STROKE WITH A FOCUS ON THE ELDERLY

FROM A GENDER AND SOCIOECONOMIC PERSPECTIVE

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ABSTRACT

Stroke is one of the leading causes of death and disability in Sweden and in the Western world. Despite this, stroke with focus on elderly is a field where few studies have been conducted from a gender and socioeconomic perspective.

The objectives in this thesis were to analyse from a gender, age and socioeconomic perspective how women were affected by stroke compared with men. The focus was on what it meant for elderly women and men to live with stroke and to explore various gender constructions among men and women. The study also included aspects such as incidence, medical treatment and case fatality after stroke.

Both quantitative and qualitative methods were used. During a two-year period (15 October 2000–14 October 2002), uniform information was collected for all cases of first-ever and recurrent (>28 days) stroke occurring in people of all ages living the region of Umeå, admitted to the University Hospital. Five different registers were used to achieve maximum coverage; the Riks-Stroke (RS) register, the Hospital Discharge Register (HDR), the Cause of Death Register, the northern Sweden WHO MONICA study, and one case-finding study in nursing homes and homes for elderly performed for this thesis. For the qualitative study a maximum variation sampling procedure was used to retrieve participants for in-depth interviews in a follow-up study. Nine women and seven men were interviewed about their experiences of treatment and care after suffering a stroke, as well as about their perceptions and experiences of help from others (health care personnel, relatives and home help personnel).

The first-ever incidence of stroke was higher among low-educated than high educated men and women. Our study showed that there was an education-related age-dependent difference in stroke incidence, where elderly women had the highest incidence of stroke. The 28-day case fatality was shown to be associated with low educational level in patients above 75 years, after controlling for sex, risk factors and acute care variables. The elderly stroke patients experienced subordination in their contacts with health care personnel and the medical context. The participants used different ways to negotiate in the subordinate position, and some of these negotiations were interpreted as being gendered. We have also shown how the elderly stroke patients minimized their own needs of help, strove for independence and accepted help. The men and the women differed in their perceptions and experiences of help from others. Also, the participants expressed multiple types of needs. The elderly stroke patients’ perceptions and experiences of help from others must be studied in relation to their life circumstances and expectations from society. Further analyses of the patients’ perceptions and experiences of help from others were interpreted as being different examples of constructions of masculinities and femininities.

Stroke with a focus on the elderly is a field where few studies have been conducted from a gender and socioeconomic perspective. With further community-based stroke incidence studies including elderly men and women and with the development of appropriately targeted interventions, the burden of stroke in the population could be reduced. More research is needed where both qualitative and quantitative methods are used, as this can provide a richer and perhaps more authentic description of the issue under investigation.

Keywords: stroke, elderly, incidence, case fatality, gender perspective, socioeconomic status, grounded theory, power relations, negotiations.
ORIGINAL PAPERS

The thesis is based on the following publications:


2. Löfmark U and Hammarström A. Education-related differences in case fatality among elderly with stroke. In manuscript.


PREFACE

This thesis and the studies on which it is based are an illustration of the journey I have taken to get a grip of stroke in the elderly from a gender and socioeconomic perspective. It all started in medical school when Anne Hammarström, who later became my supervisor, had an introductory lesson about different perspectives on explanatory models for differences between men and women. Already then I was interested in cardiovascular diseases, and with that lecture she started to open my eyes. In the beginning, it was a challenge to get a grip of gender theory, where texts and articles are so different from medical research articles. But in the Gender Research Group, the texts and articles were scrutinised by clever and thorough doctoral students, and I slowly learnt how to bring public health research and gender theories together.

During this research journey I have also worked as an intern and a resident in the medical clinic at Östersund Hospital and later as a resident in the medical clinic at Capio St Görans Hospital in Stockholm. In this way, research and clinical work helped me to stay close to the field of medicine, so that gender theories could be put into practice, although this proved to be rather difficult. Gender research within medicine is a relatively new research area, which has been both encouraging and challenging. The interest in what a gender perspective implies has proved to be inspiring, difficult and provocative to explain to fellow physicians, researchers, friends and relatives.
INTRODUCTION

The theoretical foundations of this thesis

Gender perspective

Stroke is one of the leading causes of death and disability in Sweden and in the Western world. Yet there is still a lack of knowledge of how stroke affects people, in relation to age, gender and socioeconomic status.

It is often said that women in the Western world use more health services than men; that they visit doctors more often and take more medications (Johnson et al, 2003). Still, for a long time, medical research that included women reported fewer women than men in the study sample. Consequently, researchers started to include women, with the main focus on sex differences. Much of this research can be labelled “additive research” – adding knowledge about women to a field where previous studies have focused on men. However, “additive research” is not the same as gender research in medicine. In this introduction, I will focus on what a gender perspective implies, reflect upon socioeconomic differences in health and then look at previous research on stroke in elderly from a gender and socioeconomic perspective.

What does a gender perspective imply?

Sex and gender in medicine

From a historical perspective gender became popular in medical articles, parallel to sex, at the beginning of the 1970s (Löfmark & Hammarström, 2001). A growing interest in a theoretical redefinition came from medical gender researchers during the 1980s. Still today, many medical researchers use sex and gender as synonyms and traditional medical researchers have shown little interest in a theoretical discussion of gender and sex. Today, very few medical studies on differences between women and men have their theoretical base in gender method, analysis or discussion (Löfmark & Hammarström, 2001). However, at the beginning of the 21st century, a new interest in the use of the term gender has grown strong within the field of public health (Löfmark & Hammarström, 2004). A survey has shown that more than 20 percent of public health researchers in Sweden consider themselves as gender researchers. The willingness to apply a gender perspective is believed to be due partly to last year’s political support for an increase of gender perspectives in research, in general.

However, in medical gender research, sex and gender have different meanings. The term sex refers to biological sex, female and male, for example chromosomes, hormones, whereas the term gender refers to the social, historical and cultural construction of women and men (Rubin, 1975). Gender was introduced to show that sex differences between women and men are not essentialistic, constant and never changing (Nicholson, 1994). Gender issues focus on women and on the relationship between men and women, access to and control over resources, division of labour, interests and needs (Connell, 1987). Today, many gender researchers emphasise the importance of the interplay between biological sex and social gender in the analysis, as what is considered biological might also be socially determined, and vice versa (Johansson & Hovelius, 2004).

There are a couple of important notions in gender research that need to be addressed. Gender research implies:

- critique of prevailing epistemological assumptions. There is a need to expose the stereotypical ideas underlying scientific practice and theory generally. This is done
through awareness about gender-stereotypes, and putting the “gender-glasses” on
- studying gender bias. Focusing on research where women and men are treated differently, or the same, in an unjustified manner.
- the importance of paying attention to the social contexts of men’s and women’s lives as well as studying the relations between men and women.
- that men’s and women’s own perceptions and experiences are considered highly significant. This finds expression in the selection of research methods, mainly through qualitative research.

In this thesis, the concept of sex is used when the analyses focus on differences between men and women, such as differences in stroke incidence and case fatality, where it has been difficult to perform a gender analysis developed from the quantitative results. However, the concept of gender has been used when studying the men and the women in relation to their health behaviours, where their social context is shown to be important for their actions. The concept of gender relations, doing gender and gender practices is developed in the next section.

**Doing gender and gender practices**

In gender research, gender is not regarded as something that people have – it is something people do. Accordingly, gender can be defined as a verb – doing gender – which makes the concept more like a process, where gender is produced and reproduced depending on the context in which it is used (Connell, 1987; Butler, 1990). In this way, gender is analysed as a construction which refers to how masculinities and femininities are constructed in different social and cultural contexts (Connell, 1987; West & Zimmerman, 1987).

Gender can also be viewed as a practice, as a “system of action” that is institutionalised and widely recognised but also dynamic, emergent, locally variable and shifting (Martin, 2003). Knowing how to practise gender, masculinities and femininities, is tacit knowledge and a skill that is acquired over time. Most people, men as well as women, are unaware of how this tacit knowledge is acquired and where and how they practice gender.

**Gender order and gender regime – relational theory of gender**

In all societies there is a gender order, which can be regarded as the overall way of organising gender in a given society (Connell, 1987). In the gender order, there are gender regimes or institutions where the practices of gender are enacted, in working life as well as in domestic life.

According to Connell (2002), the gender order is characterised by four relations: power relations, production relations, emotional and symbolic relations. According to the division of production, women and men are segregated in working life as well as domestic life. The division of production favours men’s position in patriarchal societies as it gives them a series of material advantages, such as higher income or easier access to top jobs (Connell, 1995). According to Connell, the structure of emotional relations is characterised, on a theoretical level, by male superiority and sexualised violence rather than reciprocity and intimacy. Finally, symbolic relations tell us how men and women can dress, use the language and what men and women, in general, are “allowed” to do. These four structures exist parallel to each other within the gender order. In the gender order, there are different gender regimes such as the labour market, the state and the family.

**The construction of masculinities**

The practice of gender is a constantly ongoing construction of masculinities and femininities. There is however a hierarchal structure within this process of construction due to the fact that
men most often are regarded as superior to women. In medical research, most studies that affect both men and women have historically been performed on men only, more specifically, on white-collar and heterosexual men (Harris & Douglas, 2000). Therefore, what these men do is regarded as the norm in society, also in societies where there are many other subgroups of masculinities related to social classes, ethnicities and sexual preferences. This hierarchal division gives priority to a certain dominant masculinity, defined as *hegemonic masculinity* (Connell, 1996).

The public face of hegemonic masculinity is not necessarily what powerful men are, but what sustains their power and what large numbers of men are motivated to support. Men learn to accept and exercise power because it gives them privileges and advantages that women or children do not usually enjoy (Kaufman, 1994). Hegemonic masculinity can be regarded as a configuration of practice, but it can also be seen as being institutionalised in large-scale gender regimes, as a process that involves both social structure and personal life (Connell, 1996). It seems likely that men can benefit from the fact that women in general are subordinated, and some women may even find that the hegemonic pattern is more familiar and manageable (Connell, 1987:2001).

Research on masculinities has grown rapidly during the last ten years, in the United States, United Kingdom and the Nordic countries (Connell & Messerschmidt, 2005). Connell’s definitions of hegemonic masculinity, subordinated and marginalised masculinities have been used by many researchers. In short, subordinated and marginalised masculinities are all related to hegemonic masculinity, but are deemed inferior and exist in the periphery of hegemonic masculinity. This growing body of research on masculinities can partly be due to the critique from lesbian and gay rights movements in the 1970s, as well as to the influence of the feminist movement (Sarvan, 1998).

I believe that the male norm needs to be challenged, questioned and changed according to the social context that is studied. It is important to remember that Connell’s definition has its origin in an Australian context and therefore cannot be valid for all societies. What is the norm in an Australian or American society might not be applicable to the Nordic countries. It has been discussed whether the Anglo-American and Australian societies are based on a more hegemonic masculinity than, for example, the Nordic countries, which seem to have other norms of masculinities (Nordberg, 2000). Maybe the difference lies in different attitudes and definitions towards the meaning of the concept of masculinities and its subgroups.

**Masculinities and health**

Behaviours related to the concept of hegemonic masculinity – denying weakness and vulnerability, dismissing any need for help, and seeking to preserve physical control – can be regarded as one of the most important risk factors associated with men’s illness (Kimmel, 1996). It is known that men have a shorter life expectancy than women, men are more often involved in car accidents than women, use more alcohol than women and suicide is three times more common in men than women (Persson et al, 2006).

It can be argued that when men suffer from chronic illnesses, such as stroke and its consequences, this may be particularly threatening to the construction of hegemonic masculinity, characterised by self-control, independence and self-sufficiency. Charmaz found in her study on men with cardiovascular diseases that they sometimes tried to conceal their illness, due to the risk of being considered “marginalised” in the gender order (Charmaz, 1995). Also, risk taking can be part of the negative health behaviours associated with the constructions of masculinities (Courtenay, 2001).
The construction of femininities
Several general points about masculinities also apply to the analysis of femininities: relationships change, new forms of femininities emerge and others disappear. There is however a fundamental difference. All forms of femininity in Western societies are constructed in the context of the overall subordination of women to men (Connell, 1987). For this reason there is no femininity that holds among women the position held by hegemonic masculinity among men. The organisation of a hegemonic form around dominance over the other sex is absent in the constructions of femininities. Power and authority are not discussed in femininity at large as they are in masculinity research (Connell, 1995).

The global dominance of men is the dominant structure which the constructions of femininities cannot avoid. The process is likely to polarise around compliance or resistance to this dominance. The option of compliance is central to the pattern of femininities which has been given most cultural and ideological support, by Connell defined as emphasised femininity (Connell, 1987). Like masculinities, the constructions of femininities have been developed within a white culture, where other dimensions such as age, sexual orientation and ethnicity are virtually invisible. Also, much of the research on femininities is based on the experiences of young women (Williams C, 2000, Willis et al, 2001; Williams SL, 2003).

Femininities and health
The perception of women and their way of shaping health and illness is often their greater ability to cope with illness (compared to men), because of the stereotypical expectations of femininity as being adaptive and passive (Coppock et al, 1995). Research on adolescent girls and boys with asthma or diabetes mellitus has shown that girls tend to assimilate their diseases to their personal and social identities (Williams C, 2000). However, the negative consequences of incorporating the disease was that the girls lowered their expectations for themselves, for example the girls often expressed guilt concerning the importance of keeping a healthy diet as well as taking part in sports and exercise. At the same time, the stereotypical expectations of masculinity included being sporty and having a more active approach to life, which could be regarded by the boys as stressful and difficult to achieve.

When it comes to the constructions of femininities and health in middle-aged to older women, there is still a lack of knowledge within the field.

Gender and ageing
Life expectancy continues to increase in Sweden. Since 1990 men’s life expectancy has increased by three years, reaching 78.4 years, while women’s life expectancy has increased by two years, reaching 82.7 years (Persson, 2006). However, the main interest among many researchers is the health standard for people of working age, both men and women. This is also a fact within feminist research, which often has failed to connect gender and age (Arber & Ginn, 1995; Arber et al, 2003). Even when gender is included in studies of elderly, it is often treated as a variable rather than as a key element in social life, in other words, gender has been “underdeveloped” in studies on the elderly (Arber & Ginn, 1995).

Research into the lives of older men and women is critical for our understanding of the ageing experience in relation to health and illness. At the same time, gender and age relations interact with class and ethnic relations in the structuring of social life (McMullin, 1995). There is a tendency to treat older women and men as “genderless”, that is, to focus on the descriptions of older biological males and females, rather than accounts of older men’s and women’s gendered life circumstances (Thompson, 1994). The present circumstances of older people can only be understood by reference to their prior life course. For example, older men’s and women’s current financial circumstances are intimately tied to their previous role in the labour market and thus their pension acquisition (Arber et al, 2003). Also, it is likely...
that social activities and interests from adult years continue to be of importance through to later life. Similarly, the pattern of friendships formed by older people during their working life and while caring for children continues to influence the nature and meanings of friendship in later life.

**Masculinities and ageing**
The growing body of mainly sociological research on masculinities in recent years has had younger men in its focus, especially relating to education, crime, unemployment, sexuality and the body (Connell & Messerschmidt, 2005). This is not only because elderly men are omitted from studies, but also because the dominant discourses of younger and middle-aged men are preserved (Thompson, 1994). Changing gender roles and relationships in later life and the challenges to masculinities with advancing age are newly emerging areas in the study of gender and ageing (Arber et al, 2003).

**Femininities and ageing**
The current generation of older women has had a very different life course compared to older men. Social and economic changes associated with advancing age are more pronounced for older women than men (Arber et al, 2003). Older women are more inclined to have financial problems and experience poorer subjective health than men. However, the lives of women have changed enormously over the past century, with the right to vote, the increasing possibilities of women’s employment, the availability of contraception and the liberalisation of abortion.

**The concept of power**
For this thesis, the concept of power was useful in the qualitative studies. The concept of power can be understood as operating in a number of different ways:

1. Power can be seen as an individual attribute, where lifestyle patterns are regarded as voluntary choices. The individual approach is generally used in clinical practice and is compatible with the biomedical model of illness (Hammarström & Ripper, 1999). From this point of view, patients are given individual responsibility for their own health and choices in life, concerning for example diet, physical training, drinking and smoking habits.

2. Power can also be seen as structurally and socially distributed, where social structures systematically advantage some groups over others. This can be exemplified by how white-collar men with cardiac or chest pain are given priority both at the emergency department and in relation to revascularisation after acute myocardial infarction compared with elderly women (Löfmark & Hammarström, 2001).

3. A third way to understand the concept of power is through a post-structuralist model of power, where power is conceptualised as productive, which means that it generates change, which is likely to have positive as well as negative effects (Hammarström & Ripper, 1999). Power in Foucault’s terms is seen as an interplay of forces operating at the level of everyday exchanges in all relationships. However, these exchanges are not equal as they are the sites at which a multitude of hierarchies are played out.

4. The concept of power can also be regarded in relation to position and gender; positional and gendered power. The concept of positional power is defined as the asymmetry in power in the patient-physician relationship, where the physician has more access to power than the patient (West, 1984). The positional and gendered power relation is best described in the case
of women physicians (Johansson, 1998). Women as physicians can be said to have positional power, but not the same power as men as physicians, which implies a status conflict for themselves and for those with whom they interact (West, 1984). There is no clear division between the positional and the gendered power. Rather, they should be interpreted as interrelated, depending on the context within which they are studied.

5. Another way of understanding power is to describe and relate it to power over (involving a relationship of domination/subordination), power to (having decision-making authority) and power within (which involves people organising with a common purpose or common understanding to achieve collective goals). The feminist movement has been influential in developing ideas about power within (Oxaal & Baden, 1997; Westerståhl, 2003). This power within refers to self-confidence, self-awareness and assertiveness. It relates to how individuals can recognise by analysing their experience how power operates in their lives and gain the confidence to act to influence and change this.

Intersectionality
Gender is a distinct and powerful form of stratification that clearly interacts with other social markers such as class and age (Macintyre & Hunt, 1997; Arber & Ginn, 1995). One of the keys to understanding the complexities of health inequalities is to look at the interplay between gender, the distribution of power and resources between different social groups (Wamala & Lynch, 2002). Within the feminist debate, the concept of intersectionality strives to problematise not only the gender system within many Western societies, but also to illuminate how the gender system interacts with other power systems; such as ethnicity, social class, age, sexual orientation and nationality (Lykke, 2003).

Socioeconomic gradient in health
The concept of socioeconomic position is used to mean the social and economic factors that influence what positions individuals and groups hold within the structure of society (Lynch & Kaplan, 2000). A variety of other terms have been used in epidemiologic literature including socioeconomic gradient, social class, social stratification, social inequality, social status and socioeconomic status (Krieger et al, 1997). In this thesis, the terms socioeconomic status and socioeconomic gradient are used.

The idea of measuring the socioeconomic gradient or socioeconomic status in social epidemiology is to describe the social stratification (Lynch & Kaplan, 2000). The socioeconomic stratification can be said to distribute structural positions in society. These positions within the stratification are powerful determinants of the likelihood of health-damaging and health-enhancing exposures, behaviours and resources (Lynch & Kaplan, 2000). With a measure such as social stratification, it is possible to study how resources, living conditions and lifetime opportunities are related to individuals’ structural positions in society and how this affects the likelihood of achieving good health. Lynch and Kaplan (2000), in an overview of the concept of socioeconomic positions in social epidemiology research, have briefly discussed three major sociological traditions, Marxian, Weberian and Functionalist. They argue in short that, according to Marx, society is stratified into classes that are determined by production and that this forms a relationship between those who own and those who do not own property (in terms of factories, financial institutions etc.). This yields a dichotomous model of class relations, an exploiting class (who own properties) and a subordinated non-propertied class, who are of necessity in conflict with each other. According to Weber, society is stratified in multiple ways: class, status and political power, and this stratification leads to unequal distribution of economic resources. Finally, the Functionalist
view describes how the social stratification in society is natural and necessary, which means that the stratification unconsciously ensures that those most qualified occupy the positions of power (Lynch & Kaplan, 2000). In this thesis, the sociological tradition more closely related to Weber is used as a point of departure.

Within health research, the distinction between the concepts of inequality and inequity has given rise to many questions and debates (Kawachi et al., 2002). Inequality in health is the term used to study differences, variations and disparities in the health achievements of individuals and groups (Kawachi et al., 2002). For example, most of the health inequalities across social groups (such as class and race) are unjust because they reflect an unfair distribution of the underlying social determinants of health (i.e., access to educational opportunities, safe jobs and health care) (Woodward & Kawachi, 2000). Inequities in health are defined as differences in health that are unnecessary, avoidable, unfair and unjust (Whitehead, 1992). Inequity is also a political concept, expressing a moral commitment to achieve social justice (Kawachi et al., 2002). However, many forms of health inequalities are also inequitable. In this thesis, the concept of inequalities is used, as I have studied differences in stroke in relation to socioeconomic status in men and women. I believe that research can create change and reduce health inequalities, in the long run.

The relationship between the socioeconomic position of individuals and populations and their health is well established (Macintyre, 1997). However, the Black Report in 1980 was one of the first reports in Europe where different theoretical explanations for socioeconomic differences in health were proposed (Marmot, 2003). After this, inequalities in health have come more and more into focus in public health research. However, at the time of the Black Report (1980) there were few data available on social inequities in other countries than Great Britain. In some welfare states, such as Sweden, it was believed that socioeconomic differences in health and growth had disappeared, so that there was no longer any need to collect information on socioeconomic differences (Macintyre, 1997). However, since 1980 an extensive body of research has been published which shows that social class gradients in mortality, morbidity and growth are found in all industrialised countries, also in Sweden (Marmot, 2003; McMunn et al., 2006).

Overall, studies focusing on inequalities tend to show greater differences among men than among women (Macintyre & Hunt, 1997). At the same time, increasing disparities appear to be mainly due to faster declines in mortality among the better-off groups. It has also been observed that the causes of death contributing to social class inequalities differ between countries (Macintyre, 1997). In order to understand the mechanisms behind social inequalities in health, it is important to address fundamental social constructs that include and analyse not only socioeconomic status but also, for example, gender and age (Wamala & Lynch, 2002).

Stroke in elderly from a gender and socioeconomic perspective

**Incidence and prevalence**

Stroke is one of the major causes of morbidity and mortality in Sweden and other industrialised countries (The National Board of Health and Welfare, 2006a). Each year between 27,000 and 35,000 persons have a stroke and the mean age of stroke patients in Sweden is now 75 years (73 years for men and 77 years for women) (Stegmayr & Asplund, 2003a). The incidence of stroke in Sweden, i.e. the rate at which a new event occurs in the population, has been shown to be relatively stable over many years, with a lower incidence of stroke in women compared with men in the age group <75 years (Stegmayr & Asplund, 2003b). Swedish studies have shown that the stroke incidence has been unchanged or even increasing slightly over the last few decades. In the older age groups (≥75 years), the
incidence of stroke is reversed, that is, Swedish women have a higher incidence than men (Hulter-Asberg & Parrow, 1991; Johansson et al, 2000; Appelros et al, 2002).

There is a clear socioeconomic gradient in incidence of stroke, where low-educated and blue-collar men and women have a higher incidence of stroke than high-educated and white-collar men and women, at least up to the age of 75 years (Jakovljevic et al, 2001a; Wolfe et al, 2002; Gillum & Mussolino, 2003).

The prevalence of stroke, i.e. the proportion of stroke-affected persons in Sweden at a given time, is more than 100,000 people (The National Board of Health and Welfare, 2006a). The risk of being affected by a stroke increases with age, but the stroke severity in Sweden has decreased in both men and women over time (Stegmayr & Asplund, 2003b). With a stable incidence but a decrease in case fatality, the prevalence of stroke in Sweden will increase. Also, with an ageing population the prevalence of stroke will increase as long as the incidence is unchanged. Consequently, more stroke patients will survive into old age, but be in need of health care and rehabilitation, as well as assistance from home help services and/or relatives. In older ages, more women than men are living alone and the consequences after a stroke regarding living conditions and the need of help at home differ between men and women (The Swedish Parliament Propositions, 2001).

**Stroke mortality**

Stroke mortality is higher in men than in women in most countries, but the differences narrow considerably above the age of 75 years (Cox et al, 2006). In Sweden, the stroke mortality has declined, mainly because the case fatality has decreased. In patients under 75 years of age, the northern Sweden MONICA study has shown that the case fatality has declined from almost 20 percent in 1985 to 11 percent in 1998 (Stegmayr & Asplund, 2003b). One important reason for the declining case fatality is probably the improved care of the stroke patients.

There is a well-known socioeconomic gradient in cardiovascular mortality (Kunst et al, 1998; Jakovljevi et al, 2001b; Feigin et al, 2003; Avendano et al, 2004; Cox et al, 2006). However, there is still a lack of stroke mortality studies that includes both men and women (Holroyd-Leduc et al, 2000), as well as studies on people older than 75 years (Cox et al, 2006). Also, in the studies performed, there are contradictory findings concerning whether the socioeconomic gradient persist into old age (>75 years) or not. In a European study on the socioeconomic gradient in stroke mortality where both sexes as well as persons >75 years were included, higher mortality rates were reported in persons with low educational level compared to higher educational level (Avendano et al, 2004). In this study, the socioeconomic differences in mortality generally decreased with age. However, others have found a persistent difference between socioeconomic status and mortality in older ages (Huisman et al, 2004).

**Risk factors, Stroke Unit care and case fatality**

**Risk factors for stroke**

The most frequent cause of stroke is atherosclerosis of the cerebral vasculature followed by cardioembolism. Overall, the traditional risk factors associated with stroke – smoking, hypertension, diabetes mellitus and atrial fibrillation – are important for both men and women. High age, hypertension and atrial fibrillation are by far the most frequent and well-documented risk factors (Pinto et al, 2004). High age represents the strongest non-modifiable risk factor associated with ischaemic stroke, while hypertension constitutes the most important modifiable cerebrovascular risk factor, confirmed in studies on primary and secondary prevention of stroke in hypertensive patients (Prospective Studies Collaboration, 2002; Pinto et al, 2004; Rosen, 2006).
Sex differences in cardiovascular risk factors have been described (Roquer et al, 2003). There is also a clear socioeconomic gradient in the cardiovascular risk factor profile between men and women (Davey Smith et al, 1998a; Hart et al, 2000; Rosen, 2006). It has been argued that women’s relatively lower levels of traditional risk factors in younger ages (smoking, alcohol consumption, diabetes mellitus and hypertension) can contribute to the age difference noticed among men and women (Roquer et al, 2003).

However, in recent years, there has been an increased frequency of younger women using tobacco in Sweden; in 2004 only five percent of the boys smoked daily or almost daily, whereas 13 percent of the girls in the 9th grade (the top of the lower-secondary school) did so (Boström, 2006). Smoking has also been shown to be more common among women aged 25–34 years, compared to men in the same age group (Peltonen et al, 1998). Similarly, there are large differences between social groups in smoking habits, and these habits appear not to have changed among men since the early 1980s. In 2002–03, around eight percent of high-educated men smoked, compared to 20 percent of low-educated men. Among women, there has been a tendency towards increasing differences (Peltonen et al, 1998; Boström, 2006). In 2002–03, around ten percent of high-educated women aged 16–84 years smoked, compared to 25 percent of low-educated women.

There are also large differences between countries in the Western world; Sweden is one of the few countries where more women smoke than men (Molarius et al, 2001). In northern Sweden, 11 percent of the men aged 25–64 years and 18 percent of the women were smokers in 2004 (Stegmayr et al, 2004).

There is a clear socioeconomic gradient in risk consumption of alcohol in Sweden among both men and women. It has been shown that 25 percent of male blue-collar workers aged 16–84 years were risk consumers in 2004 (Boström, 2006). At the same time, the level of risk consumption of alcohol was lowest among Swedish female white-collar workers with high income aged 16–84 years (eight percent) (Boström, 2006).

Hypertension is a strong risk factor for stroke in both men and women (Prospective Studies Collaboration, 2002) as well as for persons with low compared to high socioeconomic status (Davey Smith et al, 1998a). It is known that the relative risk of stroke is about same for hypertensive men as for hypertensive women; also in persons older than 75 years (Ellekjaer et al, 2001). Intervention with anti-hypertension treatment has been shown to be highly beneficial in decreasing the incidence of stroke in men and women aged <80 years (Dahlöf et al, 1991; Lithell et al, 2003). In the north of Sweden, the levels of both systolic and diastolic blood pressure have remained constant during the last ten years (Rosen, 2006). At the same time, there are Swedish studies showing the importance of adequate blood pressure control for lowering the risk of stroke (Weinehall et al, 2002), but a large proportion of the population with increased blood pressure do not receive optimal treatment (Weinehall et al, 2002; Persson et al, 2004).

Diabetes mellitus used to be related to an increased risk of death by stroke in both men and women. However, this risk has now decreased considerably, especially in Swedish women (Rosen, 2006). However, diabetes mellitus is still more common among persons with low socioeconomic status (Davey Smith et al, 1998a), especially among men (Rosen, 2006). It is also known that diabetes mellitus is more common among adult immigrants, especially among those born outside of Europe.

Non-valvular atrial fibrillation is more common among men, but as the risk increases with age, the prevalence is higher in women (Kannel et al, 1998; Sudlow et al, 1998; DeWilde et al, 2006). Still, even among apparently ideal candidates, warfarin therapy is underused for stroke prevention in patients with atrial fibrillation (Sudlow et al, 1998). No socioeconomic gradient in the incidence of atrial fibrillation has been found (DeWilde et al, 2006).
This excess rate of risk factors among persons with low socioeconomic status increases the risk of stroke. However, it has been argued that socioeconomic factors seem to outweigh traditional risk factors in predicting stroke trends (Asplund, 2005). For example, it has been calculated that in countries where the gross domestic product is low, the stroke mortality is much higher than in countries with a higher gross domestic product, also after controlling for traditional cardiovascular risk factors (Asplund, 2005). The relations between traditional risk factors, socioeconomic factors and the risk of stroke seem very complex. More studies are needed that focus on these interactions. Unfortunately, one of the largest international stroke studies, WHO MONICA, has not yet included other possibly important non-traditional risk factors for stroke, such as: physical activity, wealth, meaningfulness, happiness or medical adherence etc.

**Stroke management**

The Stroke Unit Trialists’ Collaboration has shown convincing evidence for declined case fatality and improved functional outcome in patients with acute stroke treated in Stroke Units compared to those treated in general medical wards (SUTC, 2000). More recent studies have confirmed the effectiveness of Stroke Unit care (Kalra et al, 2005). At the same time, stroke care in Stroke Units increases survival even 10 years after stroke, probably because long-term survival is related to early reduction in disability (Drummond et al, 2005). It has also been shown that although acute medical treatment with drugs such as t-alteplase is a very potent intervention, management in Stroke Units has the greatest population benefit (Gilligan et al, 2005). However, despite the strong scientific evidence for organised stroke care, it is still far from implemented, and inequalities in care continue to exist. These inequalities in stroke management are related to female sex (Di Carlo et al, 2003; Glader et al, 2003) and high age (Bhalla et al, 2005; Lamassa et al, 2001).

The reported proportion of patients treated in Stroke Units ranges from 23 percent in Australia, 31 percent in Canada, 50 percent in the UK, to approximately 80 percent in the Scandinavian countries (Norrving, 2005).

From a gender perspective, similar management of women and men in relation to admission to Stroke Unit care has been noticed in Swedish studies (Stegmayr et al, 1999; Glader, 2003). However, in a Canadian study evidence for gender bias in admission to Stroke Unit care was found (Kapral et al, 2005). A European study on resource use in stroke patients showed that women were less often diagnosed with brain imaging, Doppler examination, echocardiogram as well as angiography (Di Carlo et al, 2003). In addition, women were more physically and mentally impaired and dependent on others at the three-month follow-up, even after adjustment for age (Glader et al 2003; Di Carlo et al, 2003).

No consistent pattern of inequality has been found in relation to socioeconomic status and the provision of acute and longer-term stroke care (McKevitt et al, 2005; Cox et al, 2006). However, there are studies from Finland (Jakovljevic et al, 2001b) and Canada (Kapral et al, 2002) where inequalities in service and treatment provision for those in low-income groups have been noticed.

**Case fatality**

Case fatality can be used as a measure of the quality of acute care as well as of severity of disease. Low socioeconomic status has been shown to have an inverse relation to stroke survival, both due to worse stroke risk profiles (Davey Smith et al, 1998a; Cavelaars et al, 2000; Wolf-Meir et al, 2003), and due to less active acute stroke management (Kapral et al, 2002). Studies by Kapral and colleagues (Kapral et al, 2002) and Jakovljevic and co-workers (2001a) show that socioeconomic status is linked to an increased risk of death both at 30 days and one year after stroke. Other studies report either no association or a weak association.
between socioeconomic status and case fatality in patients aged <75 years (Peltonen et al, 2000; Weir et al, 2005; Aslanyan et al, 2003). There is still a lack of knowledge about the association between socioeconomic status and case fatality after stroke in elderly persons.
AIMS AND OBJECTIVES

The overall aim of this study was to analyse from a gender, age and socio-economic perspective how women were affected by stroke compared with men. The focus was on what it meant for elderly women and men to live with stroke and to explore various gender constructions among men and women. The study also included aspects such as incidence, medical treatment and case fatality after stroke.

The specific research questions were:

1. Was low educational level related to the risk of first-ever stroke among men and women? (Paper I)

2. Did low educational level increase the risk of first-ever stroke, after controlling for age and sex? (Paper I)

3. Did men and women with stroke have similar risk factors for stroke, did they have access to Stroke Unit care and were there any differences in relation to acute medication in different age groups? (Paper II)

4. Were there education-related differences in case fatality after stroke in different age groups? (Paper II)

5. How did elderly men and women with stroke respond to treatment and care in the acute care setting? (Paper III)

6. What were the elderly people’s perceptions and experiences of receiving help from others? (Paper IV)

7. What kind of gender constructions could be identified among elderly men and women with stroke? (for the thesis)
METHODS AND MATERIALS

For this thesis, both quantitative and qualitative research methods have been used. A combination of quantitative and qualitative methods is important within public health research, as both methods enrich one another (Foss & Ellefson, 2002; Dahlgren et al, 2004). An overview of the different papers’ populations, data collection procedure and analyses are presented in Table 1.

Table 1. Description of the participants, settings, data collection procedures and analyses performed in the different papers in the thesis.

<table>
<thead>
<tr>
<th>Paper</th>
<th>Participants</th>
<th>Setting</th>
<th>Data sources</th>
<th>Analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>n=457 213 men 244 women</td>
<td>Umeå City</td>
<td>Riks-Stroke, Hospital Discharge Register, Cause of Death Register, case finding study in nursing homes, register data from Statistics Sweden</td>
<td>Mean values, Chi 2 tests, Bonferroni multiple significance test, logistic regression analyses</td>
</tr>
<tr>
<td>II</td>
<td>n=624 337 men 287 women</td>
<td>The Municipality of Umeå</td>
<td>Riks-Stroke, Hospital Discharge Register, Cause of Death Register, register data from Statistics Sweden</td>
<td>Mean values, Chi 2 tests, Pearson’s correlation coefficient, logistic regression analyses</td>
</tr>
<tr>
<td>III</td>
<td>n=12 5 men and 7 women</td>
<td>Stroke Unit in Östersund Hospital</td>
<td>Thematically structured interviews</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>IV</td>
<td>n=16 7 men and 9 women</td>
<td>The County of Jämtland</td>
<td>Thematically structured interviews</td>
<td>Grounded theory</td>
</tr>
</tbody>
</table>

The quantitative study

Study Area

The municipality of Umeå is situated close to the coast in the northern part of Sweden. In the municipality there is one hospital; Umeå University Hospital. The total number of inhabitants in the municipality was 132,039 on 31 December 2001 (65,776 men and 66,263 women). The proportion of the population aged ≥75 years was 6.9 percent in 2001, compared with 7.6 percent for the total Swedish population (Statistics Sweden, 2003).

Population

The population consisted of stroke patients with first-ever and recurrent (>28 days) stroke occurring in people of all ages living the health care district of Umeå, admitted to the University Hospital. An acute stroke was defined as rapidly developed signs of focal or global brain dysfunction lasting >24 hours, with no apparent nonvascular cause (Tunstall-Pedoe et
In Paper I, patients with intracerebral haemorrhage, cerebral infarction and unspecified stroke were included. In Paper II, we only included patients with cerebral infarction.

Case ascertainment

During a two-year period (15 October 2000–14 October 2002), uniform information was collected for the whole population included in this thesis. Several different registers were used to achieve maximum coverage; the Riks-Stroke (RS) register, the Hospital Discharge Register (HDR), the Cause of Death Register, the Northern Sweden WHO MONICA register and a case-finding study in nursing homes and homes for elderly. The registers used will be presented below.

Riks-Stroke

The national quality assessment register for acute stroke, Riks-Stroke (RS), was set up in Sweden in 1994 to monitor the quality of stroke care and to improve the care by providing comparative feedback data in process and outcome for hospitals treating patients (Asplund et al., 2000). Since 1998 all hospitals in Sweden caring for patients with acute stroke have participated in the registration, and Umeå University Hospital has been part of the collaboration since the start. Stroke patients of all ages are included in the RS register and valid stroke diagnoses are intracerebral haemorrhage, cerebral infarction and unspecified stroke (ICD-10: I61, I63 and I64) (all positions). Transient ischaemic attack and subarachnoid haemorrhage (ICD-10: G45 and I60) are included by some participating hospitals, but not summarised in this thesis.

Data collection in RS is kept simple to ensure maximum coverage. It includes information on the patients’ sex, age, history of previous stroke, risk factors such as atrial fibrillation, living situation before the stroke, as well as the need of assistance in three primary functions of activities of daily living (ADL): mobility, personal hygiene and dressing/undressing (Appendix 1) (Glader, 2003). Items related to type of department to which the patient is admitted (i.e. medical, neurological or geriatric ward), whether or not the unit has organised stroke care (Stroke Unit), level of consciousness on admission to hospital, whether or not a CT scan was performed, antithrombotic drug treatment during the acute phase, and whether or not a postmortem autopsy was performed. At discharge, length of acute care hospital stay, diagnosis of stroke subtype according to the specified WHO criteria and further management (at home, at institutions at various levels) are recorded. The Riks-Stroke questionnaires are updated regularly and new versions of its contents are available online (http://www.riks-stroke.org/files/contents.html).

For this thesis, an additional questionnaire was constructed and used in the Stroke Unit of Umeå University Hospital during the study period. The questions in this questionnaire concerned risk factors such as previous stroke, hypertension, diabetes mellitus and smoking habits. When our study started in October 2000, only atrial fibrillation was included in the RS questionnaire. However, in January 2001 the same risk factor variables as we used in our additional questionnaire were added in the RS register. Still, an additional questionnaire improved our possibilities to validate the RS register in the Stroke Unit and collect data concerning risk factors for stroke during the whole study period.

During the study period, 15 October 2000–14 October 2002, the Stroke Unit at Umeå University was under construction. When this study started, the unit only had 12 beds, resulting in a lot of stroke patients being transferred to other medical wards when they were admitted to the hospital. Registration in RS was common in the other medical and surgical
wards compared to the Stroke Unit. We therefore decided to improve the coverage of acute stroke events by using also the Hospital Discharge Register (HDR).

**The Hospital Discharge Register**
The Hospital Discharge Register (HDR) is a register based on all patients discharged from all hospitals in Sweden. From 1987, HDR covers all public in-patient care in Sweden ([www.sos.se/epe](http://www.sos.se/epe)). Information on patients with discharge diagnoses of ICD-10; I61, I63 and I64 (all positions) was selected retrospectively from the HDR for the same two-year study period. By using the personal identification number, a link was made between the stroke events in the RS register and those in the HDR. In this way, stroke events not included in the RS register could be detected. These cases were included in our two-year registration and data from the hospital records were collected for the patients using the same questions as in the RS questionnaire.

**The Cause of Death Register**
The Cause of Death Register includes diagnoses of all patients who have died in or outside hospital ([The Cause of Death Register, 2004](http://www.sos.se/epe)). All death certificates during the study period were examined, and certified deaths from cardiovascular diseases were registered only if preceded by an acute clinically diagnosed stroke.

**The Northern Sweden WHO MONICA register**
The Northern Sweden WHO MONICA register (MONItoring trends in CArdiovascular Disease) criteria were used to validate the stroke diagnoses as well as deaths among those aged 75 years and younger ([Stegmayr & Asplund, 1992](http://www.sos.se/epe)). The MONICA Project is a population-based myocardial infarction and stroke registry established in 1985 in the two northernmost counties in Sweden. For this two-year study, the MONICA register was helpful in validating the stroke diagnoses in patients <75 years as well as providing information concerning the terminal cause of death in the death certificates.

**Case-finding study in nursing homes and homes for elderly**
To be able to fulfil the criteria for a community-based study, strong efforts were made to ascertain not only stroke cases that were hospitalised but also those that were non-hospitalised. Therefore, an attempt to register non-hospitalised acute stroke events was performed in all 25 nursing homes and homes for elderly in the city of Umeå, during six months (15 October 2000–14 April 2001). All staff in the nursing homes and homes for elderly was informed about the study and several seminars were held for the staff about risk factors and symptoms in stroke. A specially trained nurse stayed in regular contact with the different homes in order to improve the reporting of stroke events, and the physicians were contacted several times to be reminded about the purpose of the study. The study was planned to continue for the same two-year period as the other registers, but due to the fact that no stroke events were identified that were not sent to the hospital during the first six months, the study was stopped.

**Coverage**
During the study period 759 patients has been registered in RS at Umeå University Hospital. Of these, 38 were missing in the Hospital Discharge Register. The control of the Stroke Units list of admitted stroke patients revealed that all stroke patients had been entered in the RS register. Through the HDR 222 stroke patients were found who were not registered in the RS register. Of these, hospital records were missing for 30 patients and in 38 cases the stroke events had been misclassified, leaving 154 patients with stroke. At the time of the survey the
coverage of the RS register was 83 percent at Umeå University Hospital. The case-finding study of non-hospitalised older patients in 25 old peoples homes showed that all patients with stroke were sent to the emergency department. In total, 913 stroke patients aged 20–97 were found through the different registers (Table 2).

Register data from Statistics Sweden

From Statistics Sweden, the central government authority for official statistics and other government statistics, we have obtained register data concerning the socioeconomic status of the whole population in the catchment area (Umeå Municipality). Due to the Swedish personal code system, statistics are available on an individual level.

For this thesis, socioeconomic status was studied using educational level. Data concerning level of education were retrieved from the Swedish Educational Terminology (SUN, 2000). SUN is a standard for use in classifying individual educational programmes, but at the same time makes up a system for aggregating types of education into larger categories. SUN is used in central registers of official statistics, e.g. Statistics Sweden’s register of the level of education of the population. SUN has an age limit set at 75 years and data have been collected and aggregated in 1990 and 2000. For this thesis, SUN from 1990 was used for the age group 75–85 years and SUN from 2000 for the age group 20–74 years. SUN 1990 and 2000 have the same structure and assess educational levels in the same way. Due to the age limit set at 75 years, 777 of the stroke patients could be retrieved in the SUN classification (Table 2).

Table 2. Number of validated cases during the whole study period, in Papers I and II.

<table>
<thead>
<tr>
<th>Registers</th>
<th>Total number of cases during the study period</th>
<th>Cases in Paper I</th>
<th>Cases in Paper II</th>
</tr>
</thead>
<tbody>
<tr>
<td>RRS, HDR, Cause of Death register, case-finding study in homes for elderly, SUN</td>
<td>913 patients of whom 777 were aged 20–85 years</td>
<td>457 patients aged 35–85 years in the City of Umeå</td>
<td>624 patients aged 20–85 years in the Municipality of Umeå</td>
</tr>
</tbody>
</table>

Definition of variables

Internationally, diagnoses of diseases and deaths are preferably made in accordance with the rules of ICD-10. An acute stroke was defined as rapidly developed signs of focal (or global) disturbance of brain function lasting >24 hours, with no apparent non-vascular cause. The ICD-10 diagnoses used were cerebral infarction (I63.0–9), intracerebral haemorrhage (I61.0–9) and uncertain stroke (I64.9).

Age was categorised into different groups: 35–44, 45–54, 55–64, 65–74, 75–85 as well as 35–74 and 35–85. Age was also used as a continuous variable in Papers I and II.

The variables sex, age and education were dichotomised as follows: women (=1) and men (=0), high age (≥75 years=1) and low age (<75 years=0), low educational level (a maximum of nine-year compulsory school=1) and high educational level (upper-secondary education and above=0).

Previous stroke was measured as previous hospitalisation for stroke (=1). Atrial fibrillation was measured as atrial fibrillation verified by ECG (1=yes, 0=no). High blood pressure was
measured as being diagnosed with high blood pressure >140/90 (1=yes, 0=no). Diabetes mellitus was measured as being diagnosed with diabetes mellitus (1=yes, 0=no). Smoking was measured as current smoker (=1) or non-smoker (=0).

A composite index of ADL (activities of daily living) was constructed, consisting of three different activities; mobility indoors and/or outdoors, dressing with or without help and personal hygiene. Being ADL dependent on help in at least one activity was coded as 1, whereas independence in ADL was coded as 0.

Anticoagulation therapy was measured as treatment with aspirin, other antithrombotic agents or warfarin prior to the acute stroke and continued at discharge, or if the patient was put on any anticoagulation therapy during hospitalisation (1=yes, 0=not any anticoagulation therapy).

Computerised tomography (CT) was used to measure whether the patient had undergone CT during the hospital stay to verify the clinical diagnosis of stroke (1=yes, 0=no).

Stroke unit care was used as a measure, dividing the patients into stroke unit care (=1) or general medical ward care (=0) during the acute care stay.

Missing values

The level of missing values was rather low, see Table 3. However, for the logistic regression analyses we performed an imputation procedure in order to reduce the level of missing values to include all cases. Each missing value (coded as 9) was replaced with a value of 0 that represented the reference variable among the dichotomised independent variables (Rubin, 1987).

Table 3. The level of missing values (percent) among the variables.

<table>
<thead>
<tr>
<th>Variables</th>
<th>Missing values (percent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous stroke</td>
<td>6.0</td>
</tr>
<tr>
<td>Atrial fibrillation</td>
<td>6.0</td>
</tr>
<tr>
<td>Smoking</td>
<td>7.4</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>3.1</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>2.2</td>
</tr>
<tr>
<td>Assessment by physiotherapist</td>
<td>1.6</td>
</tr>
<tr>
<td>Assessment by occupational therapist</td>
<td>2.0</td>
</tr>
</tbody>
</table>

Ethical considerations

All acute stroke patients admitted to hospitals in Sweden and who are included in Riks-Stroke are informed about the registration. During the data collection period for this study, patients admitted to the Stroke Unit were informed by notes on the information board about the study. From Statistics Sweden, we received a decoded data file with information on educational level. The Regional Ethical Review Board at Umeå University approved the study, 99-378.
Statistical analyses

Data analyses were performed with the SPSS statistical package (versions 11.5 and 13.0). Comparisons of mean age between women and men were performed with Student’s t-test. The significance level was set at $p<0.05$.

In Paper I, the incidence was calculated in relation to age, sex and educational level. The incidence rate was calculated by dividing the cases in each age group as well as in each educational group, men and women respectively, with the population in that specific age group as well as in each specific educational group, average population/year. Bivariate and multivariate logistic regression analyses were conducted to investigate the relation between educational level and stroke incidence, after controlling for sex and age. The results were expressed in odds ratios (OR) for stroke and a confidence interval of 95 percent (95% CI) for odds ratio was chosen as statistically significant. We also used the Bonferroni test for multiple significance to decrease the risk of mass significance.

In Paper II, bivariate and multivariate logistic regression analyses were used in order to identify, among risk factors and acute care variables, the best independent predictors of 28-day case fatality. We controlled for age, sex and educational level in all the analyses. The results were expressed in odds ratios (OR) for stroke and the 95% CIs were calculated to describe the precision of the estimates. Correlations between the independent variables in the logistic regression analysis were <0.3 (Spearman’s rho). We also used the multiple imputation procedure, where each missing value (coded as 9) was replaced with a value of 0 that represented the reference category among the dichotomised independent variables (Rubin, 1987).

The qualitative study

The perspective in qualitative research is holistic in the sense that the settings and people are viewed in the context of the present situation. In qualitative research, the researcher develops concepts, insights and understandings from patterns in the data (Starrin et al, 1997). This approach differs from quantitative research, which collects data to assess preconceived models, hypothesis or theories. In qualitative research the researcher often interacts directly with the participants. Thus, the researcher needs to be particularly sensitive to the effects and influences he or she might have on the participants. At the same time, the research process is strengthened if the researcher is seen as a subject, who plays an important role in the research process, and if the pre-understanding of the researcher is taken into account (Lincoln & Guba, 1985; Glaser & Strauss, 1967). In the Preface to this thesis I have declared my background, my growing interest in the research field and my pre-understanding.

Grounded theory

In this thesis, the qualitative method of grounded theory was applied. The method of grounded theory has been developed by Glaser and Strauss (1967), and later by Strauss and Corbin (1998). Grounded theory includes all stages from formulating research questions, through sampling procedures, data collection, analysis and final development of concepts, hypothesis or theories (Starrin et al, 1997; Strauss & Corbin, 1998). In grounded theory the concepts of induction and deduction are the cornerstones of research (Strauss & Corbin, 1998). As I have understood the grounded theory method, the inductive process starts in observations where the interpretation of the observations leads to empirical generalisations within certain contexts and (sometimes) finally the discovery of a hypothesis or a model. The deduction process includes the testing of a theory in order to reject or confirm it. The process
of constantly going back and forth between induction and deduction, between the data material and the analysis, is called abduction (Strauss & Corbin, 1998).

Glaser and Strauss later developed different views on the concept of grounded theory. They both acknowledged that the researcher will not enter the field free from ideas, but differed considerably in how they view the importance of the researchers’ pre-understanding, in the analytic process and in the construction of a model or a theory (Glaser 1978, Strauss 1987, Strauss & Corbin 1998; Heath & Cowley, 2004). In this thesis, the grounded theory method used in the qualitative studies was more closely linked to the thinking of Strauss and Corbin (1987, 1998) than to Glaser (1978). In this way the use of an analytic framework with gender theories is legitimised as well as the lack of a final model in our analyses.

Study area
The qualitative study was carried out in the County of Jämtland, which is situated in the middle of Sweden. Jämtland is sparsely populated, with 132,000 people living in an area of 49,443 km². The region is one of the rural sectors of Sweden. The hospital in Östersund is the only hospital in the region, responsible for all acute and diagnostic care. At the time of the study the medical clinic had 92 beds, distributed in four wards. One of these wards focuses on brain damage, among them stroke patients. It was in this ward that the stroke patients for the qualitative study were selected.

Swedish elder care
Knowledge about the organisation of the Swedish elder care is important for the qualitative study. Swedish elder care is financed by tax revenue and available according to needs and not purchasing power (The Swedish Government Bills 1997/98:113). In other words, elder care is financed by the public sector and is supposed to be delivered to individuals in need, independent of sex, social class, marital status and living area. The individual pays a small fee, which is charged according to income (pension level). However, due to the deep recession in the 1990’s, the home help financed by the public sector has decreased (Larsson & Szebehely, 2006). At the same time, the number of elderly in the population continues to increase; in 1950 the number of people aged over 80 accounted for 2 percent of the population, and by 2004 this had increased to 7 percent of the population (The National Board of Health and Welfare, 2006b). Elder care has been developed to focus on the most sick and the elderly living alone in the community (Larsson & Szebehely, 2006). Home help has decreased most among elderly couples but also among single elderly with relatively small needs. The persons who today receive home help are sicker and receive more hours of home help. However, in terms of actual needs, the amount of time delivered has not increased but rather decreased (Larsson & Szebehely, 2006).

The help offered mostly concern household duties such as cleaning, cooking and washing. In 1980, 34 percent of elders (>80 years old) in Sweden received home help compared to twenty percent in 2004 (The National Board of Health and Welfare, 2006b). Due to this decrease, the demands for help from spouses, children and other relatives have increased substantially (Larsson & Szebehely, 2006). It has been found that there is a social class dimension in relation to this decrease in public help, as elderly with higher education (at least elementary schooling) tend to pay for private home help, whereas elderly with lower education turn to relatives for help (The Swedish Parliament propositions, 2001). This “informal care” also has a clear gender dimension as this help is mostly delivered by female relatives (spouse or daughters) (Szebehely, 1998).
Participants
The inclusion criteria for entering the study were women and men with stroke, older than 75 years, no aphasia or any severe disease that could prohibit participation in an interview situation. The background characteristics of the participants are presented in Table 4. All participants in this study were able to return home after the stroke; none of them was living in an old people’s home.

Every third week during the data collection period I visited the stroke ward at Östersund Hospital to look for participants for the study. Comments from nurses and information from medical records helped me to judge a person’s ability to participate. All participants who were asked agreed to participate in a first interview. When the participants were contacted regarding the second interview, two women did not want to be interviewed again, claiming they had told us everything there was to know about their experiences in their first interview. In total, 26 interviews were performed (14 with the women and 12 with the men).

Table 4. Characteristics of the participants, 75–83 years old.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Former occupation</th>
<th>Marital status</th>
<th>Need of handicap equipment</th>
</tr>
</thead>
<tbody>
<tr>
<td>woman 1</td>
<td>Shop assistant</td>
<td>Divorced, one son</td>
<td>No need</td>
</tr>
<tr>
<td>woman 2</td>
<td>Shop assistant, artist</td>
<td>Divorced, two daughters</td>
<td>Walking-frame</td>
</tr>
<tr>
<td>woman 3</td>
<td>Shop assistant</td>
<td>Widowed, new partner, one son</td>
<td>No need</td>
</tr>
<tr>
<td>woman 4</td>
<td>Shop assistant</td>
<td>Widowed, one son</td>
<td>Walking-frame</td>
</tr>
<tr>
<td>woman 5</td>
<td>Dental technician &amp; pre-school teacher</td>
<td>Widowed, two sons</td>
<td>No need</td>
</tr>
<tr>
<td>woman 6</td>
<td>Teacher</td>
<td>Married, one son</td>
<td>No need</td>
</tr>
<tr>
<td>woman 7</td>
<td>Nurse assistant in home help service</td>
<td>Widowed with three children</td>
<td>Wheelchair, walking-frame</td>
</tr>
<tr>
<td>woman 8</td>
<td>Housewife</td>
<td>Widowed, four children</td>
<td>Wheelchair</td>
</tr>
<tr>
<td>woman 9</td>
<td>Shop assistant</td>
<td>Married, one daughter</td>
<td>Wheelchair</td>
</tr>
<tr>
<td>man 1</td>
<td>Carpenter, family farmer</td>
<td>Married, one son</td>
<td>Walking-frame</td>
</tr>
<tr>
<td>man 2</td>
<td>Manufacturer</td>
<td>Married, two sons</td>
<td>Walking-frame</td>
</tr>
<tr>
<td>man 3</td>
<td>Carpenter</td>
<td>Divorced, no children</td>
<td>No need</td>
</tr>
<tr>
<td>man 4</td>
<td>Farmer</td>
<td>Married, two children</td>
<td>No need</td>
</tr>
<tr>
<td>man 5</td>
<td>Carpenter</td>
<td>Widowed, two children</td>
<td>Walking-frame</td>
</tr>
<tr>
<td>man 6</td>
<td>Farmer, woodman</td>
<td>Never married, no children</td>
<td>Stick</td>
</tr>
<tr>
<td>man 7</td>
<td>Electrician</td>
<td>Married, two daughters</td>
<td>Wheelchair</td>
</tr>
</tbody>
</table>
Sampling procedures and data collection
For this follow-up interview study a purposive sampling procedure was applied (Patton, 1990). Purposeful sampling can have several different purposes; one of which is maximum variation sampling (Patton, 1990). A maximum variation sampling (World Health Organisation, 1994) of elderly men and women with stroke was performed with regard to the background characteristics: social class, marital status and severity of illness. When all inclusion criteria and the sampling were taken into consideration, there were approximately 2 or 3 patients suitable for inclusion in the study at every visit to the hospital. At this stage, I chose to ask the patient who was closest to discharge if he or she were interested in participating in the study.

An emergent design approach was adopted, and this was achieved as the data collection and analysis went on parallel. Also, the number of participants was not decided in advance, but was guided by the narratives, the analysis and the theoretical saturation.

Oral and written information was provided to each participant about the purpose of the study. Before the interview started oral consent was obtained from all participants. They were informed that they could withdraw from the interview at any time.

The interviews were performed in the ward on the day of departure and follow-up interviews were conducted in the participant’s home after approximately 4–6 weeks during the years 2000–2002 and spring 2004. During the interviews a relaxed and friendly atmosphere developed, where the participants were open-minded and wanted to “tell their story”.

After each interview a preliminary analysis with open coding was performed, before the next interview took place. According to emergent design, the analysis of data and the selection of new participants went on simultaneously. Four of the 16 participants were included at a second data collection period (spring 2004), in order to increase the variation of the sample as well as to improve the theoretical saturation. These four participants (two women and two men) were interviewed once in their homes, approximately 4 months after the stroke. All interviews were tape-recorded, transcribed verbatim and analysed in accordance with grounded theory. Thematically structured open-ended questions were used. An interview guide was used for the interviews, see Appendix 1.

Analysis
In the first stage the interviews were read, analysed word by word, and coded in the computer program “Open Code”. That means that keywords from the text were written down in the margin of the manuscript. After this, I reread the interviews and tried to group the codes in order to find patterns of diversity between the men and the women, as well as within the group of women and within the group of men. To increase the validity of the study, my supervisor and I coded almost all interviews independently. The rest of the interviews were coded only by me. The codes were grouped into sub-categories, which were then related to each other by the categories. For example, from the analysis in Paper IV, the codes “I don’t complain”, “health care personnel occupied” and “I don’t ring the bell” were interpreted as forming the sub-category “not wanting to trouble health care personnel”.

For the thesis, an additional analysis of the participants’ perceptions and experiences of help was performed. This analysis was also performed with the method of grounded theory. The codes and the sub-categories that emerged from the analysis in Paper IV were reanalysed and interpreted as being examples of constructions of masculinities and femininities (see Results section).
Ethical considerations

All the patients gave informed consent to participate. I am a medical doctor, although not employed at the specific ward where the research was performed and not in charge of any of the participants’ care. I presented myself as a researcher to the participants. I always stressed before the interview started that participation in the study would not influence the rehabilitation and care that the men and the women received. The participants were assured that I followed the rules of confidentiality. The interview material has been stored safely and no one but the interviewer knows the participants’ real identity. The study was approved by the Ethics Committee at Umeå University as being in accordance with ethical standards (Um dnr 99-378).
RESULTS

Quantitative results

Was low educational level related to the risk of first-ever stroke among men and women? (Paper I)

Overall, the incidence of first-ever stroke was significantly higher among low-educated men and women compared to high educated men and women. In the age group 35–74 years, the men had a significantly higher annual incidence rate of stroke compared to women (438.4 vs 302.2 cases per 100,000 inhabitants). The lowest incidence rate of stroke was found among high-educated women aged 35–44 years (14.6 cases per 100,000) and the highest incidence rate was found among low-educated women aged 75–85 years (2425.8 cases per 100,000) (Paper I, Table 1).

Did low educational level increase the risk of first-ever stroke, after controlling for age and sex? (Paper I)

After controlling for sex and age in the multivariate analysis, low educational level was significantly associated with stroke in the older age group (Table 5). In the age group <75 years, the odds ratio for stroke was significantly lower among women than among men in both the bivariate and the multivariate analyses. Age was significantly related to stroke in both the bivariate analyses and also in the multivariate analyses in the age group <75 years.

Table 5. Odds ratios (OR) and 95% confidence intervals (95% CI) for stroke incidence as dependent variable.

<table>
<thead>
<tr>
<th></th>
<th>35–74 years</th>
<th></th>
<th>75–85 years</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Bivariate</td>
<td>Multivariate</td>
<td>Bivariate</td>
<td>Multivariate</td>
</tr>
<tr>
<td></td>
<td>OR 95%CI</td>
<td>OR 95%CI</td>
<td>OR 95%CI</td>
<td>OR 95%CI</td>
</tr>
<tr>
<td>Low educational</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>level</td>
<td>2.57 2.11–3.14</td>
<td>1.09 0.88–1.34</td>
<td>2.23 1.05–4.76</td>
<td>2.48 1.06–5.77</td>
</tr>
<tr>
<td>Women</td>
<td>0.53 0.43–0.65</td>
<td>0.49 0.40–0.60</td>
<td>1.03 0.87–1.21</td>
<td>1.12 0.55–2.29</td>
</tr>
<tr>
<td>Age (continuous)</td>
<td>1.11 1.10–1.12</td>
<td>1.11 1.11–1.12</td>
<td>1.04 1.03–1.06</td>
<td>0.99 0.98–1.02</td>
</tr>
</tbody>
</table>

Did men and women with stroke have similar risk factors for stroke, did they have access to Stroke Unit care and were there any differences in relation to acute medication, in different age groups? (Paper II)

No major differences were found between men and women in relation to risk factors, Stroke Unit care or acute medication in the different age groups (Table 6). The significant differences were that elderly women were more often low-educated and that they more often had atrial fibrillation compared to elderly men.
Table 6. Distribution of independent variables between men and women in different age groups (percent). n=624

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Age 20–74 years</th>
<th>p-value</th>
<th>Age 75–85 years</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Men n=213</td>
<td></td>
<td>Women n=116</td>
<td></td>
</tr>
<tr>
<td>Low educ. level</td>
<td>39.4</td>
<td>0.35</td>
<td>64.5</td>
<td>0.03</td>
</tr>
<tr>
<td>ADL dependent</td>
<td>4.8</td>
<td>1.00</td>
<td>12.5</td>
<td>0.56</td>
</tr>
<tr>
<td>Previous stroke</td>
<td>24.9</td>
<td>0.17</td>
<td>27.4</td>
<td>0.21</td>
</tr>
<tr>
<td>Atrial fibrillation</td>
<td>11.7</td>
<td>1.00</td>
<td>14.5</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>20.7</td>
<td>0.66</td>
<td>24.2</td>
<td>0.24</td>
</tr>
<tr>
<td>Hypertension</td>
<td>45.5</td>
<td>0.91</td>
<td>46.0</td>
<td>0.29</td>
</tr>
<tr>
<td>Smoking</td>
<td>21.1</td>
<td>0.47</td>
<td>6.5</td>
<td>1.00</td>
</tr>
<tr>
<td>CT performed</td>
<td>99.5</td>
<td>0.13</td>
<td>97.6</td>
<td>0.65</td>
</tr>
<tr>
<td>Stroke Unit care</td>
<td>89.7</td>
<td>0.47</td>
<td>93.5</td>
<td>0.16</td>
</tr>
<tr>
<td>Medication</td>
<td>85.9</td>
<td>0.87</td>
<td>84.7</td>
<td>0.61</td>
</tr>
<tr>
<td>28-day case fatality</td>
<td>4.2</td>
<td>0.34</td>
<td>6.5</td>
<td>0.52</td>
</tr>
<tr>
<td>90-day case fatality</td>
<td>5.2</td>
<td>0.80</td>
<td>8.9</td>
<td>0.57</td>
</tr>
</tbody>
</table>

Were there education-related differences in case fatality after stroke in different age groups? (Paper II)

In Paper II, the bivariate logistic regression analysis showed that age ≥75 years in combination with low educational level increased the odds ratios for 28-day case fatality. In addition, the bivariate regression analysis showed that some risk factors were correlated with the 28-day case fatality (ADL dependency, previous stroke, atrial fibrillation, diabetes mellitus). In the multivariate logistic regression analysis, age ≥75 years in combination with low educational level increased the odds ratios for 28-day case fatality, after controlling for sex, risk factors for stroke and acute care treatment (OR 3.21; 95%CI 1.04–9.88) (Table 7). Not receiving early medication was significantly related to 28-day case fatality in both bivariate and multivariate analysis.
Table 7. Odds ratios (OR) and 95% confidence intervals (95% CI) for case fatality at 28 days in patients aged 20–85 years with cerebral infarction as dependent variable. Bivariate and multivariate analysis. n=624

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Bivariate analysis</th>
<th>Multivariate analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR</td>
<td>95%CI</td>
</tr>
<tr>
<td>Age &lt;75 years+ high educ</td>
<td>1.00</td>
<td>Reference category</td>
</tr>
<tr>
<td>Age ≥75 years+ high educ</td>
<td>1.79</td>
<td>0.75–4.25</td>
</tr>
<tr>
<td>Age &lt;75 years+ low educ</td>
<td>1.21</td>
<td>0.53–2.79</td>
</tr>
<tr>
<td>Age ≥75 years+ low educ</td>
<td>2.12</td>
<td>1.03–4.22</td>
</tr>
<tr>
<td>Women</td>
<td>1.32</td>
<td>0.78–2.22</td>
</tr>
<tr>
<td>ADL dependent</td>
<td>3.61</td>
<td>1.47–8.82</td>
</tr>
<tr>
<td>Previous stroke</td>
<td>1.87</td>
<td>1.07–3.24</td>
</tr>
<tr>
<td>Atrial fibrillation</td>
<td>2.37</td>
<td>1.35–4.17</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>3.79</td>
<td>2.18–6.57</td>
</tr>
<tr>
<td>Stroke Unit care</td>
<td>0.41</td>
<td>0.21–0.80</td>
</tr>
<tr>
<td>Medication</td>
<td>0.12</td>
<td>0.07–0.20</td>
</tr>
</tbody>
</table>

Qualitative results

How did elderly men and women with stroke respond to treatment and care in the acute care setting? (Paper III)

According to the findings in Paper III, the elderly stroke patients experienced subordination in their contacts with the health care personnel and the medical context. There were no differences between the women and the men concerning the participants’ experiences of subordination. We identified four different sub-categories related to the categories. The sub-categories were labelled: striving for autonomy, following the rules, building alliances and criticising the care. The sub-categories were interpreted as being examples of negotiations within the hierarchic medical context. The participants used different ways to negotiate in the subordinate position, and some of these negotiations were interpreted as being gendered. These gendered negotiations were related to the sub-category building alliances, where women turned to the nurse assistants and the men turned to the nurses and therapists.

The core category was labelled “Negotiations within the hierarchic medical context”. Two different kinds of negotiations were identified. Striving for autonomy and criticising the care can be regarded as a way of expressing resistance in the subordinate position. At the same time, following the rules and building alliances seems to be an adjustment to the subordination. In relation to the concept of power, being resistant can increase the
participant’s power (power from below), whereas being adjustive can reduce the participant’s power within the hierarchic medical context.

What were the elderly people’s perceptions and experiences of receiving help from others? (Paper IV)

Before the stroke, all the women in this study had been responsible for the housework, while the married men said that their wives had the main responsibility. The unmarried men received help from female relatives before the stroke. All the participants had been able to manage at home before the stroke without major home help service. All men and women were offered home help from the community after their hospital stay. One of the differences between the men and the women concerned the social support from relatives, both before and after the stroke. The men in the study relied on help from their wives or other female relatives. For the married men, communicating with the home help services was not their business, this was arranged by their wives. Most of the women were widowed or divorced and several of them did not consider their closest relatives as their strongest supporters. Instead, many of the women expressed loneliness and insecurity about how to continue with their life after the stroke. The women were eager to take care of themselves, and some of the women refused offers from home help service after the stroke. This was not found among all women; there were women who were more accepting towards help.

In Paper IV, three categories were found and labelled: minimising one’s own needs of help, striving for independence and accepting help from others. The perceptions of help differed between the men and the women. Also, both men and women seemed to express multiple types of needs. From a gender perspective the perceptions and experiences of help can be regarded as being related to the gendered life circumstances of the participants.

What kind of gender constructions could be identified among elderly men and women with stroke?

For this thesis an additional analysis of the participant’s perceptions and experiences of help was performed. In this analysis, the perceptions and experiences have been interpreted as being examples of constructions of masculinities and femininities. The sub-categories from Paper IV are interpreted as being related to different gender constructions (Figure 1). This analysis suggests situational and relational concepts of masculinities and femininities. These gender constructions have been labelled: traditional masculinity, relational masculinity, traditional femininity and assertive femininity.

The traditional masculinity was developed from the sub-categories managing by oneself and accepting help from relatives (Figure 1). In the construction of traditional masculinity the men talked about personal responsibility in the recovery process and emphasised the importance of being able to manage by oneself. At the same time they had no problem accepting help from relatives. Belonging to this masculinity included feeling satisfied and proud of oneself, often relating successes in life to work-related efforts, even though many years had passed since retirement.

Further, relational masculinity was another possible gender construction for the elderly men in this study. This masculinity was constructed from the sub-categories not wanting to trouble health care personnel and relatives, and accepting help from health care personnel (Figure 1). Positive attitudes towards relatives and friends were expressed. This masculinity also included reflections on the meaning of life, and statements of gratitude towards health care personnel and relatives. For example, one man did not want to be a burden to his relatives and expressed guilt towards his elder sister who, in his mind, felt obliged to help him.
When he became sick. In the shaping of relational masculinity, more emphasis seemed to be put on relations with others, as well as being more reflective about the present situation and what increased dependency on others could lead to. However, the construction of relational masculinity was at the same time complex as it included an urge not to trouble health care personnel, but at the same time a willingness to accept help from them.

The traditional femininity was developed from the sub-categories not wanting to trouble health care personnel and relatives, and unwillingness to accept help from home help services (Figure 1). Traditional femininity was described as confidence in taking care of household duties as well as caring for relatives despite one’s own disability and recent hospitalisation for stroke. By minimising one’s own needs of help, traditional femininity can be interpreted as reducing one’s own importance and needs. Many of the women had their children living far away, and only talked with them over the phone. This geographical distance made it more difficult to ask for help from relatives. Even if the relatives were living nearby, they hesitated to ask for help, especially if the child was a son. When the question of home help services was discussed, some of the women were very critical of the help delivered and preferred to take care of household tasks by themselves.

Assertive femininity was developed from the sub-categories accepting help from health care personnel and home help services and not wanting to trouble relatives (Figure 1). This femininity was shaped by feelings of confidence and stubbornness, and not feeling ashamed when asking for help. In the shaping of assertive femininity, the women emphasised how they were capable of handling difficult situations, they pictured themselves as active and able to make their own choices. These women were very clear about what kind of help they wanted. For example, one of the widowed women declared that she wanted help with personal care and making the bed, at least for a couple of weeks after the stroke.

The four different constructions of gender can be interpreted as examples of health-related behaviours expressed by the men and the women in this study. In the Discussion section, the constructions of gender will be discussed in relation to previous research on masculinities and femininities.
Figure 1. Constructions of gender developed from findings in Paper IV.

**Constructions of gender**

- **Traditional masculinity**
  - Managing by oneself
  - Accepting help from relatives
- **Relational masculinity**
  - Not wanting to trouble health care personnel and relatives
  - Accepting help from health care personnel
- **Assertive femininity**
  - Accepting help from health care personnel and home help service
  - Not wanting to trouble relatives
  - Managing by oneself
- **Traditional femininity**
  - Not wanting to trouble health care personnel and relatives
  - Unwilling to accept help from home help service
DISCUSSION

Methodological considerations

Quantitative studies

Strong efforts were made to make case ascertainment as complete as possible. Some of the procedures related to validity are described in the Methods section in this thesis, but I will touch upon other important issues in the methodological discussion.

Validation of the registers included in the study

1. Validation of the Riks-Stroke register

In annual reports, all participating hospitals receive online feedback covering the previous year (Riks-Stroke, 2005). Data are displayed for each department and compared with the national average. This report is broken down by county council and may be downloaded from the Internet by participating units. Coverage, dropout rate and data quality in the RS registration have been studied in detail previously (Glader, 2003). Coverage has been calculated epidemiologically, based on an estimated incidence of a minimum of 250 and maximum of 300 stroke cases per 100,000 inhabitants. In the latest analysing report, the coverage was approximately 93 percent (Riks-Stroke, 2005).

1a. Validity checks in Riks-Stroke during the study period

For this thesis, a validation procedure of the Riks-Stroke register at Umeå University was performed during the study period by controlling the coverage of the registration. This was done by checking the Stroke Units’ list of admitted stroke patients every other month. When additional stroke cases were found, hospital records were searched for in the journal archive of Umeå University Hospital and data entered retrospectively. A final data file with all stroke patients registered in Riks-Stroke during the study period was retrieved from the Riks-Stroke Centre in Umeå in October 2003. This file also included patients diagnosed with transient ischaemic attack (TIA) (ICD-10; G45). In total, 185 patients with TIA were registered but were excluded from the final data file before the statistical analyses were performed.

1b. Case ascertainment

For this thesis, a systematic selection of every tenth hospital record of the patients in the final Riks-Stroke data file was performed. The medical records were thoroughly read to validate the diagnoses. This validation did not reveal any strokes that had been misclassified. Similarly, a validation of the stroke diagnoses in the HDR was made and in 38 cases out of 222, the stroke events had been misclassified. In conclusion, a definite stroke according to ICD-10 was found in all the RS patients and in 83 percent of the patients included only in the HDR. This difference in retrieving strokes and defining them correctly can be explained by the fact that Stroke Unit personnel are often well-educated in being aware of stroke symptoms.

1c. Case validity

Previously performed case ascertainment between Riks-Stroke and the HDR has shown that there were differences in relation to background characteristics between the populations. Patients included only in HDR were more often women, more dependent on community care and had a higher case fatality rate at both 7 days and 30 days (Glader, 2003). However, it was also shown that RS patients more often had a “definite” stroke diagnosis (94.9 percent)
compared to patients not included in RS (73.1 percent) (Glader, 2003). In this thesis, no differences were found in relation to background characteristics between the RS and the HDR populations.

2. Validation of the Hospital Discharge Register and the Causes of Death Register
The validation of HDR is usually done by comparing the Hospital Discharge Register with the Cause of Death Register (Leppälä et al, 1999). The total number of missing cases for somatic short-term care for the period 1987–1991 has been estimated to be less than two percent. For all records reported to HDR a data control is run. In 2001, the main diagnosis was missing in 0.9 percent of the hospital stays reported. The information in HDR for 1964–2000 as to whether the patient was deceased or alive at discharge has been compared with the date of death from the Swedish Cause of Death Register (CDR). For 99.91 percent of the discharges, the information in HDR corresponded to that in CDR (The Cause of Death Register, 2004).

The quality of the death certificates has been studied by the National Board of Health and Welfare (www.sos.se). The best way to verify the cause of death is by autopsy. However, the number of autopsies has decreased from about 50 percent at the beginning of the seventies to about 15 percent in 2001. The decrease varies for different ages. Among those above 85 years the number has decreased by about 85 percent, from 30 percent in 1970 to four percent in 2001 (The Cause of Death Register, 2004). As much as 99.6 percent of the death certificates were available in a validation performed in 2003 (The Cause of Death Register, 2006). However, the quality of the death certificates varies in relation to age and diagnosis; the information in the certificates is more extensive in younger people with sudden deaths, compared to elderly people with chronic diseases. A comparison of the last hospital discharge diagnosis with the death certificates, showed a fairly good agreement in deaths occurring in the hospital (83 percent), but a low agreement if the death occurred outside hospital (43 percent) (Johansson & Westerling, 2000). Previous studies have indicated that there is a risk of overestimation, as the authorities require a diagnosis with an ICD code to be accepted (Jansson et al, 1997; Goraya et al, 2000).

For this quantitative study, all death certificates during the study period were analysed. In patients <75 years, the WHO MONICA Register was used to verify the diagnosis and in patients aged ≥75 years the death certificates were retrieved from the MONICA centre where a copy of the death certificates of all deaths in stroke patients (of all ages) are kept. It could be suspected, according to previously performed validations, that the quality of the death certificates was poorer in persons 75–85 years. It is possible that this increased the risk of overestimation of the stroke incidence in elderly persons based on death certificates in this study. However, the number of cases aged 75–85 years retrieved from the Cause of Death Register was relatively low (33 cases, 13 percent of the population aged 75–85 years; see Paper I).

3. Validation of the case-finding study
For this thesis, a case finding study in the nursing homes and homes for elderly was performed. Great effort was expended to make the case ascertainment as complete as possible. To increase the validity of this study, a randomisation of six of the 25 institutional settings was performed and all medical records of persons living in these six institutions during the study period were analysed. This validation showed that all persons with symptoms of stroke had been sent to the emergency department of Umeå University Hospital. This is believed to be partly due to the close geographical distance to the hospital, and partly due to the geriatric specialists’ co-operation with the hospital (they are able to admit patients directly to the geriatric ward at Umeå University Hospital).
However, five persons who had died of stroke were identified through the Cause of Death Register retrospectively. They had been living in two of the six nursing homes and homes for elderly that had been randomised for retrospective validation. These five persons had consequently been missed in the case-finding study. The medical journals of these five persons were read and the diagnoses in the death certificates were studied. However, none of the cases were included in the final analysis of data, as the information concerning the cause of death was considered to be too scarce.

**Statistical issues**
The increasing odds ratios in the multivariate analyses compared to the bivariate analyses in Paper IV can be explained by the small study sample, indicating that the power of the study was relatively low. By reducing the number of independent variables in the multivariate analyses, we tried to stabilise the results. At the same time, low power increases the risk of Type II error. A Type II error occurs when we can find an effect in a total population, but fail to find the same effect in a study population (Janlert, 2000). For example, education-related differences in stroke incidence are found in a total population, but not in the study population.

**Measures of socioeconomic status**
An effort was made to use not only educational level but also occupational status as a measure of socioeconomic status (SEI) (Statistics Sweden, 1982). The socioeconomic classification of persons in the labour force is primarily based on their occupation. As the mean population age in this study was high, approximately 70 years, data had to be taken from two different censuses (1970 and 1990) to enable us to assess present or previous work status for the whole population. However, it was not possible to compare the classification system from 1970 with the system from 1990, as the classification of occupation changed every tenth year until 1990.

Educational level is considered to be a more stable indicator of life-long socioeconomic status and a more consistent predictor of disease than occupational status (Ross & Wu, 1996) and income (Grundy & Holt, 2000). This is because educational level does not change over the lifetime, as occupation and income might (Grundy & Holt, 2000). Others have suggested that educational level is a better predictor for women than occupational class (Härenstam & Östlin, 1998). It has been argued that the Swedish socioeconomic classification system (SEI), is more detailed in defining male-dominated occupations than female-dominated occupations, leading to incorrect coding of occupations when studying manual and non-manual occupations (Härenstam & Östlin, 1998). Also, educational level has sometimes been reported to be more closely related to cardiovascular disease than occupational status (Davey Smith et al, 1998b). In gerontological research, it has been discussed that some measures of socioeconomic status are not appropriate for studying health and illness in elderly populations. For example, household-based measures such as access to cars and housing tenure, are not always applicable for this group; analyses that use them will be biased as risk of residence in an institution is associated with both worse health and low socioeconomic status (Grundy & Holt, 2001).

In this study, low educational level was measured as a maximum of nine-year compulsory school, in both age groups. This was warranted by the fact that it is difficult to define and exact age for using different definitions of low educational level.

Attaining nine years schooling is relatively rare for persons who are aged >75 years today (SUN, 2000). In this study, only three percent of the elderly men and eight percent of the elderly women had finished nine years’ schooling. This means that the large majority of the elderly population had only six years of schooling. This might have increased the risk of an underestimation of the socioeconomic gradient in our analyses among the elderly.
Credibility, confirmability, dependability and transferability

To increase the trustworthiness of qualitative research different indicators can be used to strengthen the scientific rigour. However, there is variation in how qualitative researchers today validate their findings (Malterud, 2001). Lincoln & Guba (1985) have presented four components that reflect the assumptions of the qualitative paradigm: credibility, dependability, confirmability and transferability.

Credibility deals with whether credible and truthful findings and interpretations will be produced, that is, credibility applies to the collection of data as well as to the analysis (Hamberg & Johansson, 1994).

In this qualitative study, credibility was assured by the way the personal interviews were performed. During the interviews a relaxed and friendly atmosphere developed, where the participants wanted to “tell their story”. The follow-up interview also made it possible for the participants to develop their thoughts about previously discussed themes. The follow-up design of the study also enabled us to achieve closeness and mutual respect in the interview situation.

The method of grounded theory helped to improve the credibility. By open coding and classification of the data into different categories, we looked for codes and expressions that the participants described. Also, the search for negative cases increased the credibility. For example, as many of participants expressed acceptance of the new situation, it was important to include a participant who reacted in the opposite way. In addition, the variation within the group of women as well as within the group of men was compared in relation to social class, marital status and severity of illness.

Dependability in qualitative research is achieved through flexibility in the collection of data and analysis (Hamberg & Johansson, 1994). In this study, the number of participants was not decided in advance. Instead, it was governed by the analysis process, with the aim of reaching saturation on an analytical level. In the end, more women than men were included as it was more difficult to find variation in relation to severity of illness among the women. Some questions were added as the interviews went on, while the main themes were included in all interviews.

Confirmability means that the study should include procedures to verify that the findings and concepts described were grounded in the data (Hamberg & Johansson, 1994). The method of analysis was important in this process. Most of the interviews were read and coded by me as well as by my supervisor. By comparing and questioning each others codes and by looking for negative cases, the confirmability of the study was assured. For example, as most of the male participants expressed “pride” and reluctance about receiving help from others, we searched for male participants who were more accepting towards help from others. Also, the confirmability of the study was improved as the results and categories were recognised and considered as logical in discussions with the health care personnel at the specific ward where the interviews were performed and during research seminars.

Transferability. In qualitative research the aim is not to achieve demographic representativeness of the participants, but analytical generalisations. The aim of the research is to produce information that can be shared and applied beyond the study setting (Malterud, 2001). By describing the organisation of Swedish hospital care (Paper III) and Swedish elder
care in general (Study Area section in this thesis and Paper IV), the transferability to similar settings is strengthened.

On results

Sex differences in stroke risk

Overall, there were few differences between the men and the women in the different age groups in relation to risk factors for stroke and stroke management. However, in another Riks-Stroke study on a larger population, sex differences were shown in the pre-stroke condition (men more often had previous stroke, diabetes mellitus and smoked more often whereas hypertension was more common among women) and in the medical management, favouring the men (Glader et al, 2003). For example, more men with atrial fibrillation received anticoagulants, and at discharge more men with cerebral infarction were put on antithrombotic agents as secondary stroke prevention compared with women. This difference between the sexes was not found in our analysis; one reason could be a smaller sample size. However, we did show that men in the age group 35–74 years had a higher risk of stroke than women after controlling for educational level and age (Table 5), which has also been reported by others (Peltonen et al, 2000).

Overall, we found no education-related differences between men and women in access to stroke care, even after taking age into consideration.

Importance of Stroke Unit care

In the bivariate logistic regression analysis (Table 6), not being admitted to Stroke Unit was significantly related to an increased 28-day case fatality. Stroke Units have shown to be beneficial for survival and functional outcome for stroke patients (Langhorne & Duncan, 2001). A review within the field concludes that that the strength of Stroke Units are their organisation of multidisciplinary teams providing multiple interventions that are coordinated by multidisciplinary meetings (Langhorne & Pollock, 2002). As reported from other studies using the Riks-Stroke register on a national basis, 70 percent of the stroke population receives treatment in Stroke Units (Glader, 2003). Approximately 87 percent of our population received Stroke Unit care, a comparatively high proportion. Others have found that a much smaller percentage of stroke populations are treated in specialised Stroke Units (23–50 percent) (Norrving, 2005), despite the positive results of Stroke Unit care (SUTC, 2000). The high levels of stroke patients treated in Stroke Units in Sweden compared to other countries could be due to the long stroke research tradition in Sweden and interest in acute stroke treatment, especially in northern Sweden (Strand et al, 1985).

Socioeconomic gradient in stroke incidence and case fatality

We have shown that the incidence of stroke was higher among low-educated than high-educated men and women and that low-educational level was related to stroke in persons aged 75–85, even after controlling for sex and age. Our study is one of the first to investigate the educational gradient in stroke incidence among persons aged ≥75 years. In a review on socioeconomic status and stroke, the authors show that there is a lack of studies including persons aged ≥75 years (Cox et al, 2006).

In Paper I, no socioeconomic gradient in stroke incidence was found in the age group 35–74, after controlling for sex and age. However, there are several other studies which have
shown an association between low educational level and age below 75 years (Jakovljevic et al, 2001b; Qureshi et al, 2003; Gillum & Mussolino, 2003; Kuper et al, 2007). A socioeconomic gradient has also been reported in studies which use other socioeconomic measures, both measures on an individual level (such as occupational status, income level) (Hart et al, 2000; Jakovljevic et al, 2001a) as well as in multilevel analyses (neighbourhood deprivation scores) (Engström et al, 2001). In another study in approximately the same setting as ours, Peltonen et al (2000) found a socioeconomic gradient (measured as occupational status) in stroke incidence in both men and women aged 40–60 years. One reason for the lack of socioeconomic gradient in stroke incidence in the age group 35-74 in our study could be the smaller sample size compared to the studies mentioned above.

In Paper II, the 28-day case fatality after stroke was shown to be associated with age above 75 years in combination with low educational level, also after controlling for sex, risk factors and acute care measures. This is in line with previous research, although these studies found that the socioeconomic gradient decreased with age (Avendano et al, 2004; Huisman et al, 2004). It has been argued that this decrease with age could be due to the use of occupational class as a socioeconomic measure (McMunn et al, 2006). Occupational class is unlikely to be the best measure of socioeconomic circumstances for people who are no longer active in the labour market. Another explanation for the decrease in socioeconomic differences in mortality in elderly is an effect of a “survival bias” (Beckett, 2000). This bias means that those high- and low-educated who survive into adult age constitute a positively selected group with regard to health status, because less viable individuals have already died (van Rossum et al, 1999).

In this thesis, the socioeconomic gradient in stroke incidence and case fatality among the elderly persisted after controlling for confounding factors. This suggests other mechanisms behind the socioeconomic gradient in later life.

The relationship between socioeconomic position of individuals and populations and their health is well established (Macintyre, 1997; Marmot, 2004). One of the explanations for the socioeconomic gradient in health refers to social causation, where causal mechanisms produced by various class- and health-related factors such as life circumstances (poverty, housing, work conditions etc.) and health behaviour influence future health and ill health (Macintyre, 1986; Goldman, 2001). That is, class differences in health are caused by different accumulations of and exposures to risk factors throughout the life course, with more unfavourable conditions experienced by lower social classes (Macintyre, 1986). The social causation explanation is also partly explained by the fact that some health-damaging behaviours such as smoking, poor diet and inappropriate use of health services have a socioeconomic gradient and that this contributes to the socioeconomic gradient in ill health and early death (Macintyre, 1997). The social causation explanation has also been the focus of my discussion, and in the Implications section I will discuss the importance of life-course perspective studies in the future.

The hierarchic medical context as an example of a gender regime

The hierarchic medical context can be seen as a gender regime, where gender relations are produced and reproduced. In Paper III, we have shown that stroke patients used various ways of negotiating with the health care staff in their subordinate position to influence their situation on the ward. The negotiations can be seen as examples of gender relations or practices that are produced in relation to the actions of the health care staff. We have shown that the participants used different ways to negotiate, both adjustive and resistant, within the medical context. The health care staff’s power over the elderly women and men illustrates the relation of subordination and the participants’ adjustment to this
subordination. At the same time, the participants’ power to make their own decisions or solve problems was found to be restricted in the medical context (Westerståhl, 2003). The same experiences of subordination has been found in other studies, where preparation of patients for discharge was influenced by factors such as overprotection, paternalism, and the institution’s care routines (Proot et al, 2000; Olofsson et al, 2005; Foss & Sundby, 2003).

Stroke patients’ views of acute care have not been well documented (McKevitt et al, 2004). Noticeably absent in the literature are elderly patients’ voices and experiences, and few studies have explored patients’ perceptions and experiences from a gender perspective (Aléx, 2007). What is reported is how patients’ feelings of unreality and awareness of their changed role might lead to a psychological crisis after the stroke event (Backe et al, 1996). Other studies have found that patients appreciated the hospital care they received, valued being cared about as well as being cared for (Pound et al, 1995) and expressed high levels of satisfaction (Thomas & Parry, 1996). However, contrasting perceptions of rehabilitation therapies from patient and professional perspectives have also been investigated (Becker & Kaufman, 1995; Bendz, 2000). For patients, rehabilitation suggested that they could only recover if they worked hard enough, with the result that they felt let down when recovery did not occur. However, in the same study, interviews with health care professionals revealed that the rehabilitation process was devalued and was considered to be on the periphery of health care. Professionals’ view of recovery was dominated by the idea that the potential to influence the illness trajectory is limited. As a result, rehabilitation professionals in this setting divided patients into two categories: rehabilitation candidates and geriatric care patients. This practice was found to be based on culturally-based preconceptions of ageing and notions of appropriate rehabilitation for older people. In the longer perspective, this resulted in insufficient rehabilitation of the elderly stroke patients (Becker, 1994).

Bendz (2000) suggests that while patients and professionals are both concerned with addressing physical disability, their priorities are not identical. Moreover, what is important to patients can be excluded since their position is subordinate to that of professionals (Bendz, 2000). For example, while the stroke survivors portray themselves as individuals having had a position in society, which they want to recapture, they are portrayed as fragmented male or female bodies of a certain age with certain impairments and dysfunction in the medical records (Bendz, 2000).

It can be hypothesised that if the medical context was less hierarchic, the participants who were interviewed would feel more satisfied with the care, and the communication between the staff and the patients would be less problematic. Successful rehabilitation must start by exploring the expectations of the stroke patients themselves, followed by the stroke professionals’ knowledge and experience of rehabilitation. The multi-professional perspectives represented within the team of health care professionals must be adopted and implemented.

The home as an example of a gender regime

The home can also be seen as an example of a gender regime where gender relations are produced and reproduced. Throughout the interviews it was evident that the gendered life circumstances were of great importance for how the men and the women handled their situation during the first months after the stroke. Due to the differences between the men and the women in the distribution of domestic work even before the stroke, the offer of help from the home help services was dealt with in very different ways by the participants. For example, the men did not consider the household to be part of their duties. Instead, they presumed that either their wife, or a female relative, would help them with household activities.
The women, on the other hand, were unwilling to let the home help services take over household tasks (such as preparing food and washing clothes), and they were also cautious not to bother relatives for help. They may have felt a threat to their former duties and position as caregivers, which have also been noticed by others (Dowswell et al, 2000; Burton, 2000; Kerr & Fothergill-Bourbonnais, 2002). The loss of the homemaker role due to different diseases and conditions has been argued to be a particularly difficult adjustment (Roberto & Reynolds, 2001; Kerr & Fothergill-Bourbonnais, 2002).

At the same time, there were women in our study who proved to be more confident in demanding services for themselves. They insisted upon their right to home help services (accepting help from home help services), but were at the same time more careful about asking for help from relatives (not wanting to trouble relatives), neighbours and friends.

Constructions of gender

In Paper IV, we have shown that the participants’ perceptions and experiences of help differed between the men and the women. Also, both men and women seemed to express multiple types of needs. From a gender perspective the perceptions of help can be regarded as different ways of constructing gender. As gender constructions are produced and reproduced depending on the context, it is important to study these ongoing processes within the specific context of the participants. There is not one single way that men and women construct gender, instead there are multiple ways depending on factors such as age, social and ethnic background, etc., resulting in different masculinities and femininities in different contexts (Connell, 1987; West & Zimmerman, 1987). An interesting line of research links health with gender constructions. Here, health-related beliefs and behaviour, like other practices that men and women are engaged in, are seen as different ways of demonstrating femininities and masculinities (Courtenay, 2000; O’Brien et al, 2005). Courtenay suggests that different health behaviours are used in the daily interactions with other people in the structuring of gender.

For the thesis, an additional analysis of the participants’ perceptions and experiences of help from others was performed. This analysis suggested situational and relational concepts of gender constructions related to the participants’ gendered life circumstances.

It can be argued that the disabled elderly men in this study had to reshape their masculinity as an attempt to compensate for their new and more subordinate position as dependent on the welfare system and on female relatives, as well as losing control of their body. The traditional masculinity seemed to be the ideal form of masculinity for the men in my thesis. Within this idealised form of “hegemonic” masculinity lies an assumption which denies weakness and vulnerability, and seeks to preserve physical control. The concept of traditional masculinity could be regarded as similar to Connell’s concept of hegemonic masculinity (Connell, 1995). Courtenay has shown that a hegemonic masculinity often also considers health care utilisation and the exercise of positive health behaviours as “feminine” and therefore of less value (Courtenay, 2000). The traditional masculinity also stressed the importance of one’s own ability and activity in society. However, these ways of acting were made possible by the uneven distribution of domestic work for which wives or female relatives took responsibility.

In the shaping of relational masculinity, not wanting to trouble relatives can be interpreted as a form of gratitude towards relatives at the same time. By emphasising that relatives should not feel obliged to help out, this form of masculinity focused on having good relationships with other people. Being concerned with other peoples burdens and expressing gratitude towards them has not traditionally been seen as belonging to the idealised form of masculinity (Connell, 1995). In a study on elderly men and constructions of masculinities, it was stated that masculinities which emphasise the importance of relations are rarely visualised and
discussed (Alex et al, 2007) and can be regarded as marginalised or subordinated compared to the idealist form of masculinity (Connell, 1995).

The elderly women could be seen as demonstrating traditional femininity or assertive femininity. The construction of traditional femininity focused on rejecting help from others when it was offered and minimising one’s own needs of help. This construction can be interpreted as a strategy to reconstruct the picture of being an “ideal woman”. Our concept of traditional femininity could be regarded as similar to Connell’s concept of emphasised femininity, a femininity that supports the hegemonic status of men, emphasising the subordinate role of women (Connell, 1987). Within the traditional femininity, former duties and care giving in relation to close relatives was highly valued, in an effort to preserve what was left of the homemaker role.

The women constructing an assertive femininity were active and self-assured, they knew what they wanted and were not afraid to ask for it. It also included an urge to manage by themselves, which coincides with the concept of traditional masculinity. The assertive femininity has no similarities to Connell’s concept of emphasised femininity, but seems more related to Connell’s concept of resistant femininity (Connell, 1987). At the same time, the women seemed to be subordinated. This was exemplified by the fact that the concept of assertive femininity was also related to a fear of troubling relatives.

There is research that supports the idea that in older age gender disparities and gender relations become less important, especially for women (Silver, 2003). Older women can have more choices, greater aspirations, and can more freely express non-traditional gender and sexual orientations than younger women. This can lead to an integration of feminine and masculine characteristics (Silver, 2003). It could be interpreted to mean that the assertive femininity is an example of an integration of feminine and masculine characteristics. The construction of femininities may differ due to variations in equality between women and men in different societies, as well as due to generational differences. Today, women and men are more equal in Sweden than in several other high-income countries in the world (Human Development Reports, 2005). This includes having the highest female workforce participation, ranking among the highest in economic and political participation and decision-making for both women and men, and having power over economic resources (ranked as number three after Norway and Denmark) and a high percentage of women among the members of parliament (45%), (Human Development Reports, 2005). Even so, women in Sweden still suffer discrimination in relation to men as regards e.g. workforce participation, labour market segregation, division of unpaid work etc. (Statistics Sweden, 2006). However, the elderly women in our study, just like other elderly women in many countries, have experienced even more unequal relations with men than young women of today (concerning e.g. abilities to study at higher levels and earn money).
IMPLICATIONS FOR THE FUTURE

Integrating a gender and socioeconomic perspective in research on elderly

Gender research and socioeconomic research represent two different paradigms for understanding elderly men’s and women’s health and illness. According to the discussions in this thesis there is still a lack of research that analyses the gendered dimensions of high age and socioeconomic status in medical research. Therefore, a unified model can bring gender and socioeconomic research together in a common framework (Moss, 2002). A gendered framework could improve our understanding of the social and economic patterning of elderly persons’ health and illness and offer new directions for research, interventions and policy.

Integrating quantitative and qualitative methods in research on elderly

Our results point to the importance of using different research methods to cover multiple aspects of a research field. Knowledge gained from qualitative and quantitative approaches should not be seen as dichotomised pools of knowledge, but as different positions on a continuum of knowledge (Foss & Ellefsen, 2002). While a quantitative approach gives a broad, general view of the surface, a qualitative approach gives data that provide a deeper and more multifaceted insight. Overview (breadth) and insight (depth) provide different kinds of knowledge. More research is needed where both qualitative and quantitative methods are used, as this can provide a richer and perhaps more authentic description of the issue under investigation.

A life-course perspective on ill health in later life

In a review of social determinants of health, the authors state that health inequalities based on occupational class, education and income are well established also in older age (McMunn et al, 2006). However, little is done to elucidate the mechanisms behind these inequalities. The relative importance of current life circumstances as compared with life circumstances earlier in life is discussed within the concept of life-course perspective. The life-course perspective indicates that social circumstances from earlier life accumulate risk factors and exposures throughout the life course and determine the social and economic position that a person reaches in later life, and that these factors affect health in later life (Kuh & Ben-Schlomo, 1997; Marmot et al, 2001). Pollitt and co-workers have identified three different hypothetical models of life-course perspectives for how the social environment affects health: (1) a model which hypothesises that early life experiences increase the risk of cardiovascular diseases in later life; (2) a social mobility model, for example mobility within or between generations, in later life; (3) accumulation of psychosocial and physiological experiences and environments during early and later life that influence adult disease risk (Pollitt et al, 2005). The authors argue that multiple life-course designs within the same study offer the best approach to testing which theories best describe the links between life course socioeconomic status and cardiovascular disease risk. However, the cumulative life course model is today the best supported model, based on the number of studies using the accumulation theory (Pollitt et al, 2005). In Sweden, there are good opportunities of performing research on cardiovascular diseases with a life-course perspective, due to the availability of data from the national quality registers as well as data collected during in the population and housing census (1960–1990)
(Statistics Sweden, 2003). Thus, future research on socioeconomic status, gender and stroke could have much to benefit from applying a life-course perspective.
CONCLUSIONS

Stroke with focus on elderly is a field where few studies have been conducted from a gender and socioeconomic perspective.
Data from a community-based study in northern Sweden suggest that there are education-related, age-dependent differences in stroke incidence, with elderly women having the highest incidence of stroke.
Similarly, there is an education-related difference in 28-day case fatality in elderly stroke patients.
The elderly men and women with stroke experienced subordination within the hierarchic medical context.
Within the hierarchic medical context, the elderly stroke patients negotiated with the health care personnel in ways that either increased or decreased their power over their situation.
The elderly stroke patients’ perceptions and experiences of help from others differed between the men and the women, but also within the group of men and within the group of women.
Further analyses of the patients’ perceptions and experiences of help from others were interpreted as being different examples of constructions of masculinities and femininities. The constructions of gender were related to the patients’ gendered life circumstances.
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**RIKS-STROKE - ACUTE PHASE**

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<tr>
<th>Personal ID number</th>
<th>I I I I I I I I I I I I I I I I I I I I I I I I I I I</th>
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<tbody>
<tr>
<td>Sex</td>
<td>1 = male 2 = female I I I I I I I I I I I I I I I I I I I I I I I I I I I</td>
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<td>Name (optional)</td>
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<td>Telephone (optional)</td>
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<tr>
<td>Optional information (for instance, name and telephone number of family member)</td>
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**Reporting hospital** I I I I I I I I I I I I I I I I I I I I I I I I I I I

**Department/ward** I I I I I I I I I I I I I I I I I I I I I I I I I I I

**Date of registration** I I I I I I I I I I I I I I I I I I I I I I I I I I I

**Competed by** (name of person who completed this form) I I I I I I I I I I I I I I I I I I I I I I I I I I I

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**PRIOR TO STROKE**

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<th>Living</th>
<th>I I I I I I I I I I I I I I I I I I I I I I I I I I I</th>
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<tbody>
<tr>
<td>1</td>
<td>in own home without community support</td>
</tr>
<tr>
<td>2</td>
<td>in own home with community support</td>
</tr>
<tr>
<td>3</td>
<td>living in a community facility (for instance service flat with full board, old peoples’ home, nursing home)</td>
</tr>
<tr>
<td>5</td>
<td>other (fill in)</td>
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<tr>
<th>Living alone</th>
<th>I I I I I I I I I I I I I I I I I I I I I I I I I I I</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>the patient lives on his/her own</td>
</tr>
<tr>
<td>2</td>
<td>the patient lives with a spouse/partner or another person, for instance family member</td>
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<tr>
<th>Mobility</th>
<th>I I I I I I I I I I I I I I I I I I I I I I I I I I I</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>the patient was able (prior to this illness) to move around without supervision indoors as well as outdoors (use of support or walking stick allowed)</td>
</tr>
<tr>
<td>2</td>
<td>the patient was able to move around by his/her own indoors but not outdoors</td>
</tr>
<tr>
<td>3</td>
<td>the patient was assisted by another person when moving around or he/she was bedridden</td>
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<thead>
<tr>
<th>Toilet visits</th>
<th>I I I I I I I I I I I I I I I I I I I I I I I I I I I</th>
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<tbody>
<tr>
<td>1</td>
<td>the patient managed toilet visits on his/her own</td>
</tr>
<tr>
<td>2</td>
<td>the patient was unable to go to the toilet unaided, or used bedpan or incontinence pads or needed assistance in wiping him/herself or in dressing</td>
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<tr>
<th>Dressing</th>
<th>I I I I I I I I I I I I I I I I I I I I I I I I I I I</th>
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<tbody>
<tr>
<td>1</td>
<td>the patient was able to dress without assistance, including outdoor clothes, socks/stockings and shoes, or needed assistance only in tying shoelaces</td>
</tr>
<tr>
<td>2</td>
<td>the patient needed assistance to fetch clothes, or needed assistance in dressing/undressing or remained in his/her night-clothes</td>
</tr>
</tbody>
</table>
### RISK FACTORS

- **Previous stroke?** *(NOTE that TIA is not included)*
  - 1 = yes
  - 2 = no
  - 9 = not known

- **Atrial fibrillation at onset of stroke?** *(including intermittent fibrillation or flutter)*
  - 1 = yes
  - 2 = no
  - 9 = not known

- **Diabetes, previously known or newly diagnosed?**
  - 1 = yes
  - 2 = no
  - 9 = not known

- **Treatment for hypertension at onset of stroke?**
  - 1 = yes
  - 2 = no
  - 9 = not known

- **Is the patient a smoker?**
  - 1 = yes
  - 2 = no
  - 9 = not known

### ACUTE MANAGEMENT

- **Level of consciousness on arrival to hospital**
  - 1 = fully awake (RLS 1)
  - 2 = drowsy but responding to stimulus (RLS 2-3)
  - 3 = unconscious (RLS 4-8)
  - 9 = not known

- **CT scan during hospital stay**
  - 1 = yes
  - 2 = no
  - 9 = not known

### Antithrombotic therapy *(acute phase = first 7 days from admission to hospital)*

- **Response alternatives**
  - **Patients on treatment at onset**
    - 1 = yes, and continuing
    - 2 = yes, but discontinued and not re-started
    - 3 = yes, but discontinued, planning to re-start
  - **Patients in whom treatment is initiated during or after the acute phase**
    - 4 = yes, initiated during the acute phase
    - 5 = yes, initiated or planned to be initiated after the acute phase
  - **Other response alternatives**
    - 6 = no
    - 7 = patient included in a drug trial
    - 9 = not known

- **Drugs**
  - **Aspirin;** for instance [brand names]
  - **Antiplatelet agents (except aspirin);** for instance [brand names]
  - **Oral anticoagulants,** for instance [brand names]
  - **Anticoagulants, injection or infusion (for instance [brand names]) for stroke**
  - **Anticoagulants, injection or infusion (for instance [brand names]) for prevention of venous thrombosis**

- **Thrombolysis,** for instance [brand names]
  - **Time point for start of thrombolytic treatment** *(hour minute)*
  - **Intracranial bleeding with clinical symptoms ≤36 h after start of treatment** *(but be confirmed by CT scan or autopsy)*
  - **Did the patient improve markedly** *(for instance marked recovery of speech or paresis)* within 2 h of onset of treatment
### SEQUENCE OF CARE

#### A  ACUTE MANAGEMENT
(refers to the first episode of hospital care for the present stroke).

<table>
<thead>
<tr>
<th>Event</th>
<th>Format</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of onset</td>
<td>(yy/mm/dd)</td>
</tr>
<tr>
<td>Date of admission</td>
<td>(yy/mm/dd)</td>
</tr>
<tr>
<td>Date of discharge</td>
<td>(yy/mm/dd)</td>
</tr>
<tr>
<td>Time of onset of symptoms</td>
<td>(hour, minute)</td>
</tr>
<tr>
<td>Time of arrival</td>
<td>(hour, minute)</td>
</tr>
<tr>
<td>First admitted to</td>
<td></td>
</tr>
<tr>
<td>First department</td>
<td></td>
</tr>
<tr>
<td>Continued care during the acute phase</td>
<td></td>
</tr>
<tr>
<td>Subsequent department</td>
<td></td>
</tr>
</tbody>
</table>

1 = general ward  
2 = stroke unit  
3 = admission/observation ward  
4 = intensive care unit  
5 = other (fill in)

#### B  LATE MANAGEMENT
(refers to continued rehabilitation of acute stroke within the same health care system)

<table>
<thead>
<tr>
<th>Event</th>
<th>Format</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of admission</td>
<td>(yy/mm/dd)</td>
</tr>
<tr>
<td>Date of discharge</td>
<td>(yy/mm/dd)</td>
</tr>
</tbody>
</table>

### DISCHARGED TO

<table>
<thead>
<tr>
<th>Discharged to</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = own home</td>
<td></td>
</tr>
<tr>
<td>2 = a community facility</td>
<td></td>
</tr>
<tr>
<td>3 = geriatric/rehab department</td>
<td></td>
</tr>
<tr>
<td>4 = other acute-care department</td>
<td></td>
</tr>
<tr>
<td>5 = old peoples’ home, nursing home</td>
<td></td>
</tr>
<tr>
<td>6 = dead during hospital stay</td>
<td></td>
</tr>
<tr>
<td>7 = other</td>
<td></td>
</tr>
</tbody>
</table>

Other (specify) ..........................................................  

### STROKE DIAGNOSIS

<table>
<thead>
<tr>
<th>Stroke diagnosis</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I 61 = intracerebral hemorrhage</td>
<td></td>
</tr>
<tr>
<td>I 63 = cerebral infarction</td>
<td></td>
</tr>
<tr>
<td>I 64 = unspecified acute stroke</td>
<td></td>
</tr>
<tr>
<td>G 45 = TIA/cerebral ischemia/transient</td>
<td></td>
</tr>
</tbody>
</table>

DECEASED

<table>
<thead>
<tr>
<th>Date (date when the patient died)</th>
<th>(yy/mm/dd)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autopsy 1 = yes</td>
<td></td>
</tr>
<tr>
<td>2 = no</td>
<td></td>
</tr>
<tr>
<td>9 = not known</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Autopsy</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = yes</td>
<td></td>
</tr>
<tr>
<td>2 = no</td>
<td></td>
</tr>
<tr>
<td>9 = not known</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2. Interview guide

The method consists of thematically structured interviews with the following main themes: experiences of health care encounters, treatment and rehabilitation, living conditions e.g. economy, housing, close relations and housework.

The interviews touch upon the following research questions:

*Experiences of care and treatment:* How do elderly stroke patients feel that they have been received, cared for and treated in the health service depending on their gender?

*Elderly persons’ life experiences:* What is the meaning of different circumstances of life, such as economy, housing and close relations, for women’s and men’s rehabilitation and for opportunities for a good life, despite residual status after stroke?

*Domestic work and home help services:* What does the division of housework mean for women and for men with stroke as regards the possibility of receiving care in the home? What home help is offered and how is it perceived?