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Her PhD-thesis, Care Trajectories in the Oldest Old, demonstrates relations among health, social network, Activities of Daily Life (ADL) and patterns of care in the oldest old guided by a resource theoretical model.

The analyzed data come from two longitudinal studies: the NONA study and the H70 study. The sample in the NONA longitudinal study includes 157 individuals aged 86 to 94 years at baseline, and the H70 study sample is comprised of 964 individuals aged 70 at baseline.

The results in this thesis demonstrate that perceived resources seem to affect patterns of care to a greater extent than the more objective resources in the sample of the oldest old. On the other hand, the sociodemographic variables of gender, marital status and SES, and the more objective resources of having children nearby and number of symptoms, predicted institutionalization during a subsequent 30-year period from the age of 70. ADL score was one of the strongest predictors for both use of formal care and institutionalization in both samples, indicating an effective targeting by the formal care system in Sweden. The care at the end of life in the oldest old is challenged by the problems of progressive declines in ADL and health, which makes it difficult to accommodate in the palliative care system the oldest old who are dying. There is a need to increase the knowledge and the possibility for care staff to support and encourage social network factors and for decision-making staff to consider other factors beyond ADL.
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PERCEIVED PARTICIPATION IN DISCHARGE PLANNING AND HEALTH RELATED QUALITY OF LIFE AFTER STROKE

Ann-Helene Almborg
Abstract

The overall aim of this thesis was to investigate the patients’ and their relatives’ perceived participation in discharge planning after stroke and the patients’ health-related quality of life, depressive symptoms, performance of personal daily activities and social activities in connection with discharge. Another aim was to evaluate the psychometric assumptions of the SF-36 for Swedish stroke patients.

Prospective, descriptive and cross-sectional designs were used to study all patients with stroke admitted to the stroke unit at a hospital in southern Sweden from October 1, 2003 to November 30, 2005 each with one close relative. The total sample consisted of 188 patients (mean age=74.0 years) and 152 relatives (mean age=60.1 years). Data were collected during interviews, 2-3 weeks after discharge.

The results showed that less depressive symptoms, more outdoor activities and performance of interests are important variables that related to higher HRQoL. SF-36 functions well as a measure of health-related quality of life in Swedish stroke patients, but the two summary scales have shortcomings. Compared to a Swedish normal population, scores on all scales/components of the SF-36 were lower among stroke patients especially in the middle-aged group. Most of the patients perceived that they received information, but fewer perceived participation in the planning of medical treatment and needs of care/service/rehabilitation and goal setting. The relatives perceived that they need more information and they perceived low participation in goal setting and needs assessment. The professionals seem to lack effective practices for involving patients and their relatives to perceive participation in discharge planning. It is essential to develop and to implement methods for discharge planning, including sharing information, needs assessment with goal setting that facilitate patients’ and relatives’ perceived participation. The results suggest that ICF can be used in goal setting and needs assessment in discharge planning after acute stroke.

Key words: Discharge planning, goal-setting, health related quality of life, ICF, information, needs assessment, patient participation, relatives participation, social activities, stroke.
Original papers

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

I  Almborg AH, Ulander K, Thulin A, Berg S. Patients’ perceptions of their participation in discharge planning after acute stroke. *Journal of Clinical Nursing* (accepted)

II Almborg AH, Ulander K, Thulin A, Berg S. Discharge planning of stroke patients - the relatives’ perceptions of participation. *Journal of Clinical Nursing* (accepted)


IV Almborg AH, Ulander K, Thulin A, Berg S. Discharge after stroke - important factors for Health-Related Quality of Life (submitted)

The papers have been reprinted with the kind permission of the respective journal.
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Abbreviations and definitions

ADL  Activities of Daily Life
ANOVA Analysis of variance
BI  Barthel Index
BP  Bodily Pain (SF-36 domain)
CES-D Center of Epidemiologic Studies Depression Scale
CI  Confidence Interval (usually 95% CI)
FAI  Frenchay Activities Index
GH  General Health (SF-36 domain)
HRQoL  Health-Related Quality of Life
HSD  Honest Significant Difference
I-ADL  Instrumental Activities of Daily Life
ICF  International Classification of Functioning, Disability and Health
MCS  Mental Component Summary (SF-36)
MH  Mental Health (SF-36 domain)
MMSE  Mini Mental State Examination
QoL  Quality of Life
P-ADL  Personal Activities of Daily Life
PCS  Physical Component Summary (SF-36)
PF  Physical Functioning (SF-36 domain)
P-QPD  Patient’s Questionnaire about Participation in Discharge Planning
SD  Standard Deviation
RE  Role Emotional (SF-36 domain)
RP  Role Physical (SF-36 domain)
R-QPD  Relative’s Questionnaire about Participation in Discharge Planning
SF  Social Functioning (SF-36 domain)
SF-36  Short Form 36 Health Survey
SFS  Swedish Code of Statutes
SOSFS  The National Board of Health and Welfare Code of Statutes
VAS  Visual Analogue Scale
WHO  World Health Organization
VT  Vitality (SF-36 domain)
Introduction

In most industrialised countries, stroke is the third largest cause of death and often leads to disability, and frequently occurring symptoms. Every year in Sweden, about 30,000 people suffer a stroke. Stroke influences the patient’s whole life situation such as activities, participation in the community and quality of life. Patients with stroke constitute a large group that need a long stay in hospital and continued care and support after discharge (National Board of Health and Welfare 2006b). Swedish laws and regulations require a discharge plan to be developed together with the patient, if there is a need of continued care and service after discharge from hospital (SFS 1990:1404, SOSFS 1996:32, SOSFS 2005:27), but the health care organisations in Sweden lack national standardised methods for discharge planning. Stroke also influences the relatives’ situation and many patients are dependent on family support to perform the activities of daily life (ADL). Therefore, the relatives also need to be involved in discharge planning (National Board of Health and Welfare 2006b). The active participation of patients and their relatives is an essential part of the modern health care system in Sweden (SOSFS 2005:12).

After a patient has suffered a stroke, health status measurements might be used to examine and describe the impact of the stroke on his/her life situation, to enable planning, monitoring and evaluation of outcomes at an individual level as well as at a macro-level (McHorney 1999). Some of the most used health status measurements are the Bartel Index (BI) and the Frenchay Activities Index (FAI), and, together with the Center of Epidemiologic Studies Depression Scale (CES-D), these are used as outcome measures. However, stroke survivors’ whole life situation is affected and in order to provide a more comprehensive patient approach to the consequences of stroke health-related quality of life (HRQoL), measures may be used even in the early post-acute phase (Bugge et al. 2001, Hopman & Verner 2003). Previous studies have found that the Medical Outcomes Study, 36-item Short-Form Health Survey (SF-36) is a frequently used measure of HRQoL after suffering a stroke to describe the patients’ experiences of functioning and well-being in the physical, mental and social dimensions of life (Buck et al. 2000, Hobart et al. 2002). To our knowledge, there are few studies investigating multiple variables that contribute to the level of HRQoL a few weeks after discharge. There are few studies also evaluating patients’ and relatives’ perceptions of participation in discharge planning and investigating associated variables to perceived participation in discharge planning.
2 Aims of the thesis

The overall aim of this thesis was to investigate the patients’ and their relatives’ perceived participation in discharge planning after stroke and the patients’ health-related quality of life, depressive symptoms, performance of personal daily activities and social activities in connection with discharge. Another aim was to evaluate the psychometric assumptions of the SF-36 for Swedish stroke patients. The specific aims of the papers included in the thesis were:

- to describe stroke patients’ perceptions of their participation in discharge planning and identify the correlates to perceived participation (Paper I)
- to describe relatives’ perceptions of participation in discharge planning of patients with stroke and to identify the characteristics of patients with stroke and their relatives that corresponded with the relatives’ perceived participation (Paper II)
- to evaluate the psychometric assumptions of the SF-36 regarding data quality, scaling, reliability, and construct validity in Swedish stroke patients and to estimate the impact of stroke on HRQoL in comparison with the Swedish normative population (Paper III)
- to identify correlates to HRQoL in patients with stroke, 2-3 weeks post discharge (Paper IV).

Additional analyses were conducted for this thesis with the aim

- of evaluating the psychometric assumptions of P-QPD and R-QPD and linking the items to the International Classification of Functioning, Disability and Health (ICF).
3 Background

3.1 Stroke - general

According to the World Health Organization (WHO), stroke is defined as “a syndrome of rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than vascular origin” (WHO 1989). These definitions include brain haemorrhage, brain infarction and subarachnoidal haemorrhage but not transitory ischemic attack (TIA).

Stroke is the third largest cause of death (after cardiac disease and cancer) in Sweden. About 30,000 people suffer a stroke every year and about 20,000 of these people have first ever stroke. The incidence rises with age (National Board of Health and Welfare 2006b) and the mean age for suffering a stroke is 76 years: 73.5 years for men and 78.4 years for women. There is no difference between men (50.1%) and women (49.9%) suffering in stroke. Approximately 20% are under 65 years of age. Brain infarction is the most common diagnosis (85%), while brain haemorrhage (10%) and subarachnoidal haemorrhage (5%) are less frequent. Stroke is the physical illness that necessitates the longest stay in hospital (Riks-Stroke 2007).

3.2 The theoretical framework

The theoretical framework used for this thesis is the International Classification of Functioning, Disability and Health (ICF) (WHO 2001) to describe how stroke impacts on the patients’ life situation. Two other models are used as a framework to describe needs assessment, which is a part of discharge planning. One is a model for needs assessment and goal-setting (Liss 2006) and the other is a model for quality of life, needs assessment, outcome measures and quality of care (van den Bos & Triemstra 1999).
3.2.1 The International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) is a framework that can be used to describe how illnesses are related to different parts of body structure, body functions, activity and participation but also to environmental factors (WHO 2001). The ICF is a biopsychosocial, interactive model that can be used in rehabilitation to understand how the different parts of the ICF interact, to identify problems and to assess needs (WHO 2001).

The ICF was developed to give a standardised, common language to describe health and health-related functions and, thereby, facilitate communication about health between professionals and organisations. It makes comparisons of data possible between i.e. countries, health-care organisations and services (WHO 2001).

The ICF consists of two parts. The first part, which describes functioning and disability, includes body functions, body structures and activities and participation. The second part, which describes contextual factors, consists of environmental factors and personal factors. Body functions are the physiological and psychological functions of body systems. Body structures are the anatomical parts of the body, such as organs, limbs and their components. Activity is a person’s execution of a task or an action by an individual. Participation is a person’s involvement in a life situation. Environmental factors include the physical, social and attitudinal environment in which a person lives. Personal factors are the particular background of an individual’s life and living, and comprise features of the individual that are not part of the health condition or the health status (WHO 2001). In the model, health-related quality of life could be seen as an overall concept, which incorporates all components of ICF (Cieza & Stucki 2005).

ICF could be used as a framework in rehabilitation and improve communication between the patients and the professionals (Stucki et al. 2002). Previous research has found that ICF could be used in assessments to describe the impact of stroke in functions, activities, participation and health (Geyh et al. 2004) and could expand the nurses’ view of strategies for caring (Pajalic et al. 2006). To achieve a patient-centred approach, not only external observations of the professionals but also the patients’ perspective and their subjective experiences of health and quality of life need to be taken more into consideration, when using the ICF:s framework (Wade & Halligan 2003).
When linking the aim of the instruments to ICF, different components are included such as:

- **body functions - cognitive functions and depressive symptoms**
- **activity - self-care, mobility**
- **participation - communication, social activities and interests**
- **environmental factors - discharge planning** (Figure 1).

The aim of the questionnaires, which measure the patients’ and the relatives’ perceived participation in discharge planning, was linked to both participation in communication and to environmental factors such as services, systems, and policies in social-security services and health services. These instruments are sorted as environmental factors in this thesis since the professionals have to supply discharge planning if the patients need continued care/support, post discharge. The environmental factors such as discharge planning and length of stay in hospital can be seen as services, systems, and policies in social-security services and health services. Another environmental factor can be described as relatives’ support of the patient. Personal factors such as gender, age, education level and living arrangements are also included in the thesis.
3.2.2 **Needs assessment and goal-setting**

The central theme in discharge planning is needs assessment and goal-setting. Liss (2006) has presented a model for measurement of care needs, which describes need as the gap between the current state of health and the desired state of health (the goal). The model (Figure 2) consists of three parts:

- Measure the current state of health
- Establish the desired state of health (the goal)
- Judge necessary measures (needs of measures) to eliminate or to decrease the gap between the patient’s current and desired state of health.

The current and the desired state of health could be described by means of the following components of ICF: body functions, body structures, activity and participation. The patients’ needs of measures to eliminate or decrease the gap could be described by using the environmental factors.

*Figure 2. Model for needs assessment and goal-setting (National Board of Health and Welfare 2006a).*
A clearly defined goal is a prerequisite for a realistic needs assessment and also necessary for co-ordinating all those involved in activities such as the professionals and patients. Different goals create different series of needs. The goals have three dimensions: What is it? How much is it? and When is it to be obtained? (Liss 2003, 2006). A goal may have several functions (Liss 1999). The goal can have an action-guiding function as it provides the direction for actions. It can also serve as a motivational function for the person, and it can have a symbolic function (Liss 1999). Needs assessment of health care can be identified as two different needs (Van den Bos & Triemstra 1999):

- Professionally defined needs
- Patient-defined needs

The defined needs of the professionals refer to standards of care, clinical guidelines and evidence-based medicine. The patient’s defined needs refer to the patient’s view and perceptions of his/her needs. Needs assessment of health care focuses on measurements of quality of life and thereby reflects the patients’ perceptions (van den Bos & Triemstra 1999). Before an intervention is planned and started, the needs assessment takes place. Outcome assessment occurs after the intervention and will help to identify shortcomings in the effect of or exit from health care. Physical, psychological and social functioning is included in assessments of quality of life. Assessments of needs and outcome are related to quality of life and quality of care (Figure 3) (van den Bos & Triemstra 1999). Needs assessment requires the involvement of the patients to get their perceptions of defined Goals and Needs, which ought to be in agreement with the defined needs of the professionals (Liss 2006, van den Bos & Triemstra 1999). The International Classification of Functioning, Disability and Health (ICF) could be used as a framework for needs assessment, goal-setting and evaluation of outcomes (WHO 2001).

Figure 3. The reciprocal relation between quality of life and quality of care (van den Bos & Triemstra 1999).
3.3 The impact of stroke on the components of ICF and HRQoL

HRQoL and ICF represented two different perspectives to describe functioning and health, but earlier research showed that measurements of HRQoL could be described by the components of ICF especially by activity and participation (Cieza & Stucki 2005). However, in this thesis, HRQoL, body functions, body structures and activity/participation are used to describe the impact of stroke. Health-status measures are practical for a great variety of purposes in clinical practice, research on health services and health policy (McHorney 1999). They may be used for describing and examining how stroke impacts on individuals and, on the macro-level, for health care planning and decision-making (Geyh et al. 2007).

3.3.1 HRQoL

The WHO has defined quality of life (QoL) as an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and his/her relationship to salient features of his/her environment (WHOQOL 1993). The definition indicates that QoL refers to a subjective evaluation that is influenced by the cultural, social and environmental context (WHOQOL 1998). This definition has been the basis of many different definitions of QoL, which most often is seen as a multidimensional concept including at least physical, psychological and social dimensions (de Haan et al. 1995, WHOQOL 1998). Physical dimensions refer to symptoms such as fatigue, pain and functional status including activities such as mobility, self-care and the instrumental activities of daily life (I-ADL). Psychological dimensions refer to mental abilities, psychological distress and wellbeing. Social dimensions represent the performance of social roles and social participation. Measurements of these dimensions, together with global, overall measures of perceived health and wellbeing, are seen as the pillars of the concept of health-related quality of life (van den Bos & Triemstra 1999). QoL refers to a more generic or global concept used in political, societal and cultural issues, whereas HRQoL is used more in clinical research. HRQoL measures have been developed to measure a variety of health conditions (Berzon et al. 1993, Naughton & Shumaker 2003).
3.3.1.1 HRQoL after stroke

HRQoL changes after onset of stroke and Mayo et al (2002) found that, six months post stroke, the physical health (PCS) and the mental health (MCS) were lower compared to people without stroke. Earlier research by Hopman and Verner (2003) showed that HRQoL improved from admission to discharge from hospital, but decreased between discharge and 6 months post discharge. Wrosch and Scheier (2003) found that personal factors such as optimism and ability to adjust to unattainable goals were associated with good HRQoL. Measures of HRQoL are often a subjective evaluation of the consequences of stroke and therefore have a patient-centred approach (Geyh et al. 2007). Previous research has found variables associated to quality of life, after a patient has suffered a stroke, such as age (Hopman & Verner 2003), gender (Aprile et al. 2006, Hopman & Verner 2003), educational level (Aprile et al. 2006), depression (Aprile et al. 2006, Jaracz & Kozubski 2003, Kauhanen et al. 2000), fatigue (Naess et al. 2006), length of hospital stay (Mackenzie & Chang 2002), functional status (Jaracz & Kozubski 2003) and social participation (Jonsson et al. 2005).

3.3.2 Body functions

Stroke may cause both visible and invisible symptoms such as paralysis, paresis, dysphasia, behavioural changes, fatigue, depression, cognitive impairment or emotional changes and, on average, necessitates a longer stay in hospital than other medical conditions (National Board of Health and Welfare 2006b). Earlier research among patients with stroke found that functional impairment affected the ability to perform activities that were associated with low HRQoL (Pajalic et al. 2006). According to Patel et al (2003), cognitive impairments were reported in 39% of the patients, three months and in 35%, one year after suffering a stroke. Recovery of cognitive impairments was associated with better functional status and less institutionalisation one year after stroke (Patel et al. 2003). Previous research supported systematic screening of cognitive and perceptual functions after suffering a stroke, due the fact that not all screened impairments were documented in the charts at the hospital (Edwards et al. 2006).
Depression or depressive symptoms occur frequently after a stroke. The prevalence of depression may appear to vary depending on whether the patients are categorised by diagnostic criteria using psychiatric interview or on the basis of self-rating mood scales (Hackett et al. 2005). In a review of different studies, it was concluded that one third of all patients suffering from stroke experienced depressive illness or depressive symptoms some time after the incident (Hackett et al. 2005). The greatest risk of depression is during the first months after onset of stroke but it seems that few patients receive effective treatment for their depression (Hackett et al. 2005). Chemerinski et al. (2001) showed that reduction of post stroke depression, both minor and major, was related to greater recovery in ADL functions over the first few months after a stroke. Also limitations of social activities can be associated with depression both in short-term and in long-term follow-up, which indicates the importance of social support and social activities (Robinsson et al. 1999).

3.3.3 Body structures

Brain infarction and brain haemorrhage affect the brain structures in different ways and their localisation presents different symptoms. In this thesis, diagnosis was used to describe the characteristics of the patients.

3.3.4 Activity and participation

Stroke impacts on the patients’ activities and participation in the community and may also influence their relatives’ life situation (National Board of Health and Welfare 2006b). The patients’ goals are the recovery of the same previous roles and habits as before stroke (Bendz 2003) and the most important aspect of recovery is the return to meaningful activities (Burton 2000).
Stroke decreases the survivors’ performance of P-ADL. Mayo et al (2002) found that 33% of people with stroke have some limitations in basic activities such as bathing, walking short distances and negotiating stairs, 6 months post stroke compared with only 3% of the control group. According to Appelros (2006), 36% of first ever stroke survivors were dependent regarding P-ADL as measured by BI one year after suffering a stroke. Another study shows that about 95% of the patients had recovered their optimal ADL function within 12.5 weeks after onset (Jorgensen et al. 1995). The study by Paolucci et al. (2001) showed that mobility status was not stabilised at discharge and about 40% of the patients perceived some decline in mobility one year after stroke. Lower age, male gender, higher education and fewer depressive symptoms have been found to be predictors of better P-ADL functions as measured by BI (Aprile et al. 2006). Carod-Atal et al. (2002) found that BI at discharge was the strongest predictor for independence in social activities one year after stroke.

Recovery of social activities and participation in the community is usually more essential for patients with stroke, than recovery of specific physical functions and the families’ support in this recovery of social life is important (Burton 2000, Clarke & Black 2005). Stroke patients’ quality of life is negatively influenced by their restrictions in pursuing leisure activities (Robinson-Smith et al. 2000, Sveen et al. 2004) and difficulties in travelling on vacation (Robinson-Smith et al. 2000). According to Mayo et al (2002), meaningful activity is restricted for stroke patients (53%), 6 months post stroke, compared to people without stroke (16%). Regarding household tasks, the ratio is 51% versus 5% and, for travel, 50% versus 8%. Appelros et al (2006), showed that, one year after suffering a stroke, 59% were dependent on help in “social activities” measured by FAI and, to a large extent, the relatives provided this help. Previous research has found that increased age (Hoffmann et al. 2003), male gender, living with a partner, motor impairment (Schepers et al. 2005), cognitive impairment (Pettersen et al. 2002) and limitations in personal activities (Hoffmann et al. 2003, Pettersen et al. 2002, Schepers et al. 2005, Thommessen et al. 1999) are important predictors for limitations in social activities after stroke.

3.3.5 Personal factors

Earlier research has found that personal factors such as gender, age, educational level and living arrangements influenced HRQoL, body functions and activity/participation after stroke and these are discussed in connection with the other components of ICF, in this thesis.
3.3.6 Environmental factors

Environmental factors such as stroke unit, the professionals employed in health care and community care, professionals’ attitudes, laws, regulations, guidelines and routines could be seen as barriers or facilitators. Support from the relatives in recovery from stroke is an important environmental factor (Geyh et al. 2004) and, in this thesis, relatives and their perceived participation in discharge planning are included as environmental factors. Length of stay in hospital can be described as an environmental factor.

3.3.6.1 Stroke care in Sweden

The development of stroke units in Sweden is an important factor in achieving effective and high-quality stroke care in hospitals. Early rehabilitation with defined goals and the involvement of relatives; information concerning stroke, recovery and resources; early assessment of needs after admission and the involvement of patients and relatives in discharge planning are components that are related to good outcomes of care at a stroke unit (National Board of Health and Welfare 2006b). A stroke unit is an organised hospital unit that cares for all or almost all stroke patients. The professionals have specialised knowledge about stroke and work in a multidisciplinary team (National Board of Health and Welfare 2006b).

A stroke unit is characterised by the following:

- It is a geographically-defined unit at a hospital, which only (or almost only) cares for stroke patients
- The professionals have specialist competence in stroke and rehabilitation
- The multidisciplinary team holds meetings at least once a week. The team includes: physician, nurse, assistant nurse, physiotherapist, occupational therapist, social worker, speech therapist and has access to a psychologist and dietician
- Detailed information and instruction to patients and relatives during the hospital stay
- An established program for registration and measurement of common problems to avoid medical and other complications
- Immediate initiation of mobilisation and early rehabilitation (National Board of Health and Welfare 2006b).
At the stroke unit, the professionals are supposed to use methods for patient-centred care with goal-setting. An important part in this goal-setting process is involving patient and relatives and the professionals have to pay attention to both individuals and environmental factors (National Board of Health and Welfare 2006b). Patients and relatives will receive individualised information during the whole hospital stay and another substantial element of the process at the stroke unit is an early assessment of the need of continued care and support after discharge (National Board of Health and Welfare 2006b). Previous research has found that care at a stroke unit is more efficient and results in better outcomes for the patients than conventional care (Glader et al. 2001, Indredavik et al. 1998, Langhorne & Pollock 2002).

The stroke unit in this thesis was a combined acute and rehabilitation stroke unit in the same ward, and there was a clear point in time when the patients were administratively transferred to the rehabilitation phase although they were still in the same bed. An investigation of stroke units in Sweden did not show any differences between the stroke unit studied in this thesis and the average stroke unit in Sweden regarding care, information on the illness and information about where the patients could get help and support post discharge (National Board of Health and Welfare 2007).

3.4 Discharge planning

Definitions of discharge planning vary in the literature. Discharge planning is usually defined as a process to co-ordinate the patient’s continued care after discharge with the patient and/or relatives and other caregivers (National Board of Health and Welfare 2005, SFS 1990:1404). Rorden and Taff (1990) describe discharge planning, as a dynamic process that involves the patient, his/her family and the caregivers in a dynamic, interactive communication and collaboration regarding a range of specific skills. The process begins with an assessment of the patient’s requirements of continued care/support regarding medical, psychological, economic, and social needs, including the patient’s total well-being. The process results in agreed goals and requirements for continued care, support, and rehabilitation. Previous research has found that all team members contribute more in the multidisciplinary teamwork on discharge planning if the number of medical issues decreased and that the team members needed more training in team skills and inter-professional training for effective discharge planning to be achieved (Gair & Hartery 2001).
The stroke unit in this thesis had local guidelines for discharge planning describing the administrative routines, the measures to be taken before discharge planning and who should participate in discharge planning. The guidelines also regulate the development of a discharge plan including planned interventions and who should be responsible for the interventions planned.

3.4.1 Participation in discharge planning

The definition and application of participation varies depending on whether the focus is on the individual or societal level. Cahill (1998) described participation as “getting involved or being allowed to get involved” in decision-making and the delivery of services. According to the ICF, participation is described as “a person’s engagement in a life situation”. In the Swedish version, participation is described as involvement, taking part, being included, being accepted (National Board of Health and Welfare 2003a). Rifkin and Pridmor (2001) defined participation as empowerment. If a person has the information he or she needs in a special situation and can interpret and use it, he or she has knowledge, which translates to power. Participation requires the possession of knowledge and the ability to influence decision-making (Rifkin & Pridmor 2001). Calkins et al. (1997) found that the communication between patients and physicians about the patients’ needs of medical treatment, is a critical point in discharge planning. Charles et al. (2003) described shared decision-making as a dynamic process of interaction between the physician and the patient in three stages: information exchange, deliberation and agreement on treatment. As mentioned in the theoretical framework, in order to identify the patient’s needs, his or her actual state of health has to be assessed and the desired state of health has to be established as a goal (Liss 2001). The difference between these points constitutes the patient’s needs, and the professionals have to discuss what resources are needed to reach the goal (Liss 2001). This identification of needs is an important step and should be carried out by a multidisciplinary team together with the patient.

There are both internal and external assumptions for participation. The internal factors are body functions, ability and willingness to participate and the external factors are physical and social environments with rules and norms that facilitate participation. Experiences of participation depend on the patients’ roles in the context, their age and their personality. Participation cannot be assessed by other persons; instead, one has to ask the person about their experiences of participation (Gustavsson 2004).
Results derived from previous research about patient participation showed that most patients want to receive information about their illnesses, conditions and care, and to be involved in the decision-making process (Guadagnoli & Ward 1998), but the patients felt that they lacked the strength and knowledge to influence decision-making (Nordgren & Fridlund 2001). Earlier research has found that there is an imbalance of power between the patients and nurses, which inhibited the patients’ participation in decision-making (Henderson 2003). It has also been shown that a patient’s participation in different aspects of health care has positive effects for the patient. Participation enhances the quality of life, self-esteem, personal responsibility for their health and self-care and satisfaction with outcomes (Cahill 1996). Participation in goal-setting has a positive impact on patients’ motivation and it will influence the patients’ recovery after stroke (Holmqvist & von Koch 2001).

Patients’ participation in the care may be limited by attitudes prevailing in health care (Enehaug 2000). People working in the health care professions have to change their attitudes from seeing the patient as an object needing help, to seeing a person who takes an active part in his/her care. To create a partnership between the patient and the professionals, there must be an interpersonal relationship between them. The professionals have to understand the patients’ experiences of the situation by listening to the patients and relatives (Enehaug 2000). Henderson (1997) found that “mutual trust and rapport; a positive nurse-patient attitude; sustained nurse-patient contact and meaningful interaction” (p 112) are enhancing factors for getting to know the patient, which improves patient participation.

In this thesis, patients’ and relatives’ perceived participation in discharge planning was described as:

- Receiving sufficient information about the illness, the course of the illness, care and rehabilitation and the opportunity to ask questions and get answers
- The opportunity to participate in discussions about the Goals and Needs for care, services and rehabilitation.
This description of perceived participation in discharge planning could be linked to ICF according to the rules established by Cieza et al (2005). Communication with the patients and the relatives regarding the issue of whether they receive sufficient information and involvement in discussions regarding goals and needs could be linked to the ICF section on participation and the chapter “Communication” and “Learning and applying knowledge”. Discharge planning and the information from the professionals could be linked to the chapter “Services, systems and policies” of environmental factors in ICF.

3.4.2 Information in connection with discharge

Information is a presumption for participation (Rifkin & Pridmor 2001) and Saino et al (2001) found that receiving information and asking questions are the most important factors in participation in decision-making. If patients receive information about how to evaluate symptoms and manage medication and limitations in activities, they perceive continuity of care and that they are more prepared to manage their own care after discharge (Bull et al. 2000b), and are more satisfied with the discharge planning. According to earlier research, there is very little knowledge concerning the importance of information for recovery after stroke (Young & Forster 2007). Earlier research has found that patients in more general groups are often dissatisfied with the information received in connection with discharge (Driscoll 2000, Rowe et al. 2000), but the research regarding stroke patients’ perceptions concerning information in relation to discharge planning is limited.
3.4.3 Needs assessments and goal-setting

The evaluation of the patient’s needs after discharge is very important for the patient (Birmingham 2004). Discharge planning should involve the patient in goal-setting and the evaluation of needs and also involve different professionals depending on the patient’s problems (Birmingham 2004). However, previous research has found that the patients are often not involved in discussions concerning goal-setting (Bendz 2003, Efraimsson et al. 2004, Furaker et al. 2004, Wressle et al. 2002). The roles of professionals in discharge planning and goal-setting are often unclear according to earlier research (McKenna et al. 2000, Reed & Morgan 1999) and the staff may follow old routines, making decisions without involving the patient (Furaker et al. 2004). Patients perceive more participation in goal-setting when the professionals use a client-centred goal formulation structure with focus on the patients’ problems (Holliday et al. 2007, Wressle et al. 2002) and patients want to discuss activities that are meaningful for them. According to a study made by Florin et al. (2006), the patients were more active in discussions about needs related to activity, emotions and roles (physical and psychosocial needs) compared to needs for nursing care. Similar results have been found in the social services, where it seems that elderly persons have less opportunity to influence the decisions on home help services, which they perceived were decided from policy and not from an individual need. Needs assessment for the elderly regarding social services focused mainly on physical and practical disabilities and needs. The mental, social, existential and medical needs were neglected in the assessments (Janlöv 2006). Earlier research has found that lower age, motor impairment, fatigue and depressive symptoms are significantly related to the presence of unmet demands of chronic stroke patients (van de Port et al. 2007).

Studies concerning patients’ preferences regarding participation in decision-making have shown a range varying from a passive role, a collaborative role to an active role. Florin (2007) found that nurses thought that the patients preferred a more active role in the clinical decision-making regarding nursing care, than the patients really preferred. The option most preferred (61%) by the patients was a more passive participation role in clinical decision-making for general needs such as the patient prefers to let the nurses make the final decision about which treatment to use, but that the nurse considers the patient’s opinion seriously (Florin 2007) However, regarding other, more specific needs such as physical (58%) and psychosocial (63%) needs, several patients preferred a shared or active role. Variables such as female, living alone, higher education and senior citizens were related to a more active role in participation (Florin 2007).
3.4.4 Relatives’ participation in discharge planning

Stroke has consequences for the relatives’ life situation (National Board of Health and Welfare 2006b). Previous research has found that relatives of patients with stroke had a lower level of emotional well-being than the population in general (Wyller et al. 2003). Informal caregivers experienced more depressive symptoms when they were caring for stroke survivors who exhibited more memory problems and other behavioural and psychological symptoms (Cameron et al. 2006). The families’ support is very important for the stroke patient’s recovery (National Board of Health and Welfare 2004) and quality of life (Clarke & Black 2005). Previous research has shown that involving elderly patients and their relatives in discharge planning increased the well-being of both groups (Bull et al. 2000c). Relatives’ perceptions of being more involved in discharge planning for elderly patients increased the relatives’ satisfaction with discharge planning and continuity of care. Furthermore, they felt more prepared and experienced greater acceptance of their caring role (Bull et al. 2000a). Relatives’ involvement in goal-setting also increases the patients’ compliance in care and rehabilitation (Siegert & Taylor 2004). Patients experienced that emotional support was as important as practical help in the informal care-giving (Johansson 2001). However, a Swedish study showed that relatives of elderly patients, who need support from social services were not involved in the discussions in the needs assessments (Janlöv 2006). To our knowledge, there is less research on relatives’ perceived participation in discharge planning after stroke.
4 Methods

All four papers in this thesis present results from a larger study “Stroke patients and their relatives’ perceived participation in care planning and rehabilitation” based on all patients from two municipalities admitted to the stroke unit at a hospital in southern Sweden.

4.1 Design

The design of the studies was prospective, descriptive and cross-sectional.

4.2 Settings

The studies were based on all patients from two municipalities admitted to the stroke unit of a hospital in southern Sweden from October 1, 2003 to November 30, 2005. There were about 62,000 inhabitants living in the two municipalities in a rural district.

4.3 Participants

4.3.1 Patients (Paper I, III and IV)

The patients were consecutively included during the two years. The following inclusion criteria had to be met (Paper I, III, IV):

- a medical diagnosis of stroke (ICD-10: I 61 [brain haemorrhage], I 63 [brain infarction], I 64 [non-specified stroke])
- living in one of the two municipalities
- ability to speak and understand the Swedish language
- absence of severe aphasia
- absence of marked cognitive impairment.
Cognitive impairment was defined as a score of <24 on the Minimal Mental State Examination (MMSE) (Folstein et al. 1975) and was measured at the interview, 2-3 weeks after discharge. Patients under 65 years of age and patients with earlier stroke episodes were excluded during the first five months, but in order to increase the study group, these exclusion criteria were dropped from March 1, 2004. In this early period, 16 patients were included in the study. At the same time, CES-D was added to measure depressive symptoms.

A total of 321 patients were admitted during the study period. Of these, 38 patients died before interview, 23 patients declined participation, 28 patients had aphasia, 38 patients had cognitive impairment (<24, MMSE), four patients were excluded due to impairments in understanding and speaking Swedish and two patients could not be contacted. The total sample comprised 188 patients.

![Diagram showing the numbers of included and excluded patients and relatives.](image)

Figure 4. Numbers of included and excluded patients and relatives.
Table 1. Patients’ characteristics

<table>
<thead>
<tr>
<th>Variables</th>
<th>Patients (N=188)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
</tr>
<tr>
<td>Age groups (years)</td>
<td></td>
</tr>
<tr>
<td>≤64</td>
<td>20.7</td>
</tr>
<tr>
<td>65-74</td>
<td>26.1</td>
</tr>
<tr>
<td>75-84</td>
<td>34.5</td>
</tr>
<tr>
<td>85+</td>
<td>18.6</td>
</tr>
<tr>
<td>Education (years)</td>
<td></td>
</tr>
<tr>
<td>Elementary school (&lt;7)</td>
<td>75.0</td>
</tr>
<tr>
<td>&gt;Elementary school (&gt;7)</td>
<td>25.0</td>
</tr>
<tr>
<td>Living arrangements (before)</td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>41.0</td>
</tr>
<tr>
<td>Living together</td>
<td>59.0</td>
</tr>
<tr>
<td>Living in (before)</td>
<td></td>
</tr>
<tr>
<td>Own house</td>
<td>60.6</td>
</tr>
<tr>
<td>Own apartment</td>
<td>36.7</td>
</tr>
<tr>
<td>Care homes with more help</td>
<td>0.5</td>
</tr>
<tr>
<td>Care homes with less help</td>
<td>2.1</td>
</tr>
<tr>
<td>Living in (after discharge)</td>
<td></td>
</tr>
<tr>
<td>Own house</td>
<td>53.2</td>
</tr>
<tr>
<td>Own apartment</td>
<td>33.0</td>
</tr>
<tr>
<td>Care homes with more help</td>
<td>1.1</td>
</tr>
<tr>
<td>Care homes with less help</td>
<td>2.1</td>
</tr>
<tr>
<td>Short-stay accommodation</td>
<td>9.6</td>
</tr>
<tr>
<td>Other rehabilitation institutions</td>
<td>1.1</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>I61-brain haemorrhage</td>
<td>6.9</td>
</tr>
<tr>
<td>I63-brain infarction</td>
<td>92.6</td>
</tr>
<tr>
<td>I64-non-specified stroke</td>
<td>0.5</td>
</tr>
<tr>
<td>First ever stroke</td>
<td>80.3</td>
</tr>
<tr>
<td>Prior stroke</td>
<td>19.7</td>
</tr>
<tr>
<td>Lengths of stay in hospital (days)</td>
<td></td>
</tr>
<tr>
<td>≤5</td>
<td>22.3</td>
</tr>
<tr>
<td>6-10</td>
<td>28.2</td>
</tr>
<tr>
<td>11-30</td>
<td>28.2</td>
</tr>
<tr>
<td>31≤</td>
<td>21.3</td>
</tr>
</tbody>
</table>
Of the patients, 105 (55.9%) were males and 83 (44.1%), females (Table 1). Their total mean age was 74.0 years (standard deviation [SD]=11.2, range [R]=32-92). The mean age of the males was 72.8 (SD=10.9) years and for the females, 75.5 (SD=11.3) years. The patients’ educational level was elementary school (75%), secondary/high school (19%) and university (6%). About 59% of the patients lived together with someone and 95% were living in their own homes before stroke. After discharge, 88% lived in their own home and 10% lived in short-stay accommodation for rehabilitation. Brain infarction (I63) was the most common reason (93%) for stroke and about 80% of the patients had suffered a stroke for the first time. The average stay in hospital was 20.6 (median=10, SD=23.8, R=2-130) days.

4.3.2 Relatives and patients (Paper II)

The patients were asked to name one close relative, who could be asked to take part in the study. The inclusion criteria for the relatives were:

- ability to speak and understand the Swedish language,
- ability to participate in the study.

Of the 188 patients, 27 did not report any relatives, three relatives declined participation, five relatives could not be contacted and one relative was too ill to participate in the study. The total sample comprised 152 relatives.

The sample of relatives (n=152) comprised 48 (31.6%) males and 104 (68.4%) females, and their mean age was 60.1 (SD=12.6, R=29-86) years. The mean age for the males was 61.2 (SD=12.9) years and for the females, it was 59.6 (SD=12.4) years. Of the relatives, 61% were spouses/cohabitants of the stroke patients and 41% had elementary-school education. There were no significant differences between genders regarding age, relation to the patients or education.

The patients (n=152) comprised 86 (56.6%) males and 66 (43.4%) females, and the mean age of the patients was 73.5 (standard deviation [SD]=10.9, range[R]=37-91) years. The mean age of the males was 72.0 (SD=10.8) years and, for the females, it was 75.6 (SD=10.9) years. Of the patients, 75% had elementary-school education; 64% cohabited; 92% had brain infarction and 79% had first-ever stroke. The mean number of days spent in hospital was 17.3 (median=9, SD=19.0, R=2-112) days.
4.4 Data-collection procedures

4.4.1 Interviews with the patients

The patients’ P-ADL, such as self-care and mobility, was measured 5 (+4) days after admission by BI (Table 2). The patients were then interviewed 2-3 weeks after discharge about HRQoL (SF-36), depressive symptoms (CES-D), cognitive function (MMSE), P-ADL (BI), social activities (FAI), interests and how they perceived their participation in discharge planning (P-QPD). The patient’s P-ADL and social activities pre-stroke were also reported. The interviews were conducted in the patients’ homes or in nursing homes. Medical and demographic data were collected from the patients’ medical charts and during the interviews.

Table 2. The measurements and time for data collection

<table>
<thead>
<tr>
<th>ICF components</th>
<th>Measurements</th>
<th>Time for data collection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>5 days after admission/</td>
</tr>
<tr>
<td></td>
<td></td>
<td>during hospital stay</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2-3 weeks after discharge</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2-3 weeks</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pre-stroke status</td>
</tr>
<tr>
<td>Personal factors</td>
<td>SF-36</td>
<td>X</td>
</tr>
<tr>
<td>HRQoL</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Body functions</td>
<td>MMSE</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>CES-D</td>
<td>X</td>
</tr>
<tr>
<td>Body structures</td>
<td>ICD-diagnosis</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Activity and</td>
<td>BI</td>
<td>X</td>
</tr>
<tr>
<td>participation</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>FAI</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Interests</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Environmental</td>
<td>P-QPD</td>
<td>X</td>
</tr>
<tr>
<td>factors</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>R-QPD</td>
<td>X</td>
</tr>
</tbody>
</table>
4.4.2 Interviews with the relatives

Approximately 2 to 3 weeks after discharge, the relatives were interviewed about their perceived participation in the discharge planning process using the R-QPD and R-QPD-VAS (Table 2). The interviews were conducted in the home of the patient and the relative or by telephone (44%). Demographic data on the relatives were collected during the interviews.

4.5 Outcome measures

The influence on HRQoL, body functions, body structures and activity/participation was measured and environmental factors and personal factors were also reported.

4.5.1 Personal factors

The patients’ gender, age, educational level and living arrangements were used in analyses, in all the papers and the relatives’ gender, age, educational level and relation to the patient were used in paper II. Educational level is a better socioeconomic variable than income and occupation in studies of elderly people (Duncan et al. 2002).
4.5.2 HRQoL

HRQoL was assessed 2-3 weeks after discharge by the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36), which is a widely-used standardised generic self-reported health status measure for evaluation of physical and mental HRQoL. SF-36 consists of 36 questions, grouping 35 questions into eight multi-item scales as a measure for health: Physical Functioning (10 items), Role-Physical (4 items), Bodily Pain (2 items), General Health (5 items), Vitality (4 items), Social Functioning (2 items), Role-Emotional (3 items) and Mental Health (5 items). The remaining item concerns experience of changes in general health during the last year. All items are measured as Likert scales with varied levels (2-6 levels). The transformed scores on all eight scales range from 0 to 100, where a score of 100 indicates better health. The eight scales are weighted and summarised into two components: Physical Component Summary (PCS) and Mental Component Summary (MCS) (Sullivan et al. 2002). SF-36 has been psychometrically evaluated for the normal population in Sweden (Sullivan et al. 2002, Sullivan et al. 1995). The psychometric evaluations of SF-36 among stroke groups in Australia (Anderson et al. 1996) and the UK (Dorman et al. 1998, Hagen et al. 2003, Hobart et al. 2002, O’Mahony et al. 1998) have shown divergent results. However, only a few studies have evaluated the psychometrics assumptions of the scale in SF-36 according to data quality, scaling assumptions, reliability and construct validity among stroke patients, and none in Sweden. Cieza and Stucki (2005) found that SF-36 included 14 body functions and 24 activities/participations after linking the items to ICF.

4.5.3 Body functions

4.5.3.1 Cognitive functions

To screen patients for inclusion, their cognitive functioning was assessed 2-3 weeks after discharge using the MMSE (Folstein et al. 1975). The MMSE consists of eleven items that test orientation, memory, attention and calculation, language and construction. The maximum score is 30 and a score below 24 indicates cognitive impairment (Tombaugh & McIntyre 1992). The MMSE is widely-used screening instrument for cognitive impairment and has shown good reliability (Tombaugh & McIntyre 1992) and acceptable validity in detecting cognitive dysfunction at an early stage after stroke, among older patients (Agrell & Dehlin 2000). The limitations of using MMSE are the low reported levels of sensitivity among patients with right-side lesions (Grace et al. 1995), and within an acute stroke population (Nys et al. 2005).
4.5.3.2 Depressive symptoms
Depressive symptoms were assessed by using the Center of Epidemiologic Studies’ Depression Scale (CES-D), which is a self-report rating scale with 20 items. It was developed to identify depressive symptoms in a general population. Each item has a score between 0-3, where 0 indicated “never” and 3 “most or all of the time”. The scale could be summarised to 60 points, and a threshold of ≥16 points indicates depression (Radloff 1977). The instrument was found to be reliable and valid for screening depression in patients with stroke (Shinar et al. 1986). The internal consistency according to Cronbach’s alpha was 0.82 in this thesis.

4.5.4 Body structures
Type of lesion was registered as ICD-10 diagnosis: I 61 (brain haemorrhage), I 63 (brain infarction), I 64 (non-specified stroke) and prior or first-ever stroke were registered.

4.5.5 Activity and participation
Activity/participation in P-ADL, social activities and interests were measured. Patients’ and relatives’ perceived participation in discharge planning was linked to ICF, to participation and to environmental factors, but here it is reported as environmental factors.
4.5.5.1 The Barthel Index

P-ADL was assessed by the Barthel Index (BI) (Mahoney & Barthel 1965), which is a widely used instrument for patients with stroke. The BI consists of ten variables, each with different scores (0, 5, 10 and 15; possible range=0-100). The highest value for each item indicates that the patient performs the activity independently. A patient with a score of 100 is independent in all of the variables (Mahoney & Barthel 1965). The ten variables have been linked to ICF and measure activities in self-care and mobility (Salter et al. 2005c). BI has shown a high level of reliability (Collin et al. 1987, Hseuh et al. 2001) and validity (Wade & Hewer 1987) for different groups, including stroke patients (Shah et al. 1989). For some analyses (Paper I, II), BI was dichotomised into “independent”, with a score of 100, and “dependent”, with a score of less than 100. The internal consistency of BI according to Cronbach’s alpha was 0.88 pre-stroke, 0.93 after admission and 0.81 after discharge, for this study population.

4.5.5.2 The Frenchay Activities Index

The Frenchay Activities Index (FAI), consisting of 15 items, is widely used for assessment of social activities among stroke patients (Holbrook & Skilbeck 1983). Each item has a score on a four-point scale (0-3) and can be summarised to produce a total score between 0 (inactive) to 45 (active) and can be divided into three subscales, each with a score of 0-15. The subscales consist of domestic chores (preparing main meals, washing up, washing clothes, light housework, heavy housework), leisure/social activities (social occasions, actively pursuing hobby, travel outings/car rides, household/car maintenance, gainful work) and outdoor activities (local shopping, walking outside >15 min, driving car/bus travel, gardening, reading books) (Holbrook & Skilbeck 1983). A high score indicates an active life with a high activity level (Schuling et al. 1993). FAI has shown a high level of validity (Schuling et al. 1993) and reliability (Schuling et al. 1993) for patients with stroke. FAI has been linked to ICF and was found to measure activities/participation in four areas such as mobility, domestic life, major life areas and community, social and civic life (Schepers 2006). The internal consistency, according to Cronbach’s alpha, was 0.84 (total FAI), 0.86 for domestic, 0.64 for leisure/social and 0.62 for outdoor activities, for this study population.
4.5.5.3 Interests

The patient was also asked the question “Can you perform the interests you had before you had a stroke?” and the answers were “Yes, as before” (3), “Yes, but not really as before” (2) and “No, not especially or not at all” (1).

4.5.6 Environmental factors

4.5.6.1 Patients’ perceptions of participation in discharge planning

The questionnaire on participation in discharge planning “Patient’s Questionnaire about Participation in Discharge Planning” (P-QPD) was inspired by the Pyramid Questionnaire (PQ) (Arnetz & Arnetz 1996), which measures perceptions of the quality of care. The new questionnaire consists of 14 items and the patients rated the items on a four-point, Likert-type scale: “Yes, to a great degree” (4), “Yes, to a certain degree” (3), “No, not especially” (2) or “No, not at all” (1). Some items also had the alternative: “Not applicable” (The 14 items on the P-QPD are shown in Table 3). Face validity was established with patients and experts in the field.

An exploratory factor analysis was conducted to study the latent variables of the 14 items in P-QPD in order to examine construct validity. Principal components analysis was used for factor extraction, using direct oblimin rotation (Table 3). Three factors were found: P-Information (7 items), P-Medical Treatment (2 items) and P-Goals and Needs (5 items). The factor loadings for each item under the three factors were >0.60. The three factors explained a total of 60.4% of the variance, with factor 1 (P-Information) contributing 37.4%, factor 2 (P-Goals and Needs) contributing 15.6% and factor 3 (P-Medical Treatment) contributing 7.4%. The internal consistency was calculated using the Cronbach’s alpha coefficient, which was 0.82 for the factor P-Information; 0.87 for P-Goals and Needs and 0.66 for P-Medical Treatment. A mean value for every individual was calculated for each of the three factors, called subscales (range: 1-4 points). A higher mean value indicated a greater degree of perceived participation in discharge planning.
Table 3. Scale validity and correlations with rotated principal components in a group of stroke patients (n=188)

<table>
<thead>
<tr>
<th>Items</th>
<th>P-Information†</th>
<th>P-Medical Treatment†</th>
<th>P-Goals and Needs†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you received sufficient information concerning:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- your illness/course of illness?</td>
<td>0.70</td>
<td>-0.51</td>
<td>-0.22</td>
</tr>
<tr>
<td>- tests/examinations/treatments?</td>
<td>0.78</td>
<td>-0.32</td>
<td>-0.08</td>
</tr>
<tr>
<td>- results of tests/examinations/treatments?</td>
<td>0.78</td>
<td>-0.20</td>
<td>-0.12</td>
</tr>
<tr>
<td>- medication?</td>
<td>0.62</td>
<td>-0.17</td>
<td>-0.29</td>
</tr>
<tr>
<td>- rehabilitation?*</td>
<td>0.64</td>
<td>-0.22</td>
<td>-0.52</td>
</tr>
<tr>
<td>Did you have the opportunity to ask questions about your illness?</td>
<td>0.61</td>
<td>-0.43</td>
<td>-0.15</td>
</tr>
<tr>
<td>Have you understood the information you received about your illness?</td>
<td>0.75</td>
<td>-0.14</td>
<td>-0.26</td>
</tr>
<tr>
<td>Have you had the opportunity to participate in discussions concerning your examinations/treatments?</td>
<td>0.45</td>
<td>-0.72</td>
<td>-0.29</td>
</tr>
<tr>
<td>Have you had the opportunity to discuss the goals for your treatment with the physician?</td>
<td>0.31</td>
<td>-0.82</td>
<td>-0.35</td>
</tr>
<tr>
<td>Did you have the opportunity to participate in discussions concerning your care/services requirements after discharge?*</td>
<td>0.25</td>
<td>-0.05</td>
<td>-0.84</td>
</tr>
<tr>
<td>Did you have the opportunity to participate in discussions concerning your rehabilitation needs after discharge?*</td>
<td>0.24</td>
<td>-0.23</td>
<td>-0.82</td>
</tr>
<tr>
<td>Did you have the opportunity to discuss the goals for your care/services after discharge?*</td>
<td>0.23</td>
<td>-0.28</td>
<td>-0.75</td>
</tr>
<tr>
<td>Did you have the opportunity to discuss the goals for your rehabilitation after discharge?*</td>
<td>0.20</td>
<td>-0.53</td>
<td>-0.73</td>
</tr>
<tr>
<td>Did you participate in the construction of your discharge plan?</td>
<td>0.25</td>
<td>-0.60</td>
<td>-0.76</td>
</tr>
<tr>
<td>% of variance</td>
<td>37.4%</td>
<td>7.4%</td>
<td>15.6%</td>
</tr>
<tr>
<td>Eigenvalue</td>
<td>5.235</td>
<td>1.038</td>
<td>2.191</td>
</tr>
</tbody>
</table>

* Additional items
† Correlation between each item in P-QPD and rotated (orthogonal-Oblimin) principal component

Strong association (r>0.70), moderate to substantial association (0.30<r<0.70), weak association (r<0.30).
The patients were also asked to give their Overall Rating of Patient's Perceived Participation in Discharge planning on a visual analogue scale (P-QPD-VAS). The question asked was: “How do you perceive your participation in your discharge planning?” One point on the scale corresponded to “No participation at all” and ten points corresponded to “Complete participation”. The results of the VAS scale were not used in the papers, but were used in the thesis.

4.5.6.2 Relatives’ perceptions of participation in discharge planning

“Relative’s Questionnaire about Participation in Discharge Planning” (R-QPD) was created by the authors and was based on the Pyramid Questionnaire (PQ) (Arnetz & Arnetz 1996, Verho & Arnetz 2003) which measures perceptions of quality of care in different areas such as, for example, information/communication and participation. The Pyramid Questionnaire has shown a good level of validity and reliability for relatives (Verho & Arnetz 2003). The relatives rated each item in the same way as the patients did. The questionnaire consisted of 10 items, which were all selected from the original Pyramid Questionnaire to measure perceived participation in discharge planning according to the definition for this study (Table 4). Face validity was established with relatives and experts in the field.

An exploratory factor analysis was conducted to study the latent variables of the 10 items in R-QPD to examine construct validity. Principal components analysis was used for factor extraction, using direct oblimin rotation (Table 4). Three factors: R-Information-Care/Support (4 items), R-Information-Illness (3 items), and R-Goals and Needs (3 items) were found. The factor loadings for each item of the three factors were >0.54. The three factors explain a total of 66.6% of the variance, with factor I (R-Information-Care/Support) contributing 39.3%, factor II (R-Information-Illness) contributing 15.0%, and factor III (R-Goals and Needs) contributing 12.3%. The Cronbach’s alpha coefficient was 0.81 for factor R-Information-Care/Support, 0.72 for factor R-Information-Illness, and 0.65 for factor R-Goals and Needs. A mean value was calculated for each relative for each of the three factors, called subscales, in the same way as for the patients.
Table 4. Scale validity and correlations with rotated principal components in a group of relatives of stroke patients (n=152)

<table>
<thead>
<tr>
<th>Items</th>
<th>R-Information-Illness †</th>
<th>R-Information-Care/Support †</th>
<th>R-Goals and Needs †</th>
</tr>
</thead>
<tbody>
<tr>
<td>R-Information-Illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 Have you received sufficient information concerning your relative’s illness/progress?</td>
<td>-0.72</td>
<td>0.51</td>
<td>0.40</td>
</tr>
<tr>
<td>2 Have you received answers to your questions?</td>
<td>-0.87</td>
<td>0.34</td>
<td>0.21</td>
</tr>
<tr>
<td>3 Have you understood the information regarding your relative’s illness?</td>
<td>-0.89</td>
<td>0.23</td>
<td>0.12</td>
</tr>
<tr>
<td>R-Information-Care/Support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 -your relative’s medication?</td>
<td>-0.37</td>
<td>0.69</td>
<td>0.23</td>
</tr>
<tr>
<td>5 -your relative’s rehabilitation?</td>
<td>-0.40</td>
<td>0.82</td>
<td>0.41</td>
</tr>
<tr>
<td>6 -your relative’s care after discharge?</td>
<td>-0.26</td>
<td>0.88</td>
<td>0.44</td>
</tr>
<tr>
<td>7 -community support with illness (i.e. assistance devices, sick-leave, transportation service)?</td>
<td>-0.25</td>
<td>0.81</td>
<td>0.21</td>
</tr>
<tr>
<td>R-Goals and Needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Did you have the opportunity to participate in discussions concerning your relative’s examinations/ treatments?</td>
<td>-0.29</td>
<td>0.34</td>
<td>0.54</td>
</tr>
<tr>
<td>9 Did you participate in planning your relative’s care?</td>
<td>-0.11</td>
<td>0.25</td>
<td>0.88</td>
</tr>
<tr>
<td>10 Have you had the opportunity to discuss the goals for your relative’s care?</td>
<td>-0.19</td>
<td>0.32</td>
<td>0.85</td>
</tr>
<tr>
<td>% of variance</td>
<td>15.0%</td>
<td>39.3%</td>
<td>12.0%</td>
</tr>
<tr>
<td>Eigenvalue</td>
<td>1.500</td>
<td>3.928</td>
<td>1.230</td>
</tr>
</tbody>
</table>

† Correlation between each item in P-QPD and rotated (orthogonal-Oblimin) principal component
Strong association (r>0.70), moderate to substantial association (0.30<r>0.70), weak association (r<0.30).

 Relatives were also asked to give their “Overall Rating of Relative’s Perceived Participation in Discharge Planning” (R-QPD-VAS) on a visual analogue scale (VAS): “How do you perceive your participation in discharge planning?” in the same way as for the patients.
4.6 Statistical analysis

4.6.1 Papers I-IV

The SPSS statistical software package, version 13.0 for Windows, was used for all analyses and the statistical significance level was set at <0.05 (two-tailed). Descriptive statistics were used in all papers (Table 5). Independent t-test and chi square analyses were used to compare subgroups for age and gender differences (paper I-IV).

Table 5. Statistical analysis

<table>
<thead>
<tr>
<th></th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
<th>Additional</th>
</tr>
</thead>
<tbody>
<tr>
<td>T-test</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Chi-test</td>
<td>X</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>ANOVA</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple Regression</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Principal component analysis</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
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<tr>
<td>Spearmans’ correlation coefficient</td>
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<td>X</td>
<td>X</td>
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<tr>
<td>Cronbach’s alpha</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standard scores</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

In paper I, univariate analysis of variance (ANOVA) was used to examine differences in demographic and clinical characteristics in the three subscales P-Information, P-Medical Treatment, P-Goals and Needs such as gender, education, living arrangements (living alone or cohabiting), experience of stroke (first ever or previous stroke), and P-ADL (independent or dependent). In order to check for age, this characteristic was used as a covariate. One-way, between-group analyses of variance (ANOVA) with post-hoc tests (Tukey HSD) were conducted to explore differences in the variance of the three subscales of P-QPD. In these analyses, the dependent variables were the subscales, and the independent variables were: age (<64 years, 65-74 years, 75-84 years, or >85 years) and of length of hospital stay (<5 days, 6-10 days, 11-30 days, >31 days).
Multiple regression analyses with backward selection mode were performed (Paper I, II, IV) to determine associated independent variables (Table 6) to:

- patients’ perceived participation measured by the three subscales of P-QPD (Paper I)
- relatives’ perceived participation measured by the three subscales of R-QPD and R-QPD-VAS (Paper II)
- patients’ HRQoL measured by SF-36 (Paper IV).

Related variables with non-significant p-values between <0.1 to >0.05 were retained in the regression analysis when they improved the explanation of the model.

In paper III, psychometric analysis of SF-36 was conducted. Tests of scaling assumptions with the summated-rating method were performed using descriptive statistics for item responses, equivalence of the mean score of the items, standard deviation, skewness, and item-scale correlation (item-own-scale correlation and item-other-scale correlation). Different minimum values have been recommended for item-own-scale correlation to examine item convergent validity; these minimum values vary between 0.20 and 0.40 (McHorney et al. 1994, Steiner & Norman 2003). In this study, we used $r \geq 0.40$. Discriminant validity of items and rates of scaling success were analysed by comparing the differences between item-own and item-other scale correlations. Differences of more than 2 standard errors of the correlation coefficient ($2 \times 1/\sqrt{n}$) were considered significant (Sullivan et al. 1995). Cronbach’s alpha was used to examine the scales’ internal consistency reliability. According to Steiner and Norman (2003) an acceptable alpha-value should be between 0.70 and 0.90. Descriptive statistics are reported for each scale score. A principal component analysis with oblimin rotation was used to analyse construct validity for the two summary scales (PCS and MCS). Oblimin rotation is used when there is a stronger correlation than 0.30 between the factors (Pallant 2006).

The Student’s t-test was used to compare mean values between the stroke patients and the Swedish normative population study (Sullivan et al. 2002). The overall populations were compared as well as the age groups 45-64 years, 65-74 years, and $\geq 75$ years. Standard scores (mean stroke minus mean population, divided by the SD of the population study) were calculated to facilitate comparisons.
Table 6. Multiple regression analyses with backward selection mode were performed to determine associated independent variables to the dependent variables in paper I, II and IV

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Dependent variables</th>
<th>P-QPD</th>
<th>R-QPD, VAS</th>
<th>SF-36</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personal factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Patient</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Gender*</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Education*</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Living arrangements*</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>First ever/previous stroke*</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relative</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Gender*</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Education*</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td><strong>Body functions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CES-D</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td><strong>Activity and participation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BI before onset</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>BI after admission</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>After discharge</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BI</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>FAI domestic</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>FAI outdoor</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>FAI leisure/social</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Interests</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td><strong>Environmental factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LOS</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>P-Information</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>P-Medical Treatment</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>P-Goals and Needs</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

* Binary variables and the other variables were continuous variables
1 First ever/previous stroke is a factor of the illness not a personal factor

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4.6.2 Additional analysis

Psychometric analyses were performed for P-QPD and R-QPD as presented in Paper III.

The items of the instruments were assigned to ICF according to the rules set by Cieza et al. (2005). The coding process was carried out by two persons (OT, RN experts in ICF) independently of each other. The coding process includes identification of meaningful concepts within the items. The content concepts were linked to the most precisely ICF categories. If an item includes more than one concept, each concept was linked separately. The results of the two linkers were compared and if there was some disagreement in the results, the linkers had a discussion to achieve consensus. The intercoder reliability was calculated.

4.7 Ethical approval

Ethical considerations in this thesis followed the ethical principles of research in respect of autonomy, beneficence, non-malfeasance and the principle of justice (MFR 2000). Ethical approval for this study was received from the Research Ethics Committee at Linköping University (Dnr 03-328). All eligible patients and relatives, according the inclusions’ criteria, were given oral and written information including the aim and the expected benefits of the study, information on how data were to be collected, information regarding confidentiality, information concerning the voluntary nature of participation in the study, and that withdrawal would not affect any treatment. The information also included how to get in touch with the author (AHA). The risk that dependence would influence the patients’ and relatives’ standpoint was minimised by the fact that the author (AHA) was not involved or employed in the care. Confidentiality was secured by coding all respondents with a number and they were informed that the results were only presented on the group level. The codes alone were used to identify the respondents in the database and the list of codes and names was stored in a safe. The patients and the relatives were included if they gave oral consent to participation.
The patients and their relatives were contacted by telephone to choose the time for the interviews. The patient interviews were performed in the patients’ home or the places where the patients were living. The relatives could also choose how the interviews should be performed, where the patients lived or by telephone. The patients and their relatives were shown respect when the author visited their home for the interviews. The respondent’s condition during the interviews was also respected and, if the respondent was too tired, the interview was postponed and continued later. No significant benefit for the patients and relatives included in the study could be attained, but they represented a large group in the health care system, which will benefit from the results in the future. Increased knowledge and understanding of patients with stroke and their relatives’ perceptions of participation in discharge planning and factors associated with HRQoL may hopefully develop the quality of care and thereby the HRQoL of patients with stroke.
5 Results

5.1 HRQoL (Papers III, IV)

For all SF-36 scales, the mean scores were significantly lower for the whole stroke group compared to the Swedish normative population study (Paper III). The largest differences in standard scores for the whole stroke group were found for the following scales: the Role-Physical scale (-2.129), the Physical Functioning scale (-1.959), the Social Functioning scale (-1.103) and the Role-Emotional scale (-1.096). The smallest difference was found in the Mental Health scale (-0.275). The largest differences in standard scores were found in the age group 45-64 years (Figure 5).

Figure 5. Deviations from standardised SF-36 mean scores for the stroke patients in this study (age-groups: 45–64, 65-74, 75 and older) and from the Swedish population normative scores. Mean=0 and SD=1.
Comparisons by age groups showed lower mean scores for all scales for stroke patients in the middle age group versus the same age group in the normal population. The other two age groups (65-74, ≥75 years) had significant lower mean scores on the Physical Functioning, the Role-Physical, the Social Functioning, the Role-Emotional scales, and the PCS compared with the Swedish normal population. The young-old (64-75) group had even lower mean scores for Vitality. The stroke group’s lowest mean score was for the Role-Physical scale (a score of 15.5) and the highest mean score was for the Mental Health scale (75.4). The males had significantly higher HRQoL in Physical Functioning (p=0.004), Vitality (p=0.013) and Physical Component Summary (p=0.035) than the females.

5.1.1 Variables related to HRQoL

The multiple regressions analyses with the eight scales of SF-36, as dependent variables, revealed eight models, one for each scale, that were significant. The models explained 72% of the variance in Physical Functioning and 56% of the variance in Mental Health. In the other six models, the variables explained between 16% and 38% of the variance in the scales (Table 7 and 8). Low scores on the CES-D depression scale were related to better HRQoL in all the SF-36 scales and contributed to the largest part of the explanation for the variances on the four different mental scales.

Personal activities were related to only one scale (Physical Functioning). However, social activities were associated with better HRQoL on six scales, where outdoor activities were related to five scales (Physical Functioning, Role-Physical, General Health, Vitality, Social Functioning); domestic activities were related to Mental Health and leisure/social activities to Physical Functioning. The patients’ performance of their interests as before stroke was positively associated with two scales (Role-Physical, Social Functioning).

Patients’ perceptions of participation in discharge planning were related to two physical scales and to one mental scale. The subscale, P-Information, was positively associated with Physical Functioning and the two other subscales (P-Medical Treatment and P-Goals and Needs) were negatively associated with Social Functioning versus Physical Functioning and Role-Physical.

Age was negatively related to Physical Functioning. Educational level was positively related to HRQoL in Social Functioning. A shorter stay in hospital meant higher HRQoL in Physical Functioning and Role-Emotional.
Table 7. Multiple regression analyses of variables associated with health-related quality of life (SF-36) on the physical scales for the patients

<table>
<thead>
<tr>
<th>Physical scales</th>
<th>Physical Functioning</th>
<th>Role-Physical</th>
<th>Bodily Pain</th>
<th>General Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>R²</td>
<td>0.719</td>
<td>0.228</td>
<td>0.159</td>
<td>0.282</td>
</tr>
<tr>
<td>F</td>
<td>43.748</td>
<td>11.761</td>
<td>15.205</td>
<td>20.900</td>
</tr>
<tr>
<td>p-value</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Stand.β</th>
<th>p-value</th>
<th>Stand.β</th>
<th>p-value</th>
<th>Stand.β</th>
<th>p-value</th>
<th>Stand.β</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-0.228</td>
<td>&lt;0.001</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>Gender</td>
<td>-0.073</td>
<td>0.100</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>Education</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>Living arrangements</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>Length of hospital stay</td>
<td>-0.146</td>
<td>0.008</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>CES-D</td>
<td>-0.172</td>
<td>0.001</td>
<td>-0.177</td>
<td>0.017</td>
<td>-0.418</td>
<td>&lt;0.001</td>
<td>-0.457</td>
<td>&lt;0.001</td>
</tr>
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<td>0.145</td>
<td>0.018</td>
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<td>...</td>
<td>...</td>
</tr>
<tr>
<td>FAI domestic</td>
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<td>...</td>
<td>...</td>
<td>...</td>
<td>0.135</td>
<td>0.079</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>FAI outdoor</td>
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<td>&lt;0.001</td>
<td>0.259</td>
<td>0.001</td>
<td>...</td>
<td>0.157</td>
<td>0.043</td>
<td></td>
</tr>
<tr>
<td>FAI leisure/social</td>
<td>0.125</td>
<td>0.042</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>Interests</td>
<td>...</td>
<td>...</td>
<td>0.181</td>
<td>0.018</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>P-Information</td>
<td>0.115</td>
<td>0.032</td>
<td>...</td>
<td>-0.131</td>
<td>0.086</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>P-Medical Treatment</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>P-Goals and Needs</td>
<td>-0.155</td>
<td>0.002</td>
<td>-0.202</td>
<td>0.005</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
</tbody>
</table>

Gender (male=0/female=1); education (elementary school=0/>elementary school=1); living arrangements (living alone=0/cohabiting=1)
<table>
<thead>
<tr>
<th>Mental scales</th>
<th>Vitality</th>
<th>Social Functioning</th>
<th>Role-Emotional</th>
<th>Mental Health</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>R^2</strong></td>
<td>0.379</td>
<td>0.270</td>
<td>0.298</td>
<td>0.563</td>
</tr>
<tr>
<td><strong>F</strong></td>
<td>49.058</td>
<td>11.717</td>
<td>16.907</td>
<td>68.598</td>
</tr>
<tr>
<td><strong>p-value</strong></td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

- Gender (male=0/female=1); education (elementary school=0/high school=1); life experience (living alone=0/cohabiting=1); medical treatment; information; interest; physical and social functioning; leisure activities; social devices; medical care; goals and needs.

| Living arrangements (living alone=0/cohabiting=1); education (elementary school=0/high school=1); life experience (living alone=0/cohabiting=1); medical treatment; information; interest; physical and social functioning; leisure activities; social devices; medical care; goals and needs. |
|--------------|---------|-------------------|----------------|--------------|
| Age          | …      | …                 | …              | …            |
| Gender       | …      | …                 | …              | …            |
| Education    | …      | …                 | …              | -            |
| Living arrange. | … | …                 | …              | …            |
| Length of hospital stay | … | …                 | …              | …            |
| CES-D        | …      | …                 | …              | …            |
| ALSQ         | …      | …                 | …              | …            |
| P-Info       | …      | …                 | …              | …            |
| P-Med Treatment | … | …                 | …              | …            |
| P-Goal Needs | …      | …                 | …              | …            |

Table 8. Multiple regression analyses of variables associated with health-related quality of life (SF-36).
5.2 Body functions (Paper IV)

Depressive symptoms were measured by CES-D; the patients’ mean value was 9.9 (SD=7.9) and 19.0% had 16 points and above (cut-off point). The women (mean value=11.7, SD=8.2) had significantly higher mean value (p=0.013) than the men (mean value=8.6, SD=7.5).

5.3 Activity and participation (Paper IV)

The patients’ P-ADL performance, measured by BI, decreased significantly (p<0.001) from 98.1 (SD=6.1) pre stroke to 92.3 (SD=14.4) after discharge. There were no statistically significant differences between genders on the two occasions for measurement.

Social activities, assessed by FAI, decreased significantly after suffering a stroke. The patients’ mean values were 29.6 (SD=8.1) pre stroke and 18.6 (SD=10.5) after discharge (p<0.001). The patients’ mean scores in domestic activities decreased from 11.3 to 9.0 (p<0.001), from 8.7 to 4.6 (p<0.001) in leisure/social activities, and from 9.6 to 4.9 (p<0.001) in outdoor activities. Women had a higher level of activity performance in domestic chores (p=<0.001) than men, both pre- and post stroke. Men had higher performance levels in leisure/social activities (p<0.001) and outdoor activities (p=0.017) than women, pre stroke, but not post stroke.

Among the patients, 19.8% rated that they performed their interests: “Yes, as before”; 47.1% performed their interests: “Yes, but not really as before” and 33.2%: “No, not especially or not at all”. There were no statistically significant differences between the genders.
5.4 Environmental factors

5.4.1 P-QPD (Paper I)

The results of the P-QPD showed that, for questions 1-5 in the P-Information subscale, 72%-87% of the patients perceived that they had received information to a “high degree” or to a “certain degree”. About 29% of the patients had had the opportunity to discuss the goals for their treatment with their physician. About half of the patients perceived that they had been allowed to participate in discussions relating to their needs for care/services after discharge and one third perceived that they had participated in discussions about their needs for rehabilitation after discharge. About 15% of the patients had had the opportunity to discuss the goals for care/services and their rehabilitation after discharge and 38% of the patients perceived they had been able to participate in the development of their discharge plan.

The patients rated the highest mean value of perceived participation in P-Information: 3.2 (SD=0.7) and lower mean values in P-Medical Treatment: 1.9 (SD=1.0) and P-Goals and Needs: 2.0 (SD=1.0), (Table 2). The mean value of the Overall Rating of Patient’s Perceived Participation in Discharge Planning was 6.1 (SD=3.2, R=1-10). No statistically significant gender differences were observed. Patients with relatives who participated in this study had higher mean scores in P-Information (p=0.006) than patients without relatives.

5.4.1.1 Variables related to P-QPD

The multiple regression analysis (Table 9) generated five variables (Paper I), which were differently related to the three subscales. Age and P-ADL, 2-3 weeks after discharge, explained 20%, versus, 14%, of the variance in the two subscales: P-Information and P-Medical Treatment (p<0.001). A higher degree of P-ADL, 2-3 weeks after discharge, and lower age were associated with higher scores on the subscales: P-Information and P-Medical Treatment, (Table 9). Age was not significant for P-Information. Four variables were related to P-Goals and Needs (p<0.001) and explained 10% of the variance. A lower degree of P-ADL performance at 5 days, a higher degree of P-ADL performance at 2-3 weeks after discharge, higher education than elementary school and a longer hospital stay were associated with higher scores in Goals and Needs. Length of stay was not significantly associated with P-Goals and Needs. P-ADL, at 2-3 weeks after discharge, made the largest single contribution to all subscales.
Table 9. Regression towards the subscales for P-Information, P-Medical Treatment, and P-Goals and Needs

<table>
<thead>
<tr>
<th></th>
<th>P-Information</th>
<th>P-Medical Treatment</th>
<th>P-Goals and Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>R</td>
<td>0.201</td>
<td>0.139</td>
<td>0.107</td>
</tr>
<tr>
<td>F</td>
<td>23.043</td>
<td>14.724</td>
<td>5.268</td>
</tr>
<tr>
<td>p-value</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Stand. β</th>
<th>p-value</th>
<th>Stand. β</th>
<th>p-value</th>
<th>Stand. β</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-0.115</td>
<td>0.096</td>
<td>-0.262</td>
<td>&lt;0.001</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>Education level</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>0.147</td>
<td>0.043</td>
</tr>
<tr>
<td>Length of hospital stay</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>0.195</td>
<td>0.060</td>
</tr>
<tr>
<td>P-ADL, 5 days after admission</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>-0.263</td>
<td>0.045</td>
</tr>
<tr>
<td>P-ADL, 2-3 weeks after discharge</td>
<td>0.402</td>
<td>&lt;0.001</td>
<td>0.200</td>
<td>0.006</td>
<td>0.326</td>
<td>0.002</td>
</tr>
</tbody>
</table>

Education level: 1=elementary school, 2=>elementary school

5.4.2 R-QPD (Paper II)

Among the relatives, 56%-68% reported positively according to R-Information-Illness. Only 33% were completely satisfied with the information received about the illness and course of illness. About half of the relatives thought that they did not receive any information at all in medication (53%), rehabilitation (51%), care (46%), and community support (49%). About 80% perceived no participation in discussions regarding the planning of their relatives’ care/treatments/examinations or in discussions on the goals for their relatives’ care/treatment. Between 8% and 27% perceived that the questions were not applicable. Mean values of each subscale were: 2.98 (SD=1.09, R=1-4) for R-Information-Illness; 1.95 (SD=1.03, R=1-4) for R-Information-Care/Support; and 1.36 (SD=0.66, R=1-4) for R-Goals and Needs. The mean value of the R-QPD-VAS was 3.89 (SD=3.40, R=1-10). There were no significant differences between relatives who were interviewed in person or by telephone.
### Table 10. Regression towards the three subscales for R-Information-Illness, R-Information-Care/Support, R-Goals and Needs, and R-QPD-VAS

<table>
<thead>
<tr>
<th></th>
<th>R-Information-Illness</th>
<th>R-Information-Care/Support</th>
<th>R-Goals and Needs</th>
<th>R-QPD-VAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>R²</td>
<td>0.097</td>
<td>0.187</td>
<td>0.223</td>
<td>0.326</td>
</tr>
<tr>
<td>F</td>
<td>3.660</td>
<td>15.573</td>
<td>10.196</td>
<td>13.517</td>
</tr>
<tr>
<td>p-value</td>
<td>0.007</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

### Patient Gender

- Gender: 0=male, 1=female
- Education: 1=elementary school, 2>elementary school
- Living arrangements: 1=living alone, 2=cohabiting
- Length of stay in hospital: 1=≤3 months, 2=3–6 months, 3>6 months

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Education</th>
<th>Living arrangements</th>
<th>Length of stay in hospital</th>
<th>R-Information-Illness</th>
<th>R-Information-Care/Support</th>
<th>R-Goals and Needs</th>
<th>R-QPD-VAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>78</td>
<td>0.149</td>
<td>0.145</td>
<td>0.198</td>
<td>0.136</td>
<td>0.267</td>
<td>-0.130</td>
<td>0.090</td>
</tr>
<tr>
<td>1</td>
<td>98</td>
<td>0.032</td>
<td>0.154</td>
<td>0.169</td>
<td>0.149</td>
<td>0.222</td>
<td>-0.130</td>
<td>0.090</td>
</tr>
<tr>
<td>0</td>
<td>44</td>
<td>0.004</td>
<td>0.144</td>
<td>0.198</td>
<td>0.136</td>
<td>0.267</td>
<td>-0.130</td>
<td>0.090</td>
</tr>
</tbody>
</table>

**Scoring Key:** R-Information-Illness: 1=Emotion, 2=Cognitive, R-Information-Care/Support: 1=Emotion, 2=Cognitive, R-Goals and Needs: 1=Emotion, 2=Cognitive, R-QPD-VAS: 1=Emotion, 2=Cognitive, 3=Cognitive
5.4.2.1 Variables related to the three subscales of R-QPD and the R-QPD-VAS

Multiple regression analysis revealed 2-5 variables that explained 10% to 33% of the variance in the four scales, (Table 10). Length of stay in hospital and patients’ educational level were associated with all scales. Longer stay in hospital and higher education levels for the patients, contributed to a higher perceived participation on the part of relatives on all scales. The fact that patients and relatives were females was associated with higher perceived participation in R-Goals and Needs, and female relatives perceived more participation than males on the VAS-scale. Three of the five variables were statistically associated (p<0.05) with the scores for R-QPD-VAS: patient’s education level, length of hospital stay and relative’s gender. Length of stay in hospital made the largest single contribution, (beta=0.47), to the VAS-scale.

5.5 Methodological findings

5.5.1 SF-36

The psychometric analyses of SF-36 showed that correlation coefficients for the item-own-scale correlations exceeded 0.40 for 94% of the items. Two items: “I seem to get sick easier than others” (11a) and: “I expect my health to get worse” (11c), in the General Health scale correlated with a value, >0.30. The item-own-scale correlation for “Overall rating of general health” (item 1) within the General Health scale was 0.56, but this item had a higher correlation with the Physical Functioning (0.60) and Vitality (0.57) scales. The correlation coefficient for the item: “I feel worn out” (9g) and its own scale (Vitality), was 0.44; it had a slightly higher correlation with the Mental Health scale (0.49). Eight items: (3a, 9a, 9e, 9h, 9i, 11a, 11b, and 11d), correlated with the expected scale, but these correlations were not significant, as the item-own-scale correlations did not exceed the item-other-scale correlation by 2 standard errors.
Table 11. Results of Item-Scaling Tests and Reliability Estimates

<table>
<thead>
<tr>
<th>Scale</th>
<th>#</th>
<th>Convergent Item Correlations</th>
<th>Scale Reliability</th>
<th>Content Validity</th>
<th>Inter-Scale Reliability</th>
<th>Item-Scale Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>MH</td>
<td>5</td>
<td>0.37-0.74</td>
<td>0.69-0.80</td>
<td>0.63</td>
<td>0.20-0.54</td>
<td></td>
</tr>
<tr>
<td>RP</td>
<td>3</td>
<td>0.27</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BP</td>
<td>2</td>
<td>0.19</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GH</td>
<td>5</td>
<td>0.31-0.64</td>
<td>0.66</td>
<td>0.23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>VT</td>
<td>4</td>
<td>0.37</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RE</td>
<td>4</td>
<td>0.57</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MH</td>
<td>3</td>
<td>0.37</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Number of items and number of item-convergent-validity tests per scale
† Correlation between items and expected scale, corrected for overlap
‡ Correlations between items and other scales
§ Number of significant correlations to expected scale

Correlations between items and expected scale corrected for overlap.
The results of our evaluation of item-discriminate validity and scaling success rates showed significant item-scale correlations (corrected for overlap) in four of the eight scales, with a scaling success of up to 100% (Table 11). The scaling success rating was 99% for the Physical Functioning scale, 97.5% for the Mental Health scale, and 75% for the General Health and Vitality scales.

The internal consistency reliability for the eight scales was greater than 0.70 (Cronbach’s alpha). For five scales, Cronbach’s alpha was greater than 0.80 and, for the Physical Functioning scale, Cronbach’s alpha was greater than 0.90. The scale inter-correlations were lower than the respective alpha values (R=0.19 to 0.57) (Table 11).

For seven out of eight scales, scores varied between 0 and 100. There was positive skewness (+1.91) for the score distribution of the Role-Physical scale and negative skewness (-1.00) for the Mental Health scale; thus, respondents’ answers were toward poorer function and to better function, respectively. Skewness for the other six scales ranged between -0.59 and -0.04. Four scales had no floor and ceiling effects. Two scales had floor effects (Role-Physical, 70.8%; Role-Emotional, 33.5%) and two scales had ceiling effects (Role-Emotional, 42.2%; Bodily Pain, 36.8%).

Factor analysis showed that two factors explained 57% of the variance: the MCS explained 45% and the PCS explained 12%, (Table 12). As expected, in the SF-36 model, the Physical Functioning, General Health, and Role-Physical scales loaded on the PCS, while the Bodily Pain scale loaded on the MCS instead of on the PCS. Also, as expected, the Role-Emotional, Mental Health, Vitality, and Social Functioning scales loaded on the MCS.
Table 12. Scale Validity and Correlations with Rotated Principal Components

<table>
<thead>
<tr>
<th></th>
<th>Rotated Principal Components</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mental †</td>
</tr>
<tr>
<td>Physical Functioning</td>
<td>0.33</td>
</tr>
<tr>
<td>Role-Physical</td>
<td>0.40</td>
</tr>
<tr>
<td>Bodily Pain</td>
<td>0.58</td>
</tr>
<tr>
<td>General Health</td>
<td>0.55</td>
</tr>
<tr>
<td>Vitality</td>
<td>0.74</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>0.60</td>
</tr>
<tr>
<td>Role-Emotional</td>
<td>0.76</td>
</tr>
<tr>
<td>Mental Health</td>
<td>0.85</td>
</tr>
<tr>
<td>Eigenvalue</td>
<td>3.58</td>
</tr>
<tr>
<td>Variance (%)</td>
<td>45</td>
</tr>
</tbody>
</table>

† Correlation between each SF-36 scale and rotated (oblimin) principal component. Strong association, $r \geq 0.70$; moderate to substantial association, $0.30 < r < 0.70$; weak association, $r \leq 0.30$

5.5.2 P-QPD

The item-own–scale-correlations showed that the correlations’ coefficient for all items exceeded the value $>0.40$ (Table 13), which showed a good item-convergent validity. The median for item-scale correlation, for the two subscales with more than two items, was between 0.60 for P-Information and 0.68 for P-Goals and Needs. Five items (1, 5, 6, 8, 9) correlated with the expected scale, but these correlations were not significant.

The evaluation of item-discriminant validity and scaling success ratings showed significant item-scale correlations to 100% in P-Goals and Needs, 71% in P-Information and no significant correlations in P-Medical Treatment (Table 13).

The Cronbach’s alpha coefficient was 0.82 for the factor: Information, 0.87 for the factor: Goals and Needs and 0.66 for the factor: Medical Treatment (Table 13). When including all items on the total scale: Total discharge planning, the Cronbach’s alpha was 0.87. The inter-correlation between the scales was lower than respective Cronbach’s alpha values ($R=0.36-0.50$).
Table 13. Results of item scaling tests and reliability estimates (n=188)

<table>
<thead>
<tr>
<th>Subscales</th>
<th>k*</th>
<th>Range of item correlation</th>
<th>Item scaling tests</th>
<th>Scale</th>
<th>Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Item-convergent validity †</td>
<td>Item-discriminant validity ‡</td>
<td>Success/total §</td>
<td>Scaling success (%)</td>
</tr>
<tr>
<td>P-Information</td>
<td>7</td>
<td>0.49-0.67</td>
<td>0.14-0.47</td>
<td>10/14</td>
<td>71</td>
</tr>
<tr>
<td>P-Medical Treatment</td>
<td>2</td>
<td>0.49</td>
<td>0.10-0.43</td>
<td>0/ 4</td>
<td>0</td>
</tr>
<tr>
<td>P-Goals and Needs</td>
<td>5</td>
<td>0.66-0.73</td>
<td>0.15-0.44</td>
<td>10/10</td>
<td>100</td>
</tr>
</tbody>
</table>

*Number of items and number of item-internal consistency tests per scale
†Correlation between items and hypothesised scale, corrected for overlap
‡Correlations between items and other scales
§Number of hypothesised significantly higher/total number of correlations
Internal-consistency reliability (Cronbach’s alpha)
There was negative skewness (-1.10) for the Information-illness scale. Two scales had floor effects (P-Medical Treatment, P-Goals and Needs).

The correlation between the Total Discharge Planning and Overall Rating of Perceived Participation in Discharge Planning scales was $r=0.58$ ($p<0.01$).

The results of the multiple regression analysis showed that all three subscales in P-QPD had a statistically significant relation to P-QPD-VAS (Table 14). A higher score for each subscale was associated with higher perceived participation in discharge planning. All subscales contributed to 37% of the variance in P-QPD-VAS. Goals and Needs made the strongest contribution: (beta=0.34), Information: (beta=0.26) and Medical Treatment: (beta=0.17).

Table 14. Multiple Regression analysis towards P-QPD-VAS as a dependent variable and P-Information, P-Medical Treatment, P-Goals and Needs as independent variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>P-QPD-VAS</th>
<th>$R^2$</th>
<th>$F$</th>
<th>p-value</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>P-Information</td>
<td>0.262</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P-Medical Treatment</td>
<td>0.165</td>
<td>0.024</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P-Goals and Needs</td>
<td>0.339</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5.5.3 R-QPD

The item-own-scale correlations showed that the correlations' coefficient for nine out of ten items exceeded the value: >0.40 (Table 15). The median of item-scale correlation for the three subscales varied between 0.57 for R-Information-Illness and 0.70 for R-Information-Care/Support. Four items: (1, 4, 5, 8), correlated with the expected scale, but these correlations were not significant.

The evaluation item-discriminant validity and scaling success ratings showed significant item-scale correlations to 75% in R-Information-Care/Support and 67% in R-Goals and Needs and R-Information-Illness (Table 15).
Table 15. Results of item-scaling tests and reliability estimates (n=152)

<table>
<thead>
<tr>
<th>Subscales</th>
<th>k*</th>
<th>Range of item correlation</th>
<th>Item-scaling tests</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Item-convergent validity †</td>
<td>Item-discriminant validity ‡</td>
<td>Success/total §</td>
</tr>
<tr>
<td>R-Information-Illness</td>
<td>3</td>
<td>0.49-0.67</td>
<td>0.14-0.45</td>
<td>4/6</td>
</tr>
<tr>
<td>R-Information-Care/Support</td>
<td>4</td>
<td>0.49-0.75</td>
<td>0.24-0.51</td>
<td>6/8</td>
</tr>
<tr>
<td>R-Goals and Needs</td>
<td>3</td>
<td>0.32-0.56</td>
<td>0.25-0.34</td>
<td>4/6</td>
</tr>
</tbody>
</table>

*Number of items and number of item-internal consistency tests per scale  
†Correlation between items and hypothesised scale corrected for overlap  
‡Correlations between items and other scales  
§Number of hypothesised significantly higher/total number of correlations  
Internal consistency reliability (Cronbach’s alpha)
The Cronbach’s alpha coefficient was 0.81 for factor: R-Information-Care/Support, 0.72 for factor: R-Information-Illness, and 0.65 for factor: R-Goals and Needs (Table 15). When including all items on the total scale: Total discharge planning, the Cronbach’s alpha was 0.78. The inter-correlation between the scales was lower than respective Cronbach’s alpha values (R=0.35-0.48).

There was positive skewness (2.01) for the score distribution of R-Goals and Needs. Three scales had floor effects (R-Information-Illness, R-Goals and Needs, R-QPD-VAS) and one scale had a ceiling effect (R-Information-Illness).

The correlation between the scales: R-Total Discharge Planning and R-Overall Rating of Perceived Participation in Discharge Planning was r=0.63 (p<0.01).

The output from the multiple regression analysis showed that the two subscales: R-Information-Care/support and R-Goals and Needs in R-QPD had a statistically significant relation to R-QPD-VAS (Table 16). A higher score on each subscale was associated with higher perceived participation in discharge planning. All subscales contributed 42% of the variance in R-QPD-VAS. R-Information-Care/Support made the largest contribution: (beta=0.50) and R-Goals and Needs: (beta=0.22) and R-Information-Illness: (beta=0.05).

Table 16. Multiple Regression analysis towards R-QPD-VAS as a dependent variable and R-Information-Illness, R-Information-Care/Support, R-Goals and Needs as independent variables

<table>
<thead>
<tr>
<th></th>
<th>R-QPD-VAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>R²</td>
<td>0.424</td>
</tr>
<tr>
<td>F</td>
<td>33.148</td>
</tr>
<tr>
<td>p-value</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>R-Information-Illness</td>
<td>0.046</td>
</tr>
<tr>
<td>R-Information-Care/Support</td>
<td>0.504</td>
</tr>
<tr>
<td>R-Goals and Needs</td>
<td>0.222</td>
</tr>
</tbody>
</table>

p-value

60
5.5.4 Linking the items of P-QPD and R-QPD to ICF

The results obtained from linking the items of P-QPD and R-QPD showed that the meaningful concepts of the items were linked to the 1st and 2nd level of ICF categories (Table 17). The items of P-QPD were linked to participation in the chapter: Communication and Learning and applying knowledge and to environmental factors in the chapter: Services, systems and policies. The items of R-QPD were linked to participation in Communication and environmental factors such as Services, systems and policies and Products and technology. The intercoder-reliability was 0.97 for P-QPD and 0.85 for R-QPD.

Table 17. Results of linking the items of P-QPD and R-QPD to ICF

<table>
<thead>
<tr>
<th>ICF-code</th>
<th>ICF-category</th>
<th>P-QPD</th>
<th>R-QPD</th>
</tr>
</thead>
<tbody>
<tr>
<td>p175</td>
<td>Solving problems</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>p177</td>
<td>Making decisions</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>p3</td>
<td>Communication</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>p310</td>
<td>Communicating by receiving - spoken messages</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>p325</td>
<td>Communicating by receiving - written messages</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>p350</td>
<td>Conversation</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>p355</td>
<td>Discussions</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>e1</td>
<td>Products and technology</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>e5</td>
<td>Services, systems and policies</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>e540</td>
<td>Transportation services, systems and policies</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>e570</td>
<td>Social security services, systems and policies</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>e575</td>
<td>General social support services, systems and</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>policies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e580</td>
<td>Health services, systems and policies</td>
<td>14</td>
<td>10</td>
</tr>
</tbody>
</table>
6 General discussion

6.1 Findings - HRQoL

Stroke has a negative impact on HRQoL, especially in the middle-aged group. In the two groups of elderly patients, HRQoL was lower than in the Swedish normal population on the two physical scales: Physical Functioning and Role-Physical and the Physical Component Summary scale. Scores for the three mental scales: Vitality, Social Functioning, and Role-Emotional were also lower than for the same age groups in the Swedish normal population. These findings are in line with previous research concerning stroke patients (Bugge et al. 2001, Mayo et al. 2002). A possible explanation for our findings of low HRQoL in role and functioning scales is that this study was performed shortly after discharge, allowing only a short time for recovery of roles and habits. It is well known that stroke frequently causes impairment of physical, cognitive, emotional, behavioural, and social functions, all of which affect stroke survivors’ performance of daily activities, and consequently, their traditional roles and habits. Recovery might also be inhibited by different barriers in the environment at home, such as limited support from relatives, lack of social support or services, etcetera. Our findings of low HRQoL for the Mental Health and Vitality scales could be explained by the fact that depressive symptoms and fatigue are frequent among stroke patients, which tallies with other studies of stroke patients, which reported that depression and fatigue are predictors of HRQoL (Naess et al. 2006).

6.1.1 Associations between HRQoL and other components of ICF

Our findings showed that all eight scales of SF-36 were negatively affected by depressive symptoms. However, performances of personal interests and social (domestic, outdoor, social/leisure) activities were associated with higher HRQoL on several scales. One model (Physical functioning) showed a strong association between independent and dependent variables, and two models (Vitality; Mental Health) showed a moderate association and the remaining five models showed a weak association. These suggest that there are other factors that may be involved in the models of the seven scales of SF-36 with moderate or weak association.
6.1.1.1 The association of body functions with HRQoL

It is well known that there is a strong relationship between mood and HRQoL (Aprile et al. 2006, Jaracz & Kozubski 2003, Kauhanen et al. 2000), which this thesis also confirmed. The findings of this thesis showed that depressive symptoms explained a large part of the variance in the mental scales, but also that the physical scales were related to depressive symptoms, especially the scales: Bodily Pain and General Health. However, it is important to stress that several of the items on the SF-36 mental scales are very similar to the items on the depression scales. An essential part in rehabilitation after stroke is the discovery and treatment of depressive symptoms.

However, the aetiology of depression after stroke is complex and can be explained both by biological and social factors. There are two main ways of diagnosing depression. One is to use questionnaires, which usually give a kind of depression score that may be seen as a measure of depressive symptoms, but by using cut-offs, one can also get a diagnosis of depression. The other way is the classical psychiatric interview ending in a diagnosis of depression or not. In general, depression diagnoses based on questionnaires such as CES-D show a higher prevalence compared to diagnoses based on clinical interviews. In our study, according to the CES-D scale, 19% of the subjects had depression (cut-off ≥16 points), which is a lower prevalence rate compared to earlier studies (King et al. 2002). Previous studies found that one out of three patients with stroke had depression at discharge (cut-off ≥16 points at CES-D) and that the prevalence rate decreased to one out of four, 6-10 weeks after discharge (King et al. 2002). The findings of this thesis also showed gender differences in depressive symptoms. The women had more depressive symptoms than the men. This is in accordance with earlier studies of stroke patients, three months after stroke (Glader et al. 2003), and also with studies of normal, elderly, Swedish populations (Jansson et al. 2004).

6.1.1.2 Associations of personal factors with HRQoL

The patient’s personal factors, such as age, gender and education were also associated with HRQoL. Our findings support physical and mental health as latent factors in HRQoL among stroke patients and the impact of stroke on mental HRQoL is greater for patients aged 45-64 years, compared to older stroke patients. This may be due to the fact that stroke occurs suddenly and unexpectedly, and middle-aged patients have not learned coping strategies for their new life situation and daily activities so soon after discharge. Older patients are more likely to have had previous illnesses, which might have required the development of coping strategies.
Another possible explanation is that the elderly anticipate health problems to a greater extent and regard them as a normal part of life and common among their age-peers. Older patients suffer more often from co-morbidity, which may diminish the relative impact of stroke. There were gender differences in the HRQoL, as the females had lower HRQoL than males, which is in agreement with earlier studies (Bugge et al. 2001, Gargano et al. 2007, Hopman & Verner 2003).

6.1.1.3 Activity and participation associated with HRQoL

The results of this thesis showed that suffering from a stroke led to deteriorated activity/participation in self care, mobility and social activities. The BI scores pre-stroke for these patients were the same as for a normal population (Hachisuka et al. 1999). The BI scores remained lower post discharge compared to pre-stroke status. These results suggest the importance of needs assessment within self-care and mobility for the planning of interventions, post discharge. A review of randomised controlled trials showed that interventions by occupational therapists focusing on improving P-ADL after stroke can reduce the risk of further problems with P-ADL. The thesis results showed that more independence in P-ADL was associated with higher HRQoL, which is a confirmation of earlier research (Bugge et al. 2001, Carod-Artal et al. 2000, Jaracz & Kozubski 2003, Jonsson et al. 2005). The results of this thesis suggest the importance of the recovery of more independence in P-ADL in order to increase HRQoL among stroke patients.

Patients’ performance of social activities decreased after stroke on all three subscales and highlights the importance of needs assessment in social activities. The results showed that more frequent outdoor activities were related to higher HRQoL on both physical and mental scales. The frequency of outdoor activities was found to be linked to better physical ability and social participation among elderly patients (Fujita et al. 2004, Kono et al. 2007). Swedish guidelines recommend that stroke patients should not drive a car for three to six months after a stroke (National Board of Health and Welfare 2006b). The present study was carried out in a rural area, where most people need a car for transportation and social participation and there is no access to public transport. These circumstances influenced the patients’ opportunities to go shopping, visit friends or relatives, and participate in the community. Previous research found that loss of ability to drive a car was related to lower social participation and more depression (Legh-Smith et al. 1986). Our suggestion, therefore, is that discharge planning ought to include discussions about needs for interventions that promote and increase the stroke patients’ outdoor activities to facilitate participation in social life.
Our findings showed that performing interests as before suffering a stroke correlated with better HRQoL in physical roles and social functioning, but only 20% of the patients performed their interests as before stroke. These results are in line with an earlier study by Mayo et al (2002), who found that three out of four stroke patients lacked meaningful activities six months after onset and boredom could lead to depression and deterioration of function. The present findings could be explained by the fact that most of the patients in this study are retired and their performance of interests is an essential part of their physical roles and social functioning. Therefore, needs assessment, concerning the performance of interests, is an important element in discharge planning, in order to evaluate how patients can handle their earlier interests or find new ones. All team members have a responsibility for needs assessment of the patients’ activities and participation, but especially the occupational therapists could support the patients’ performance of activities and their recovery of the ability to handle their roles. In short, interventions to increase the patients’ performance of interests ought to be a substantial part of needs assessments in discharge planning.

6.1.1.4 Environmental factors associated with HRQoL

Environmental factors such as patients’ perceived participation in discharge planning were less associated with HRQoL. Patients’ perceived satisfaction with received and shared information was related to better physical functioning and better physical roles. The present findings suggest the importance of patients’ participation in sharing information that facilitates the understanding of the consequences of stroke for finding coping strategies to handle the new life situation after stroke and to achieve a good HRQoL. Earlier studies highlight the importance of sharing information in discharge planning (Bull & Roberts 2001). However, in this thesis, high perceived participation in discussions about Goals and Needs was associated with lower physical functioning and physical roles. One suggestion might be that the patients who were frailer and needed considerable care and support post discharge were more involved in discussions and planning of continued care and support than patients who were not so ill.
6.2 Findings-Environmental factors

6.2.1 Patients’ perceived participation in discharge planning

Most patients perceived satisfaction with their participation within the subscale P-Information. Sharing information with the professionals and possessing knowledge are important prerequisites for involvement in discussions concerning Goals and Needs in discharge planning. The additional findings also showed that patients’ perceptions of receiving and sharing information contribute to their overall ratings of participation in discharge planning. Information about the illness and the course of the illness, medication, and rehabilitation may prevent patients from having unrealistic expectations about the extent of possible recovery and facilitate realistic goal setting.

According to the subscale P-Medical Treatment, 60-70% of patients perceived that they did not participate in this part of the discharge planning process. These results may be explained by a paternalistic approach, where the physician and other professionals use one-way communication to provide information, assuming that they know what is best for the patient, even if the patient silently disagrees (Charles et al. 2003). On the other hand, physicians and other professionals may assume that a patient knows more about treatment and recovery than the patient actually does (Calkins et al. 1997). Another explanation for the low scores on the P-Medical Treatment subscale may be that patients did not wish to be involved in discussions concerning their treatment, as they regard this as a matter to be handled only by professionals (Charles et al. 2003). The additional findings showed that P-Medical Treatment made a minor contribution to overall ratings of perceived participation in discharge planning.

According to the laws and regulations applicable (SFS 1990:1404, SOSFS 2005:27, SOSFS 2005:12), the patients and their relatives should participate in the care such as discharge planning, including goal-setting and the evaluation of needs. The additional findings showed that perceived participation in goal setting and needs assessment made the largest contribution to patients’ overall ratings of participation in discharge planning. In the present study, discussions of the patients’ needs and goals seemed to be unusual in the discharge planning process. This was in line with earlier studies, which have also found that patients are seldom involved in discussions concerning goal setting (Bendz 2003, Efraimsson et al. 2004, Furaker et al. 2004, Wressle et al. 2002).
If the patients are involved in goal setting, their anxiety and distress decrease (McGrath & Adams 1999). Furthermore, a lack of communication between caregivers at the hospital, primary care and the community care services (Bull & Roberts 2001, Dunnion & Kelly 2005) may limit discussions with patients about their Goals and Needs (Atwal 2002, Bull & Roberts 2001, McKenna et al. 2000). Perhaps the professionals discuss continued care, services, and rehabilitation without clearly-defined goals, which might be due to the absence of methodology for involving the patients in goal setting. If the professionals do not discuss needs and goals with the patient, how can the patient and the professionals know that the decisions regarding continued care, services, and rehabilitation are correct? The role of the professionals in discharge planning and goal setting is often unclear (McKenna et al. 2000, Reed & Morgan 1999) and they may follow dated routines that include making decisions without involving the patient (Furaker et al. 2004). Earlier research has found that patients perceived more participation in goal setting when a client-centred goal formulation structure with a focus on the patients’ problems was used (Florin et al. 2006, Wade & Halligan 2003, Wressle et al. 2002). Goal setting is a motivation factor for the patients (Liss 1999). The professionals ought to involve the relatives in the discussions if the patients agree. The social aspects of discharge planning are often ignored or neglected by professionals who are focused on recapturing lost function (Atwal 2002, Pearson et al. 2004), while the patients are focused on recapturing their previous social position or adapting to a different life situation (Bendz 2003). Elderly patients’ functioning regarding activity and participation was documented to a lesser extent and goals were undocumented in the patients’ charts, which indicated shortcomings in the professionals’ documentation and/or methods of discharge planning (National Board of Health and Welfare 2008). Our conclusions are that professionals need to develop methods and routines for sharing information, but especially methods for goal setting and identification of needs in the patient’s whole life situation. All professionals, with their unique knowledge in different domains, ought to support the patients in the needs assessment of all components of ICF.

6.2.1.1 Associations between patients’ perceived participation in discharge planning and other components of ICF

The regression analyses revealed that personal factors such as lower age, higher education, activity/participation such as P-ADL performance were associated with patients’ perceptions of higher participation in discharge planning.
All three regression models showed a weak association between independent and dependent variables, which suggests that there are other factors that may be involved in explaining the variances. In this study, younger patients perceived participation to a higher degree in P-Information and P-Medical Treatment than elderly patients. This difference may be due to sensory and memory problems and disability in the elderly (Ryden & Tornkvist 2006). Elderly patients might not dare to ask questions and often want professionals to take the initiative (Sainio et al. 2001). In addition, older patients may feel less involved because the professionals might treat them more paternalistically than they do with younger patients (Bull & Roberts 2001).

It is well-known that individuals in higher social groups often get better care (de Gaudemaris et al. 2002). Higher education was associated with more perceived participation in discussions about P-Goals and Needs. Patients with higher education might discuss and ask questions to a greater extent or the professionals may have other attitudes to patients with a higher education.

P-ADL performance after discharge explained most of the variance in the regression model, but this is a complex variable. More dependence regarding P-ADL, 5 days after admission was associated with a higher degree of perceived participation in P-Goals and Needs. One explanation might be that these patients were more dependent on continued care, post discharge and, for this reason, the professionals had to involve them in discussions about Goals and Needs to a greater extent. On the other hand, more independence, 2-3 weeks after discharge, was associated with higher perceived participation on all three subscales, which could suggest that those patients were in a better condition and were more capable of taking a more active part in discharge planning and of discussing their whole life situation. The patients, who were more dependent with regard to P-ADL, 2-3 weeks after discharge, had lower scores also regarding P-Information and P-Medical Treatment. The reason may be that the information is standardised and not individualised to meet the needs of each patient. Information should be individualised to maximise its relevance to each patient (Eldh 2006, National Board of Health and Welfare 2003b, Wiles et al. 1998). However, the level of dependency among the patients may limit their ability to ask questions and understand their situation, after a stroke. According to research in other groups of patients, older age, low education and poor ADL functioning are related to poorer participation in decision-making (Florin et al. 2006, Hamalainen et al. 2003, Pelkonen et al. 1998), which is in agreement with the results of this thesis.
6.2.2 Relatives’ perceived participation in discharge planning

In this study, it was found that stroke patients’ relatives often did not perceive that they had participated in the discharge planning process, particularly not in goal setting and in identifying the patient’s needs. Relatives responded less negatively about whether they had received information about the illness, compared to whether they had received information about care and support. The relatives’ ratings of their overall perceptions of participating in discharge planning were also low. A variation was noticed concerning characteristics of the patients’ and relatives’ association with the three subscales and the VAS-scale. The additional results showed that the relatives’ perceptions of information about care/support made the largest contribution to their overall ratings of participation in discharge planning. Second to that, perceived participation in Goals and Needs was most important and there was also a minor contribution from receiving and sharing information about the illness.

Three quarters of the relatives perceived dissatisfaction with the information they received about stroke. Dissatisfaction with information regarding stroke, the consequences of stroke, and care and support after stroke has been reported in other Swedish studies (National Board of Health and Welfare 2000, National Board of Health and Welfare 2004, Olofsson et al. 2005) and in other countries (Grant et al. 2004, Rodgers et al. 2001, Smith et al. 2004, Wiles et al. 1998). These findings suggest that, although relatives expected more information, they failed to ask relevant questions about the patient and his/her situation. Low participation in sharing information could also be due to the absence of a routine on the part of the professional to engage relatives in an open and meaningful dialogue about stroke and recovery from stroke. Establishing a process for providing relatives with oral and written information about stroke could promote a dialogue (Olofsson et al. 2005, Walldal et al. 2002, Wiles et al. 1998). Our findings support the need for the development and implementation of processes that facilitate relatives’ participation in information sharing, especially regarding information about care and support in order to increase their overall ratings of perceived participation in discharge planning.
Most of the relatives were dissatisfied with their perceived participation in the discussions about the patients’ recovery goals, which could be explained by an absence of goal setting or a lack of involvement in discussions about goal setting. This result correspond to earlier research by Monaghan et al. (2005), who found that only 4-20% of the relatives were involved in the patients’ rehabilitation goal setting. Our findings suggest that the relatives and professionals in the healthcare and social services have different expectations regarding goal setting, or that the lack of discussion about the impact of stroke on the patients’ and relatives’ daily lives precludes realistic goal setting. According to Glazier et al. (2004), relatives reported having more goals than the patients and team members did, and there was an overall disagreement about goals among patients, family members, and healthcare team members. Stein et al. (2003) found that relatives of patients with stroke overestimated the patients’ functional status. Stroke often affects patients’ social skills (Smith et al. 2004), but the social aspects of the condition are often ignored or neglected in the discharge planning process (Atwal 2002). Lui et al. (2005) assert that the goal setting process is complex, and there is a need for clear guidelines to help professional teams, patients and relatives to set realistic goals. The present results might also suggest that some of the relatives who answered negatively did not want to be involved in discharge planning or in managing the patients in recovery. Maybe they had not been asked to participate or they did not know how important their support is for the patients’ recovery. Cott (2004) found that patients with chronic disorders wanted their relatives to participate in goal setting. Visser-Meily et al. (2006) support family-centred care for stroke patients, when the strengths and needs of the whole family are taken into consideration in the rehabilitation process. The involvement of patients and their families in goal setting increase the patients’ compliance in the care and rehabilitation process (Siegert & Taylor 2004). Another possible explanation for the results of the thesis, concerning the low perceived participation in goal setting and identification of needs, could be that the patient did not receive the planned and desired resources for care and support post discharge and, for that reason, the relatives experienced less participation.
6.2.2.1 Associations between relatives’ perceived participation in discharge planning and other components of ICF

The regression analyses revealed that patients’ personal factors, such as higher education and female gender; relatives’ personal factors, such as female gender and environmental factors, such as a longer stay in hospital were associated with relatives’ perceptions of higher participation in discharge planning. One model (R-QPD-VAS) showed a moderate association between independent and dependent variables, and the other three models (R-Information-Illness, R-Information-Care/support, R-Goals and Needs) showed a weak association. This suggests that there are other factors that may be involved in the models to explain the variance.

Relatives’ and patients’ gender influenced their perception of participation. Female relatives and the relatives of female patients perceived themselves to be more involved in discussions about Goals and Needs and female relatives also perceived a higher participation in the overall ratings of discharge planning than male relatives did. One explanation might be that women, traditionally, are more responsible for care and so were more active in discharge planning. Our findings may also suggest that the relatives of female patients were more involved in discharge planning since the female patients more often lived alone. On the other hand, recent studies have indicated that women get less attention concerning diagnostic resources and therapeutic interventions than men in stroke care (Di Carlo et al. 2003), which contradicts our results.

Length of stay in hospital explained most of the variance in the model. Relatives of stroke patients who required a longer stay in hospital perceived more participation in the patients’ discharge planning. Longer stays increase the opportunity to inform and involve the relatives and earlier research has found that the relatives of patients whose stay in hospital was longer were more satisfied with the information (van der Smagt-Duijnsee et al. 2001). Those with a long stay in hospital probably have more problems, which makes discharge planning more important for the relatives.
According to current regulations (SFS 1990:1404, SOSFS 2005:27), the professionals shall facilitate relatives’ participation in care and discharge planning. Our results showed that practice was at variance with the regulations, since the relatives perceived low participation in discharge planning. In order to meet and support patients’ needs post discharge, and because stroke also influenced the relatives’ daily life, relatives ought to be involved in the discharge planning process to a higher extent than the findings of this study suggest. Most stroke survivors need continued care and support from their relatives post discharge and, in one review, two years after their stroke, more than half of the stroke patients were dependent on relatives’ support for P-ADL (National Board of Health and Welfare 2004). Relatives’ involvement in discharge planning is of the greatest importance for managing the stroke survivor’s recovery (Bull & Roberts 2001, Grimmer et al. 2004, Pearson et al. 2004).

The findings of this thesis identify a need for the development of processes to involve relatives in sharing information, as well as establishing effective methods of goal setting and needs assessment in order to facilitate relatives’ perceived participation in the discharge planning process.

6.3 Methodological considerations

In order to evaluate the strengths and the limitations of this study, there are several methodological considerations to be addressed. There is a need to evaluate internal, external, construct and statistical conclusion validity in quantitative data, as well as some considerations regarding measures such as construct validity, psychometric characteristics and sensitivity to change (Kazdin 2003).

6.3.1 Internal validity

Internal validity refers to the extent to which the independent variables may be considered to account for the results, changes or group differences, instead of other factors or influences, called threats to internal validity (Kazdin 2003). “Instrumentation” is a threat to internal validity, and refers to changes in the measuring instrument or measurement procedures, over time (Kazdin 2003). This threat is not relevant in this thesis since the same instruments and scoring were used during the collection of data. The same measurement procedure was also used during the whole study. “Selection bias” did not occur in the study as all admitted patients were included consecutively.
6.3.2 External validity

External validity relates to the extent to which the results can be generalised beyond the sample, settings and circumstances in which the study was conducted (Kazdin 2003). Threats to external validity are: sample characteristics, stimulus characteristics and settings, reactivity of assessment and timing of measurement. The study consisted of the same proportion of younger patients (21%) below 65 years as in the Swedish stroke population (20%). The exclusion of prior stroke at the beginning of the study may have lowered the percentage of patients with prior stroke (20%) compared to the stroke population in Sweden (33%). The exclusion of the patients with aphasia and/or cognitive impairment may have lowered the mean age (74.0 years, men=72.8 years, women=75.5 years). The mean age of the whole stroke group in our study (76.8 years, men=75.8 years, women=78.4 years) is nearly the same as for the stroke population in Sweden (76 years, men=73.5 years, women=78.4 years). The exclusion criteria may also have affected the gender differences since our study comprised slightly more men (56%) than women (44%), compared to all stroke patients at the stroke unit (52% men and 48% women) and compared to the Swedish stroke population (51% men and 49% women). One strength was the low number of patients (11%) and relatives (2%) that declined participation. The patients who declined had almost the same mean age, and there was no gender difference. There were also very few missing data during data collection. Thus, it would seem that the sample in this study is fairly similar to the general stroke population in Sweden.

A limiting factor is that the results reflect local care, treatment, rehabilitation and routines for discharge planning in one hospital. The selected stroke unit in this study had somewhat more patients who were satisfied with the information given about the illness and about where they could seek help for problems after discharge but there were somewhat more patients who were dissatisfied with the care, compared with other stroke units in Sweden (Riks-Stroke 2007). The length of stay in hospital (21 days) was longer for our study population compared with the mean value of 13 days for acute stroke care and 17 days, for all hospital care, for the Swedish stroke population, during 2006 (Riks-Stroke 2007).

Reactivity of assessment refers to the fact that the respondents respond differently from how they would usually respond, when they are aware that they are being assessed (Kazdin 2003). This threat to external validity may have influenced the results of the study. In some instruments (P-QPD, R-QPD), the patients’ and relatives’ perceptions were used and, in SF-36 and CES-D, the patients were asked about their experiences. The performance of P-ADL and social activities was based on self-reports, which may affect the answers.
The time for measurement may have influenced the results (Kazdin 2003). Patients’ and relatives’ perceived participation was measured 2-3 weeks after discharge. The strength here is that the patients and relatives have had time to reflect on the discharge planning and how their life situation has been changed after stroke. One limitation is that the patients’ and relatives’ expectations might have changed after discharge and, therefore, their perceptions of participation in discharge planning may have altered. An example of this could be that the patient did not receive the planned and desired care and support post discharge and, for this reason, the patients and relatives experienced less participation. The time when the measuring of body functions, activity/participation and HRQoL took place, 2-3 weeks after discharge, may be too short for the patients to be able to return to their previous roles and daily activities.

6.3.3 Construct validity

A threat to construct validity might be the investigators’ expectations (Kazdin 2003). In this study, we asked about the patients’ and the relatives’ perceptions of participation in discharge planning, which should occur if the patients need continued, or new care/medication/support/rehabilitation. Most stroke patients have some need of continued or new care/medication/ support/rehabilitation and should, therefore, have had some form of discharge planning. The aim of the thesis was to study their perceptions of participation in discharge planning and the interviewer’s expectations may have affected the results, but we used standardised instruments, which limited the threat to construct validity.

6.3.4 Statistical conclusion validity

Statistical conclusion validity refers to the extent to which a statistical relation can be identified and aspects of the quantitative evaluation that influence the conclusions of the study, which may lead to misleading and false conclusions (Kazdin 2003). This category of validity is viewed as a risk of Type I and Type II errors. Type I error refers to the risk of rejecting a null hypothesis although it is true. The risk of Type I error depends on the significance level. In order to avoid Type I error, the level: p<0.05 was used in the study. Type II error refers to the risk of accepting the null hypothesis although it is false, which could occur with low statistical power.

A power calculation indicated that the sample size was enough to minimise the risk of Type II error.
6.3.5 Considerations concerning the selection of measures

The selection of instruments used in this thesis was based on considerations such as the construct validity of the measure, psychometric properties, and the sensitivity of the instrument to changes or differences (Kazdin 2003).

Construct validity in assessment refers to whether the measurements used assess the proposed underlying constructs (Kazdin 2003). In this thesis, well-known and well-validated instruments were chosen, such as: SF-36, CES-D, BI, FAI and MMSE. One limitation was the lack of established measurements for patients’ and relatives’ perceived participation in discharge planning. P-QPD and R-QPD were, therefore, partly developed from other questionnaires on quality of care, and construct validity was tested for the new instruments. The results showed three underlying factors in each instrument. VAS was also included to evaluate the overall ratings of perceived participation. The validity and reliability are uncertain for the VAS when used by itself but, in this thesis, VAS is used together with other questions (Torrance et al. 2001). The construct validity of SF-36 was also tested and the results showed that the instrument had good construct validity but the two summary components have some shortcomings.

To determine whether a scale or instrument yields reproducible and consistent results, its reliability is assessed. The reliability of the instruments (SF-36, CES-D, BI, FAI, MMSE) has been tested in earlier research. The internal consistency, measured by Cronbach’s alpha, is a common way of measuring reliability, which refers to the extent to which the items are related to each other.

Sensitivity of the measure refers to the capacity of the instrument to reflect systematic variation, change or differences in response.

The MMSE was chosen to measure cognitive functions for screening the patients to be included in the studies. The advantage of MMSE is that it is a brief, easily administered and widely used instrument for stroke patients (Salter et al. 2005a), and has moderate sensitivity and specificity to detect general cognitive functioning (Blake et al. 2002).

The CES-D is a well-known instrument for screening depressive symptoms. It is a generic instrument and has proved to be valid and reliable for patients with stroke (Shinar et al. 1986) and the Cronbach’s alpha value was very good, for this study population.
The BI was used to assess self-care and mobility and it is a well-established outcome measure among stroke patients (Salter et al. 2005c). The advantage is that BI is easy to administer and has shown validity (Shah et al. 1989) and good reliability (Hseuh et al. 2001) among stroke groups. The Cronbach’s alpha value was very good for this study population.

The FAI is a widely used measure of social activities after stroke and is easy to administer. We used three subscales according to Holbrook and Skilbeck (1983), although this has been questioned in previous research as factor analyses have shown different results regarding extracted factor solutions among stroke patients (Bond et al. 1992, Schuling et al. 1993, Sveen et al. 1999). Schepers (2006) found that FAI, when linking the items to ICF, measures four different chapters of ICF, mobility, domestic life, major life areas and community, social and civic life. A limitation is that some researchers have found gender differences for the subscales of FAI used (Holbrook & Skilbeck 1983). The Cronbach’s alpha values were very good for two subscales but somewhat low for the leisure/social activities subscale, in this thesis.

The SF-36 is widely used to measure HRQoL. The present study of stroke patients confirms to a great extent the scale assumptions of SF-36, but demonstrates some differences. Convergent validity was good for 94% of the items. Further research is needed to evaluate item-scale correlations for stroke groups at different intervals following stroke onset. Scaling success ratings were high except for two scales: General Health and Vitality. The limited scaling success does not support item-discriminate validity. The non-significant correlations could be due to the small sample size, as the standard error would be smaller with a larger sample (Ware Jr & Gandek 1998). The internal consistency was good for three scales (>0.70) and very good or excellent for five scales (>0.80). These internal consistency ratings are better than those reported in most other studies of stroke patients, where correlations lower than 0.70 have been reported for the General Health (Hobart et al. 2002), Social Functioning (Hobart et al. 2002), Vitality (Anderson et al. 1996, Hagen et al. 2003) and General Health scales (Hagen et al. 2003). We found that the other-scales correlation for each scale was lower than the reliability coefficient, supporting the idea that each scale measures a distinct concept.
Floor and ceiling effects are problems in health-related measurements; they limit the usefulness of a scale for evaluating outcomes. There were considerable floor and ceiling effects on three scales; this was also reported in previous studies of stroke patients (Hagen et al. 2003, Hobart et al. 2002, O’Mahony et al. 1998). In generally well-functioning populations, notable floor effects do not exist, while ceiling effects are more common (Sullivan et al. 2002, Sullivan et al. 1995). The ceiling and floor effects on the Role-Physical and Role-Emotional scales may relate to the fact that these scales have only four or five levels, making fine discriminations between individuals difficult. Another possible reason for the floor effects is that measurements were performed 2-3 weeks after discharge; thus the patients had had limited opportunity to participate in their usual daily activities. For seven scales, the hypothesised association with each dimension was fulfilled, with moderate or strong associations. We used oblimin rotation when the factors had a higher correlation, >0.30 (Pallant 2006), but earlier research on SF-36 used varimax when they suggested no correlation between the factors. We also used analysis with varimax and this analysis showed rare similar results. The Bodily Pain scale had divergent loading and was moderately associated with MCS instead of PCS. This probably indicates that stroke patients consider bodily pain more of a mental characteristic. The MCS explained most of the variance in the SF-36 scales, which pattern is divergent to that of Hobart et al. (2002). Our findings demonstrate shortcomings in summarising to PCS and MCS, which is in line with earlier studies among stroke survivors (Hobart et al. 2002) and in general groups (Taft et al. 2001).

P-QPD and R-QPD were developed from an existing questionnaire (Pyramid Questionnaire [PQ]), as a measure of quality of care. PQ included different indices of quality of care and we selected items which assessed the patients’ and relatives’ perception of their experiences of information and involvement/participation in discussions about Medical Treatment and Goals and Needs of care and support according to our theoretical explanation of participation in discharge planning. The linking of the items to ICF also supports the hypothesis that patients’ and relatives’ perceived participation in communication in discharge planning is dependent on different environmental factors. The professional team could act as facilitators for or barriers to giving patients and relatives the opportunity to receive information and to be involved in discussions on discharge planning. We used the concept, “perceptions”, when we asked our questions, 2-3 weeks after discharge. The concept, “experiences”, could have been used if we had made the interviews in connection with the situation. We established face validity of the selected items with experts in the field, patients and relatives.
The factors analysis of the P-QPD revealed three factors. P-QPD has good internal consistency reliability and good item-convergent validity, which is a strength in the questionnaire. The item-discriminant validity was good for two scales (P-Information, P-Goals and Needs), but less valid for P-Medical Treatment. There were substantial floor effects on two subscales (P-Medical Treatment and P-Goals and Needs), which limited the discrimination of changes. There was a moderate correlation (r=0.58) between the total summarised scale and the P-QPD VAS, which validated the questionnaire. The three subscales explained only 37% of the variance in P-QPD-VAS and participation in Goals and Needs made the largest contribution.

R-QPD was developed in the same way as P-QPD and the factor analysis revealed three factors. R-QPD has good internal consistency reliability for the subscales and a good item-convergent validity for nine out of ten items. The item-discriminant validity was good for the subscales, and the non-significant correlations could be due to the small sample size. Two subscales and the VAS had floor effects (R-Information-illness, R-Goals and Needs, R-QPD-VAS) and one scale had a ceiling effect (R-Information-care/support), which limited the discrimination of changes. There was a moderate correlation (r=0.63) between the total summarised scale and the R-QPD VAS. The three subscales explained only 42% of the variance in R-QPD-VAS and Information-care/support made the largest contribution. One limitation is that inter-observer and intra-observer reliability were not tested for P-QPD and R-QPD.
7 Future research

The present thesis indicates that further research on discharge planning for stroke patients is important and that the following items need to be elucidated:

- different methods for goal setting and the identification of needs to facilitate stroke patients’ and their relatives’ perceived participation in discharge planning
- how ICF could be used in needs assessment in discharge planning
- how perceived participation in discharge planning affects body functions, activities, participation and HRQoL at other times after stroke
- other factors that explain patients’ and relatives’ perceptions of participation in discharge planning
- correlation between patients’ and relatives’ perceptions of participation in discharge planning
- continued development and evaluation of P-QPD and R-QPD
8 Conclusions and clinical implications

The results of the present study showed that less depressive symptoms, more social activities especially outdoor activities and performance of interests are important variables, related to higher HRQoL, 2-3 weeks after discharge. Ability to perform personal activities, lower age, education (elementary school), and shorter hospital stay were also related to higher HRQoL. The fact that patients perceived participation in discharge planning was both positively and negatively associated with these results may be useful to consider in discharge planning and in planning interventions to promote adaptation and recovery in the whole life situation after stroke. Performances of personal, social activities and interests were lower 2-3 weeks after stroke compared with pre-stroke status, which suggests the importance of needs assessment of activities/participation in discharge planning.

Patients’ perceptions of participation in discharge planning showed that most individuals perceived that they received information, but fewer perceived participation in the planning of Medical Treatment and needs of care/service/rehabilitation and goal setting. Younger patients, higher education, less independence according to BI, 5 days after admission, and more independence, 2-3 weeks after discharge, were related to the patients’ perceptions of higher participation in discharge planning.

The relatives’ perceived participation in discharge planning showed that they need more information and knowledge about stroke, the consequences of stroke, care/medication/rehabilitation and support, in order to facilitate their participation in goal setting. The relatives perceived low participation in goal setting and needs assessment. Longer stay in hospital, patients with higher education, female patients and female relatives were positively associated with relatives’ perceptions of participation in discharge planning.

SF-36 functions well as a measure of health-related quality of life in Swedish stroke patients, but the two summary scales have shortcomings. Our findings support good divergent validity of SF-36 for discriminating health-related quality of life in stroke groups compared to normal populations.
Compared to a Swedish normal population, scores on all scales/components of the SF-36 were lower among stroke patients in the middle-aged group, and scores for five or six scales/components were lower among stroke patients in the older age groups.

The results suggest the importance of follow-up with needs assessment after discharge, when the patients have lived some time in their usual environment, to evaluate the patients' whole life situation for planning new and/or continued care, support and rehabilitation.

Professionals need to pay more attention to the patients' and relatives' perceived participation in order to facilitate their perceived participation in discharge planning.

The professional teams seem to lack effective practices for involving patients and their relatives so that they perceive participation in discharge planning. It is essential to implement routine methods for sharing information and to include the patients and their relatives in goal setting and the identification of needs. Such methods may improve the efficacy of goal-orientated care, available services, and rehabilitation after discharge.

The ICF was found to be functional as a framework to evaluate the patients' health conditions after stroke and to describe the associations between the variables in this thesis. The results suggest that ICF can be used in goal setting and needs assessment in discharge planning after acute stroke.
9 Sammanfattning (in Swedish)

Uppfattad delaktighet i vårdplanering efter stroke samt hälsorelaterad livskvalitet några veckor efter utskrivning

Patienters aktivitetsförmåga, delaktighet i samhället och hälsorelaterad livskvalitet påverkas negativt efter insjuknade i stroke. Förutom aktiv rehabilitering är närståendes stöd viktigt i tillfrisknande och återtagande av funktionsförmåga. Lagar, föreskrifter samt nationella riktlinjer för stroke-sjukvården i Sverige föreskriver att professionerna ska underlätta för patienten och nästående att vara delaktiga i vården och vårdplanering. Tidigare forskning har visat att patienter och nästående ofta inte får tillräcklig information och inte upplever att de är delaktiga i målformulering i vården, men det finns relativt lite kvantitativ forskning om patienter med stroke och deras näståendes delaktighet i vårdplanering i samband med utskrivning från sjukhus.

Tidigare studier visar att hälsorelaterad livskvalitet bör mätas i ett tidigt skede för att få patienternas direkt upplevelse av konsekvenserna av att ha fått stroke. Vad vi känner till finns det endast några få studier som undersöker multipla variablars relation till hälsorelaterad livskvalitet några veckor efter utskrivning från sjukhuset. I denna avhandling används skalan SF-36 för att mäta hälsorelaterad livskvalitet, vilket är psykometriskt testat på normalpopulation i Sverige, men SF-36 är inte testat för patienter med stroke i Sverige.

De övergripande syftena med denna avhandling var att beskriva: hur patienter, som insjuknat i stroke och hur deras närstående uppfattade delaktighet i vårdplanering i samband med utskrivning från sjukhuset; patienternas hälsorelaterade livskvalitet, depressiva symptom samt utförande av personliga och sociala aktiviteter. Ytterligare ett syfte var att utvärdera de psykometriska antagandena för SF-36 gällande patienter med stroke i Sverige och bestämma relaterade variabler till hälsorelaterad livskvalitet efter stroke några veckor efter utskrivning. Ett annat syfte var att genomföra psykometrisk analys av frågeformulären för patienternas samt närståendes uppfattade delaktighet i vårdplanering samt överkodning av frågorna till ICF.
För att beskriva en persons hälsotillstånd kan WHO:s klassifikation av funktionstillstånd, funktionshinder och hälsa användas. I denna avhandling används ICF:s komponenter: kroppsstruktur, kroppsfunktion, aktivitet, delaktighet samt omgivningssfactorer för att beskriva patienters hälsotillstånd efter insjuknande i stroke.

Figur 6. ICF-modellen med de inkluderade komponenterna i avhandlingen.

Totalt deltog 188 patienter (medelålder=72.8, standardavvikelse [SD]=11.2, variationsvidd 32-92 år) varav 105 (55.9%) var män (medelålder=72.8, SD=10.9 år) och 83 (44.1%) kvinnor (medelålder=75.5, SD=11.3). Folkskola var vanligaste utbildningen (75%). Drygt hälften (59%) av patienterna bodde tillsammans med någon annan och 95% av samtliga bodde i eget boende innan insjuknandet. Hjärninfarkt var den vanligaste orsaken (93%) till stroke och 80% av patienterna hade sin första stroke. Medelvärdetiden på strokeenheten, omfattande både akut stroke och rehabilitering, var 20.6 (SD=23.8, R=2-130) dagar. Totalt deltog 152 närstående till de 188 patienterna (27 patienter angav ingen närstående, tre närstående avböjde deltagande, fem svarade inte och en var för sjuk för att delta). Av de närstående var 104 (68.4%) kvinnor (medelålder=59.6, SD=12.4 år) och 48 (31.6%) män (medelålder=61.2, SD=12.9 år). Den totala medelåldern var 60.1 (SD=12.6, variationsvidd=29-86) år. Av de närstående var 61% maka/make/sambo och 41% av de närstående hade enbart folkskola.

Hälsorelaterad livskvalitet mättes med SF-36, bestående av 36 frågor fördelade på åtta delskalar, som kan summeras till två överordnade skalar för fysisk respektive mental hälsa. Kroppsfunctioner såsom depressiva symptom mättes med Center of Epidemiologic Studies Depression Scale (CES-D), som består av 20 frågor. Mini Mental State Examination (MMSE) användes för att bedöma kognitiva funktioner för inklusion i studien. Patienternas aktivitet och delaktighet mättes med Barthel Index, som mäter tio olika aktiviteter inom personliga dagliga aktiviteter (P-ADL) inom personlig vård och förflytning. Frenchay Activities Index användes för att mäta sociala aktiviteter inom 15 områden, fördelade på tre delskalar: hushålls-, utomhus- och fritids/social aktiviteter. En fråga tog upp om patienterna kunde utföra de intressen som de hade före insjuknandet.
Frågeformulären om patienternas och närståendes uppfattade delaktighet i vårdplanering mäter både delaktighet och omgivningsfaktorer. Frågeformuläret ”Patientens delaktighet i vårdplanering i samband med utskrivning från sjukhus” (P-QPD) utvecklades från Pyramid Questionnaire (Arnetz & Arnetz 1996). Det innehöll 14 frågor, som efter faktoranalys, fördelades på tre frågeområden: P-Information-Sjukdom ( erhållit tillräcklig information om sjukdom, konsekvenser av sjukdom; möjlighet att ställa frågor samt förstå erhållen information), P-Medicinsk Behandling ( möjlighet att delta i diskussioner om undersökningar/behandlingar samt målet för dessa med läkare) samt P-Mål och Behov ( möjlighet att delta i diskussioner om behov av vård/stöd/rehabilitering efter utskrivning och om målen med insatserna samt delaktighet i utformningen av vårdplanen). Frågorna besvarades på en fyrradig ska, ”ja, i hög, grad” (4), ”ja, delvis” (3), ”nej, inte särskilt” (2) och ”nej, inte alls” (1). En allmän skattning av deras delaktighet i vårdplanering besvarades på en VAS-skala från ”inte alls delaktig” (1 poäng) till ”mycket delaktig” (10 poäng). På liknande sätt utvecklades ”Närståendes delaktighet i vårdplanering i samband med utskrivning” (R-QPD) från Pyramid Questionnaire (Verho & Arnetz 2003). Det består av 10 frågor, efter faktoranalys fördelade på tre frågeområden: R-Information-Sjukdom ( erhållit tillräcklig information om sjukdom, konsekvenser av sjukdom; erhållit svar på sina frågor; förstått informationen), R-Information-Vård/Support ( erhållit tillräcklig information om läkemedel, rehabilitering, vård efter utskrivning samt samhällets stöd) samt R-Mål och Behov ( möjlighet att delta i diskussioner om undersökningar/behandlingar och dess mål samt delaktig i planeringen av vården). Svarsalternativen och allmän skattning av deras delaktighet besvarades på en VAS-skala på likartat sätt som för patienterna.

Datainsamlingen skedde med personlig intervju av patienter och närstående 2-3 veckor efter utskrivning från sjukhus, då patienterna även rapporterade status om P-ADL och sociala aktiviteter innan insjuknandet. Patienternas P-ADL bedömdes även efter inskrivning på sjukhuset.

Resultatet visar att patienter med stroke hade statistiskt signifikant sämre hälsorelaterad livskvalitet i samtliga delskalor och de två komponenterna jämfört med en svensk normal population. Samma jämförelse men fördelat på olika åldersprodukter visade på att den yngsta gruppen (45-64 år) hade sämre livskvalitet i samtliga skalor än den svenska normal populationen (Figur 7). För de äldre åldersgrupperna (65-74, 75+) fanns det statistiskt signifikanta skillnader i fem eller sex delskalor/komponenter.
Resultatet visade att färre depressiva symptom var relaterat till högre hälso- relaterad livskvalitet i samtliga fysiska och mentala delskalor i SF-36 två till tre veckor efter utskrivning från sjukhuset. Sociala aktiviteter såsom utomhusaktiviteter samt utförande av intressen som före insjuknandet korrelerade till bättre hälso- relaterad livskvalitet. Patienternas uppfattningar om delaktighet i vårdplanering bidrog endast lite till att förklara skillnaden i hälso- relaterade livskvalitet. Yngre ålder, utbildning (folkskola), kortare vårdtid samt bättre P-ADL-förmåga var relaterade till bättre livskvalitet inom olika delskalor. Studien visade att 20% av patienterna kunde utföra sina intressen som innan insjuknandet och 19% hade depressiva symtom. Patienternas förmåga att utföra P-ADL och sociala aktiviteter hade försämrats efter insjuknandet.
När det gällde resultatet att patienternas uppfattade delaktighet visade det sig att 72-87% av patienterna uppfattade att de fått information, kunnat ställa frågor och förstå informationen i hög eller delvis grad. Tjugonio procent av patienterna uppfattade att de var delaktiga i diskussionerna om medicinsk behandling och 38% uppfattade att de diskuterat målen med läkaren i hög eller delvis grad. Ungefär hälften (47%) uppfattade att de varit med i hög eller delvis grad och diskuterat sitt behov av fortsatt vård/service och en tredjedel (33%) sitt behov av fortsatt rehabilitering. Endast 15-17% av patienterna uppfattade att de varit med och diskuterat målsättningen med vården/servicen/rehabiliteringen för tiden efter utskrivning från sjukhuset. Omkring en tredjedel (38%) uppfattade att de varit delaktiga i utvecklingen av sin vårdplan inför utskrivningen. Patienternas uppfattade delaktighet i de olika subskalorna var P-Information 3.2 (SD=0.7), P-Medicinsk Behandling 1.9 (SD=1.0) och P-Mål och Behov 2.0 (SD=1.0). Medelvärden för patienternas allmänna skattning av delaktighet i vårdplanering inför utskrivning var 6.1 (SD=3.2) på VAS-skalan. Yngre patienter, patienter med högre utbildning än folkskola, patienter som är mer beroende i P-ADL vid inskrivning var relaterat till att patienterna uppfattade mer delaktighet i vårdplanering.

När det gäller resultatet om närståendes uppfattade delaktighet visade det sig att 56-68% av de närstående hade en positiv uppfattning gällande information om sjukdomen, varav 33% var fullständigt nöjda med informationen. Mellan 46% och 53% av de närstående uppfattade att de inte alls hade fått tillräcklig information om vård, läkemedel, stöd/omsorg och rehabilitering. I diskussionerna om mål och behov av vård och stöd var det mellan 82% till 84% av de närstående som uppfattade sig som inte alls delaktiga. Medelvärden för varje subskala var: R-Information-Sjukdom 2.98 (SD=1.09), R-Information-Vård/Stöd 1.95 (SD=1.03) och R-Mål och behov 1.36 (SD=0.66). Närståendes allmänna skattning av deras delaktighet i vårdplanering hade medelvärden 3.89 (SD=3.40) på VAS-skalan. Närstående till: kvinnliga patienter; patienter med högre utbildning än folkskola; patienter med längre vårdtid, samt kvinnliga närstående, var relaterade till att närstående uppfattade mer delaktighet i vårdplanering.


Psykometrisk analys av de båda frågeformulärerna P-QPD och R-QPD visade på god reliabilitet och validitet för delskalorna, men det förekommer tak- och golveffekter, som begränsar möjligheterna att se förändringar.
Överkodningen av frågorna i P-QPD och R-QPD till ICF resulterade i kategorier inom delaktighet såsom Att tillämpa kunskap och Kommunikation samt inom omgivningsfaktorer såsom Services, tjänster, system och policies samt Produkt och teknik vilket överensstämmer med beskrivningen av uppfattad delaktighet i vårdplanering i samband med utskrivning.

Slutsatser:
- Vid jämförelse med svensk normalpopulation var hela strokegruppens hälsorelaterade livskvalitet lägre i alla åtta delskalor och de två summerade komponenterna. Speciellt den medelålders gruppen (45-64 år) hade lägre hälsorelaterad livskvalitet.
- Depression är vanligt förekommande efter stroke, men det var färre patienter (19%) som hade depression jämfört med resultat från andra studier.
- Utförande av personliga och sociala aktiviteter hade minskat 2-3 veckor efter utskrivningen jämfört med innan insjuknandet. Endast 20% av patienterna kunde utföra sina intressen som före insjuknandet.
- Resultatet visar på att få depressiva symptom, sociala aktiviteter såsom utomhusaktiviteter samt utförande av sina intressen som före insjuknandet är viktiga variabler som är relaterade till ökad hälsorelaterade livskvalitet 2-3 veckor efter utskrivning. Även P-ADL, uppfattad delaktighet i vårdplanering, kortare vårdtid, yngre ålder och utbildning (folkskola) är variabler som är relaterade till patienternas hälsorelaterade livskvalitet. Resultat som kan vara betydelsefulla att beakta i behovsbedömningen vid vårdplaneringen, för att planera interventioner som stödjer tillfrisknandet och bidrar till ökad hälsorelaterade livskvalitet.
- Studien om patienternas uppfattade delaktighet i vårdplanering i samband med utskrivning lämnade följande huvudfynd: 1) de flesta patienterna uppfattade att de fått information, 2) men färre uppfattade delaktighet i diskussionerna gällande planeringen av medicinsk behandling och behov av vård/service/rehabilitering samt målformulering, 3) yngre patienter, högre utbildning (>folkskola), och mer oberoende i P-ADL 2-3 veckor efter utskrivning var relaterat till att patienterna uppfattade högre delaktighet i vårdplanering.
Studien om närståendes uppfattade delaktighet i vårdplanering visar på tre huvudsyynd: 1) närstående uppfattade att de behöver mer information och kunskap om stroke, konsekvenserna av stroke, vård/läkemedel/service/omsorg/rehabilitering för att underlätta delaktighet i målformulering, 2) närstående uppfattade låg delaktighet i diskussionerna gällande målformulering och behovsbedömning, och 3) närstående till: kvinnliga patienter; patienter med längre vårdtid; patienter med högre utbildning (>folkskola) och kvinnliga närstående var relaterat till att närståendes uppfattade högre delaktighet i vårdplanering i samband med utskrivning.

SF-36 fungerar bra som mätning av hälsorelaterad livskvalitet för svenska patienter med stroke, men de två summerade komponenterna har vissa brister. Resultaten visar på god divergent validitet av SF-36 för att diskriminera hälsorelaterad livskvalitet hos patienter med stroke och normalpopulationen.

Avhandlingen visar att ICF kan användas för att beskriva funktionsstillstånd och funktionshinder efter insjuknande i stroke.

Hälso- och sjukvårdsorganisationerna tycks sakna effektiva rutiner för att involvera patienter och deras närstående, så att de uppfattar delaktighet i vårdplanering i samband med utskrivning. Metoder för behovsbedömning och mål-fokuserad vård i samband med planering av fortsatt vård och omsorg efter utskrivning från sjukhuset kan öka effektiviteten och kvaliteten enligt tidigare forskning.

Därför är det nödvändigt att införa och utvärdera metoder så att patienter och närstående uppfattar att de fått information och att de uppfattar att de har möjlighet till delaktighet i målformulering och identifitering av behov. Professionerna behöver rikta mer uppmärksamhet åt patienter och närstående i olika subgrupper för att underlätta och stödja deras delaktighet i vårdplanering.
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Ann-Helene Almborg

Ann-Helene Almborg is a Registered Occupational Therapist graduated from the School of Health Sciences in Jönköping in 1977. She has a Master of Science degree in Occupational Therapy and has worked as occupational therapist within different areas e.g. hand and home rehabilitation. She has also been the manager of a unit for rehabilitation in primary care. Ann-Helene Almborg has participated in health care projects such as development of IT support for discharge planning of patients with stroke, and development of methods for maintaining information and for operational review in health care and social services for patients with stroke.

Ann-Helene Almborg’s PhD-thesis, Perceived Participation in Discharge Planning and Health Related Quality of Life after Stroke, focuses on stroke patients’ and their relatives’ perceived participation in discharge planning and the patients’ life situation 2-3 weeks after discharge. The total sample consisted of 188 patients (mean age=74.0 years) and 152 relatives (mean age=60.1 years). The results showed that less depressive symptoms, a higher frequency of outdoor activities and performance of interests as before the stroke, were related to higher health related quality of life 2-3 weeks after discharge. The results also showed that the patients and their relatives perceived low participation in discharge planning especially in needs assessment and goal-setting. The results indicate that it is essential to develop and to implement methods for discharge planning, including sharing information, needs assessment with goal-setting that facilitate patients’ and relatives’ perceived participation in discharge planning.