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EATING SITUATIONS AMONG WOMEN AND MEN POST- STROKE

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'Eating is arguably the most fundamental of human activities.

*Each of us must eat or we die, and usually have to eat a
number of times each day' (Capaldi 1996, p.3)*

ABSTRACT

Background: Eating occurs as a frequent activity in everyday life and one common consequence after stroke is the negative impact on the ability to eat.

Aim: The overall aim of this study was to explore eating difficulties and experiences among women and men with acute stroke, three and six months after stroke.

Method: In **Study I**, 104 patients with acute stroke were recruited at the stroke unit, Danderyd Hospital in Sweden. Patients who were unconscious, had no oral food intake, severe aphasia or confusion, had no spouse who could give consent for participation, were non-Swedish speaking were excluded. Three months post-stroke 36 patients were followed-up regarding eating difficulties in **Study II**. To detect eating difficulties in **Study I and II**, the patients were observed during one standardized meal using a structured observation protocol. Nutritional and oral status, neurological function, neglect, degree of dependency in ADL, participation and well-being were also assessed. To explore the individual's experience and management of eating difficulties in **Study III and IV**, semi-structured interviews were performed at 3 and 6 months.

Results: The most common eating difficulties observed in the acute phase were in managing food on the plate, to have sufficient food consumption and to have an adequate sitting position during meal. In the acute phase, the only significant gender difference that remained, when other factors were taken into account, was inadequate food consumption if being a woman. After stroke people experience a striving for control to eat safely and properly and after six months they have a desire to master eating situations according to previous values and habits. Among the persons with eating difficulties, three months post-stroke, improvements regarding sitting position and managing food on plate and in mouth were shown, but the proportion of patients with insufficient food consumption had increased. In the acute phase, women experienced lower well-being than men did. Despite neurological and functional improvements, the well-being remained unchanged.

Conclusions: Eating difficulties after stroke are multifaceted and have to be observed as a complex eating situation including eating-related activities. There is also a need to consider other people's involvement in the eating situation. Therefore, it is important to take the time to ask the individual about the experience, previous habits and attitudes on the new eating situation.

Keywords: Eating, stroke, nursing, nutritional status, psychological well-being

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CONTENTS

1	Introduction.....	1
1.1	The consequences of stroke.....	1
2	Background.....	3
2.1	Neurological impairments after stroke.....	3
2.2	Recovery from stroke.....	3
2.3	Activities of daily living.....	4
2.4	Well-being and quality of life following stroke.....	4
2.5	Gender and stroke.....	4
2.6	Eating as a functional, cultural and social activity.....	5
2.7	Eating difficulties.....	5
2.8	Consequences of eating difficulties post-stroke.....	7
2.9	Eating difficulties and gender.....	8
3	AIM.....	9
3.1	General aim.....	9
3.1.1	Specific aims.....	9
4	METHODS.....	10
4.1	Participants.....	10
4.2	Instruments and questionnaires.....	13
4.2.1	Observation of meal.....	13
4.2.2	Barthel Index.....	14
4.2.3	Impact on participation and autonomy questionnaire.....	14
4.2.4	Letter Cancellation Task.....	14
4.2.5	Line Bisection Test.....	15
4.2.6	Mini Nutritional Assessment.....	15
4.2.7	National Institute of Health Stroke Scale.....	16
4.2.8	Revised Oral Assessment Guide.....	16
4.2.9	Well-being questionnaire-12.....	16
4.2.10	Semi-structured interviews.....	17
4.3	Data analysis.....	18
4.3.1	Analysis Study I.....	19
4.3.2	Analysis Study II.....	20
4.3.3	Analysis Study III.....	20
4.3.4	Analysis Study IV.....	20
4.4	Ethical considerations.....	21
5	RESULTS.....	22
5.1	Study I.....	22
5.2	Study II.....	23
5.3	Study III.....	24
5.4	Study IV.....	25
5.5	Conclusions.....	25
6	DISCUSSION.....	27
6.1	Eating difficulties.....	27
6.2	Eating situations.....	27
6.3	Food consumption and gender.....	28

6.4	Psychological Well-being in eating situations	29
6.5	The social perspective of eating situations	29
6.6	Awareness of eating difficulties	30
6.7	Methodological considerations.....	30
6.8	Clinical implications.....	32
7	Further studies	34
8	Populärvetenskaplig sammanfattning	35
9	ACKNOWLEDGEMENTS.....	37
10	REFERENCES	39

LIST OF ABBREVIATIONS

ADL	Activities of daily living
ANCOVA	Analysis of covariance
BI	Barthel Index
BMI	Body Mass Index
ICD -10	International Classification of Diseases – 10
ICF	International Classification of Functioning, Disability and Health
IPA-S	Impact on Participation and Autonomy Questionnaire
LBT	Line Bisection test
LCT	Letter Cancellation Task
MNA	Mini Nutritional Assessment
NIHSS	National Institute of Health Stroke Scale
OR	Odds Ratio
ROAG	Revised Oral Assessment Guide
QoL	Quality of life
UN	Unilateral neglect
WBQ-12	Well-Being Questionnaire -12

1 INTRODUCTION

1.1 THE CONSEQUENCES OF STROKE

The definition of stroke according to the World Health Organisation is ‘rapidly developed clinical signs of focal or global disturbance of cerebral function, lasting more than 24 hours or until death, with no apparent non-vascular cause’ (WHO 1988, p.108). The subtypes of stroke are ischaemic (85%), haemorrhagic (10%) and subarachnoid (5%). In Sweden, approximately 30,000 persons were registered with either first-ever (73%) or recurrent (26%) stroke in 2008, and the proportion of gender was 51% male. The mean age for patients with first-ever stroke was 73.2 years among men and 78.3 years among women. Nearly 80% of the patients with stroke were over 65 years of age (Riks-Stroke 2008).

Stroke causes about a million hospital days each year in Sweden. In 2008, the patients with stroke in acute hospitals in Sweden had a median length of stay of eight days (including post-stroke care) and the total stay at the hospital was 16 days (Riks-Stroke 2008). The total cost due to stroke in Sweden, including direct and indirect cost, was estimated to 12.3 billion SEK. The direct cost includes medical and non-medical expenditure and the indirect cost implies the cost for production loss due to loss in working ability (Ghatnekar et al. 2004). The results from a more recent study showed a loss of 18.5 working weeks per person due to stroke and thereby generating a high indirect cost (Lindgren et al. 2008). Moreover, social service was a large part of the direct cost (Ghatnekar et al. 2004) and 34% of the patients with stroke in Sweden were living in special accommodations or granted some kind of assistance as home care from the social services (Riks-Stroke 2010).

Besides the major impact on the person with stroke and the society, the significant others’ well-being is affected (Franzén-Dahlin et al. 2006, Larson et al. 2008, Forsberg-Wärleby et al. 2004), and especially among women (Franzén-Dahlin et al. 2006, Larson et al. 2008). Half of the persons living at home after stroke reported that they were dependent on help from spouses three months post-stroke (Riks-Stroke 2008). For instance, relatives to persons with eating difficulties felt that providing food had become important and they experienced themselves as providers of the family member’s health and well-being and supervised the food intake (Johansson and Johansson 2009). On the other hand, the family of persons with eating difficulties felt socially isolated or anxious about not being able to help their next of kin, but

although providing help in eating could also be experienced as meaningful (Jacobsson et al. 1996).

According to the International Classification of Functioning, Disability and Health (ICF), eating is classified as a component of activities and participation and is accordingly viewed as a ‘complex relationship between the individual’s health condition and environment and personal factors’. To be able to capture all aspects of activities and participation as eating, a biopsychosocial approach is recommended (WHO 2001). The choice of instruments in this thesis is based on the ICF components: body function, activities and participation.

The physical impairments due to stroke and impact of stroke on patients’ everyday life with special focus on eating will be presented in the following part of the thesis.

2 BACKGROUND

2.1 NEUROLOGICAL IMPAIRMENTS AFTER STROKE

The limitations in the provision of blood to the brain tissue can cause sudden onset of motor, sensory, and/or cognitive impairments. *Motor impairments* imply unilateral paresis in the arm, leg or face combined or unaccompanied and no difference in proportion between an affected right or left side of the body was shown (Rathore et al. 2002). The most common symptom post-stroke in the acute phase was weakness or paresis and this occurred among 70% (Kimura et al. 2004) and 81.6% (Rathore et al. 2002) respectively. Paresis in the arm was most prevalent followed by paresis in the leg and face (Rathore et al. 2002). Other clinical symptoms that might be present are visual impairments as hemianopia or diplopia (Rathore et al. 2002). Furthermore, reduced consciousness, walking impairments, speech problems, nausea, vomiting and vertigo or dizziness might occur (Kimura et al. 2004, Rathore et al. 2002). Sensory impairments were present among 44.5% of patients with stroke and more frequently present at the left side of the body (Rathore et al. 2002). Cognitive impairments involve problems in executive functions, memory, language, visuospatial functions (Rasquin et al. 2004, Oksala et al. 2009), speed, orientation, attention, language, praxis, and calculations (Rasquin et al. 2004). Executive problems and visuospatial functions were predictors of poor survival (Oksala et al. 2009). In this thesis it has also been of interest to describe prevalence of unilateral neglect which is a common neurological impairment after stroke in the right hemisphere and which is defined as an impaired ability to attend to stimuli in the left hemisphere (Halligan and Marshall 1993).

2.2 RECOVERY FROM STROKE

The neurological status among persons with stroke changes over time and most recovery in neurological impairments occurred during the first three months post-stroke (Skilbeck et al. 1983, Suenkeler et al. 2002). In addition, the recovery was experienced as beginning to slow down at 2-6 months post-stroke (Eilertsen et al. 2010). The severity of the stroke has been shown to affect the post-stroke recovery and, among the patients with the most severe stroke improvements could occur up to five months post-stroke (Jorgensen et al. 1995). However, functional recovery after stroke continued up to one year post-stroke (Elmståhl et al. 1996), but most improvements in ADL have occurred the first month post-stroke (Mayo et al. 1999). Another part of the recovery was to be able to participate in social settings, which was experienced as important among persons with stroke (Burton 2000).

2.3 ACTIVITIES OF DAILY LIVING

Despite recovery, stroke often causes limitations in function and activities performed in everyday life, such as feeding, grooming, bathing, getting dressed, bladder and faecal functioning and walking (Mercier et al. 2001). Self-care is activities, which humans have to learn to manage, and the aim of self-care is to maintain vital functions, health, and well-being. Difficulties in performing self-care can occur due to functional impairments, when the balance between capability to perform self-care and the person's demands of how to conduct self-care disagree (Orem 2001). A person who is ill or disabled might need complete or partial assistance in self-care which can imply maintaining a sufficient intake of food and water (Orem 2001). At three months post-stroke, 20.7% are dependent on other people in activities of daily living (Riks-Stroke 2008). Activities of daily living after stroke have been shown to be related to subjective physical health which is a part of quality of life (Pajalic et al. 2006). The impact on quality of life and well-being post-stroke will be further presented in the next paragraph.

2.4 WELL-BEING AND QUALITY OF LIFE FOLLOWING STROKE

Well-being is included as one of the components in instruments which intentions are to measure quality of life (QoL) (Salter et al. 2008). According to the ICF, well-being is part of the domains in human life and includes physical, mental and social aspects (WHO 2001). In this thesis, focus will be on one of the components: psychological well-being. Well-being has been found to be affected among patients after stroke (Nilsson et al. 2001, Clarke et al. 2002) and also among spouses to patients with stroke (Nilsson et al. 2001, Larson et al. 2008).

Quality of life was affected post-stroke and this change could remain for a long time (Muus et al. 2010, Sturm et al. 2004, Patel et al. 2006, Suenkeler et al. 2002) and 43-63% had not regained their quality of life one year after stroke (Muus et al. 2010, Suenkeler et al. 2002). Age, stroke severity at the onset of stroke, neglect, low socioeconomic status and the female gender were predictors of quality of life (Sturm et al. 2004).

2.5 GENDER AND STROKE

In several studies of people suffering from stroke, gender differences in different aspects have been shown, but some of the findings are inconclusive. For instance, several studies showed that women are 4-5 years older than men when they suffer from stroke (Glader et al. 2003, Barrett et al. 2007, Di Carlo et al. 2003, Gall et al. 2010, Gargano and Reeves 2007, Kapral et al. 2005, Lai et al. 2005, Petrea et al. 2009). Some reported that women also suffered from a more severe

stroke (Di Carlo et al. 2003, Gall et al. 2010) while others did not (Barrett et al. 2007). Moreover, women were more dependent in activities of daily living (Glader et al. 2003, Kapral et al. 2005, Lai et al. 2005, Petrea et al. 2009). In a study by Barrett et al. (2007) weakness was more common among women than men, in contrast to the findings of Gall et al. (2010), Lai et al. (2005), and Kapral et al. (2005). Women with stroke experienced that their restricted body function was a limitation in their activities in daily living after discharge from the hospital (Eilertsen et al. 2010).

A depressed mood and poorer QoL were shown to be more common among women than men three months and two years post-stroke (Glader et al. 2003, Gargano and Reeves 2007, Sturm et al. 2004). Although, in another study six months post-stroke no difference between women and men was shown regarding QoL (Kapral et al. 2005).

2.6 EATING AS A FUNCTIONAL, CULTURAL AND SOCIAL ACTIVITY

One of most frequent functional activities in humans' everyday life is eating. Among healthy individuals in comparison to persons with stroke, no difference in eating activities was shown (Campos et al. 2008). Eating is so much more than just a practical event, since eating was experienced as fundamental and common for all humans, this activity has become natural to share with others and even with unfamiliar people (Simmel 1994). In the Nordic countries, eating was performed either alone or took place as a social event, but the habits for social events differed between the countries. Mostly, eating took place with family members and usually at home (Holm 2001). Among elderly persons in Swedish geriatric settings, proper behaviour, as the table manners were shown to be of importance (Sidenvall et al. 1996). The results showed that the participants focused on, the aspects, 'Mind your manners' which involved their difficulties in management of tools for eating, 'keeping clean', and to 'conduct at table' (Sidenvall et al. 1996).

2.7 EATING DIFFICULTIES

Eating difficulties might occur in different steps of the eating situation and eating difficulties have been defined as '*Difficulties that, alone or in combination, negatively interfere with the preparation and intake of served food and/or beverages...*' (Westergren et al. 2001a, p.258). Eating difficulties occurred frequently in the acute phase and in the rehabilitation settings as 40-80% of the patients with stroke had difficulties to eat (Axelsson et al. 1984, Poels et al. 2006, Westergren et al. 2001a). Nurses reported eating difficulties among more than half of the

patients at nursing homes in Sweden (Kumlien and Axelsson 2002). In comparison, eating difficulties were also present among 49% of in-hospital patients (Westergren et al. 2008). A higher proportion of patients with stroke had, in comparison to other groups in the hospital, food left around the mouth (Carr and Hawthorn 1988b), had more difficulties with chewing, were dribbling with food (Carr and Hawthorn 1988a), and had difficulties in completing a meal (Foundas et al. 1995).

In the acute phase the most common eating difficulties among stroke patients in Great Britain were problems related to arm movement as cutting food, loading cutlery, and oral insertion of food (McLaren and Dickerson 2000); in Sweden hoarding of food in the mouth was the most common problem (Axelsson et al. 1984). 'Eats three-quarters or less of served food', 'manipulating the food on the plate' and 'transportation of food to mouth' were the most common difficulties in a rehabilitation setting (Westergren et al. 2001a). However 'food leaking from the mouth' followed by 'hoarding food in the mouth' and 'spilling by transport to mouth' were the most common eating difficulties reported in a different study (Poels et al. 2006). Westergren et al. (2002b) detected three components of eating difficulties: ingestion, deglutition, and energy. The first part of eating, ingestion, involved the activities conducted before the food reaches the mouth like manipulating food on the plate, transport of food to the mouth and sitting position. The component deglutition comprised of the stage when the food reached the mouth, like opening and/or closing the mouth, manipulating food in the mouth and swallowing difficulties (Westergren et al. 2002b). Swallowing difficulties are common after stroke affecting 30 to 53% (Barer 1989, Smithard et al. 1997, Crary et al. 2006, Smithard et al. 2007). Energy was the component that focuses upon patients' food consumption and energy to eat: alertness, aberrant eating time and eating less than served food (Westergren et al. 2002b).

In this thesis, eating situations imply that eating is an activity which takes place in different contexts and sometimes in interaction with other people. Eating situations include the activities which occur before, during and after the eating activity, such as preparation of meals, shopping, cooking, baking, transporting of food to the table, taking food from a buffet and washing up. Difficulties can occur during eating situations and not only in the eating activity.

Improvements in eating abilities occurred during the hospital stay, except in alertness, (Westergren et al. 2002a), but eating difficulties can be persistent for a long time (Axelsson

1988, Perry and McLaren 2001) and 66% still had difficulties left six months post-stroke (Perry and McLaren 2001). The eating difficulties also remained six months post-stroke among 44% of patients with stroke and impaired communication, despite improvements in function (Perry 2004). Six months post-stroke, swallowing, ingestion and energy to eat were present among 27, 20 and 7% respectively (Westergren 2008). During the first week post-stroke, recovery in swallowing ability occurred (Barer 1989, Smithard et al. 1997) and also among 67% three months post-stroke (Westergren et al. 2001b). Individual improvements in eating ability were shown after eating training sessions with a nurse (Jacobsson et al. 1997).

2.8 CONSEQUENCES OF EATING DIFFICULTIES POST-STROKE

Eating difficulties have been associated with different consequences for the individual and for instance, 'swallowing difficulties' and other eating difficulties like 'alertness' and 'eats three-quarters or less of served food' were predictors of malnutrition in a rehabilitation setting (Westergren et al. 2001a). The only predictor found in another study was aberrant eating speed at admission to rehabilitation (Poels et al. 2006). In the acute phase, no association was found between eating problems and malnutrition (Crary et al. 2006, Axelsson et al. 1989), although swallowing difficulties were associated with a poor outcome (Smithard et al. 2007). Patients with eating difficulties post-stroke might also have other associated problems. One of the consequences after post-stroke was malnutrition with a reported frequency ranging from 9 to 35% among patients in hospital settings (Axelsson et al. 1988, Crary et al. 2006, Davalos et al. 1996, Davis et al. 2004, Poels et al. 2006, Westergren et al. 2002a, Yoo et al. 2008). In most studies focusing on nutritional assessment of stroke patients, different instruments have been used, and some of the instruments were not tested for validity and reliability which might explain the variation in reported frequencies (Foley et al. 2009). The detection of patients with malnutrition is important since undernourished persons with stroke had a poor outcome such as death or infections (FOOD Trial Collaboration 2003, Davalos et al. 1996, Andersson et al. 2004, Gariballa et al. 1998, Davis et al. 2004) and they developed pressure ulcers (FOOD Trial Collaboration 2003, Gariballa et al. 1998, Westergren et al. 2001a). The patients' oral status is of importance after stroke, since poor oral health status was associated with undernourishment (Andersson et al. 2002b). Moreover, eating difficulties turned out to be one of the predictors of short- and long-term weight loss (Jönsson et al. 2008) and at admission to rehabilitation ingestion difficulties were indicators of longer hospital stay (Westergren et al. 2002a). Furthermore, Westergren et al. (2002a) showed that higher dependency in ADL was a predictor of longer hospital stay. One of the activities in ADL is feeding and some of the persons with

eating difficulties were in a need for help from others to be able to eat. In rehabilitation settings 16-52.5% of the patients were dependent on help when eating (Poels et al. 2006, Westergren et al. 2001a) and 82.5% among persons in nursing homes (Kumlien and Axelsson 2002). Experiences of having eating difficulties post-stroke were described as feelings of shame, feelings of discomfort in mouth and from food, fear of choking and feelings of being dependent on others (Jacobsson et al. 2000). Post-stroke, a strive for getting back to a normal life was shown (Carlsson et al. 2004, Perry and McLaren 2003a), but some of the participants were only getting by, and tried to adapt to the new situation six months post-stroke (Perry and McLaren 2003a). Feelings of being abandoned in the recapturing of functional eating was described by participants 18 months post-stroke (Carlsson et al. 2004). Along with social support and age, eating-related disabilities were predictors of quality of life (Perry and McLaren 2004).

2.9 EATING DIFFICULTIES AND GENDER

Gender differences have been found in studies focusing on stroke and eating difficulties, showing that women consumed less of the served food than men did and did not improve to the same extent during rehabilitation (Westergren et al. 2002a). Another study showed, however, that energy intake did not differ between women and men six months post-stroke (Perry and McLaren 2001). Some of the persons with eating difficulties were dependent on others when eating and differences regarding dependency between women and men were found in some studies (Petrea et al. 2009, Unosson et al. 1994). Contradictory, no gender differences were found regarding dependency in another study (Westergren et al. 2001a). Difficulties with shopping, ingestion, and being a female were predictors of poor nutritional status when considering ADL six months post-stroke in a Swedish sample (Westergren et al. 2008).

To conclude, stroke implies a change in everyday life and this might result in a burden for the individual, spouses, and the society. Eating is an activity that occurs frequently in everyday life, and after stroke, difficulties in eating are frequent. Gender differences have earlier been identified regarding eating difficulties post-stroke; however, further studies are needed. This thesis aims to contribute with further knowledge on eating difficulties among women and men, and the individual's own experience and management of those difficulties.

3 AIM

3.1 GENERAL AIM

The overall aim of this study was to explore eating difficulties and experiences among women and men with acute stroke in the acute phase, three and six months post-stroke.

3.1.1 Specific aims

The specific aims for each of the included studies were:

- To examine and compare gender differences in eating difficulties among patients with stroke in an acute setting in relation to different functional and neurological impairments. **(Study I)**
- To compare eating difficulties among patients three months after stroke in relation to the acute phase. **(Study II)**
- To explore the experience of eating difficulties among patients with stroke three months after stroke onset. **(Study III)**
- To explore the experience and management of eating situations among persons affected by stroke, six months after stroke onset. **(Study IV)**

4 METHODS

In order to detect the functional, neurological and psychological abilities among persons with stroke and eating difficulties a descriptive and comparative approach with quantitative instruments were used. Moreover, the persons' individual experience of eating difficulties was explored with semi-structured interviews.

4.1 PARTICIPANTS

Initially, patients with acute stroke were recruited at an acute stroke unit, Danderyd Hospital, Sweden.

The exclusion criteria were: unconsciousness, non-Swedish speaking, had no oral food intake, had severe aphasia or confusion, and no spouse who could give consent for participation. Patients that were not possible to observe at the hospital because of either short-time leave or discharge from the hospital were also excluded.

A flow chart of the included and excluded participants in **Study I-IV** is presented in **Figure 1**.

The recruitment of patients with stroke for the studies was conducted by systematically checking enlisted patients at the stroke unit. The stroke diagnosis was controlled with staff at the stroke unit and ICD-10 diagnoses were retrospectively retrieved from the medical records.

In **Study II**, three months post-stroke, stroke patients with solely reduced alertness or swallowing in the acute phase and remaining problems or 2-7 observed eating difficulties were included.

Participants in **Study III and IV** were selected from the study population in **Study I and II**.

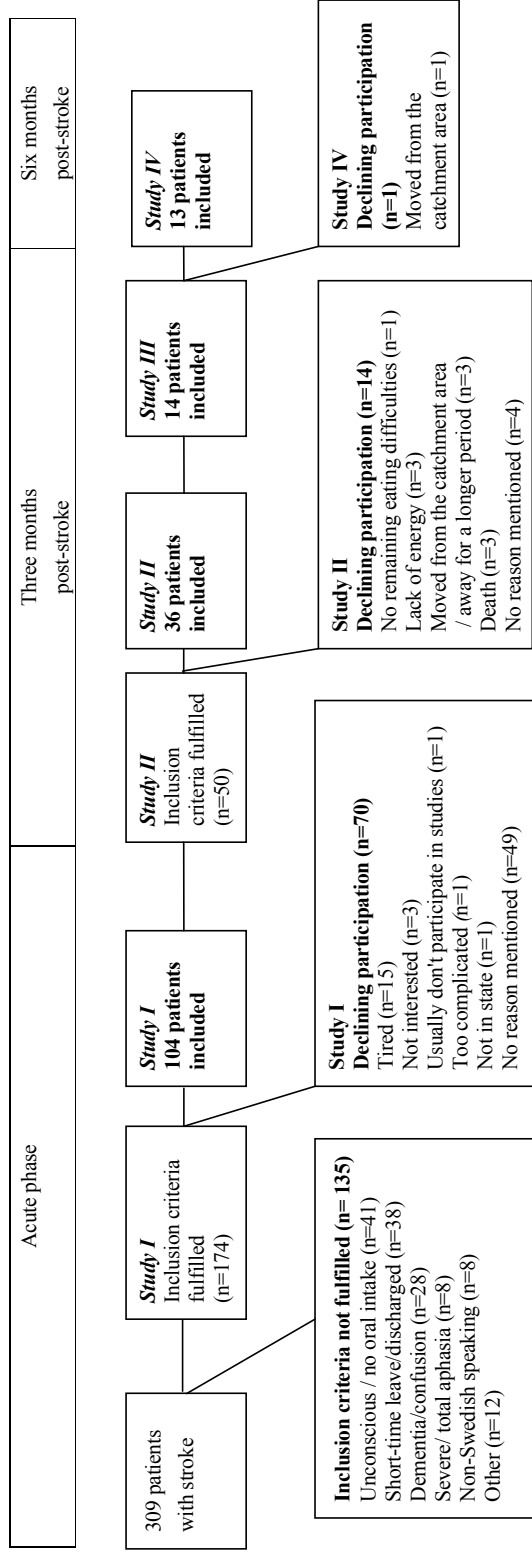


Figure 1. Flow chart of included patients/persons with stroke in each of the studies in the thesis

4.2 INSTRUMENTS AND QUESTIONNAIRES

A number of instruments, tests and interviews were used in the different studies included in this thesis, and an overview of this is shown in **Table 1**.

Table 1. An overview of the instruments, tests and interviews used in the four studies included in this thesis

Instrument/test/interview	Study I	Study II	Study III	Study IV
Barthel Index	X	X	X	X
Impact on participation and autonomy questionnaire		X		
Letter Cancellation Test	X	X		
Line Bisection Test		X		
Mini Nutritional Assessment	X	X		
National Institute of Health Stroke Scale	X	X	X	X
Observation of meal	X	X	X	X
Revised Oral Assessment Guide	X	X		
Semi-structured interviews			X	X
Well-being questionnaire-12	X	X		

4.2.1 Observation of meal

Eating difficulties were assessed by individual meal observations of each participant in the acute setting, the participant's home setting or a conference room at a hospital. The structured observation protocol ('Observation of a meal') consists of nine items: sitting position, managing food on the plate, transporting food to the mouth, opening and closing the mouth, manipulating food in the mouth, swallowing, food consumption, reduced alertness/energy and aberrant eating speed. Each of the items can be rated either as 'good, normal' or 'changed, difficulties, or aids needed'. A guide with instructions of how to rate was available and applied. The internal consistency of the instrument as measured with Cronbach's alpha was 0.89. A guide regarding the observation protocol was available and used during data collection. For instance, to be classified as a normal eating ability in the item management of food on the plate, independence in cutting food was needed. In addition, fork and knife should be used when appropriate. In the item 'food consumption', a normal portion was supposed to be eaten. This version of the instrument has not been tested for reliability, but a principal component analysis of the instrument resulted in three components: ingestion, deglutition and energy (Westergren et al. 2002b).

4.2.2 Barthel Index

Barthel Index (BI) of activities of daily living was used to assess functional status (Mahoney and Barthel 1965). The total score ranges from 0-100, where lower scores represent poor functional status. The degree of dependency was for instance assessed on the following items feeding, personal hygiene, bathing, walking ability, stair climbing, and bowel and bladder function. By asking the participants or in some cases spouses or health care personnel involved directly in the patients' care (i.e. mostly registered nurses, enrolled nurses and physiotherapists) functional status was estimated. Internal consistency, as measured with Cronbach's alpha, was 0.95 in this study sample. When the instrument's validity and reliability was studied in a Swedish setting among patients with stroke it was determined as good (Röden-Jullig 1994). Moreover, the construct validity of the instrument was shown to be strong when compared to the Functional Independence Measure (FIM)(Gosman-Hedström and Svensson 2000). A limitation of the instrument is the ceiling effect and floor effect which imply that the score does not always correspond to the actual functional level (Dromerick et al. 2003).

4.2.3 Impact on participation and autonomy questionnaire

Aspects of participation and autonomy were assessed by using the Swedish version of the Impact on Participation and Autonomy Questionnaire (IPA-S) (Lund et al. 2005), originally developed by Cardol et al. (1999). In the acute phase and at the three-month follow-up, the questions in the area of self-care and one question about perceived problems with participation were selected for comparison. Each item of the instrument had five scoring options (0-4), except for the single question about perceived problems, which included three options (no problems, minor problems and severe problems, (0-2). As assessed by Cronbach's alpha, the questions in this area had an internal consistency reliability of 0.94. Higher scores on the IPA-S correspond to poorer participation and autonomy. A Rasch-analysis of IPA-S in patients with spinal cord injury showed that the instrument has good internal validity since the goodness-of-fit was acceptable, but some of the items did not fit (Lund et al. 2007). The original version of the instrument has shown to be reliable and valid for use in chronic disorders as stroke (Cardol et al. 2001).

4.2.4 Letter Cancellation Task

The Letter Cancellation Task (LCT) was used to measure unilateral neglect (Mesulam 1985, Tham and Tegner 1996). The paper sheet was placed in front of the participant

and should not be moved during the test. The participants were instructed to circle every 30 'A' letters on an A4 paper with distracting letters (Tham et al. 2001, Mesulam 1985, Tham and Tegner 1996). The minimum and maximum score of LCT is 0 and 30, respectively. The participants were classified into groups based on the total score: mild neglect (21-27), moderate neglect (11-20), severe neglect (0-10) (Tham et al. 2001) and no neglect (28-30). The test has shown to be sensitive (Ferber and Karnath 2001, Jehkonen et al. 1998), but the combination with the Line Bisection might have increased the sensitivity for detecting patients with neglect (Appelros et al. 2004, Jehkonen et al. 1998).

4.2.5 Line Bisection Test

In the Line Bisection test (LBT), the participants were instructed to bisect a 200 millimetre (mm) long and 5 mm wide line drawn on A4 paper with an x mark (Tham and Tegner 1996). A ruler was used to measure the distance in mm from the participant's x mark to the centre. A deviation >10 mm from the centre of the line indicated unilateral neglect (UN) (Tham and Tegner 1996). The combination of LBT and LCT might have increased the possibility of detecting patients with neglect (Appelros et al. 2004, Jehkonen et al. 1998).

4.2.6 Mini Nutritional Assessment

The participants' nutritional status were examined using the Mini Nutritional Assessment (MNA) (Vellas et al. 1999). This nutrition screening and assessment tool includes four types of assessment: anthropometric, general, dietary and subjective (Vellas et al. 1999). The total score of the MNA can range from 0-30 and <17 indicates malnutrition. A score between 17 and 23.5 indicates a risk of malnutrition and ≥ 24 implies a classification of 'well-nourished'. Different types of scales had to be used when the weight was assessed. For instance, a chair scale or hoist scale were used. The weight was measured with light clothes on, but without shoes. In **Study II**, a portable scale was used in the majority of the cases, but in some cases the scale from special accommodations had to be used. The instrument is valid (Vellas et al. 1999) and reliable (Bleda et al. 2002). The Swedish version of the MNA has been shown to be valid among elderly persons in Sweden (Christensson et al. 2002) and during the data collection a guide in Swedish was available (Unosson et al. 2004). The instrument has not yet been tested for validity and reliability on persons with stroke, but it can be suitable as the stroke population is mainly elderly (Foley et al. 2009). The instrument's

internal consistency reliability was 0.70 as measured by Cronbach's alpha in the present studies.

4.2.7 National Institute of Health Stroke Scale

A version of the National Institute of Health Stroke Scale (NIHSS) with motor hand function was used to examine neurological impairments and stroke severity (Jönsson et al. 2008, Hacke et al. 1998). The instrument contains items such as 'level of consciousness', 'best gaze', 'visual', 'facial palsy', 'motor arm', 'motor leg', 'limb ataxia', 'sensory', 'best language', 'dysarthria' and 'neglect'. The score of NIHSS ranges from 0 to 46, with lower scores implying less severity of the stroke. The internal consistency reliability in this sample was 0.73 (Cronbach's alpha). The reliability of the instrument is established (Goldstein and Samsa 1997). The data collection was preceded with a video training to improve the reliability of the Stroke Scale (Lyden et al. 1994), but certification of the assessor was not performed in this present study. The medical records were used in a retrospective data collection, performed by the research group to complete missing data. Retrieving data from medical records is validated and has been shown to be a reliable method for the NIHSS instrument (Kasner et al. 1999).

4.2.8 Revised Oral Assessment Guide

The participants' oral status was evaluated according to the Revised Oral Assessment Guide (ROAG) (Andersson et al. 2002b). The protocol included items such as 'voice', 'lips', 'mucous membranes', 'tongue', 'gums', 'teeth', 'dentures', 'saliva' and 'swallowing'. Each item was assessed on a three-point scale. However, ahead of the statistical analysis the rating scale was converted into two categories (1=healthy and 2=oral health problem) as presented by Paulsson and colleagues (Paulsson et al. 2008). Cronbach's alpha in the sample of the studies in this thesis was 0.69. The inter-rater reliability of the instrument ranged from moderate to very good (Andersson et al. 2002a) and showed to be valid when nursing staffs' and patients' oral assessments were compared (Paulsson et al. 2008).

4.2.9 Well-being questionnaire-12

Psychological well-being was measured by the Swedish version of the instrument Well-being questionnaire-12 (WBQ-12) which has been determined to be valid and reliable (Wredling et al. 1995, Bradley 1994). The questionnaire consists of 12 items separated into three subscales ('Negative well-being', 'Energy' and 'Positive well-being'), each

with four items. In contrast to ‘Positive well-being’, which includes only positively worded items, the subscale ‘Negative well-being’ contains four negatively worded questions. The subscale ‘Energy’ consists of two positively and two negatively worded questions. Each item is rated on a four-level Likert scale with 0=not at all to 3=all the time. The sum of the overall scale General well-being (range 0 to 36) was retrieved by a summation of the scores from the three subscales (range 0-12) according to the manual. The higher scores the higher degree of well-being. In the studied sample the internal consistency reliability in each of the scales, as calculated with Cronbach’s alpha, was 0.72 (Negative well-being), 0.53 (Energy), 0.81 (Positive well-being) and 0.74 (General well-being).

4.2.10 Semi-structured interviews

Interviews were carried out both in the qualitative **Study III** and **Study IV** in order to capture the participant’s experience of eating difficulties. To get as rich descriptions of their experience as possible a semi-structured interview guide with open-ended questions with follow-up questions was developed and applied in each of the two studies (Kvale 1997). The development of the interview guide in **Study III** was inspired by the interview guide previously used in two published studies regarding experience of eating difficulties in the United Kingdom (Perry and McLaren 2003a, Perry and McLaren 2003b). In **Study IV**, the development of questions was based on the findings from **Study III**. The interview guide on **Study III** opened up with questions on person’s previous and present experience of eating. The following excerpts from the interview guide in each of the two studies illustrate how the questions were further narrowed in order to introduce the participant into the aim of the study.

Study III

- Tell me about your experience of eating and drinking before you suffered from stroke?
- Can you describe your situation after your stroke event?
- Can you describe, with as much detailed as possible, how you have been able to eat and drink since the stroke event?
- Tell me how you experience eating with others?

Study IV

- Can you tell me about your experience of meal situations after your stroke!
- How do you manage your eating difficulties today?
- How do you manage shopping for food?
- Can you describe in as much detail as possible how you manage meals in the company of unfamiliar people?

The interview guide was gradually modified during the data collection process. The modification was based on the findings according to the recommendations of Grounded theory (Charmaz 2006). For instance, the properties of the category ‘thinking when eating’ were further explored by adding one question as well as a follow-up question to the last two interviews. The interviews were digitally, audio recorded in both **Study III** and **Study IV**. Most interviews lasted between 15-30 minutes in **Study III**, and 20-50 minutes in **Study IV**. The interviews were mostly conducted in the participants’ homes and only performed by the author of this thesis. In some cases, the interview took place in conference rooms at a hospital.

4.3 DATA ANALYSIS

Several statistical analyses were conducted in this study (Table 2). Distribution of sexes, age, and previous stroke was analysed with descriptive statistics.

The internal consistency reliability of each instrument, except for the Letter Cancellation Task and Line Bisection test, was, when applicable, analysed with Cronbach’s alpha coefficient in **Studies I and II**.

Table 2. Statistical analyses used in the four studies included in the thesis

Analysis	Study I	Study II	Study III	Study IV
Analysis of Covariance (ANCOVA)	X			
Cronbach's Alpha coefficient	X	X		
Constant comparative analysis (Grounded theory)			X	X
Fischer's exact test	X			
Independent student's t-test	X			
Kolmogorov test	X			
Logistic regression (forced entry)	X			
Mann-Whitney <i>U</i> -test	X			
Mc Nemar test		X		
Paired <i>t</i> -test		X		
Pearson chi-square test	X			
Wilcoxon signed rank test		X		

4.3.1 Analysis Study I

To analyse the proportion of women and men with or without eating difficulties a chi-square test was performed. The independent *t*-test was used in instruments without skewness. In the case of skewness, Mann-Whitney *U* test, Chi-square test or Fisher's exact test were performed regarding the analyse of the neurological impairments, functional level, nutritional status and neglect. The skewness was controlled with analysis of histograms and Kolmogorov-Smirnov test and Shapiro-Wilk test.

To examine associations with gender and eating difficulties a logistic regression was performed using the forced entry approach (Hosmer and Lemeshow 2000). The initial selection of variables for the logistic regression was guided by clinical experience from the research group and on the results in studies on eating difficulties and stroke (McLaren and Dickerson 2000, Westergren et al. 2001a, Westergren et al. 2002a). The selected variables included in the analysis were gender, age, the BI-score and the items motor arm and level of consciousness from the National Institute of Health Stroke Scale. In the case of missing values, the test was not selected for the analysis.

An interim analysis was conducted to detect if more patients were needed. An analysis of covariance (ANCOVA) was performed and the dependent variable was the number

of eating difficulties and the independent variables were gender, age and previous stroke. Significant differences between women and men were detected and the data collection could therefore be stopped.

4.3.2 Analysis Study II

Differences in eating difficulties were detected with McNemar's test. Wilcoxon signed ranks test was computed to determine differences in a paired sample on ordinal or higher data and Paired t-tests were computed when applicable. A complete-case analysis was applied, which implied that participants who did not complete the instrument were discarded in the analysis of the instrument. The Barthel Index had one missing value in the follow-up and the imputation method of carrying the last observed value forward was applied.

4.3.3 Analysis Study III

A constant comparative analysis was applied, using the principles of grounded theory. Comparisons were constantly performed within each interview and between interviews. The result of the analysis was constantly compared with the original data to ensure it was grounded on the data (Charmaz 2006, Glaser and Strauss 2007). A single line or words in a line were analyzed together or alone and developed into code/codes. Memos on the ideas from analysis were documented throughout the whole analysis using the best available technique. Clustering was used to illustrate connections between categories. Line-by-line coding was followed by focused and theoretical coding. Based on the findings in the analysis, further questions and participants were included (Charmaz 2006). To achieve saturation a theoretical sampling was applied, which implied that participants with more severe eating difficulties were included to get richer descriptions of the phenomena. Saturation was reached in the qualitative studies when data collection no longer rendered any further knowledge on the developed categories (Charmaz 2006).

4.3.4 Analysis Study IV

The analysis in **Study IV**, was a qualitative constant comparative approach influenced by the principles of grounded theory (Glaser and Strauss 2007) within a constructivist perspective (Charmaz 2006). In similarity with **Study III**, the analysis was initiated with line-by-line coding and continued with focused coding to develop categories.

Memos were written during the analysis and used to develop categories. In contrast to **Study III**, the analysis began after all data was collected.

4.4 ETHICAL CONSIDERATIONS

The four studies included in this thesis were approved by the Regional Ethics Committee, Karolinska Institutet, Stockholm, Sweden (Dnr: 2006/1072-31/2). The studies are performed in accordance with the guidelines for ethical principles of the Helsinki Declaration (World Medical Association Declaration of Helsinki 1964). In the acute phase, the participants/spouses received verbal and/or written information about the project. Information was given regarding that participation in the present study was voluntary and that participants had the right to end their participation at any time. If the participant suffered from aphasia and/or disorientation, a spouse was contacted for informed consent. All data was handled anonymously and only the research group had access to the collected data. The transcriptions of the interviews in **Study III** and **IV** did not include expressed names of persons, places and institutions mentioned to protect the participants' confidentiality.

5 RESULTS

In the acute phase, 104 patients with stroke were included. Different selections of this sample was then included in **Studies I-IV**. Ischemic stroke was present among 79.8% (n=83) of the participants, 29.8% had a previous stroke, and 45.2% were living alone before the stroke. Further characteristics of the participants in **Studies I-IV** are presented in **Table 3**.

Table 3. The age (years) and numbers of included participants in each study

	Study I (n=104)	Study II (n=36)	Study III (n=14)	Study IV (n=13)
Age, median (range)	78.0 (27-93)	74.5 (40-88)	(59-87)	(60-87)
Women (n)	56	21	7	7

5.1 STUDY I

Between women and men differences regarding neglect or oral status were not detected in the acute phase, but women had a significantly higher degree of stroke severity, lower level of energy and lower total well-being. In comparison to men, women were more dependent in ADL. A higher proportion of women were also classified as malnourished, but men were instead at risk of malnutrition ($p = 0.003$).

One or more eating difficulty was present among 81.7% (n=85) of the patients. If no other aspects were considered, women were more likely to have one or more eating difficulty ($\chi^2=4.64$, $df=1$, $p=0.031$). Adjustments were made for the items ‘dependence’ and ‘motor dysfunction of the right arm’, which reduced the OR for being a woman and having eating difficulties by more than 10%. Age and level of consciousness were not added to the model. After the adjustments, no association between being a women and presence of eating difficulties remained. The model fitted the data as measured by the Hosmer-Lemeshow goodness-of-fit test, ($p=0.968$, $\chi^2=0.551$). The frequency of patients with 7-9 eating difficulties was higher among women than men.

The most common eating difficulties were observed in the items ‘managing food on the plate’ (66.3%) followed by ‘food consumption’ (54.8%), and ‘sitting position’ (45.2%). The risk of having inadequate food consumption and reduced alertness was higher

among women than men without adjustments for other aspects. Inadequate food consumption remained as the only eating difficulty associated with the female gender when the OR was adjusted for confounders.

5.2 STUDY II

The results from this study are based on a comparison between two time points: the acute phase and three months post-stroke.

From the acute phase to three months post-stroke a significant reduction was observed in difficulties with 'sitting position', 'managing food on the plate' and 'manipulating food in the mouth', i.e. several participants had improved their abilities in these areas. Eating difficulties such as 'reduced alertness', 'aberrant eating speed' and difficulties 'transporting food to the mouth', 'opening and closing the mouth' and 'swallowing' remained unchanged. The proportion of participants with inadequate food consumption was larger 3 months post-stroke in comparison with the acute phase. A reduced severity of the stroke and improved functional status had occurred three months post-stroke. The number of persons with unilateral neglect had decreased over time in both tests of neglect (LBT and LCT).

The general well-being, including the subscales negative well-being, energy and positive well-being remained unchanged three months post-stroke.

Nutritional status was improved during the first three months post-stroke ($t=-2.463$, $p=0.019$) and the mean value was 21.51 (SD=2.503) in the acute phase and 22.83 (SD=3.332) at the three-month follow-up. A risk for malnutrition was present among 77.8% (n=28) of the participants in the acute phase versus 36% (n=20) three months post-stroke. Two persons (5.6%) were classified as malnourished both in the acute phase and after three months. The presence of oral health problems did not differ between the acute phase and three months post-stroke ($p=0.774$).

There was an improvement over time between perceived participation in self-care regarding *when* the participants wanted the activity to take place, except for the item 'going to bed and getting up when one wants'. The perceived participation in self-care on personal hygiene, getting dressed and grooming *in the way they wanted* remained the same over time.

5.3 STUDY III

Three months post-stroke the participants described their experience of eating difficulties during the first months post-stroke, and losses in bodily functions. Consequently, their ability in eating situations or eating-related activities was impaired.

The participants experienced a 'striving for control' in eating situations. This core category was followed by the strategies: 'being careful when eating', 'analysing consequences', 'avoiding activities', and 'needing help from others'. 'Eating safely' and 'eating properly' were parts of the core category and strategies.

Eating properly implied what the participants experienced as acceptable or not during meals, and *eating safely* involved the experience of eating without consequences, for instance, without losing one's breath.

Being careful when eating was part of *striving for control*, and *careful* implied that they had to be cautious and observant about how they ate in relation to *eating properly* and *eating safely*. For example, they prevented consequences, to *eating safely*, i.e. not letting the food get stuck in their mouth or not biting themselves.

In the *striving for control*, the participants were *analysing consequences*. The participants had to think about their way of being when they were eating, and becoming more aware of their behaviour. Some participants compared their own way of eating with how other people ate, and 'how you are supposed to behave'. They had to calculate whether efforts to *eat safely* or *properly* would work or not.

Avoiding activities was part of *striving for control* to *eat safely* and *eat properly* and implied that activities that usually had been performed in eating situations before their stroke in eating situations were avoided. Some participants avoided using one of their hands when eating. In social settings, they had to be careful of where, what, and with whom they ate, and sometimes they avoided eating situations with others.

As a strategy in their *striving for control* to *eat safely* and *properly*, some participants *needed help from others*. *Others*, for example, were a spouse or health care professionals. In particular, when food had to be cut or when tough food was served, the need for help from others emerged among several of the participants.

Some participants felt that they got feedback from others on how they ate, were reminded, and received others' opinion if they did not *eat safely* or *properly*. The feedback was experienced as nagging, awful, and brought feelings of being treated like a child, influencing the pleasure of eating.

Lower food intake was assessed as a problem by the observer, contradictory to the participants' perceived situations.

5.4 STUDY IV

The findings of this study were based on the participant's experiences of constant struggling with eating situations six months post-stroke.

The participants experienced a desire to mastering eating situations, but there were individual differences in how they mastered and experienced the situations. For instance, different perspectives on *eating perfectly* were expressed. The differences in mastering were related to their values what was of importance to each person, as well as their previous eating habits, how they used to eat before their stroke. Most participants had trouble to master eating situations post-stroke.

In order to master the eating situation, other people such as spouses were important and involved in the eating situation. Other people could be facilitators in the eating situation, but some participants experienced that unfamiliar people made the eating situation more difficult.

New ways of mastering the eating situations were necessary, and could become a new habit. Some of the participants had accepted and got used to the new eating situation.

5.5 CONCLUSIONS

Eating difficulties were common among patients with acute stroke, but the difference between women and men in frequency did not remain when other factors were considered. The most common eating difficulties in the acute phase after stroke were to manage food on the plate, to have sufficient food consumption and to have an adequate sitting position during the meal. Food consumption was the only eating difficulty, which was associated with gender when other factors were taken into account. Three months post-stroke, improvements regarding sitting position and managing food on

plate among the persons with eating difficulties were shown, but the proportion of patients with unsatisfied food consumption had increased. Despite neurological and functional improvements, well-being remained unchanged. According to the participants' experiences, the persons with stroke are striving for control to eat safely and properly and after six months they have desire to master eating situations according to previous values and habits.

6 DISCUSSION

The four studies included in this thesis have highlighted different aspects of eating difficulties during the first six months post-stroke. Both quantitative and qualitative approaches have been used in the exploration.

The following discussion will focus on the most common eating difficulties, followed by food consumption among women and psychosocial well-being over time.

6.1 EATING DIFFICULTIES

The frequency of eating difficulties in the present study is higher than earlier reported during the hospital stay with frequencies of 40-80% (Axelsson et al. 1984, Poels et al. 2006, Westergren et al. 2001a). The variance in reported frequency might be explained by discrepancies in time point for assessments and different study populations.

However, 49% of the patients with different diagnosis suffered from eating difficulties at Swedish hospitals (Westergren et al. 2008). The most common observed eating difficulties in present study i.e. managing food on the plate, food consumption and sitting position are in line with the findings in several other studies (McLaren and Dickerson 2000, Westergren et al. 2001a, Axelsson et al. 1984, Jacobsson et al. 2000, Poels et al. 2006). One study showed that persons with stroke felt abandoned to manage their eating difficulties on their own for a long time after stroke (Carlsson et al. 2004).

6.2 EATING SITUATIONS

Three months post-stroke, the importance of difficulties in activities before and after the meal emerged as being important. Therefore, the area of interest was expanded from eating difficulties and denominated as the eating situation. The expansion was further explored, with questions about shopping and cooking. These eating-related activities were expressed by some participants as more problematic than just eating.

The complexity of the problems are verified in another study as cooking and buying food emerged as a problem among more than half of persons with stroke six months post-stroke (Westergren 2008).

6.3 FOOD CONSUMPTION AND GENDER

The proportion of patients with inadequate food consumption was high in the acute phase and increased significantly among those with eating difficulties three months post-stroke. Insufficient food consumption was experienced by the participants as highlighted by other people like their spouses or health care professionals. The food consumption was also shown to be low among stroke patients at nursing homes in Sweden and about 30% had a poor food intake as reported by the nurses (Kumlien and Axelsson 2002). One of the most common eating difficulties in the present study were difficulties in managing food on the plate and according to the findings of another study, arm function was one of the prerequisites to manage this task and was a predictor of reduced energy and protein intake (McLaren and Dickerson 2000). As shown in the present study, an impaired arm function may not only be associated with functional difficulties as cutting, and transporting the food to mouth, but can also be experienced as embarrassing and associated with improper eating.

The absence of taste after stroke was in the present study, described as being related to difficulties in one's own proper management during the eating situation, which adds another perspective of eating difficulties. In addition, some of the participants negatively experienced the pleasure of eating when others were nagging and reminding them about their food consumption. This loss of pleasure is in line with the findings in other studies, which also reported that eating was not experienced as enjoyable or desirable after the stroke (Jacobsson et al. 1996, Jacobsson et al. 2000). On the other hand, nurses experienced themselves as being 'nagging' when trying to provide sufficient food intake was provided at nursing homes in Sweden (Kumlien and Axelsson 2002).

This insufficient food consumption among stroke patients, and especially among women, is in line with findings from another study where 86% of the women had low food consumption in comparison to 70% among men (Westergren et al. 2002a). Among elderly women with stroke an inadequate energy intake was found (Andersson et al. 2004), which confirm the findings in the present study. The recommended energy intake in healthy individuals throughout all ages is, according to the Nordic nutrition recommendations lower among women than men (Nordic Council of Ministers 2004). The energy balance among the participants was not controlled for in this study design, but should be of interest in further studies. Perhaps proper eating behaviour is of greater

importance for women than for men after stroke, but has not been explored in this study.

6.4 PSYCHOLOGICAL WELL-BEING IN EATING SITUATIONS

Significantly lower psychological well-being was reported among women in the present study and some of the previous studies on gender differences have shown that being a woman is associated with depression and poorer quality of life than among men (Cumming et al. 2008, Glader et al. 2003, Gargano and Reeves 2007, Sturm et al. 2004, Jönsson et al. 2005). Another study reported that being a woman was one of the predictors of poor nutritional status at six months post-stroke (Westergren 2008). In turn, depression or indications of depression, have been associated with weight loss (Jönsson et al. 2008), poor nutritional status and inadequate food intake (Perry and McLaren 2004).

Psychological well-being remained unchanged despite improvements in almost all physical functions in present study, but in six of the nine assessed eating abilities, there was no change from acute phase to three months post-stroke. Eating difficulties have also been shown to have a small, but significant effect on quality of life six months post-stroke (Perry and McLaren 2004). The well-being is an important issue as some participants experienced that eating situations had worsened after the stroke.

6.5 THE SOCIAL PERSPECTIVE OF EATING SITUATIONS

When eating with unfamiliar people the participants in the present study had feelings of embarrassment and shame. However, the feelings of shame were shown to be individual and related to the person's own values. Experiences of shame and embarrassment have earlier been described in other studies regarding eating difficulties and stroke (Jacobsson et al. 1996, Jacobsson et al. 2000, Sidenvall et al. 1996, Perry and McLaren 2003b).

A study on interventions after stroke and severe eating difficulties showed that, despite eating training, the participants with stroke did not choose to eat with other people, except for their spouses (Jacobsson et al. 1997). This is in line with the findings of other studies, where eating with other people was avoided among patients with dysphagia (Ekberg et al. 2002) or elderly women with either stroke, Parkinson's disease or Rheumatoid arthritis (Gustafsson et al. 2003). This 'social withdrawal' was

interpreted as an adaptation and the reasons mentioned were feelings of shame due to spilling and other eating difficulties (Gustafsson et al. 2003). The feelings of shame and embarrassment when eating is in accordance with the Model Of Human Occupation since a person might feel ashamed if he/she acts in opposition to his/her personal values as derived from the culture (Kielhofner 2007). However, onset of disabilities might force a person to revalue his/her convictions about what is right or wrong (Kielhofner 2007) for instance regarding how to eat. Consequently, failure in the striving for control to eat safely and/or properly and to master eating situations according to one's own values and previous habits might be a possible explanation to the unchanged well-being among persons with stroke despite the occurrence in recovery of other factors.

The desire of mastering the eating situation according to individual values and previous habits as experienced by the participants in the present study may not be fulfilled in nursing homes, since Swedish studies on elderly persons showed that the meal situation was not shaped by individual needs, habits, and wishes (Sidenvall 1999, Sydner and Fjellström 2005). Instead, meal situations were based on the constitution of the living situation and its social framework (Sydner and Fjellström 2005).

6.6 AWARENESS OF EATING DIFFICULTIES

In the present study, the participants described a strategy of telling other people about their eating problems. Their awareness of their own present difficulties can be one of their strategies to facilitate a safer eating situation. An increased awareness of disabilities and function have been reported among patients with stroke during the first year, and in turn increased awareness was closely related to how ADL was performed (Ekstam et al. 2007).

6.7 METHODOLOGICAL CONSIDERATIONS

A limitation in the present study, which might influence the generalisability and representativeness, is the large number declining participation due to different reasons. The main reason for declining participation was not given among the majority of the persons with stroke.

The instrument for detecting the eating difficulties was not tested for reliability. The advantages of the instrument were that it was developed for a Swedish setting, included a guide of how to rate. As the rating scale is dichotomous, it might not be sensitive

enough for detecting differences over time. The instrument has now been further developed and have good validity and reliability as an instrument for screening of eating difficulties (Westergren et al. 2009).

An alternative instrument developed for detecting eating difficulties exists, and it was tested for validity and reliability among stroke patients in an acute setting in Great Britain (McLaren and Dickerson 2000). Despite the psychometric tests, the instrument was not validated for a Swedish setting nor translated into Swedish at the time of the study and therefore not used.

Further, another limitation with this study is the restricted amount of observations. Only one eating situation per individual was observed in Study I, which might be insufficient, especially regarding food consumption, as meals are distributed during the whole day. An alternative method could have been to let the patients document their food consumption in a food diary as used among women with stroke, Parkinson's disease or Rheumatoid arthritis (Andersson et al. 2004). However, some of the participants in the present study had difficulties to complete some of the questionnaires on their own and may therefore have problems to complete a diary. On the other hand, a strength of the present study is that persons with eating difficulties in Study II had undergone a structured observation on two standardised meals at two different time points. Another strength, was that the same participants were studied over time and thereby constituted their own controls.

Some of the participants in the present study had difficulties to read and complete the questionnaires WBQ-12 and IPA-S and therefore got help from the researcher. Different ways of collecting data may impact the reliability of the instrument (Polit and Beck 2004b).

During the analyses in the qualitative studies, the author had a pre-understanding due to his clinical experience of working as a registered nurse at a stroke unit. He used the previous knowledge to better understand how the participants experienced eating difficulties. According to Charmaz (2006) the finding in constructive grounded theory is the researchers' interpretation of the studied phenomenon.

The limited duration in some of the interviews, due to communication impairments, such as aphasia among some of the participants may have reduced the richness of the data, which is important in grounded theory (Charmaz 2006). The repeated contacts with the same researcher during six months time may though have created a more comfortable situation for the participants to express their experience and management of eating difficulties. In qualitative studies, a comfortable and safe interview situation is important to be able to get as rich data as possible (Kvale 1997). The credibility has also been strengthened by using the constant comparative analysis as each of the developed codes and categories were controlled in the data during the whole process (Charmaz 2006). An investigator triangulation was applied as the members of the research group, who are experienced clinicians in the field of stroke care, discussed the analyses and memos and were part of the development of categories (Polit and Beck 2004a).

Ultimately, the goal when using grounded theory as an approach is to develop a theory (Charmaz 2006, Glaser and Strauss 2007), but this was not achieved, as further studies are needed with other people i.e. spouses involved in the eating situation. An interpretive description (Thorne et al. 1997, Thorne et al. 2004) was reached and a model could be developed. Saturation was reached with respect on the aim of the study. The findings of the qualitative studies are not possible to generalise, but it was not the purpose with these studies. These qualitative studies offer an opportunity for health care professionals to get a broader understanding of how eating difficulties can be experienced and managed after stroke.

One strength of this thesis is that eating difficulties have been studied both with a quantitative and qualitative approach. A triangulation of quantitative and qualitative methods may strengthen the credibility (Polit and Beck 2004a) and has been suggested as an appropriate approach to be able to capture different aspects of having a stroke (Clarke 2009). In other words, the combination of approaches might have increased the understanding of eating difficulties among stroke patients.

6.8 CLINICAL IMPLICATIONS

Inadequate food consumption was mainly assessed as a problem by the observer, and not identified as a problem by the stroke patients themselves, which indicate a need for

further evaluations with meal observations and a dialogue on food consumption with the persons with stroke.

The findings in the present study indicate a need for health care staff to observe and, if possible, initiate a dialogue about the person's individual values and previous habits in eating situations from a functional and social perspective. The focus should not only be on the specific eating difficulties but also the social context since other people were shown to be involved in eating situations among persons with stroke, and they could either be experienced as facilitators or generating hard, uncomfortable or embarrassing situations. Special attention should be drawn to the food consumption among women in the acute phase and the person's management and experience of eating with unfamiliar people.

Eating difficulties after stroke are multifaceted and have to be observed as an eating situation in the company of others. It is of importance to take the time to ask the individual about their experiences, previous habits and values on the new eating situations.

7 FURTHER STUDIES

Further studies of the complex eating situations for persons with stroke and eating difficulties should include other persons involved in the eating situations i.e. spouses, health care professionals, friends and so on, in order to develop theories and to test them in clinical settings.

Based on this theories and exploration of the complex eating situation for persons with stroke and eating difficulties, more sensitive instruments and methods have to be developed to detect gender differences i.e. values, demands, habits and changes over time.

The next step in further studies would be to conduct a client-centred, randomised controlled trial intervention that focuses on increasing well-being, social participation and life satisfaction among patients with stroke and eating difficulties.

8 POPULÄRVETENSKAPLIG SAMMANFATTNING

I Sverige insjuknar ungefär 30 000 personer per år i stroke. Det är inte bara den enskilde individen som drabbas av sjukdomens konsekvenser utan även de anhöriga. Svårigheter att äta är vanligt förekommande både i den akuta fasen och under rehabiliteringen. Känslor av skam och obehag kan upplevas vid svårigheter att äta. De vanligast förekommande svårigheterna som har observerats vid måltider är hanteringen av mat på tallrik, mängd intagen mat och ansamling av mat i munnen.

Vikt förlust, längre vårdtid, sämre livskvalitet och undernäring har hos patienter med stroke i tidigare studier associerats med svårigheter att äta. Undernäring kan i sin tur bidra till komplicerande tillstånd såsom uppkomst av trycksår, infektioner och död. Tidigare studier har visat att kvinnor med stroke har högre medelålder, äter mindre mängd mat både vid ankomst och vid utskrivning från rehabiliteringsavdelning och är mer beroende vid ADL vid tre månader.

Det övergripande syftet med denna avhandling var att undersöka hur kvinnor och män med akut stroke upplever och hanterar svårigheter att äta tre och sex månader efter insjuknandet.

Syftet med **delstudie I** var att undersöka om det finns könsskillnader när det gäller svårigheter att äta hos patienter med akut stroke i förhållande till funktion och neurologiska funktionsbortfall. Ätsvårigheter var vanligt förekommande och de tre vanligast förekommande svårigheterna som observerades var hanteringen av mat på tallrik, mängd uppäten mat och sittställning under måltid. Den enda statistiskt säkerställda könsskillnaden som kvarstod när andra aspekter hade beaktats var att kvinnor åt mindre mängd mat. De upplevde också sämre välbefinnande. För att kunna upptäcka de patienter, speciellt kvinnor, som behöver närmare övervakning och stödsatser kan observationer av måltid vara nödvändiga. Måltiden kan utgöra en viktig möjlighet till ett rehabiliteringstillfälle.

I **delstudie II** var syftet att jämföra ätsvårigheter hos patienter med stroke tre månader efter insjuknandet i jämförelse med det akuta skedet. Förbättringar kunde observeras avseende sittställning vid måltid och hanteringen av mat på tallrik och i munnen. Andelen personer med otillräckligt matintag ökade signifikant från akutskedet till tre

månader efter insjuknandet. Trots att förbättringar kunde observeras i neurologiskt status och förmågan att sköta aktiviteter i dagligt liv var välbefinnandet oförändrat.

Syftet med **delstudie III** var att genom intervjuer utforska individens upplevelse av ätsvårigheter tre månader efter insjuknandet i stroke. Personerna upplevde att de hade en strävan efter kontroll i ätsituationer med målet att äta säkert och på ett propert sätt. För att uppnå detta efter insjuknandet, uppmärksammade de hur den nya ätsituationen fungerade. Deltagarna upplevde att det var nödvändigt att ta det försiktigt under måltid och man undvek vissa aktiviteter för att äta på ett propert och säkert sätt. De upplevde också att de fick påminnelser av andra personer när det gällde sättet att äta och mängd uppäten mat, men att de på olika sätt behövde hjälp av andra personer för att uppnå de egna målen. Ätrelaterade aktiviteter som att laga mat, diska, ta mat från en buffé och transportera maten till bordet upplevdes också som problematiska. För vissa deltagare var de ätrelaterade aktiviteterna mer problematiska än själva ätandet.

I **delstudie IV** var syftet att utforska hur personer med stroke upplever och hanterar ätsituationer sex månader efter insjuknandet. Deltagarna upplevde en önskan om att kunna bemästra ätsituationer utifrån personens egna värderingar och tidigare vanor. Ätsituationer upplevdes och hanterades med andra ord på ett individuellt sätt. Andra personer var viktiga i bemästrandet och kunde antingen vara personer som underlättade eller försvårade ätsituationerna. Obekanta personer kunde upplevas som besvärande. Studiedeltagarna hade efter sex månader upptäckt nya sätt, att bemästra och hantera ätsituationer, men en del hade accepterat att situationen inte blev bättre.

Svårigheter att äta efter stroke är komplexa och de måste ses som en del av en ätsituation där andra personer är involverade. Studierna visade på att de finns olika perspektiv på vad som är problematiskt vid ätandet och det är därför viktigt att inte bara observera patienten utan även ta sig tid att fråga individen om upplevelsen, tidigare vanor och värderingar angående den nya situationen.

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