patients ignored the first symptoms of neurological damage although they all were in places where they could easily get in contact with a qualified hospital. At the time all patients had arrived at hospital two of them had been driving their cars despite the neurological symptoms.

### **Theme two: Treating the body as a defective device**

The patients treated their body as a controllable, albeit defective, instrument. A patient was more irritated than concerned when her little finger lost function. She decided to drive her car to servicing even though she understood that this was a dangerous and illegal action.

Another patient compared his body to a computer. He should control computers; they should not control him. Two patients trained in the rehabilitation to the limit of their capacity even though they knew that moderately training might be better for their body.

**Theme three: Need of being met as a person by a person in consultations**

These patients had two demands in medical consultations. They should be met on an equal level, as a person by a person, and they wanted explicit expert information about diagnosis and treatment. Without these prerequisites both the health care provider and her or his prescriptions were rejected. On the other hand, if the patients were satisfied with the encounter they were very concordant and worked hard on their rehabilitation.

One patient contacted her district health care centre at the onset of stroke symptoms. She met a deputy doctor whom she disrespectfully considered as “cute” and not as an expert. She ignored his referral to a hospital. On the other hand she considered the emergency department as a place where patients were ignored. Another described in-hospital departments as places where patients were observed in such a way as to cause embarrassment instead of talked to as persons. Often, the health care system was unable to offer these patients a doctor who fulfilled their demand of competence and behaviour. Instead, they picked information from sources at hand, for instance books and friends.

**Theme four: Need of controlling decision-making**

The patients’ relatives were expected to confirm their decisions, not to contradict them. A patient did not phone her elder son when she got stroke symptoms because she expected him to tell her to go to a hospital. She phoned her younger son because she knew that he “always supports me”. Most relatives accepted this order and abstained from interfering with the patients’ decisions. Hence, although the patients had an extended social network, they were lonesome.

## 6.2 Understanding an aphasic survivor

Study II explored what rehabilitation meant to an aphasic stroke survivor. The findings are described in an essence that is constituted by five themes.

**The essence: To be goal oriented in a life of dichotomies**

Rehabilitation meant to the informant to behave in a goal-oriented manner towards recuperation, balancing between dichotomies.

He struggled to achieve the goal of natural social encounters without embarrassing misunderstandings. Avoiding misunderstandings required adapta-

tions to people around him. However, adaptations made the encounters unnatural and misunderstandings were not avoided after all.

He found it necessary to train at his language beyond the prescriptions of the professionals, if he were to improve. Therefore, he required difficult exercises. However, he had to define and abstain from tasks beyond his actual capacity because failures had a discouraging influence.

If he were to endure the tough task of being in a continuously ongoing practice, he had to believe that the practice would bring him back to his former life and, on the other hand, he also had to prepare for the situation that might occur, should he not achieve this goal. Hence, he had to prepare for conflicting outcomes and at the same time be both optimistic and realistic.

The informant thought that he and not his next of kin or the professionals had to carry the full responsibility for the rehabilitation process, balancing the dichotomies that were caused by his impairment.

He had the responsibility for adapting to avoid misunderstandings with those close to him. He had to make those close to him believe that his lost function would return and at the same time prepare them for the possibility that he might not regain his language. He was the one responsible for choosing demanding exercises that would improve his speech as well as exercises that did not exceed his actual capacity.

It was he who was obliged to control this comprehensive process between the dichotomies.

“... I cannot ask someone who usually works on these things that they take me over and think everything ... I must try and describe for other person ... I have gotten better after that in the hospital so now it works better and better ... but suddenly practice, practice, practice ... I feel it's alpha and omega to get somewhere.”

### **Theme one: Lost expression of oneself as a thinking and acting person**

The survivor could not express himself as the thinking and acting person he still was. His life was full of thoughts and actions which had become impossible to express coherently. He felt socially outside.

### **Theme two: Adapted behaviour**

To be socially inside was to the aphasic survivor to communicate with other persons in a natural way. Yet, when he did so, others misinterpreted him and he misunderstood them. Because he took responsibility for this embarrassment, he found that it was he who had to adapt his behaviour in encounters with other people.

### **Theme three: Rehabilitation in the personal network**

The survivor considered an active social engagement with family, friends and colleagues as a prerequisite for a successful rehabilitation. As he expressed it: 'to be open' to social interactions.

Openness meant, however, also that it was his obligation to prepare all important persons in his environment for the possibility that he never regained his former language.

### **Theme four: Rehabilitation in the professional network**

In the rehabilitation the informant demanded to be engaged in dialogues with professionals that involved him in what was going to happen. Rehabilitation meant to be encouraged. He felt contempt about being observed instead of involved.

### **Theme five: Rehabilitation as goal direction**

Rehabilitation meant to the survivor a regained language good enough to get him back in job. He thought that a goal-orientated behaviour was the prerequisite for this. The survivor understood at the beginning of his rehabilitation that rehabilitation meant to strive for recuperation and to prepare for a life with reminiscent language dysfunction as well. This dichotomy was not evolved in his rehabilitation leaving him unprepared for a changed future.

## **6.3 Uncertainty and time models**

In Study III was elucidated the use of time models in stroke patients' narratives about uncertainty. The participants were the entire sample of 19 stroke survivors.

The survivors described the stroke event as an autobiographical disruption [139]. Their future had become uncertain and time models were embedded in their narratives in order to handle this existential problem. The models were: 'Time cycles and dissolution of time limits', 'Exchange of time' and 'Exclusion from time'.

### **Time cycles and dissolution of time limits**

Time cycles meant recurrences of events. This kind of cycles had been disrupted by the stroke and the survivors searched for novel time cycles in order to regain day-to-day coherence.

A time cycle could also dissolve time limits between past and future and mean that past events could return as similar events in future. A final step in

dissolution of time limits transcended death and meant post mortal resurrection.

### **Exchange of time**

In narratives about social interactions the informants described time as an entity which they exchanged with others. To receive time from near ones was important to the informants. To be able to give the near ones time in exchange was of equal importance. Exchanged time might be compared to a gift. Without the commitment, which a gift is expected to contain to its giver and its receiver, exchanged time decreased in value.

### **Exclusion from time**

Finally some informants excluded the stroke from present time to decrease its influence on ongoing activities. The stroke was treated as an object which could be excluded from time and thus from interfering with pleasant moments in present time.

## **6.4 The path to social reintegration after stroke**

The aim of Study IV was to explore the meaning of rehabilitation to elderly, Swedish stroke survivors.

The survivors experienced a series of lost functions and abilities that deprived them of their former social habits and positions. Their actions to regain the lost abilities fell within a framework of cognitive and behavioural strategies. Cognitive strategies comprised intrapersonal, attitudinal means. Behavioural strategies mirrored interactions with people in the survivors' environments. The core category which subsumed their experiences and endeavours was social reintegration. See table 2.

Below, the core category, the survivors' losses, their cognitive and behavioural strategies are described in the order mentioned.

### **6.4.1 Social reintegration**

The core category which expressed the ultimate goal for rehabilitation to the survivors was social reintegration. This meant that it was easier for them to accept physical disabilities than to be excluded from full enjoyment of social life. At the beginning of their rehabilitation they had seen the regaining of lost abilities as the only means to social reintegration. Gradually they realized that they had to find their own paths to a satisfying, rewarding togetherness with other persons and in society.

“My wife has supported me all the time and been my coach...I think I could manage on my own but it has worked better with her support...Then one

might say that the social contacts that I have had in different associations, my appointments, the fellow members have said, can't you come, can't you do...can't you return. Helping them doing things that has spurred me, that one has felt needed.” (80-year-old man)

Table 2. The path to social reintegration of elderly stroke survivors in Sweden. In cognitive strategies the survivors tried to achieve social reintegration through changed attitudes and ways of thinking. In behavioural strategies they decided how to act in their environment.

Losses 5.4.2	Cognitive strategies 5.4.3	Behavioural Strategies 5.4.4	Social reintegration 5.4.1
Physical and cognitive function Social relations <i>Play-in-togetherness</i> <i>Everyday narratives</i> <i>Self-esteem</i> Certainty	Suppression Comparison Intellectualisation Positive thinking Normalisation Religious and magical beliefs	Taking responsibility Searching support Doing experiments Taking risks	Meant that the survivors were able to acknowledge uncertainty, play in togetherness, give and receive everyday narratives and feel self-esteem

#### 6.4.2 Losses

The survivors' losses were 'physical and cognitive functions', 'relations' (including 'play-in-togetherness', 'everyday narratives' and 'self-esteem') and 'certainty'.

##### Physical and cognitive function

Immediately after the stroke, the survivors spoke about rehabilitation as regaining function. After a year, however, damaged functions had often become an acknowledged part of the everyday life of some. Others still considered regaining functions as the dominating issue.

##### Social Relations

The survivors had lost their former social relations. Before the stroke social relations had relied on a mutual understanding between the survivors and other people in their context. After the stroke the survivors found that other persons did not understand their changed conditions for social enjoyment.

Thus relations the way they had been before the stroke were lost. The survivors were not able to tackle this gap of understanding between them and their near ones. Neither did any survivor find that it was dealt with in the support she or he received from professionals.

#### *Play in togetherness*

The survivors had lost their ability to play. Play has been defined an activity performed for subjective pleasure rather than a serious or practical purpose [140]. To the present survivors play meant not only subjective pleasure; for instance attending concerts, theatre and opera and doing hobby activities etc. Play meant events of subjective pleasure shared with others in a variety of places. Several survivors found play in vocational activities. Some had a job or performed activities that related to their former professions. Others engaged in political networks or similar opinion-making associations. Although these activities had a practical purpose the survivors participated for pleasure.

However, the survivors did not receive support from professionals for re-suming mutual play. Many had thus to abstain from playing the way they had done before the stroke. They were resigned and their social network remained disrupted.

#### *Everyday narratives*

The importance of having lost the ability to tell everyday narratives in social life was especially stressed by participants who had taken part in autonomous support groups for stroke survivors. Everyday narratives were narratives about all kinds of events in which the survivors in a wide sense recently had taken part. Encounters in this way often started with small talk and advanced into conversation about more serious matters. In the support groups priority had been given to the exchange of everyday narratives and talk about experiences of stroke had been excluded. However, the group participants also raised the problem that only a few had assumed the role as narrators. Those who experienced an eventless post stroke life were reduced to audience even though they had previously been experienced story tellers. This finding in the present groups corroborated our observations in a previous study about professionally supported stroke groups. In these groups recounting narratives had to be facilitated through a novel definition of 'an event worth talking about' [6]. Not until the participants had changed their definition of a narrative could the silent survivors begin to tell stories.

#### *Self-esteem*

The survivors' self-esteem had been connected with their feeling of being a person estimated by others. Thus, when relations were destroyed the survivors' self-esteem was lost. Because the survivors were close to or above the pensionable age in Sweden their active participation in the community was

not longer requested. They had to get the feeling of being socially valuable person through activities of play. Play and everyday narratives thus had become prerequisites for the survivors' ability to socially integrate as a person with pride in her or himself.

#### Certainty

At the same time as the survivors began the rehabilitation they faced a loss of certainty. They had before the stroke had an un-reflected knowledge of human mortality [141,142]. After the stroke they realized that a relapse in a fatal stroke might occur at any time.

The loss of certainty made the survivors plan in a narrowed perspective of time. It became a barrier to actions even though the physical ability for their performance was restored. For instance, the survivors abstained from visiting relatives in other towns, counties or countries. The lost certainty in this way had settled as an inner barrier and prevented them from actions of significance to their social integration.

The lost certainty continued to be a restraint and many survivors' social networks remained disrupted because of this.

### **6.4.2 Strategies to diminish the losses**

Through cognitive and behavioural strategies the survivors attempted to reduce the impact of their losses. Cognitive strategies changed the way the losses were experienced. Behavioural strategies became guidelines about how to master the changed situation.

#### **6.4.4 Cognitive strategies**

##### Suppression

In the first interviews the survivors' distress was salient. After one year, however, they tried to suppress thoughts about stroke. The stroke was an event that should belong to the past.

The survivors preferred to describe themselves as persons who had been acutely ill. They preferred not to see themselves as chronically ill persons.

##### Comparison

The survivors compared their situation with that of others. Downward comparison with more severely damaged stroke victims meant that the situation might have been worse. Upward comparison with survivors who managed to improve their life and health meant that the situation might become better.

### Intellectualization

Intellectualization helped the survivors balance conflicting demands. It was rational to not let thoughts about inevitable, future events interfere with the joy of present life. It was rational to not comply with unreasonable demands of others. Rational thinking could for instance defend a survivor's right to choose a social life according to his own wishes in spite of contemporary trends.

### Positive thinking

Thinking positively put expectations of a positive outcome in the foreground in spite of facts that indicated a negative outcome.

Regaining abilities could be seen as a challenge. A challenge added a feeling of enthusiasm.

Thinking humorously soothed embarrassing situations. Humour appeared in delightful events and in interplay with others.

### Normalization

Normalization focused satisfactory everyday events that were left unchanged by the stroke. These fragments of former life re-established a partial continuity of life and helped the survivors ignore the impact of their losses.

### Religious and magic beliefs

Reconciliation with lost certainty could be achieved through religious and magic beliefs. The threat of a next stroke might be solaced through belief in the providence of God and resurrection after death. Lost certainty could also be soothed by magic thinking, i.e. influence on events by supernatural forces, not being part of the comprehensive belief system of a religion [142]. For instance, an informant had survived a serious accident as a child. She took this as a sign that she was meant to be a survivor also of stroke accidents. Another informant found consolation in the belief that after an evil event always follows a good event.

## **6.4.5 Behaviour strategies**

### Taking responsibility

Most survivors stated that they themselves took the responsibility for their training and its outcome. Many did want to be in control of their own training and goal-setting. In addition they expected dialogues with clinicians about how to perform the practice.

Some concluded that they had to take responsibility because nobody else did. On the other hand, a few found that because of their damages they were unable to be responsible.

### Searching support

At important turning points in their rehabilitation, however, the survivors wanted clinicians to give them psychological support through listening and encouragement. Yet they normally lacked this kind of support in their treatment.

Obviously psychological support was acknowledged as a complement to the physical rehabilitation. When the physical rehabilitation was ended, psychological support was also ended.

A trustful relation to a physician did not always imply psychological support. Surprisingly, one survivor did not expect her physician to take care of emotional aspects in stroke treatment.

### Doing experiments

Many survivors experimented and developed individual means for resuming activities. A trustful relation to a clinician who had explained how to practice could inspire experimenting. For instance a survivor in a consultation had a good description of his balance disturbance. Thereafter he performed training of balance without further contact with care providers. When a trustful therapeutic relation was lacking however, experimenting also meant activities beyond the recommendations of professionals.

Thus risks often trespassed limitations set by clinicians and implied a risk of maltreatment. The risks were also risks of physical accidents and social failures when for instance a survivor went to a conference abroad or travelled with subway.

However, the survivors saw risk taking experiments as a prerequisite for the achievement of social reintegration although they performed these activities on their own.

## 7 Discussions

### 7.1 Discussion of findings

Throughout the studies the present survivors revealed their lived experiences about stroke disease and stroke illness. They made explicit statements. They wrapped their messages in narratives. One communicated through a language distorted by aphasia. The survivors talked about the meaning of acute stroke symptoms, social losses, existential crises, disabilities and rehabilitation. They spoke about how they found strategies for overcoming their disabilities in order to achieve indispensable life goals. They also spoke about that support from care providers according to their experienced needs could be difficult to find in the health care system. Frequently there was a discrepancy between the survivors' experience of needs and the care providers' understanding of their task. Below these findings and their consequences for encounters between stroke patients and care providers are discussed.

#### **7.1.1 Acute stroke and delayed treatment**

Study I revealed how the acute stroke symptoms threatened four victims' sense of control of body, autonomy and integrity. These victims demanded that care providers encountered them as a person by a person and at the same time managed to behave as an expert.

The findings were in line with the observation that mere knowledge about stroke does not influence arrival time at hospital [143]. Some stroke patients delay hospital arrival because they cannot make sense of their symptoms or need to maintain a sense of normality [144]. The present study implies that information campaigns about stroke symptoms also should imbue people with a strong sense of the intimate connection between preserving control of body function, autonomy and integrity and immediate contact with health care in case of neurological symptoms.

There are stroke victims who understate their right to emergency care and need reassurance from others to search for treatment [144]. The present pa-

tients, however, did not question their right to care and did not accept the involvement of near persons in their decisions. Instead they turned the focus from being a question of qualities of patients to being a question of the qualities of their health care providers. Many doctors still find it difficult to meet their demand of being a person who encounters a person [52,67,68,145-148]. It was therefore impressive that their claim of being met as peers also contained a proposal of a therapeutic alliance [149].

In a therapeutic alliance the patient and the provider find each other in explicit goals for the encounter and in a feeling of a personal bond. In the rehabilitation phase of persons with brain damage the alliance is a prerequisite for awareness and compliance [150]. The present findings imply that patient may have a demand of a therapeutic alliance that influences their behaviour even during the acute phase of their disease. This kind of explicit and non-verbal communication emerges in a dynamic balance between patient and health care provider. The health care provider must at the same time behave as an understanding person and a problem-solving expert. She or he has to see the patient as an autonomous person and at the same time as a patient [151]. Acquiring this competence is a learning process that takes place in parallel with the biomedical education of a physician and must be achieved through experience, reflection and learning [152].

At an emergency department the patients can expect to enter into a doctor-centred, not a patient-centred, environment and be treated accordingly [153]. In primary care, on the other hand, a patient centred behaviour is widely accepted and has been developed for some years [154,155]. Stroke patients with the demands of the present patients therefore might behave in a different way vis-à-vis an organization for treatment which applied the principles of patient centredness of primary care integrated with the capacity to perform evaluation and treatment of emergency care. It should have a reputation of encountering patients as persons met by persons. Starting projects with this kind of organizational change may be important considering the too high number of patients who delay emergency stroke treatment [156]. “No treatment is effective, if those who need it ... do not seek it” [37].

### **7.1.2 Making an aphasic person understandable**

The delicacy of the balance between disease and illness perspective in the interplay between survivor and clinicians was further highlighted in Study II about the aphasic survivor. The professional who should support the survivor into a meaningful future needed to understand the meaning of the aphasia in his entire life situation. Access to this understanding could be found through what he told about his speech damage, his treatment and his plans. His experience could be described as being in an ‘uncanny’ body [64]. The body, a person’s home in the world, contains the intentional functions - the instruments - that give the person a projective, intentional power into the world. In illness the device is defective and the person cannot act as before. The per-

son needs therefore to reflect upon her or his body both as the biological damaged instrument and as the instrument that expands into its comprehensive context. To many stroke survivors this means that they have to handle a complex of motor and cognitive impairments and therefore very different actions in the spatial world. For the present aphasic stroke survivor the situation was different. He could still act autonomously in his *spatial* world; but one single function, his body's tool for access to the *relational* world of human beings was damaged. This very well-defined loss twisted his perception of the meaning of rehabilitation into the simplification of repairing his defective language. As an aphasic person he had needed a rehabilitation expert who could listen and respond to the individual, complex, interior perspective of his situation [81].

The question of a possible failure, which he had considered of great importance at the beginning of the rehabilitation, was not reflected on at all. It was, eventually, reassumed by a specialist in medical rehabilitation after almost a year. By that time his initial understanding, that rehabilitation meant reflection about different outcomes, had faded.

He also lived a distressing, dichotomized life with his next-of-kin. Perhaps the most devastating effect of aphasia is its effect on interpersonal life [157]. Aphasic persons suppress feelings, feel alienated and frustrated; feelings that they have a need to communicate. A professional contact with competence to analyse what they recount and to create an understanding and caring communion that involves their relations may lower their distress [158,159]. They need, as Toombs has it, a patient-physician relationship which, as a unique kind of face-to-face relationship, conveys the meaning of their illness into the context of their particular biographical situation [52]. Not just trying to have the language repaired, but make the defective language work in a totality of relevance.

The voices of survivors with communication deficits are not sufficiently heard in qualitative research settings compared to the voices of survivors with an undamaged language [81,160]. Neither was the voice of the aphasic man heard in his rehabilitation setting. A qualitative analysis might have been a means to get reflecting dialogues with professionals in a search for the meaning of his illness in his planning for future life. The challenge is how to make such an analysis feasible in ordinary clinical job.

### **7.1.3 Understanding the existential uncertainty of stroke victims**

In Study III was further evolved ways of understanding stroke survivors' illness experiences. The stroke had made the survivors aware of the uncertainty of their future and they experienced an autobiographical disruption. Confronted with these aspects of temporal uncertainty, they recounted narratives to convey their experiences.

Clinicians often find it difficult to respond appropriately when stroke patients talk about the uncertainty of their future [6,14,75,161]. From a disease

perspective a stroke patient's future *is* uncertain [13,21,162-164]. Hence, a professional is not able to give a survivor a biomedical answer that makes her or his uncertain future certain. The present survivors, however, constructed narratives over time models that aimed at reconciliation with their autobiographical disruption. The task of their care providers was to recognize their temporal mode of coping in the narratives and help them to employ the most appropriate strategies [165].

The plots of the narratives and the time models used in the narratives were probably dependent of the context of the informants. Anxiety connected to human finitude is multidimensional with a complex relationship between anxiety and defence. The defence mechanisms are accordingly multifaceted: feeling of immortality, belief of existence after death, preservation of the dead body, repression and suppression [142]. For instance, stroke victims in North America had an uninterrupted autobiographical flow. They used former life experiences to create autobiographical coherence, and age, religion, and comorbidity to temper anxiety [74,166]. The Swedish survivors had other forms of life experiences. They were seriously surprised by their stroke. It profoundly changed their life and blurred their future. The uncertainty scared them and they searched for meaning in a way that was probably representative for people living in a secularized Swedish context [167].

The cyclical time model gave predictability to the near future of day-to-day life. Yet, the distant future also had to be imagined with a sense of certainty [125]. Therefore the stroke survivors found support in cyclical time model to dissolve time limits into the distant future on a linear temporal line. Their transgression of temporal limits made the boundaries between a life in contingency and a life in belief in a supreme guidance indistinct. To older stroke survivors in the US supreme guidance meant the guidance of God [74]. Few Swedish informants explicitly talked about a specific religious solution to their problem. This did not mean that they were without a transcendent belief. Their spirituality, however, could be disguised in the use of the cyclical time model in their narratives. In this way Swedish survivors achieved a belief not so different from a religious conviction. They merely used other descriptions.

Exchange of time was important in the survivors' social interactions. Seen through the perspective of the narratives, it was obvious that their identity pictures were reinforced by temporal exchanges. Time was a gift, voluntarily donated and received and of equal value to transacting agents. In modern, Western society, time has become commoditized as an object for selling and buying [115]. Although the survivors did not talk in commercial terms, the Western way of thinking of time as a commodity might be an explanation to the importance of exchange of time. The statement of the old woman, who declared she did not deserve to live, if she did not give time in return to her generous grandchildren, became understandable. Viewing social interaction

in the light of exchange of time made this kind of narratives about social togetherness meaningful.

Finally, the survivors excluded stroke from time. Conscious suppression or unconscious repression are two psychological reactions to finitude [142,168]. The actual informants deliberately suppressed the stroke and excluded it for a moment from time. They planned for social events through recounting narratives about how they should take place. The narratives extended over the short period of a social encounter. Between the beginning and the end of this period the stroke was not allowed to exist. By excluding the stroke from narrative time the informants allowed preferred issues to prevail in the social event. For patients with cancer, delightful events can give moments of suspense, where the bodily distress is unobserved [169]. The stroke survivors created joyful moments through the narrative exclusion of stroke from time.

#### **7.1.4 The social reintegration**

The meaning of rehabilitation to the survivors was social reintegration. They could accept their physical disabilities; their strategies aimed at giving them access to a life that again made them valid members of their social network.

Stroke survivors' need of consideration of psychosocial components of rehabilitation is well known [75,170]. Nonetheless the present survivors did not find that their need for support towards social reintegration was included in their rehabilitation. The rehabilitation was ended when they had achieved physical independence. Their experiences were in line with the observation of Hafsteinsdottir that survivors fail to resume social activities even though they have regained most of their lost functions and practically are able to participate [171]. The question remains as to *why* they do not regain former activities. According to the present studies the reason might be that their needs for support remained unobserved. The attendant question was *why* they did not get the support. The present studies contained some answers to this question.

#### **7.1.5 Play**

Development of sociability is not an effect of being physically able to socially participate. Sociability is the consequence of participation in a context that is meaningful to the individual [172]. Before the stroke the present survivors had been socially active in a multiplicity of activities outside their homes. They needed to regain the ability to *be* those activities again, not just able to *do* the activities [173]. To *be* an activity means to have the sense of being integrated with the role that is expressed in the activity. The present survivors spoke about *being* social activities in terms of play. Play has been defined as an activity which gives subjective pleasure without a practical purpose [174]. The survivors described however play as moments of subjective pleasure shared with other people. Before the stroke the survivors had

played together with others in places disseminated over a large geographic area. Because their need for rehabilitation performed in these places was not attended to, many survivors abstained from returning to *being* former joyful activities in togetherness with their near ones, remaining socially disintegrated.

A significant finding was that several survivors were engaged in vocational activities. Although the vocations had practical purposes their main purpose apparently was to perform play in a network. Return to work is a major factor in the subjective well-being of stroke survivors below the age of 60 years [86,175]. Young age, lack of work and leisure activities are related to the perception of unmet demands concerning autonomy and participation [176]. Our findings shed light on the fact that even at old age a vocational activity can be crucial to the subjective well-being of a survivor. The survivors searched for self-esteem in their play and their vocation. Without self-esteem survivors are more vulnerable to depression [177]. When their self-esteem is preserved the probability of a positive outcome of their rehabilitation is enhanced [178].

#### **7.1.6 The rehabilitation strategies of the survivors**

The survivors' experiences around their behavioural strategies exposed how they without support from professionals had to find their own means to become socially reintegrated. The strategies implied turns of their illness perspective from explicit dysfunctions to subjective dysfunctions [95]. According to Paterson's theory about shifting perspectives of chronic illness, the turns implied shifts from illness in the foreground to wellness in the foreground [76]. Illness in the foreground had meant training of functionally defined dysfunctions that was easily administered. Wellness in the foreground dealt with subjectively defined disabilities. Attendance to such needs meant that the survivors' narratives about their turns in illness perspective had to be considered. The narratives explained why some survivors were more satisfied than others independent of their disability [179].

The loss of certainty remained a barrier between the survivors and their social reintegration. They realized that they might have another stroke at any time, a risk their care providers could reduce, not eliminate [13]. According to Charmaz a transition to an uncertain life after a life-threatening illness is 'an awakening to death' [180]. The ill person has to acknowledge the uncertainty if she or he is to be able to continue into a good enough future [180].

The present survivors dealt with their lost certainty through well-known defence strategies such as 'suppression', 'comparison' and 'normalization' [168]. They told a variety of short narratives about 'intellectualization', 'positive thinking' and 'religious and magic beliefs' revealing strategies aiming at overcoming their losses. Faircloth has described how stroke survivors through a coherent narrative flow transform the life disruptive stroke accident into a non-disruptive event [74]. The present survivors disclosed a pat-

tern of narratives which aimed at neutralizing the impact of the lost certainty on their path to social reintegration.

Interesting in a European context were the narratives that contained magical thinking. Recently it has been highlighted that in a few European countries, Sweden included, an increasing majority does not belong to any religious denomination or consider themselves as non-believers [167]. According to our findings this ongoing secularization should not mislead care providers to refraining from transcendent issues in dialogues with stroke survivors. They should however be addressed through questions about the meaning and coherence of life disguised as magic perceptions. Ill persons need creative illusions as an extension of their destructive biomedical ‘reality’ [181]. A task for clinicians is to make the frame wherein stroke survivors can merge explicit knowledge about stroke with narratives that create meaning and coherence.

### **7.1.7 Implications for rehabilitation**

In mutual play activities the survivors and their near ones had needed opportunities to share mutual, positive feelings and exchange everyday narratives and reciprocal estimation. Their rehabilitation had been carried out in hospitals and in their homes. The findings of the studies implied that these important parts of rehabilitation should take place where survivors usually had experienced joy together with family and friends. Rehabilitation of neurologically damaged patients supervised by professionals have formerly been successfully performed under quite difficult environmental conditions [182]. Although some of the present survivors performed rehabilitation in other regions alone, the majority needed support from professionals with a broad knowledge of how to facilitate their strategies. This could have taken place through: supportive dialogues; transfer of the task to local lay or professional supporters or Webb based communication technology [183,184].

The findings also entailed that a change of notions of disabilities qualifying for rehabilitation should take place. To define a subjectively experienced barrier to social reintegration as a disability should to a greater extent be optional resting on the experiences of the single survivor. This change could be achieved through a change of care providers’ understanding of their task. Some care providers within a discipline understand their job as a question of working according to standards. Others see as their professional task to enhance their professional competence through the experiences of every singular patient [185]. The present survivors’ experiences reflected how their care providers understood their job in a restricted way [161]. Hence stroke rehabilitation could be developed through pedagogical interventions within the rehabilitation disciplines to help care providers get a new understanding of their job [152]. In this way subjectively defined dysfunctions and strategies could be acknowledged as issues in rehabilitation of stroke survivors, and rehabilitation activities and technology developed accordingly. Access to the

stroke patients' way of thinking about their experiences might be achieved firstly through asking them to recount their narratives around getting and living with stroke. Secondly through the use of feasible, qualitative methods as a routine in rehabilitation planning and evaluation [186]. Without such knowledge professionals just share their patients' uncertainty, being excluded from the proper supportive dialogues about the survivors' own aspects of their stroke [6,75].

## 7.2 Discussion of methods

### 7.2.1 Sample

Nineteen survivors participated in the studies. After the fifteenth interview the interviewees revealed few experiences different from the antecedent. The researcher estimated that a level of saturation was achieved and the sampling for the qualitative study was ended [112,132]. However, this meant that the criteria for 'theoretical sampling' according to GT not was followed to the letter in study IV.

Two of the studies were case studies comprising one and four survivors respectively. A case study can provide important and detailed knowledge about the experiences of few individuals, easily lost in studies about larger samples [187]. The intention of a case report is to convey a clear message about an important phenomenon rather than to describe an enigmatic case [188]. Thus a case study identifies topics for further research or development and adds heuristic knowledge to a problem [189]. The present studies revealed the experiences of survivors with problems that might be overlooked in research, treatment or in society. It was important that a multidisciplinary team could make an aphasic survivor understandable through a phenomenological analysis method. It was also important to understand a subgroup of persons who delayed arrival for emergency care of stroke.

The composition of the entire sample implied limitations for the *relevance* of the findings and conclusions. The survivors had been invited to participate in a study about support groups. The majority of the participants was therefore mobile and independent and, with one exception, without serious communication problems. They were living in a Swedish city. The women were almost all single and the men were living with a partner. The same 38 interviews were analysed throughout the entire project. This produced a deep and comprehensive knowledge about the experiences of the participants. However, it made the research first and foremost relevant to groups of survivors similar to the above described.

The survivors had recently gone through a stroke and received stroke treatment and rehabilitation. Three of them had met the researcher as a consultant before they entered the study. Obviously the interviews brought the survivors into a situation that reminded them of previous, medical consultations about stroke. They were generally influenced by this at the beginning of the interviews and told the researcher that the interview was their first opportunity to share illness experiences with a professional. This made them on the one hand eager to tell with the openness of a confident patient. On the other hand, they saw the interviewer as a physician. This seemed to influence what they decided to convey about their experiences. The researcher therefore endeavoured to establish an atmosphere of not being within a health care institution in the interview setting.

Finally, 11 survivors had been randomly selected to participation in an intervention with support groups. However, no difference was observed in the interviews between the participants and the non-participants of support groups.

### **7.2.2 Researcher**

The researcher had worked for many years in geriatric rehabilitation and had a comprehensive pre-understanding about rehabilitation of stroke survivors. It was not possible and not even desirable, to completely neutralise this pre-understanding.

The pre-understanding was the soil from which the research questions in the research emerged. It was also a prerequisite for an empathetic, human understanding between the informants and the researcher.

On the other hand the pre-understanding made it difficult and at times impossible for the researcher to see the boundaries between his own pre-conceptions and results that emerged from the data. The researcher frequently reflected on these pitfalls to bracket or bridle the pre-understanding to be open to the undistorted voices of the interviewees [190].

The researcher's vocation influenced his behaviour in the interviewer/interviewee discourse. The first interview transcriptions revealed a patient/physician discourse rather than a research dialogue. This meant that the interviewer practiced an active, supportive listening with an abundance of visual and verbal signals to the interviewees. Reading of the transcripts revealed how this negatively influenced the spontaneity of the interviewees. The interview technique had to be changed into a model of quiet listening with fewer supportive or probing questions and cues.

### **7.2.3 Rigour**

An informant in a qualitative study tells the same story about an experience in different ways. Another informant tells a different story about the same

experience. Thus, one cannot validate - in the strict meaning of the word - the consistency of the present research through validating the idea of one story against the information in another [191]. Therefore combinations of quantitative and qualitative methods were planned for at the beginning of the project. This triangulation might have enriched the understanding of the studied phenomena [192]. The quantitative studies should involve intervention groups and control groups. The sample, however, became far too small to give the quantitative studies the necessary power. The qualitative results, on the other hand, became far too fascinating to the researcher. In consequence the quantitative analyses were abandoned.

Therefore the positivist criteria of trustworthiness in research, internal validity, reliability, objectivity and generalization/external validity were not applicable to the studies in the rigorous sense of these words. Other meanings of the criteria or other criteria of validity had to be reflected on. Lincoln and Guba have proposed the corresponding criteria: credibility, dependability, confirmability and transferability [193,194]. Some researchers have also argued that in dealing with the complexity of human life, goodness of research might include a criterion of sensibility to catch the complexities of human experience [195,196]. However, in spite of these endeavours to establish different criteria for good research in qualitative research a criterion of 'validity' remains and the corresponding criteria of Lincoln and Guba are still the standards of reference [192,197,198]. Malterud has drawn the conclusion that the concept *validity* remains essential [192]. In addition comes in qualitative research a criterion of *relevance*, i.e. that a research report is 'a contribution to ongoing dialogue and exploration rather than a documentation of an invariant fact' and 'the dialogue affects the meanings of social experiences' [192,199].

Malterud finds that a criterion of *reflexivity* should be added, i.e. 'an attitude of attending systematically to the context of the knowledge construction, especially to the effect of the researcher, at every step of the research process' [192,200].

The researcher must be aware of and share her or his preconceptions. It is mandatory for the researcher to reflect on the research from *metapositions*, i.e. to create a distance from the study setting [201]. In order to achieve these metapositions the findings and interpretations of the present studies were repeatedly discussed with co-writers from different disciplines. They were exposed to criticism in front of research fellows within a broad, multidisciplinary research context. They were also presented at conferences to researchers from different countries.

## 8 Summary

- Stroke victims who delayed hospital arrival beyond time limits for thrombolytic treatment had a strong need for control of body, autonomy and integrity and demanded to be encountered in consultations as a person by a person. To make them search for emergency evaluation in time might demand an emergency care treating them according to their needs.
- Because of the damaged language the rehabilitation of an aphasic survivor may unilaterally focus on language training ignoring her or his need for comprehensive support and planning for the future. Implementation of a qualitative research method for text analysis adapted to rehabilitation use might ensure aphasic survivors a more adequate rehabilitation.
- Time models in spoken narratives help survivors to overcome uncertainty and recreate narrative coherence in their lives. Professionals can support survivors through revealing and reinforcing these models in a supportive dialogue.
- The meaning of rehabilitation to survivors is social reintegration. Many probably do not socially reintegrate because their own strategies and subjective disabilities are unacknowledged in their rehabilitation. Through a more comprehensive understanding of disability and rehabilitation, integrating illness-as-lived perspectives with biomedical perspectives, subjective dysfunctions and rehabilitation strategies could be acknowledged in stroke rehabilitation. Thus, disability after stroke might be defined as: All effects of a stroke event which a survivor experiences as a hindrance to social reintegration. Rehabilitation after stroke might be defined as: All means that support a stroke patient to achieve social reintegration.

## 9 Future Research

- In order to get an increased understanding of how to minimize patients' delay for emergency stroke treatment, further qualitative studies should be done with samples of stroke survivors from different contexts and with different demographic profiles.
- The possibilities of the use of qualitative methods in ordinary clinical rehabilitation of stroke survivors need to be further examined (e.g. through computer supported transcriptions and construction of simplified analytical models).
- The effects of education of professionals in analysis of transcribed patient narratives should be further studied.
- The concepts of dysfunction that constitute the meaning of rehabilitation to stroke survivors should be further developed in qualitative studies. Organizational models for outreach rehabilitation should be developed and evaluated.

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.



## 11 Summary in Swedish

Stroke är en akut uppstådd, symptomgivande neurologisk åkomma orsakad av en kärlskada. Den påverkar fysiska, kognitiva och psykiska aktiviteter. I inledningsskedet är behandlingens syfte att eliminera eller minska de fysiska effekterna av nervskadan. Följderna av en stroke spelar emellertid mycket snart efter insjuknandet också roll i den drabbades liv som helhet.

Denna avhandling syftar till att utforska livet efter strokes mening för äldre stroke patienter. Nitton personer har intervjuats vid två tillfällen och intervjuarna har analyserats med kvalitativa metoder.

Delstudie I handlade om fyra personer som sköt upp sin akuta behandling så länge att de inte kunde få behandling med blodproppsupplösande medel. De visade sig ha ett starkt behov för kontroll över kropp, integritet och autonomi. Att förmå personer med detta behov att söka akutvård i tid skulle kräva en mera patientcentrerad modell för patientkommunikation inom akutstroke-vård.

I delstudie II kom en man med skadat språk till tals. Eftersom hans språk i möten med behandlare var svårförstått blev hans behov av stöd psykiskt, socialt och i framtidsplanering inte tillgodosett. Tillämpning av en kvalitativ analysmetod i rehabiliteringen skulle ha kunnat leda till ett bättre tillgodosende av hans behandlingsbehov.

Stroke patienter upplever oftast ett tillstånd av ovisshet inför framtiden. I delstudie III påvisades hur informanterna använde sig av tidsmodeller i narrativer för att återskapa tidsmässiga sammanhang i sina liv. Förståelse av sådana narrativer skulle kunna hjälpa behandlare att lämna bättre psykologiskt stöd.

Den öppna frågan varför stroke patienter ofta inte återupptar sociala aktiviteter fast de fysiska förutsättningarna finns kunde enligt delstudie IV bero på att subjektiva strategier och subjektivt upplevda aktivitetsproblem inte sågs som relevanta i informanternas rehabilitering. En ändrad förståelse av stroke rehabiliterings mening skulle kunna leda till en rehabilitering som gav stroke patienter ett bättre stöd i social re-integrering.



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