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UNDERSTANDING THE LINKS: THE EXPLORATION OF CARE TRANSITIONS BETWEEN HOSPITAL AND CONTINUED REHABILITATION IN THE HOME AFTER STROKE

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UNDERSTANDING THE LINKS:
THE EXPLORATION OF CARE TRANSITIONS BETWEEN HOSPITAL AND CONTINUED REHABILITATION IN THE HOME AFTER STROKE

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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“I believe in the complexity of the human story, and that there’s no way you can tell that story in one way and say, this is it. Always there will be someone who can tell it differently depending on where they are standing… this is the way I think the world’s stories should be told: from many different perspectives”

- Chinua Achebe

ABSTRACT

Background: Uncoordinated care transitions are known to be a risk of a substantial burden for patients and significant others with a risk of adverse events, rehospitalisation and dissatisfaction with services. After acute hospital care, people with stroke often need continued rehabilitation which entails a care transition such as from hospital to continued rehabilitation in the home environment.

Aims: The overall aims of this thesis were to generate knowledge about and describe the care transition process from hospital to the home from the perspective of people with stroke, significant others and healthcare professionals. In addition, the aim was to investigate the concept of participation in a co-design of person-centred care transitions.

Methods and participants: Four papers were included. Paper I and II were based on a prospective observational study including 190 people with stroke and 89 significant others. Data were collected from medical records by standardized questionnaires, performance-based tests, and from the Stockholm Region computerized register of healthcare contacts. Paper I was a prospective observational study where data were analysed with descriptive statistics and regression analysis to explore associations between healthcare utilization and independent variables. Paper II was a cross-sectional study where regression analysis was used to explore associations between perceived quality and independent variables. Paper III was a qualitative grounded theory study of the care transition process including 16 people with stroke, 7 significant others and 48 healthcare professionals. Data was collected through focus group interviews, individual interviews, and interviews in dyads. Paper IV included 3 people with stroke, 1 significant other, 10 healthcare professionals and 1 facilitator. Data was collected using observations, field-notes, interviews and questionnaires and was analysed by qualitative content analysis to investigate how participation manifests itself in a co-design process.

Results: A majority had a very mild or mild stroke. There was a large variation in the number of visits with the neurorehabilitation team and other outpatient contacts which seemed to correspond to the level of functioning and stroke severity. The perceived quality of the care transitions indicated that there is room for improvements in the discharge process, especially regarding preparation for discharge and support for self-management post-discharge. Few clinical characteristics were associated with the perceived quality of the care transition. The care transition was described to consist of several parallel processes in need of synthetization and coordination in order to provide care transitions based on the needs of people with stroke and significant others. Patients and significant others described the care transition as a transformation from a passive attendant at the hospital to becoming an uninformed agent at home after discharge. The manifestation of participation in a co-design process was shown to be affected by multifactorial interrelated links such as the composition of groups, the climate and adaptations among the participants, the balancing of roles and power, a shared understanding, leadership and adaptive process. Participation varied between individuals, groups, steps within the process and the topic of conversation.

Conclusion: The care transition from hospital to continued rehabilitation in the home needs to be adapted to the varying needs of people with stroke and significant others. The preparation for discharge and information and support for self-management need to be enhanced. Patients and significant others need to be involved in their care during all steps of the care transition process. A perceptive dialogue between patients/significant others, healthcare professionals and across organizations is needed to facilitate coordinated and person-centred care transitions. Participation in a co-design process needs to be asserted continuous reflection, discussion and adaption in order to facilitate the unique knowledge and experience of the involved stakeholders.

SAMMANFATTNING

Bakgrund: Okoordinerade vårdövergångar kan innebära en stor börda för patienter och närstående samt risk för negativa händelser, återinläggning på sjukhus och missnöje med vården. Efter den akuta sjukhusvården behöver personer med stroke oftast fortsatt rehabilitering vilket innebär en vårdövergång såsom från sjukhus till fortsatt rehabilitering i hemmiljön.

Syfte: Det övergripande syftet med denna avhandling var att generera kunskap om och beskriva vårdövergången från sjukhus till hemmet utifrån personer med stroke, närstående och hälso- och sjukvårdspersonalens perspektiv. Dessutom var syftet att undersöka hur begreppet delaktighet manifesterar sig i en medskapande process av person-centrerade vårdövergångar.

Metod: Denna avhandling omfattade fyra studier. Studie I och II baserades på en prospektiv observationsstudie av 190 personer med stroke och 89 närstående där data samlades från journaler, standardiserade frågeformulär och tester samt från Region Stockholms dataregister över vårdkontakter. Studie I var en prospektiv studie där deskriptiv statistik och regressionsanalys användes för att beskriva och undersöka samband mellan vårdanvändning och oberoende variabler. Studie II var en tvärsnittsstudie där regressionsanalys användes för att studera samband mellan upplevd kvalitet av vårdövergången och oberoende variabler. Studie III var en kvalitativ studie av vårdövergångsprocessen baserad på grundad teori och omfattade 16 personer med stroke, 7 närstående och 48 hälso- och sjukvårdspersonal. Data samlades genom fokusgrupper, individuella intervjuer och intervjuer i dyader. Studie IV omfattade 3 personer med stroke, 1 närstående, 10 hälso- och sjukvårdspersonal och 1 facilitator. Data samlades med observationer, fältanteckningar, intervjuer och frågeformulär och analyserades med kvalitativ innehållsanalys för att undersöka hur delaktighet manifesterar sig i en samskapande process.

Resultat: En majoritet av deltagarna hade en mycket mild eller mild stroke. Det var en stor variation i antal neuroteamsbesök och annan öppenvård vilken tycktes avspegla funktionstillstånd och svårighetsgrad av stroke. Den upplevda kvaliteten på vårdövergången indikerade brister vad gäller förberedelser inför utskrivning och stöd för egenvård efter utskrivning. Det fanns få samband mellan patienternas karaktäristika och den upplevda kvaliteten på vårdövergången. Vårdövergången beskrevs bestå av flera parallella processer som behöver syntetiseras och koordineras för att vårdövergången ska kunna utgå från behoven hos personer med stroke och närstående. Patienter och närstående upplevde att de i samband med vårdövergången övergick från att vara passiva under sjukhusvistelsen till att plötsligt utan förberedelse och stöd ansvara för sin hälsa efter utskrivningen. Det fanns ett behov av att skapa länkar och förbättra dialogen mellan patient/närstående och vårdpersonal under alla steg i vårdövergången. Manifesteringen av delaktighet i en samskapande process påverkades av olika aspekter så som gruppsammansättning, klimat och anpassning bland deltagarna, balans mellan olika roller, maktfördelning, gemensam förståelse, ledarskap och anpassningar i processen. Deltagandet varierade mellan individer, grupper, steg i processen och samtalsämne.

Konklusion: Vårdövergången mellan sjukhus och fortsatt rehabilitering i hemmet för personer med stroke och deras närstående behöver anpassas utifrån individers behov och förutsättningar. Förberedelsen inför utskrivning med information och stöd för egenvård bör förbättras. Patienter och närstående bör involveras i vårdövergångens alla delar och för att främja koordinerade och person-centrerade vårdövergångar behövs en mer person-centrerad dialog mellan patient, närstående, hälso- och sjukvårdspersonal samt mellan vårdgivare. Man bör i en samskapande process kontinuerligt reflektera över och diskutera begreppet delaktighet för att kunna underlätta deltagarnas möjlighet att bidra med sin unika kunskap och erfarenhet.

LIST OF SCIENTIFIC PAPERS

I. Lindblom S, Tistad M, Flink M, Laska AC, von Koch L, Ytterberg C. Referral-based transition to subsequent rehabilitation at home after stroke: one-year outcome and use of healthcare services. *In manuscript*

II. Lindblom S, Flink M, Sjöstrand C, Laska AC, von Koch L, Ytterberg C. Perceived Quality of Care Transitions between Hospital and the Home in People with Stroke. J Am Med Dir Assoc. 2020 Jul 29:S1525-8610(20)30563-6.

III. Lindblom S, Ytterberg C, Elf M, Flink M. Perceptive Dialogue for Linking Stakeholders and Units During Care Transitions – A Qualitative Study of People with Stroke, Significant Others and Healthcare Professionals in Sweden. International Journal of Integrated Care. 2020;20(1):11.

IV. Lindblom S, Flink M, Elf M, Laska AC, von Koch L, Ytterberg C. The manifestation of participation within a co-design process involving patients, significant others and healthcare professionals. *Submitted*

CONTENTS

LIST OF ABBREVIATIONS

MRC	Medical Research Council
PCC	Person-Centred Care
LOS	Length of Stay
CAS	Complex Adaptive System
CTM-15	The Care Transition Measure
BI	Barthel Index
CCI	Charlson Comorbidity Index
SIS	Stroke Impact Scale
PADL	Personal Activities of Daily Living
IADL	Instrumental Activities of Daily Living
FAI	Frenchay Activities Index
MoCA	Montreal Cognitive Assessment Scale
mRS	Modified Rankin Scale
IQR	Interquartile Range
SD	Standard Deviation

1 INTRODUCTION

The papers of this thesis are part of The Missing Link Project (1) where the overall aim is to develop and evaluate new person-centred transitions between hospital and continued rehabilitation in the home for people with stroke.

The project draws on the guidelines from the Medical Research Council (MRC) on the development and evaluation of complex interventions (2). A phased approach in three steps is therefore used: 1) Development; 2) Design/Testing; 3) Evaluation/Implementation. This thesis is based on the first step of the guidelines and attempt to identify problems, needs and explore the current context, to inform the next phase of the project.

The overall intention with this thesis was to lay the foundation to develop a care transition based on the needs, preferences and values of the stakeholders concerned. To be able to achieve this, it was important to include the people it concerned in the research. This thesis explores and generates knowledge about the current care transition between hospital and the home from a multitude of perspectives. The exploration involves the perspective of people with stroke, significant others and healthcare professionals.

In order to develop and evaluate a new person-centred transition between hospital and the home, we wanted to generate knowledge of how the current care transition is perceived and experienced by the stakeholders involved, understand the local context, what the care transition service constitutes and how it affects the outcomes for people with stroke and their significant others. Furthermore, a new person-centred transition was developed in a participatory design with patients, significant others, and healthcare professionals. In this process, the concept of participation in a co-design process was examined. This can contribute to the area of participatory design, which is an increasingly used strategy and method in healthcare.

2 BACKGROUND

2.1 CARE TRANSITIONS

Care transitions, defined as "*a set of actions designed to ensure the coordination and continuity of healthcare as patients transfer between different locations or different levels of care within the same location*" (3) is an essential part of a healthcare system, particularly from the viewpoint of patients and their families, as they can be considered the only constant in the movement through the healthcare system (4). The reason for this could be attributed to a fragmented healthcare system consisting of boundaries between organizations and professionals (5). From a health system perspective, care transitions are often an underdeveloped part, perhaps as the phenomenon often entails a gap between healthcare levels, settings, and providers with an ambiguity around what, when and how responsibility, accountability and information is transferred (6). From the patients perspective, care transitions can be recognized as a shattering and vulnerable episode in both patients' and their significant others' lives and have been proven to threaten patient safety (7-10).

The boundaries of, and gaps between, various healthcare organizations and providers in transitions of care have been shown to affect the coordination and continuity of care, which can render a substantial burden for patients and their significant others (11, 12). Poor communication and/or, collaboration, and inadequate provision of information between organizations and providers (10, 13) are a risk of adverse events such as delayed or defaulted follow-up (7), incomplete or delayed procedures (14), medication errors (15-17), information loss, lack of support to help navigate the healthcare system and unnecessary healthcare utilization (4, 11, 13, 18-20).

In addition, failed care transitions affect the efficiency of the healthcare system and result in increased cost. Studies in the United States have shown that approximately one-fifth of patients have at least one emergency room visit or were readmitted to hospital within 30 days of discharge (8, 21). Results from Sweden indicate similar figures with a reported number of 20% rehospitalized within 30 days of discharge (22). Improved care transitions have been suggested as a potential action to reduce rehospitalizations (8, 21, 22) and even though results are inconclusive, transitional care interventions have been shown to reduce the risk of readmission (23).

However, at the forefront, and those ultimately affected by the care transition are the patients and significant others (13, 14, 24). To avoid failure and poor outcomes there is a need to explore, understand and involve the experiences of patients and significant others to be able to conduct care transition based on the needs of the individual.

2.1.1 Care transitions from the perspective of the individual

The views and experiences of patients, significant others and healthcare professionals on care transitions have been explored in numerous studies conducted on a wide range of conditions and diagnoses. Compassionate communication and empathy between healthcare professionals

and the patients and significant others has been described as an essential element for a successful care transition (25). However, a common experience among both patients and their significant others is a stressed and forced process upon discharge, leaving little time for information, involvement and education (26-28). The forced process is often explained by healthcare professionals as lack of time (27), and workload and pressure on productivity (27, 29, 30). Even though healthcare professionals put a lot of effort into preparing the discharge, the encounter does not always contain elements that reflect the actual needs of the patients that will help them manage, post-discharge (30). Patients and significant others often feel unprepared coming home, and experience insecurity on how to manage their health and daily life (27, 31, 32). On the other side, patients who are prepared and considered to have received sufficient information have been described to be more satisfied and experience less stress (33). Significant others have reported being unprepared and overwhelmed by the responsibility entailed in managing the provision of their family member after discharge (12). Having someone to turn to for guidance and answers to questions is desired by both patients and significant others, especially when navigating and coordinating between care providers (12, 26). To avoid problems with poor experiences in relation to care transitions several studies highlight the importance of individualization and involvement of patients and significant others, both through information and joint decision-making (12, 26-28, 31). Depending on former experience, illness and external factors, care transitions are experienced in different ways, indicating there is no one-size-fits-all solutions when conducting care transitions (3). One patient group often exposed to care transitions and that might be extra vulnerable in times of discharge are people with stroke due the abrupt and sudden onset of disease with potential life-changing consequences.

2.2 STROKE

2.2.1 Etiology and epidemiology

Stroke is defined as *"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 of vascular origin"* (34). The definition differentiates stroke from transient ischemic attacks which have the same underlying causes as stroke but entail a temporary episode of similar symptoms. It further, distinguishes from stroke mimics that shares similar clinical signs and symptoms with stroke but have a non-vascular underlying cause. The most common stroke mimics are psychiatric disorders, seizures, toxic-metabolic syndromes, tumours, infections and migraine (35). Stroke is characterized as a neurological deficit due to a focal injury in the central nervous system caused by a vascular origin (36). The injury is caused by deficits in the vascular system with disturbances in blood flow to the brain tissue. The hinder to blood supply can be caused either by an occlusion of an artery leading to focal cerebral ischemia (ischemic stroke) or by a rupture and bleeding of an artery (haemorrhagic stroke) causing injury to the focal brain tissue (36, 37). Ischemic stroke constitutes 87% and haemorrhagic stroke 13% of all stroke cases (37).

The absolute number of strokes is increasing and affects approximately 14 million people globally each year (38), of which 5.5 million people die due to their stroke. However, the overall age-adjusted incidence has decreased during the last 20 years, which is especially visible in high-income countries. This is explained by better prevention and control of risk factors such as high blood pressure, tobacco use, and atrial fibrillation (39). In Sweden, the age-adjusted incidence and mortality have decreased by 40% during the last decades (40). The incidence rate is approximately 262 per 100 000 individuals/year (41). However, the incidence of first-time-ever stroke varies between the regions in Sweden, with a range from 211 per 100,000 up to 360 per 100,000 (41). About 25,500 people have a stroke each year in Sweden (42), and approximately 6,200 die due to stroke (40). Stroke often affects older people, the mean age in Sweden is 75 years, and 70% of those affected by stroke are over 70 years (40). Stroke affects slightly more men than women (41). However, as women live longer and the stroke incidence is higher in older age, women have more stroke events, more severe strokes, and poorer outcomes (43). Stroke is the second leading cause of death and disability worldwide (44, 45) and a large burden of cost (46). A significant proportion of survivors have remaining disability and impairments that cause limitations to activities and participation in everyday life (45).

2.2.2 Consequences of stroke

Stroke entails an abrupt onset and inevitably leads to a sudden change in life for the person and significant others. Stroke can render a large variety of signs and symptoms, both in a short- and long-term perspective (47, 48). Commonly reported impairments in conjunction with stroke are related to body functions such as neuromusculoskeletal, and movement functions typically related to weakness in one body-half, but also incontinence, dysphagia, and coordination deficits (47, 49). Reported non-motor impairments consist of aphasia, depression, and deterioration in cognitive functions such as attention, memory, concentration, and alertness. Sensory, perceptual, and visual impairments might also be present (47). Being affected by one or several of these impairments might have an impact on activities and participation in everyday life and an overall impact on the quality of life in people with stroke (48, 50). Common activity limitations are related to problem solving, speaking, changing and maintaining body position, arm and fine hand use, walking, toileting, bathing, dressing, eating, and housework activities such as washing and cleaning (51). Participation restrictions commonly affected are interpersonal interactions and recreation and leisure (50). The abrupt consequences of stroke can affect an individual's life as a whole, and the acute stage has been described to render a state of crisis and confusion, and feelings of uncertainty (52). Also common are experiences of discontinuity in body, function, and identity, together with a change in social status and roles within social relationships (53, 54).

Depending on the degree of disability, variation, and multitudes of impairments and emotional burden generated due to stroke, there is often a need for rehabilitation and support to recover and regain functions. Organization of stroke management varies, but as the period of recovery often proceeds over a longer time span, it will entail care transitions that need to be performed in ways that facilitate the rehabilitation and recovery process.

2.2.3 Acute stroke management

There is strong evidence that acute stroke care should be provided in stroke units at hospital, with benefits of increased survival rates, independency in activities in daily living (ADL), and an increased possibility to live at home after discharge (55). The procedures related to stroke unit care include the acute medical assessment, observation and treatment, early management and rehabilitation, and preparations for discharge (56). In Sweden, 90% of stroke patients are treated in stroke units (42). Alongside all the various facilities included in an emergency hospital, the acute stroke unit comprises a multidisciplinary team specialized in stroke management, including registered nurses, physicians, assistant nurses, physiotherapists, occupational therapists, speech and language therapist, dieticians, and medical social workers. During the past decades, much improvement has been made in the acute medical care of stroke, which has led to a decrease in length of hospital stay (LOS) (42, 57). The improved medical care can partly be attributed to the positive effect that endovascular thrombectomy and intravenous thrombolysis has made on reducing disability (58, 59). As the effects of treatment are dependent on time, considerable efforts have been devoted to implementing prehospital stroke care and triage systems to enable a faster assessment and processing; this reduced time from stroke onset to treatment has shown positive outcomes (60).

Despite these improvements in the acute stage, there is a lack of consensus on how to organize and provide follow-up care and rehabilitation after discharge from the stroke unit (61, 62). Further, more knowledge is necessary on how to provide care transitions to meet the needs of the individuals despite a complex and fragmented system (20). The abrupt onset of stroke, together with a short-compromised LOS, limits the possibility for preparation and participation in discharge-planning (63, 64). With a short length of inpatient care, there is often a need for a period of post-discharge rehabilitation, to recover and regain functions but also for the provision of psycho-social support (18).

2.2.4 Rehabilitation after stroke

Rehabilitation comprises the efforts to ensure that a person, based on the individual needs and preconditions, regains or maintains the best possible functional ability. Rehabilitation should contribute to, and create conditions for an independent life and active participation in society (65).

Stroke rehabilitation includes a complex set of processes with early, coordinated and multifaceted efforts provided from different professions and service providers (66) with the ultimate challenge of reducing impairments and promoting the activity and participation of people with stroke. This should be done by optimization of early outcomes, triage to subsequent care and rehabilitation, and individualized therapeutic care (67-69). This optimization has been surrounded by a discussion among researchers and clinicians about the need to rethink the decisions and selection of therapies and how the discharge policies early post-stroke are underpinned in order to facilitate the support and recovery of people with stroke (70).

Many people who suffer a stroke are in need of rehabilitation that often requires the expertise and support from the multidisciplinary team specialized in stroke management and recovery. The rehabilitation should entail a goal-oriented process that is preceded by an assessment based on the needs of the individual, followed by interventions aimed to fulfil the aims and goal, continuous follow-up, and reassessment and adjustment of goals and interventions (68). The recovery process can be divided into different phases: 1) the acute (0-7 days); 2) the early sub-acute (7 days - 3 months); 3) late sub-acute (3-6 months); and chronic (>6 months) (67).

As the consequences and needs after stroke vary between individuals, there are several commonly used trajectories in the organization of stroke care. In general, the most common way of organizing care and rehabilitation after stroke unit care includes: inpatient rehabilitation, either at hospital or a rehabilitation facility; nursing home care; or continued rehabilitation in primary care, either at home or at an outpatient clinic (71).

To be able to provide rehabilitation that starts early, is coordinated both regarding assessments, interventions and follow-up procedures, requires a healthcare system that is integrated and adapted to the needs of the individual. Despite this, there is lack of knowledge on how to provide continuous rehabilitation across the fragmented healthcare system, especially after the acute care and rehabilitation at hospital.

However, there is one health service model for people with stroke that there is evidence that when transitions and continued rehabilitation are well coordinated it can reduce deaths, long-term dependency in daily living and promote competence in self-management in contrast to other transition and rehabilitation models (72). Early supported discharge (ESD) consists of coordinated transitions where an interdisciplinary team, together with the patient, plans and coordinates the discharge and then continues the rehabilitation in the home environment (72, 73). Despite the evidence and a high priority in the national guidelines for stroke care the implementation of ESD has been difficult to achieve (73). One reason for this could be the difficulties in implementing the cross-organizational bridging that ESD contains (74) within complex and fragmented healthcare systems with difficulties providing coherent services across different organizations. Hence, more knowledge is needed on how new models of care and rehabilitation including cross-organizational bridging, can be adapted to fit existing healthcare systems and local contexts.

2.2.5 Stroke healthcare in Sweden

In Sweden, the regions are responsible for providing citizens with good quality healthcare and to promote the health of the entire population. The healthcare system is divided between the 21 regional councils and 290 municipalities. At macro level, the central government is responsible for establishing principles, guidelines, and steering the agenda with the help of law and ordinances. The Health and Medical Service Act regulates the responsibility of the regions; they are each responsible for organizing the healthcare within their county. Hence, despite uniform Swedish national guidelines (75), the stroke care and rehabilitation vary, both in terms of how it is organized but also in terms of quality and compliance with the national guidelines (76). Further, at meso level, the providers of care can be steered within both the public and

private sector but all on behalf of the tax-funded system. Healthcare in Sweden is publicly financed through taxes, with only a small sum representing co-payment. The annual out-of-pocket payment per person is limited to 1,100 Swedish kronor (about 110 EUR). All costs above that sum are publicly funded. All outpatient care for citizens above the age of 85 is publicly funded, and free of charge for the individual.

2.2.6 Stroke care and rehabilitation in Stockholm

In Region Stockholm, the largest healthcare region in Sweden, the immediate and acute care and rehabilitation after stroke are provided in an acute stroke unit at hospital. After the immediate medical treatment and rehabilitation at hospital, the discharge destination depends on the needs of the individual. The alternatives consist of either inpatient rehabilitation, outpatient rehabilitation at clinic, discharge to a care facility or nursing home, or the alternative, which is the focus of this thesis – the discharge and transition from hospital to home with continued rehabilitation in the home environment. In Stockholm, more than 50% of those who survive their stroke are discharged directly to home (42). This, in combination with a short hospital stay, increases the need for support after discharge to manage the health condition, recover, and regain functions.

In Region Stockholm, people with stroke that are discharged from hospital to home are offered a referral to rehabilitation in the home environment, provided by a multidisciplinary neurorehabilitation team in the primary care. This healthcare service model differs from ESD by only providing rehabilitation in the home environment without a supported discharge. The existing services provided in Stockholm do not align with recommended national guidelines for stroke care (75) and have not yet been evaluated. Further, there is a lack of knowledge about the procedures, healthcare utilization, and outcomes as well as on how transitions to continued rehabilitation in the home environment are experienced from a patient perspective.

2.2.7 Care transitions in stroke care and rehabilitation

Care transitions between healthcare providers after a stroke can render a burden on both patients and their significant others with the challenges of managing their own health and recovery (11), but also in navigating through the healthcare system (18). The experience of discharge and care transitions in stroke care have been investigated from the perspective of patients, significant others, and the healthcare professionals. The sudden change in life caused by stroke has been expressed both by people with stroke and their significant others (77, 78). While the transition to home has been described as a relief and a step towards normalization, it may also cause uncertainty and anxiety for the condition itself as well as issues around how to handle symptoms and undertake everyday activities (78, 79).

Patients highlight information and the preparation for discharge as an important part of their care (80). The content of information should focus on both the retrospective perspective of the stroke and hospitalization as well as on the future, i.e. self-management (80, 81), including medical management, how to manage the health condition, rehabilitation, and re-engaging with the community. People with stroke and their significant others have expressed a need for being

prepared what to expect coming home. For example what available support there were (80) or guidance how to navigate between different care providers in the community (18). Several studies have also highlighted the varying needs of information and support at different events and during the different phases of the care trajectory (82, 83). Studies have also reported the importance of having healthcare professionals "knowing the patient" and addressing the unique situation and needs of the patient and their significant others in order to provide the best support during different stages of the care continuum (80, 83).

A recent comprehensive review and meta-ethnography, including 51 studies with more than 500 people with stroke and informal caregivers' addressing the experiences of post-discharge, i.e. primary care and community healthcare services was conducted (84). The review highlights a perceived marginalization and abandonment of people with stroke, passivity in the relationship between patients/significant others and healthcare professionals and the changing needs after stroke of both patients and caregivers. The study indicates a need to involve patients and their significant others, and to understand their needs in order to provide services and support to meet the varying requirements of individuals (84).

2.2.8 Transitional care interventions for people with stroke

Attempts have been made to improve care transitions between hospital and the home for people with stroke (85). Overall, a large heterogeneity of interventions, outcomes measures, and context, together with small sample sizes makes comparisons hard to achieve and limits the opportunities to draw any far-reaching conclusions on best practice.

The use of case managers to coordinate care has been studied in relation to care transition in people with stroke but without any significant results in readmission rates or physical outcome compared to conventional care (86-89). Some study-specific significant results have been reported, such as improved stroke knowledge (86), mental quality of life (88), and decreased depression rates (88, 89). Case management interventions, in combination with stroke-related information, improved patient-reported physical health and activation, compared to usual care, or case management only (90).

Follow-up visits in connection to discharge from hospital, either conducted in the home, at clinic, and/or by telephone, have shown limited effects post-discharge. No effect on quality of life and satisfaction with care, and only minor effects on reduced anxiety levels (91) and increased self-management skills have been found in comparison with conventional care (92). Offering educational and support programs for patients and caregivers has been tested but without any differences in outcome in comparison to conventional care (93, 94).

Studies that use a combination of active components, such as follow-up visit or follow-up by telephone, information, education, and self-management programs, together with repetitive instead of one-time events, does, perhaps not surprisingly, seem to be more effective in relation to transitional care outcomes (23, 85, 95). This is supported by findings outside the area of stroke which indicate that the most effective transitional care interventions in improving quality, meeting the needs of patients and families, and reducing rehospitalization are the

multifaceted ones, i.e. those that use an individualized approach and integrate services across organizations (24, 62, 96-100). Interventions that commence at the hospital and continue after discharge seems to be more effective compared to interventions conducted after discharge (101). This might be strengthened by the inconclusive outcomes regarding individualised discharge planning at hospital (102). Further, interventions are suggested to include empowerment and self-management skills (96, 101).

One further challenge with transitional care interventions is the difficulties in implementing multicomponent interventions in clinical practice. Recently, one of the most promising studies targeting care transitions in stroke published results from their large pragmatic cluster-randomized controlled trial. The Comprehensive Post-Acute Stroke Services (COMPASS) intervention included a 48-hour telephone follow-up, with a subsequent clinical visit targeted between 7-14 days post discharge, together with structured individualized care plans addressing secondary prevention stroke education, recovery, and referral to community services (103). However, the study reported no significant effect of the intervention on functional status, mortality, or disability. The interesting findings were seen in implementation rates, as only 35% of participants received the full intervention, and 52% of the participating organizations did not pursue the program. This indicates that healthcare organizations are not prepared to modify their service delivery model to accommodate a comprehensive transitional care program based on current knowledge of patients' needs and best practice. The findings shed light on the importance of involving relevant stakeholders in the design of new interventions in order to incorporate the needs and preferences of the stakeholders into the intervention. Involving patients, their significant others, and healthcare professionals, with their knowledge and experience about the context, is recommended (4) and could help develop solutions that are adapted to the specific needs of individuals and the specific contexts, and hopefully facilitate implementation in clinical practice (96). Methods that facilitate stakeholder participation in the design and improvement of healthcare service are therefore preferable.

2.3 PARTICIPATORY DESIGN

In order for new care transitions to be based on the needs of the users, i.e. patients and significant others and be feasible to conduct in clinical practice and context, there is a need to involve the service users in methods that highlight the stakeholder experience and knowledge, and that facilitate the collaboration among them. A method that corresponds to these criteria is participatory design, often called co-design. Participatory design is *"a process of trying to explore, investigate and understand the needs and experiences of service users, as well as developing and supporting a mutual learning between multiple participants. The participants typically undertake the two principal roles of users and designers where the designers strive to learn the realities of the users' situation while the users strive to articulate their desired aims and learn appropriates means to obtain them"* (104). Participatory design has also been described as a research methodology and a way to understand knowledge by doing (105). Participatory design is co-interpreted and co-constructed by researchers and participants who will use the design. It assembles methods in an iterative process so that the emerging design is based on knowledge and an understanding of participants' needs (105).

Participatory design originates from the democratization of workplaces in Scandinavia in the 1970s (106). The methods of empowering and involving employees in joint decision-making regarding computer-based systems in workplaces made an impact on organization, working methods, and production tools (106). Two underlying features of participatory design have been described. The first one is related to democracy, power, and control, as those who are affected by design should also participate in the design process. The second one is outcome-related, meaning that the participation of users will contribute to the design of successful high-quality solutions. Participatory design has been described as a methodology of involving relevant stakeholders in the co-design of services (107). Hence, participatory design involves stakeholders who have experience, knowledge, and are affected by the design of the service in focus. Over the years, participatory design has extended its area of use. One of the areas that has applied participatory design is the healthcare sector (108). The intention is to involve relevant stakeholders and users of services, e.g. patients, significant others, and healthcare professionals in the development and improvement of new health services. This has been suggested to result in health services that better meet the needs of users, improve outcomes, and that are more likely to be implemented in practice (108). However, the use of co-design approaches have proved to be complex (109) and come with the risk of reinstating existing power dynamics, of not being able to redistribute power to end users, and of providing a tokenistic approach to participation (110-112).

Participation has been referred to as *"the ultimate transcendence of the users' role from being merely informants to being legitimate and acknowledged participants in the design process"* (104). Several frameworks and ways of classifying participation in a continuum of different levels have been developed (113-115). Perhaps the most well-known framework and most used in relation to participatory study design in healthcare is Arnstein's ladder of citizen participation (115). Arnstein intended citizen participation as a categorical term for citizen power. She argued that without the redistribution of power, participation is an "empty and frustrating process for the powerless". The framework is illustrated by a ladder with eight rungs, ranging from manipulation and non-participation to full citizen control (115). Arnstein's method of grading participation has been debated (116-118). The hierarchical approach has been said to miss out on the complexity of participation (119). Further, there is a call to lay focus on and more critically investigate how participatory design processes handle issues of power and participation as the literature to a large extent have failed to address these issues (120). Those who have addressed the issue have acknowledged that the use of participatory design provides no guarantee for equal partnership (121). Hence there is a need to generate more knowledge on how participation manifests itself within these complex processes in order to conduct processed based on equal participation.

2.4 CONCEPTUAL FRAMEWORKS

In order to understand the complexity of care transitions, this thesis uses three interconnected concepts, presented in Figure 1: 1) Person-centred care is used as a goal and a means to emphasize the importance of the person, and of individualisation when conducting care transitions; 2) integrated care and the Rainbow Model for Integrated Care are used to emphasize the need for links within and between organizational setting and levels and 3) complexity theory is used to elaborate on the complex dynamic of interrelated factors and actors within the care transitions.

2.4.1 Person-centred care

The concept of person-centred care (PCC) is used in this thesis to emphasize the importance of having the perspective of the person with stroke as a foundation to guide the actions made to ensure continuity and coordination during the care transition. PCC may be seen as an ethical and humanistic goal in itself (122, 123) and has been put high on the agenda of policy makers as a civil right and as a means to empower patients and improve health outcomes (124-126). PCC is recognised as a paradigm shift in contrast to the historical prevailing paternalistic model, where patients are seen as passive recipients of care (127).

The implications of PCC permeate the Swedish Health and Medical Services Act (128), and the Swedish Patient Act (129). The Swedish Agency for Health and Care Services Analysis has expressed the need for the healthcare system to move from a fragmented view of the patient to a holistic approach, from one-size-fits-all solutions to individualized solutions, and from patients as recipients of care to co-creators of healthcare (125). Further, the governmental inquiry initiated in 2017 “Coordinated development for good quality, local health care” submitted their final proposals in March 2020. The proposals for a structural healthcare reform highlight PCC, integration and the involvement of citizens in the design and development of healthcare as critical success factors towards a transformation of the healthcare system (127).

There is no unifying definition or consensus of PCC, and the concept has been provided with a plethora of definitions which take different starting points but often overlap (130). However the theoretical understanding and view of person-centred care within this thesis is inspired by the concepts of Pickers Foundation of PCC, the conceptual analysis of person-centredness in relation to rehabilitation made by Leplège and colleagues (122), and the work on person-centred care by Ekman and colleagues (123). The meaning of PCC in this thesis encompasses: 1) a holistic and biopsychosocial approach, focusing not only on the disease but on the person and the life situation as a whole (122) – this includes the view of the patient as an individual, a person with unique needs, values, preferences, and resources; 2) the patient’s role as an expert, active participant and cocreator in their own care and rehabilitation, instead of being a passive recipient (unless that is what they desire); 3) the forming of a partnership between patient and healthcare professionals that is based on mutual respect and dignity (123); 4) the patient narrative and dialogue with healthcare professionals should contribute to the formation of a partnership, a common understanding and shared-decision-making, which in turn could contribute to the individualization and tailoring of the care transitions, and enable a

responsiveness to the needs, values, and expectations of the individual (122, 123). The four elements of PCC in this thesis can be seen in Figure 1.

2.4.2 Integrated care and the Rainbow model

Since care transitions, in addition to patients and significant others, also include a multitude of interrelated healthcare professionals, which in turn are situated within different organizations and levels of care, this thesis also uses integrated care as a concept to try to conceptualize and understand the links between these different stakeholders.

Integrated care has been described as a means to achieve person-centred care (131). The concept of integrated and coordinated care is often used as an antipole to fragmented and episodic care (132). Integrated care is a multifaceted concept provided with different meaning, depending on the eye of the beholder and where s/he is located within the system. The concept has been defined from both a system (131) and process-based perspective (133). However, one definition that rhymes well with the PCC and participation, is the rather short but comprehensive definition by the coalition of health and social care charities in England, National Voices:

"My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes."(134)

This definition highlights' the outcome and experience of the end-user as the main focus to achieve integrated care (134). The definition is utilized by the Government of the United Kingdom as a frame for their integrated care strategies (135).

Due to the complexity of integrated care several taxonomies have been developed in order to help understand the concept. In this thesis, the Rainbow Model for Integrated Care was chosen to conceptualize and understand the different dimensions that influence care transitions. The Rainbow Model for Integrated Care was developed by Valentijn and colleagues to summarize, and encapsulate the concept of integrated care in a conceptual framework and taxonomy (136-138).

The conceptual framework, presented in Figure 1, aligns with the approach of the PCC as it proceeds from a person and population health-focused perspective. This view reflects a biopsychosocial perspective that is based on the preferences, needs, and values of the person and/or populations (138). The framework presents integrated care in several interrelated dimensions, viewed both from a vertical and horizontal perspective.

As seen in Figure 1, integration can be provided within different levels; the micro, meso and macro level (132). The focus of this thesis is on the micro and meso levels, although the macro level cannot be ignored as the levels are interrelated. To fulfil a full system integration the different levels, require both a horizontal integration across sectors and a vertical integration across the different levels in the model.

The micro level and clinical integration entail coherent methods and processes of care and rehabilitation that are provided in a collaborative and coordinated way to individuals. It contains to what extent clinical care and rehabilitation are coordinated between professionals and sectorial boundaries in a system. Clinical integration should have a PCC approach to provide services based on the needs of the individual. Another important aspect of clinical integration is patients' roles as a co-creator in the care and rehabilitation process; this entails the accountability of patients, to be the driver and coordinate their care whenever possible.

The meso level includes professional integration, which refers to the partnership between professionals both within and between organizations. The partnership is based on shared competences, roles, responsibilities, and accountability to provide a comprehensive continuum of care to a defined population (138). The meso level also consists of the organizational integration and different structures to deliver and provide services to fulfil the needs of the population. This entails how organizations are structured and brought together. Organizational integration requires a collective responsibility among organization's and service providers, along with the entire care continuum, to coordinate and align in the delivery of services based on the needs of individuals and populations.

The macro level includes the integration on a system level which entails a system holistic approach and focuses on the needs of the population to improve efficiency, quality of care, quality of life and satisfaction with services (138). At the macro level a combination of legislation, policies, and financing structures affect the possibility for integration to succeed.

There are different degrees and intensity in which organizational integration can be achieved, ranging from segregation to full integration (139, 140). Segregation refers to a state where every organization is autonomous and functions independently. Contrary to segregation, there is full integration, where the resources of different organizations are pooled to create a new organization to provide services based on the needs of a specific group of people. Between these two contrasts is the degree of linkages and coordination. Linkage is the connection between separate organizational units by means of referral of patients, communication, and the clarity between units and professions about who is responsible for what type of activity. Coordination is a more structured degree of integration. For the most part, it involves a network of different organizational units by integrating services through an informational exchange, as for example by conducting care transitions within chains of care. Finally, there is the full-service integration, where new organizations can be created with the development of services based on the needs of a specific patient group (140).

To be able to support the different levels and dimensions of integration, both functional and normative integration are described as significant contributors. Functional integration refers to the support functions and activities built around the primary process of service delivery. It could, for example, mean the financing, management, policies, guidelines, and informational systems such as an integrated medical record. Normative integration refers to the coherency between actors that is formed by shared values, culture and goals across individuals, professionals, and organizations (137).

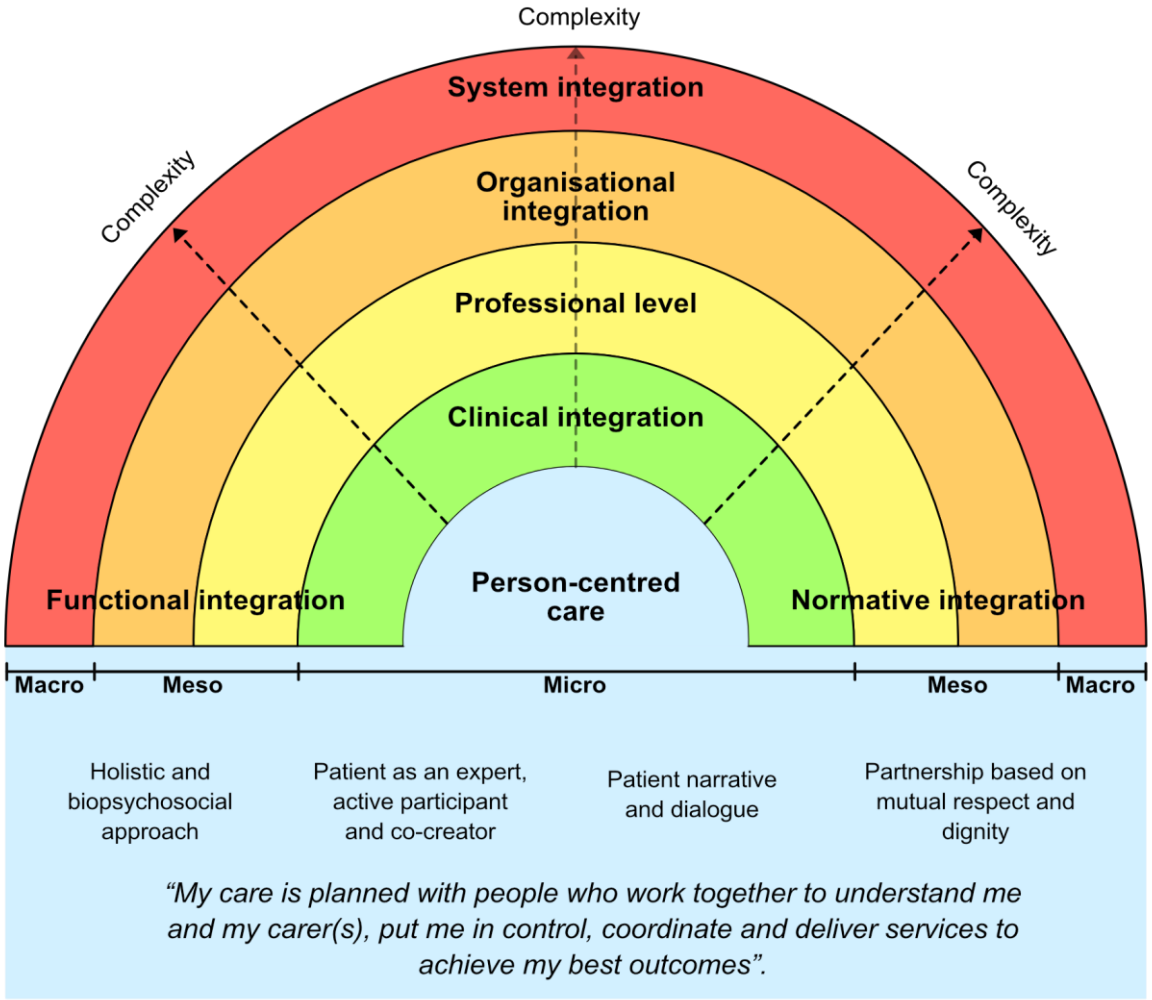

Figure 1. The Rainbow Model of Integrated Care with the incorporation of elements of Person-centred care, and complexity used in this thesis. Modified from Valentijn et al (138).

2.5 THEORETICAL FRAMEWORK

2.5.1 Complexity theory

Complexity theory is used within this thesis, as PCC and integrated care can be seen as complex concepts to be applied in a complex system for people with complex needs, and by people who operate with complexity on a daily basis (professionals). For example, the way a person is affected by illness relates to the type of illness/disease and biological, psychological and socio-environmental factors. In addition, the behaviour of a person is influenced by previous experiences, beliefs, expectations, the environment, social relationships and how these factors in turn are related to the wider, social, political, and cultural system. All of these factors and systems are dynamic and interrelated, meaning that change in one part might lead to change in another part, or the person's behaviour as a whole (141).

Complexity theory has gained increased attention from researchers and organization's as healthcare is more frequently recognized as a complex system (142). Complexity is described as *"a dynamic and constantly emerging set of processes and objects that not only interact with*

each other but come to be defined by those interactions" (143). Healthcare is facing several challenges when it comes to conducting complex interventions and the provision of person-centred and integrated care in complex systems. Complexity theory has been used to try to explore and understand healthcare, from a clinical, organizational, and research perspective (144-147). For a time, healthcare has been influenced by reductionist thinking. As a response, complexity theory has been suggested as a paradigm shift, through acknowledging complexity and uncertainty as means to unravel, understand and improve healthcare (142). Complexity theory questions the reductionist view of healthcare as a mechanical unit that can be dismantled and understood in fragments. Instead, complexity theory focuses on the relationships and interconnections between the components and agents of a system. Hence, the theory is suitable for exploring and understanding care transitions. Using complexity theory to study healthcare has been said to provide a deeper understanding than using only the traditional positivistic approaches, which study linear relationships and strive for cause and effect explanations (143, 148).

Complexity theory, interchangeably used with the term complex adaptive systems (CAS), is a "collective set of individual agents with freedom to act in ways that are not totally predictable, and whose actions are interconnected so that the action of one part changes the context for other agents" (142). CAS is characterized by numerous *agents* that interact *dynamically* and in a *non-linear* fashion (141, 142, 149). The dynamic and non-linearity of the system contributes to its *unpredictability*. The *interactions* and *connectivity* between the agents within the system is perhaps the most important part of CAS, as it is the fundamental reason for how the system behaves. CAS also evolves or devolves through *feedback-loops* that contributes to adjustments in the behaviour of the agents and system. The behaviour, outcome, and pattern of the interactions between agents is referred to as the *emergence*. CAS is not an autonomous system; instead CAS are *embedded* in a wider context of *nested systems*. CAS therefore need to be seen in the context of their environment, and that they will act within an overall system with several CAS that relate and interact with each other. Another characteristic of CAS is the fuzzy and permeable boundaries. Finally, agents and systems *co-evolve* and *self-organise* to best fit with context and environment (145, 149).

3 RATIONALE

Within the context of a fragmented healthcare system, uncoordinated care transitions are known to be a risk of substantial burden for patients and significant others with risk of adverse events, rehospitalisation and dissatisfaction with services. Further, patients report insufficient information and support to manage their health condition after discharge.

Despite a multitude of research conducted on care transitions there is a large heterogeneity regarding studied perspectives, populations, and contexts. The care transition process, which is the focus of the present thesis, has not been studied before. Hence, there is a lack of knowledge about the patient-related outcomes and healthcare utilization in connection to this transition. There is also lack of knowledge on how the care transition is experienced from the perspective of patients, their significant others, or healthcare professionals. It is therefore important to explore and understand the care transition process between hospital and the home from the perspective of all these involved stakeholders in order to guide the future development of care transitions.

Due to the sudden onset and possible life-changing consequences, people with stroke and their significant others are a particularly vulnerable group in connection to care transitions as they often lack experience of the illness itself, the sequential procedures, and also the healthcare system as a whole. Therefore, it is important to understand how different factors impact the experience of the care transition from hospital to home in people with stroke and significant others.

Participatory study designs are becoming an increasingly used methodology within the development and improvement of healthcare. Despite reports on problems with power imbalances and the risk of the method being used in a tokenistic manner, little is known on how the core of the methodology, participation is manifested. Thus, there is a need to increase our knowledge on how participation manifests itself within these complex processes involving patients, significant others and healthcare professionals in the design of healthcare improvement.

4 AIMS

The overall aim of this thesis was to generate knowledge about and describe the care transition process from hospital to the home from the perspective of patients, significant others and healthcare professionals. A further aim was to investigate the concept of participation in a co-design of a person-centred transition.

The specific aims of the papers:

I To explore and describe the healthcare utilization during one year and health outcomes at 3 and 12 months, of people with stroke receiving a care transition to subsequent rehabilitation in the home and their significant others.

II To explore the perceived quality of the care transition and factors associated with perceived low quality in people with stroke.

III To explore the transition process between hospital and the home with continued rehabilitation in the home environment from the perspective of people with stroke, significant others, and healthcare professionals.

IV To investigate how the concept of participation manifests itself including the enablers and barriers in a co-design process that involves people with stroke, significant others, and healthcare professionals.

5 METHODS

5.1 STUDY DESIGN

This thesis consists of four different papers. Paper I was a prospective observational study and Paper II was an observational/cross-sectional design, based on the same prospective observational data collection. Papers III and IV used a qualitative study design. A summary of the included papers is shown in Table 1.

Table 1. Overview of study designs and methods of Papers I-IV.

Paper	**I**	**II**	**III**	**IV**
Study design	Prospective observational study	Observational/Cross-sectional study	Qualitative study	Qualitative study
Data collection	Medical records, questionnaires, performance-based tests and register-based data	Medical records and questionnaires	Focus groups, semi-structured interviews and interviews in dyads	Observations, field-notes, reflections, interviews and questionnaires
Time period	April 2016-February 2019	April 2016-February 2018	June 2016-January 2018	November 2019-January 2020
Participants	People with stroke, n=190 and significant others, n=89.	People with stroke and stroke mimic, n=189.	People with stroke, significant others, and healthcare professionals. Total n=71.	People with stroke, significant other, healthcare professionals, and facilitator. Total n=15.
Data analysis	Descriptive statistics, analysis of variance, univariable and multivariable linear and logistic regression	Descriptive statistics, parametric tests, analysis of variance, univariable and multivariable linear and logistic regression.	Constructivist grounded theory	Inductive content analysis

5.2 CONTEXT

All papers in this thesis were conducted in the Region Stockholm, Sweden focusing on the care transition between a stroke unit or geriatric stroke ward and continued rehabilitation in the home environment, as depicted in Figure 2. The participants were recruited from four inpatient units, either a stroke unit or geriatric unit, at two hospitals: Danderyd Hospital and Karolinska University Hospital. For patients with a stroke in need of continued rehabilitation at home, a referral-based care transition from hospital to continued rehabilitation in the home environment is provided. Responsible for the subsequent rehabilitation in the home environment is a multidisciplinary neurorehabilitation team, situated within primary care. The care transition is initiated by an electronic referral in which the hospital notifies the neurorehabilitation team about the patient and of the discharge. The team is obliged to initiate contact with the patient within 48 hours from discharge.

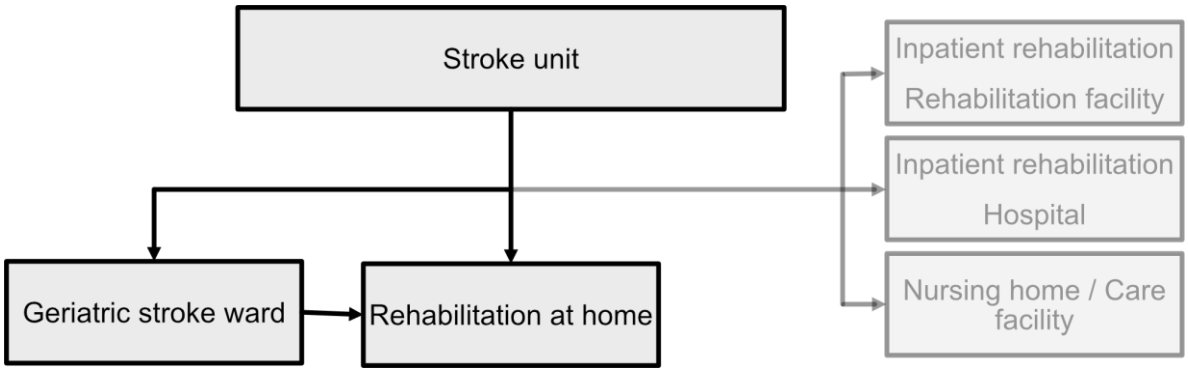

Figure 2. Potential discharge destinations after the stroke unit. The discharge destination in the focus of the present thesis is marked in bold.

5.3 PARTICIPANTS AND PROCEDURES

5.3.1 Paper I and II

For Papers I and II, all patients with a suspected stroke diagnosis who were referred to a neurorehabilitation team were eligible for inclusion. A stroke diagnosis accounted for the diagnosis of ischemic stroke and intracerebral haemorrhage and was determined by the responsible physician at the ward based on the International Classification of Diseases (ICD-10). However, due to occasional difficulties to diagnose, and due to delays in confirming the diagnosis before discharge from the hospital, some people were discharged with a stroke diagnosis that was later changed. These individuals, referred to as stroke mimic, answered the questionnaire on perceived quality of the care transition and were included in Paper II but excluded from Paper I.

The health professionals at the hospital gave oral and written information about the study. For patients who agreed to participate a written informed consent was obtained. In total, 206 patients agreed to participate in the study, of whom 15 had a stroke mimic diagnosis. Significant others were identified by the patient with stroke and were invited to participate They received written information about the study and a written informed consent was obtained. In total, 89 significant others agreed to participate.

5.3.2 Paper III

People with stroke and significant others in Paper I and II were invited to participate based on purposive and theoretical sampling. In addition, healthcare personnel who were directly involved in or had valuable insight about the care transition process under study were invited to participate. All participants received oral and written information about the study and a written informed consent was obtained. In total, 71 participants were included: 16 people with stroke, 7 significant others, and 48 healthcare professionals.

5.3.3 Paper IV

People who had had a stroke, significant others of people who had had a stroke, and healthcare professionals who participated in a participatory design study, a co-design process with the aim to develop a new care transition between hospital and continued rehabilitation in the home environment for people with stroke, were invited to participate.

The recruitment of patients and significant others to the participatory design study was done through advertising information leaflets among two patient organizations: the Swedish Stroke Association (150) and Neuro Sweden (151). Criteria for inclusion were:

a) had a stroke and experienced the referral-based care transition from hospital to continued rehabilitatation in the home in the Stockholm Region, or
b) were a significant other to a person meeting the above mentioned criteria
c) were able to participate in all five workshops
d) were able to communicate in Swedish

Healthcare professionals from the stroke unit and geriatric ward at Danderyd Hospital and two corresponding neurorehabilitation units were invited to participate. All participants received oral and written information about the study and a written informed consent was obtained before inclusion in the study. The employers of the participating patients, their significant others, and healthcare professionals received compensation for the time they were absent from their workplace. A total of three patients who had experienced a stroke, one significant other, nine healthcare professionals, and one facilitator participated in the study.

The co-design process was conducted using a design thinking methodology and approach (152). Design thinking has been described as containing five elements: 1) User centred focus, which seeks to understand and empathize with the users and let this guide the work and further also assumes the involvement of the users during the different steps of the process; 2) Problem framing, containing an openness to the unexpected and being comfortable with complexity and ambiguity, and the challenging and reframing of the problem in the attempt to explore and synthesize research insights; 3) Visualization, which represents the way of working through visualization and aims to stimulate thinking by making ideas and insights visual; 4) Experimentation, which represents an energetic, curious, and creative mindset together with a continuous iterative way of working with early prototypes to learn and make progress; and 5) Diversity, which refers to a holistic perspective, seeking to include diverse perspectives,

backgrounds, and personalities when creating teams that will collaborate during the co-design process (152).

The co-design process, shown in Figure 3, contained five half-day workshops, held at Openlab, a design-lab and challenge-driven innovation community in Stockholm. The workshops were moderated by a facilitator from Openlab, trained in design thinking and the double-diamond model that was used as a framework during the workshop series (152, 153). The participants of the workshop series were divided into three groups of four to five participants each, in order to facilitate creativity and participation. The groups were composed with the intention to, as far as possible, generate a variation in patients/significant others, professionals and allocation within the care trajectory.

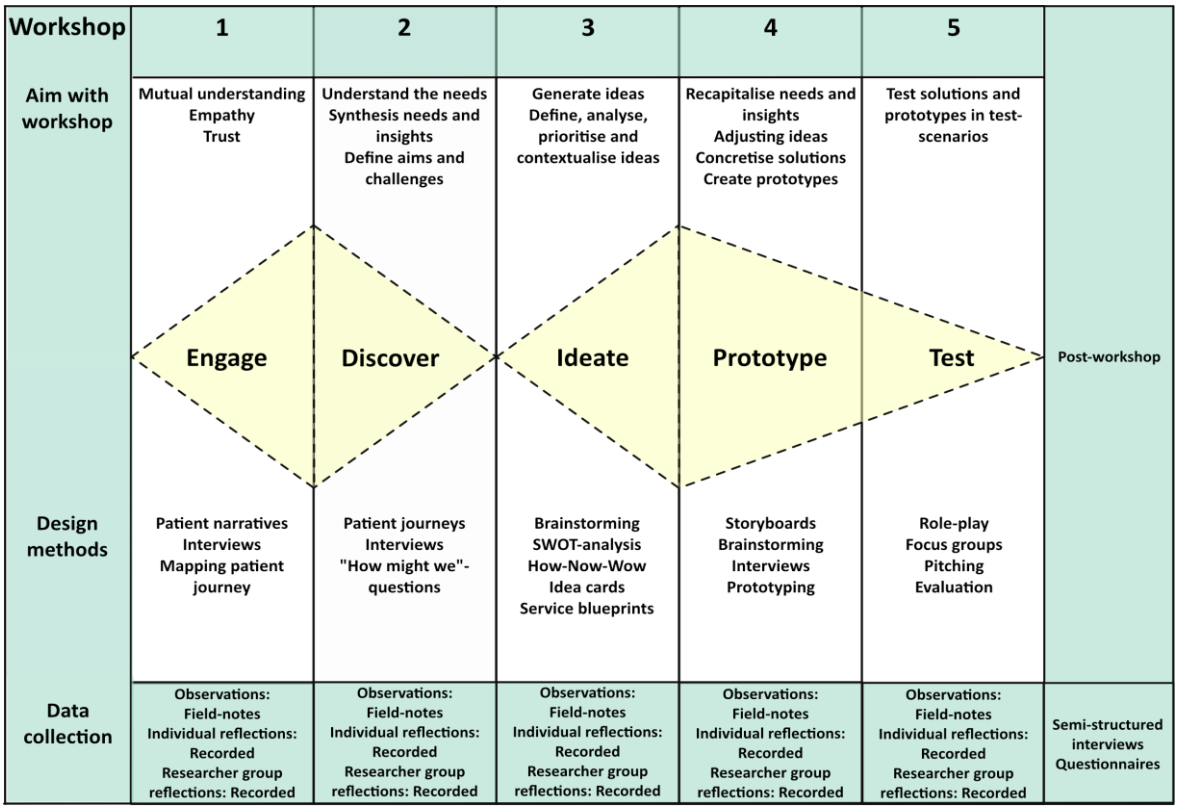

Figure 3. Schematic overview of the co-design process with aims, design methods and type of data collection for each workshop.

5.4 DATA COLLECTION

5.4.1 Papers I and II

The participants rated their perceived recovery from stroke before being discharged from hospital. The participants' characteristics, length of stay at hospital, disease-related data, and functioning at the time of discharge were collected from the medical records. One-week post discharge the perceived quality of the care transitions was collected by letter. At 3 and 12 months post-discharge, data were collected face-to-face by standardized questionnaires and performance-based tests during visits either in the participants' home, at the outpatient clinic at hospital, or at another convenient place chosen by the participants. See Table 2 for an overview of the data collected, instruments and the time of collection.

Table 2. Overview of collected data, instruments/source and time collected in Papers I and II.

Data	Instrument/Source	Time of data collection				Paper	
		Baseline	1 week	3 months	12 months	I	II
People with stroke							
Patient characteristics							
Age	Medical record	•				•	•
Sex	Medical record	•				•	•
Cohabiting	Medical record	•				•	•
Education level	Questionnaire			•		•	•
Work status	Medical record	•				•	•
Home care pre-stroke	Medical record	•				•	•
Perceived quality							
Perceived quality of the care transition	Care Transition Measure		•				•
Disease-related data							
Type of stroke	Medical record	•				•	•
Aphasia	Medical record	•				•	•
Reperfusion therapy	Medical record	•				•	•
Stroke severity	Barthel Index	•		•	•	•	•
Comorbidity	Charlson Index	•				•	•
Perceived impact of stroke	Stroke Impact Scale	•		•	•	•	
Functioning							
Activities of daily living	Katz IADL, PADL Barthel Index	•		•	•	•	•
Walking ability		•		•	•	•	•
Perceived recovery from stroke	SIS Recovery	•		•	•	•	•
Social and lifestyle activities	Frenchay Activities Index			•	•	•	
Cognition	Montreal Cognitive Assessment				•	•	
Disability	Modified Rankin Scale			•	•	•	
Healthcare utilization							
Length of stay	Medical records	•				•	•
Healthcare utilization	Computerized register	→	→	→	→	•	
Significant others							
Characteristics, burden							
Age	Questionnaire			•	•	•	
Sex	Questionnaire			•	•	•	
Relation	Questionnaire			•	•	•	
Cohabiting	Questionnaire			•	•	•	
Caregiver burden	Caregiver Burden Scale			•	•	•	

PADL: Personal activities of daily living, IADL: Instrumental activities of daily living, SIS: Stroke Impact Scale

5.4.1.1 Use of healthcare services

Data on the use of healthcare services were obtained from the Region Stockholm computerized register. The register contains all healthcare contact and hospitalizations carried out within the publicly tax-funded healthcare services within the Stockholm Region. We obtained data from a period of 12 months post-discharge stroke onset. The information about outpatient contacts contained information about level of care, type of visit, provider of service, professional conducting the visit, and location of visit. The inpatient care episodes contained information about hospitalizations, length of stay (LOS), reason/diagnosis of hospitalization, and place of hospitalization.

5.4.1.2 Measurements

In Papers I and II, several types of measurements were used to collect data.

Perceived quality of care transitions

The Care Transition Measure (CTM-15) was used to assess the perceived quality of care transitions (154, 155) in which four areas of importance for quality care transitions are identified: information transfer, preparation for what to expect next, support for self-management, and encouragement to assert preferences (156). The CTM-15 is a unidimensional scale assessing perceived quality in care transitions with a 15-item questionnaire. (3, 154, 155, 157). The affirmative stated items are rated on a four-point Likert scale ranging 1 = “strongly disagree”, 2 =“disagree”, 3 =“agree” and 4 = “strongly agree” (157). For each item an additional response of “don’t know/not applicable” is available. The items are summarised to a total score and computed as the total sum divided by number of answered items, minus 1, divided by 3, and multiplied by 100 in order to get a total score of 0-100 for each respondent. The total score reflects the overall perceived quality of the care transition, with lower scores indicating a poor-quality care transition, and higher scores indicating a higher quality care transition.

Disease-related data

Stroke severity was categorized based on the Barthel Index (BI) (158). The BI measures to what extent an individual can function independently and perform activities in activities in daily living (ADL). The index measures 10 personal care and mobility activities i.e. feeding, bathing, grooming, dressing, bowel control, bladder control, toileting, transfer from chair, and stair climbing. Each item scores 0, 5 or 10 points, generating a total sum between 0-100, where a higher score indicates a higher degree of independence. The BI is commonly used in stroke trials (159-161) and is considered reliable (162) and valid in people with stroke (160, 163). In Papers I and II the BI was categorised as: very mild stroke (95-100), mild stroke (50-94) and moderate/severe stroke (0-49) (164). The BI at time of discharge was collected from medical records and at 3 and 12 months assessed during face-to-face visits.

Comorbidity was categorised using the Charlson Comorbidity Index (CCI) (165). The index is calculated by a weighted score (1-6) of 19 pre-defined conditions related to their association with one-year mortality (165). The CCI was calculated on the basis of ICD-10 diagnosis that was collected from the medical records. In both Papers I and II, the CCI was categorised as no comorbidity (scores 0), low comorbidity (scores 1-2), and moderate/severe comorbidity (scores >2).

Functioning

Perceived impact of stroke was assessed with the Stroke Impact Scale 3.0 (SIS) at the home visit at 3 and 12 months (166, 167). SIS entails a total of 59 items divided in eigth domains: strength (4 items); memory (7 items); emotions (9 items); communication (7 items); ADL/IADL (10 items); mobility (9 items); hand function (5 items); and participation (8 items). Each item is scored on a Likert-scale ranging from 1-5. The total score of each domain is transformed to generate a total sum between 0-100, with higher scores indicating less impact from stroke (166). The SIS is considered to have good reliability and validity in the sub-acute stroke population and recommended as an appropriate tool to tailor rehabilitation interventions and in following progress in people with stroke (168, 169).

Perceived recovery from stroke was collected before discharge, and at 3 and 12 months. The participants rated their perceived recovery from stroke on a sub-scale of the Stroke Impact Scale (167). The sub-scale entails a visual analogue scale (VAS) from 0-100, where 0 indicates "not recovered at all" and 100 indicates fully recovered after stroke. The self-rated recovery sub-scale has shown good responsiveness and an ability to detect changes between 3- and 12-months post stroke (170).

Personal ADL was assessed by the KATZ Personal-ADL Index (PADL) (171, 172), and collected from medical records before discharge, and at face-to-face visits at 3 and 12 months. The index consists of six activities: feeding, bathing, dressing, continence, toileting and transfer, each scoring 1 if the person is independent and 0 if the person is dependent. A total score from 0 to 6 is calculated. A score of ≤ 5 was categorised as dependent in PADL and >5 as independent. The KATZ PADL is one of the most widely used ADL instruments (173) and its reliability and validity is considered satisfactory in the stroke population (174)

Instrumental ADL was assessed using the KATZ Instrumental ADL Index (IADL) (171, 172) and collected during face-to-face interviews at 3 and 12 months. The index consists of four items: cooking, cleaning, transportation and shopping. Each item is scored 0 if the person is dependent and 1 if independent. A total score of 0 to 4 is calculated. The index is a commonly used measure of ADL and its reliability and validity have been proven satisfactory in the stroke population (171, 175).

Walking ability was collected from medical records at time of discharge and during face-to-face interviews at 3 and 12 months. Walking ability was categorised as unable to walk/walks with assistance and support, walks with walking aid, or walks without aid or support.

The frequency of social and lifestyle activities was assessed with the Frenchay Activity Index (FAI) (176, 177). The FAI was collected during face-to-face-interviews at 3 and 12 months. The FAI consists of 15 items each scoring 0-3 regarding how frequently each activity is performed. The different activities can be divided into three different domains: domestic chores, leisure/work and outdoor activities (177). The index is summarised to a score ranging from 0-45, and a lower total score indicates more severe participation restrictions. The FAI has been validated and recommended for use in the stroke population (178).

The Montreal Cognitive Assessment Scale (MoCA) was used to assess and identify mild cognitive impairment at 12 months (179, 180). The MoCA consists of eight domains: short time/work memory, visuospatial abilities, executive functions, attention, concentration, language, and orientation to time. A total score ranging from 0-30 is calculated with lower scores indicating more severe cognitive impairment.

The modified Rankin Scale (mRS) was used to assess the degree of disability caused by stroke during face-to-face visits at 3 and 12 months (181). The mRS was scored on a six-point Likert scale ranging from 0 to 5 categorised as: 0) no symptoms; 1) no significant disability despite symptoms; 2) slight disability; 3) moderate disability; 4) moderate/severe disability; and 5) severe disability. The mRS has been claimed to be reliable if assessed with a structured interview (182, 183) and valid and preferable to use for people with stroke (184).

Burden of significant others

The Caregiver burden scale was used to assess the subjective burden of significant others at 3 and 12 months (185). The scale consists of 22 items, scored on a 4-point Likert scale (1: No, not at all; 2: No, barely; 3: Yes, to a certain extent; 4: Yes, to a great extent/often) related to the significant other's health, psychological well-being, relations, social network, physical workload, and environmental aspects. The total score ranges from 22-88 points, with higher scores indicating a higher burden for the significant other. The reliability and validity of the scale has been found sufficient for caregivers of people with stroke and dementia (185).

5.4.2 Paper III

Data was collected through focus groups, individual semi-structured interviews, and semi-structured interviews in dyads. The interview guide aimed at generating a description of the discharge and transition process from hospital to the home and capturing the views and perspectives of the participants. To begin with a purposive sampling was used to generate as many perspectives of the care transition process as possible. The data collection and data analysis were done concurrently, and as the analysis started to generate emerging categories, theoretical sampling was used to generate data based on the emerging categories and theory and fulfil theoretical saturation. Further the ongoing analysis also formed the interview guide as analytic directions and theories emerged. In total, 38 different interviews were conducted. Of these, 10 were focus groups; 24 semi-structured individual interviews; and 4 interviews in dyads. Individual interviews and interviews in dyads were conducted either in the participant's home, at the neurology clinic, or at another convenient place chosen by the participant. The

focus group interviews were conducted at the hospital or the neurorehabilitation unit. Focus groups and interviews were digitally recorded and transcribed verbatim.

5.4.3 Paper IV

During the co-design process data were collected through observational methods, field-notes, and recorded reflections. Further, after the last workshop, the participants were invited to participate in a semi-structured interview or answer open-ended questions in an electronic questionnaire about their experience of the co-design process. Data collection methods during the co-design process can be seen in Figure 3.

Observational methods

Three researchers per workshop were responsible for observing one group each and taking field-notes during the workshops. The field notes were transcribed verbatim.

When tasks were performed involving all participants as a whole, the researchers observed the activity in the whole room. The observations were guided by the aim and research questions of the study, shown in Table 3. For each workshop a protocol was created including the research questions and the agenda with the elements on the agenda numbered to be able relate the field notes to different elements and methods conducted during the workshop. The field notes were transcribed verbatim and were on average 1700 words.

Field notes

The three researchers and the facilitator each recorded an individual reflection about the completed workshop. After the individual reflections the researcher held a recorded group reflection on their experiences of the completed workshop. The recorded reflections were transcribed verbatim.

Semi-structured interviews and questionnaires

Individual semi-structured interviews were conducted with patients, the significant others, the facilitator, and one healthcare professional from each group with the intention to seek a variation in profession and allocation within the care trajectory. The questions and focus of the interview guide are shown in Table 3. Probes and follow-up questions were used to get a deeper understanding of the participants' views and perspectives of the process. The interviews were recorded and transcribed verbatim. One of the interviewees did not want to be audio recorded, so instead notes were taken. All participants who were not invited to participate in an individual interview were sent an electronic questionnaire with open-ended questions, with the same focus and questions as the interviews, as shown in Table 3.

Table 3. The guiding questions of observations, interviews and questionnaires in Paper IV that informed the data collection.

Observation	Interviews/Questionnaire
What enables and hinders participation within a co-design process?	Can you describe how it was to participate in these workshops?
Are all participants in the group included in the discussion and is everyone's opinion requested?	How do you think the collaboration has worked with your group?
Does everyone in the group have equal opportunities to communicate and speak their mind?	How did you experience the possibility to put forward what was important to you?
Do participants communicate most with their peers or with other participants?	To what extent do you think you have been listened to?
Is any perspective given priority? If so, on what grounds?	In what way was it difficult/easy to express what you wanted to say?
	How do you think the arrangement and content of the process have affected your ability to express your views?
	How has it been for you to understand the perspective of the others?
	What facilitated or hindered everyone's perspective from emerging?
	How do you think the arrangement could have been made differently to enable everyone's participation on equal terms?

5.5 DATA ANALYSES

Overall, for all papers, descriptive statistics were used to present quantitative data. Continuous and normally distributed data were described with mean, standard deviations and minimum and maximal values. Normality plots, values for skewness and kurtosis and the Shapiro Wilks test were used to test normal distribution. For skewed data the median, interquartile range (IQR) and minimum and maximum values were used. For ordinal and categorical data, the frequencies and proportions were used to present data.

5.5.1 Paper I

To describe different patterns of healthcare utilization after a referral-based care transition, four groups were created based on the number of visits by the neurorehabilitation team: Group 1 had zero visits; group 2, 1-3 visits; group 3, 4-15 visits in the first two quarters; and group 4, ≥17 visits over more than two quarters. Analyses were made for each group independently and on the whole sample. Outpatient care was categorised as total outpatient contacts: specialist care, emergency visits, primary care, home care, rehabilitation with neurorehabilitation team, other type of rehabilitation, and other outpatient contacts. Further, the outpatient contacts were categorised based on professions: assistant nurse, physician, district nurse, registered nurse, dietician, physiotherapist, occupational therapist, speech and language therapist, medical social worker, psychologist and other type of contacts.

Inpatient care was categorised as initial hospitalization: length of stay; recurrent hospitalizations: number of hospitalizations, length of stay, the associated diagnosis, and number of days passed since discharge post stroke. Healthcare utilization was described with median, IQR, and minimum and maximal values due to the skewed data.

In order to explore the associations between total visits with neurorehabilitation team and other outpatient contacts, linear multivariable regression models were created. As both dependent variables – the total visits with the neurorehabilitation team and the total outpatient contacts, except visits with the neurorehabilitation team – were skewed, they were log-transformed. The independent variables were age, sex, educational level, civil status, home care services before stroke, stroke severity, comorbidity (the CCI was used as a continuous scale), aphasia, reperfusion therapy, LOS, ambulation and perceived recovery.

5.5.2 Paper II

The CTM-15 was analysed using both an aggregated total score and the proportions of each item dichotomised into either Disagree (scores 1 and 2) or Agree (scores 3-4). To explore potential differences in patients' characteristics with regard to the mean total score of the CTM-15, the independent sample t-test was used for dichotomized variables and one-way analysis of variance (ANOVA) and the Tukey post hoc test for variables with more than two groups. To investigate differences in characteristics between participants agreeing or disagreeing with the items of the CTM-15, univariable logistic regression analyses were performed. Further, in order to explore associations between low perceived quality (total score of CTM-15) and the independent variables, linear multivariable regression models were created. The independent variables, i.e. age, sex, educational level, civil status, home care services before stroke, stroke severity, comorbidity, aphasia, reperfusion therapy, LOS, ambulation, and perceived recovery were chosen due to an interest in exploring whether clinical characteristics had any influence on the perceived quality of care transitions.

5.5.3 Paper III

In Paper III, the analysis was directed by constructivist grounded theory. The analysis followed four analytical steps: initial, focused, axial and theoretical coding as described by Charmaz (186). The analysis was an iterative process and constant comparison was used throughout by comparing data, within and between interviews for similarities and differences, but also to confirm and check data and form data collection. Memo-writing was used to compile thoughts and ideas in relation to emerging theory.

Initial coding was conducted using line-by-line coding. Each line was assigned a short code or phrase in attempt to capture the meaning and actions of the text, and to stay close to the data, for example: "*attempts made to communicate*".

After line-by-line coding, a condensation and conceptualisation of the existing codes took place in order to explain larger segments of data, for example "*Desire for dialogue*". The focused coding entailed synthetization of the most significant and sometimes frequent codes making

most sense in relation to the analytical direction. The categorisation was then used to compare to larger segments of data and form the continued data collection.

In order to break down categories and understand their properties and dimensions, axial coding was used. This was a way to look for patterns between categories and understand and describe relationships between data. Sometimes this step rendered a recategorization of categories.

As a next step, a process of theoretical coding took place. In this process a conceptualization of categories and a search for relationships between categories was conducted, emerging in a core category.

5.5.4 Paper IV

In Paper IV, the analysis was conducted using an inductive content analysis (187). The different data sources (units of analysis) were analysed separately. For each data source, the unit of analysis was divided into meaning units comprising words, sentences, or paragraphs related to each other. Thereafter, the meaning units were condensed without interpretation in order to abstract and preserve the core meaning of the unit. The next step included the labelling of each meaning unit with a code through the interpretation of the underlying meaning. After coding the meaning units, a clustering of the codes with similar meaning into subcategories was conducted. At this point, the subcategories of the different data sources were compiled and clustered through a comparison back and forth between data. As a final step, the subcategories were analysed by their latent content in order to cluster and abstract subcategories to the formation of categories.

5.6 ETHICS

All studies and procedures within the thesis were conducted according to the ethical principles of the Declaration of Helsinki (188). All participants received oral and written information about the studies and had to give their written consent before inclusion. Ethical approval was obtained from the regional ethical committee in Stockholm, registration number 2015/1923-32/2 (Papers I, II, III), with two amendments, registration number 2016/2560-3Z respectively 2017/1130-32 (Paper I), and registration number 2019-04209 (Paper IV).

6 FINDINGS

This section summarizes the findings from the included papers of the present thesis. Paper I describes the healthcare utilization and outcomes of people with stroke and the burden of care of significant others; Paper II describes the perceived quality of care transitions and associated characteristics; Paper III describes the perspectives of people with stroke, significant others, and healthcare professionals on the care transitions between hospital and the home; and Paper IV explores how participation manifests itself, including the enablers and barriers to participation within a co-design process involving people with stroke, significant others and healthcare professionals. Details of the results can be found in the separate papers. Flowchart of the included papers and participants can be seen in Figure 4. Baseline characteristics of the participants in papers I-IV are outlined in Table 4.

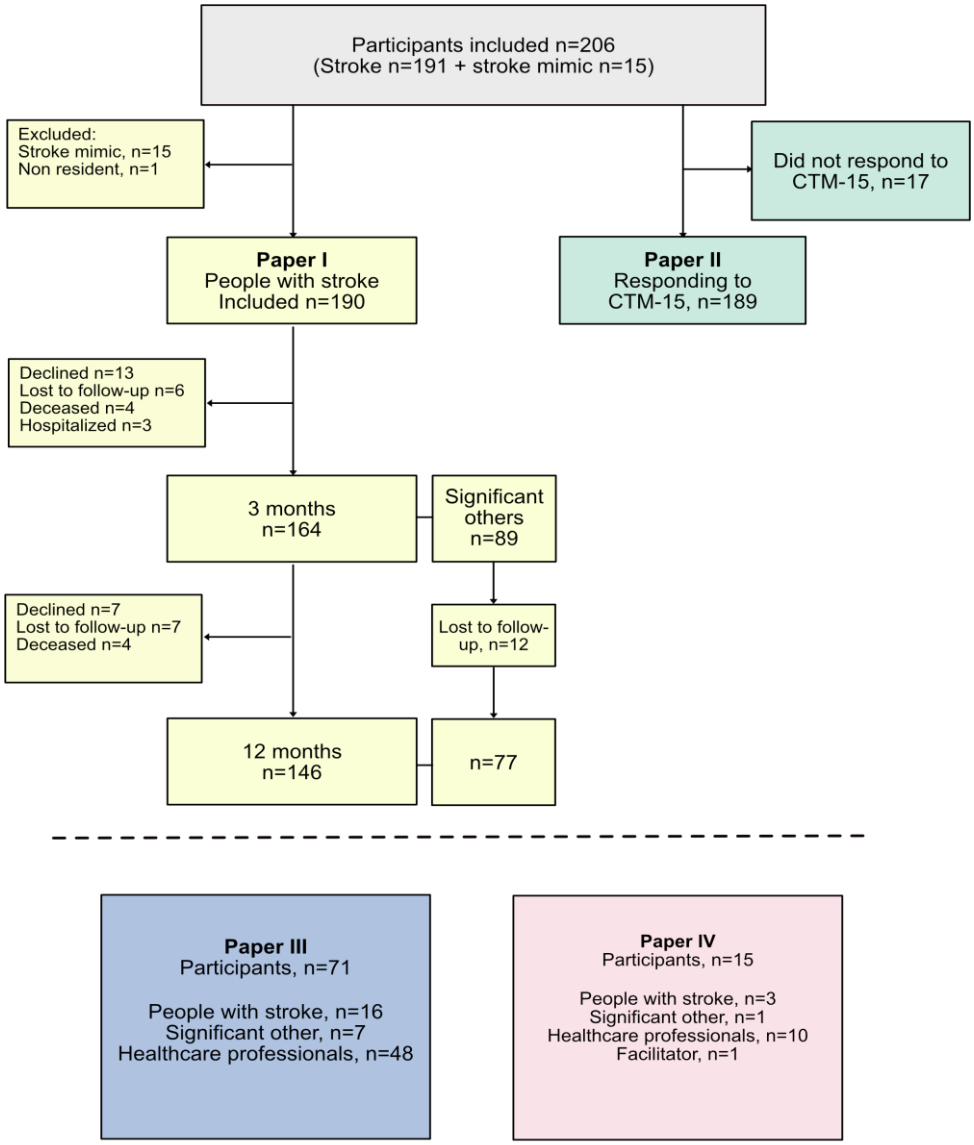

Figure 4. Flowchart of the included papers and participants of the present thesis.

Table 4. Overview of participants characteristics of the four included papers.

Paper	I	II	III	IV
Persons with stroke	***n=190***	***n=189***	***n=16***	***n=3***
Age, median (IQR) range	76 (69-84) 35-99	76 (69-82) 35-99	73 (64-81) 40-82	74 57-92
Women, n (%)	78 (41)	75 (40)	7 (44)	2 (67)
Cohabiting, n (%)	123 (65)	125 (66)	12 (75)	3 (100)
Stroke severity, n (%)				
Very mild	100 (53)	106 (56)	10 (63)	
Mild	75 (39)	67 (35)		
Moderate/severe	15 (8)	16 (9)	6 (37)	
Significant others	***N=89***	-	***n=7***	***n=1***
Age, median (IQR) range	70 (60-77) 36-90		66 (59-69) 48-79	52
Women, n (%)	64 (72)		5/2	1/0
Cohabiting, n (%)	70 (79)		5/2	1/0
Healthcare professionals	-	-	***n=48***	***n=11***
Age, median (IQR) range			45 (36-56) 25-70	44 (36-51) 29-55
Women, n			44	11
Experience at current workplace, years			8 (5-12) 0.1-29	8 (3-8) 2-8
Occupation, n				
Physiotherapist			16	4
Occupational therapist			12	2
Physician			6	1
Nurse			6	1
Speech and language therapist			4	2
Social worker			3	-
Stroke coordinator			1	-
Facilitator			-	1
Location				
SU/GU/NT			19/10/19	4/1/5

IQR: Interquartile range, SU: Stroke unit, GU: Geriatric unit, NT: Neurorehabilitation team.

6.1 HEALTHCARE UTILIZATION AND OUTCOMES - PAPER I

The baseline characteristics, disease-related data and outcomes at 3 and 12 months of the four separate groups based on the number of visits with the neurorehabilitation team are presented in Table 5.

Table 5. The characteristics, disease-related data and functioning at discharge, 3 and 12 months of participants in Paper I.

At discharge, median (IQR) min-max	**Group 1, n=22**	**Group 2, n=73**	**Group 3, n=57**	**Group 4, n=38**
Age	71 (62-81) 39-93	75 (68-85) 39-97	79 (72-85) 35-99	77 (70-84) 45-91
Men, n (%)	16 (71)	49 (67)	27 (47)	20 (53)
Cohabiting, n (%)	15 (68)	49 (67)	34 (60)	25 (66)
Help from home services before stroke, n (%)	3 (14)	12 (16)	15 (26)	10 (26)
Working, n (%)	6 (27)	17 (23)	9 (16)	5 (13)
Reperfusion therapy, n (%)	5 (23)	17 (23)	9 (16)	4 (11)
Stroke severity, n (%)				
Very mild	17 (77)	49 (67)	23 (40)	11 (29)
Mild	4 (18)	22 (30)	30 (53)	19 50)
Moderate/severe	1 (5)	2 (3)	4 (7)	8 (21)
Aphasia, n (%)	3 (14)	7 (10)	5 (9)	6 (16)
Charlson Index, n (%)				
No/Low/Moderate-severe comorbidity	11(50) / 8(36) / 3(14)	41(56) / 5(34) / 7(10)	24(42) / 23(40) / 10(18)	17(45) / 15(39) / 6(16)
Katz ADL, before stroke, dependent, n (%)	2 (9)	3 (4)	9 (16)	6 (16)
Katz ADL post-stroke, dependent, n (%)	3 (14)	14 (19)	25 (44)	22 (58)
Barthel Index	95 (94-100) 5-100	95 (90-100) 30-100	90 (77-100) 0-100	85 (60-95) 15-100
Walking ability, n (%)				
Walks independently without aid and support	18 (82)	49 (67)	20 (35)	7 (18)
Walks with walking aid	2 (9)	18 (25)	25 (44)	14 (37)
Unable to walk/Walks with assistance and support	2 (9)	6 (8)	12 (21)	17 (45)
SIS Recovery	80 (32-91) 0-100	71 (50-90) 0-100	60 (50-80) 10-100	50 (30-60) 0-100
Length of stay, days	3 (1-3) 1-22	3 (2-7) 1-25	11 (4-18) 1-69	17 (7-25) 1-89

3 months, median (IQR) min-max	**Group 1, n=20**	**Group 2, n=63**	**Group 3, n=45**	**Group 4, n=36**
Barthel Index	100 (0) 80-100	100 (0) 65-100	100 (82-100) 30-100	95 (71-100) 20-100
KATZ PADL	6 (0) 5-6	6 (0) 3-6	6 (5-6) 2-6	6 (4-6) 0-6
KATZ IADL	4 (2-4) 0-4	4 (2-4) 0-4	1 (0-4) 0-4	1 (0-2) 0-4
Walking ability, n (%)				
Walks independently without aid and support	18 (90)	51 (81)	30 (67)	24 (67)
Walks with walking aid	1 (5)	8 (13)	11 (24)	5 (14)
Unable to walk/Walks with assistance and support	1 (5)	4 (6)	3 (7)	7 (19)
SIS Recovery	90 (63-97) 30-100	85 (70-98) 0-100	70 (50-80) 0-100	53 (31-76) 0-100
Significant others	**n=7**	**n=28**	**n=28**	**n=26**
Caregiver Burden Scale	41 (27-44) 24-48	29.5 (23-40) 22-76	38 (28-49) 23-69	41 (32-52) 22-72
12 months, median (IQR) min-max	**n=20**	**n=53**	**n=41**	**n=32**
Montreal Cognitive Assessment	27 (23-29) 15-30	27 (24-28) 10-30	23.5 (20-27) 9-30	21 (19-26) 8-29
Barthel Index	100 (96-100) 75-100	100 (0) 50-100	100 (90-100) 5-100	95 (76-100) 30-100
KATZ PADL	6 (0) 5-6	6 (0) 1-6	6 (5-6) 0-6	6 (5-6) 1-6
KATZ IADL	4 (2-4) 0-4	4 (2-4) 0-4	3 (0-4) 0-4	2 (0-4) 0-4
Walking ability, n (%)				
Walks independently without aid and support	17 (85)	43 (81)	26 (63)	24 (75)
Walks with walking aid	0	6 (11)	7 (17)	2 (6)
Unable to walk/Walks with assistance and support	1 (5)	1 (3)	7 (17)	6 (19)
SIS Recovery	90 (80-100) 5-100	90 (80-98) 50-100	70 (42-90) 0-100	60 (42-79) 0-100
Significant others	**n=7**	**n=24**	**n=26**	**n=20**
Caregiver Burden Scale	31 (26-55) 23-60	27 (22-33) 21-58	37 (27-54) 22-67	44 (30-63) 23-71

IQR: Interquartile range, I/P/ADL: Personal / Instrumental /Activities of Daily Living, SIS: Stroke Impact Scale, self-rated recovery.

6.1.1 Neurorehabilitation team

The first neurorehabilitation team visit was conducted within 48 hours for 8% of the participants; 2-7 days in 44%; 7-14 days in 38%; and 10% had their first visit after more than 14 days. A total of 1,891 visits, 14% of the outpatient contacts, were registered with the neurorehabilitation team during the one-year study period. The visits per group during the first year after stroke are shown in Table 6. Neurorehabilitation team visits by location, home/outpatient clinic, and by team/professions are depicted in Figures 5 and 6 respectively.

Table 6. Number of visits with neurorehabilitation team during the 12-month study period, per group.

	Group 2, n=73		**Group 3, n=57**		**Group 4, n=38**	
Visits with neurorehabilitation team	Visits/ users	Median(IQR) Min-Max	Visits/ users	Median(IQR) Min-Max	Visits/ users	Median(IQR) Min-Max
1st quarter	113/72	1 (1-2) 0-3	421/57	7 (5-10) 2-14	739/38	17 (14-24) 5-57
2nd quarter	2/2	0 (0) 0-1	40/19	0 (0-1) 0-7	347/36	7 (3-10) 0-46
3rd/4th quarter	0	0	0	0	229/20	1 (0-6) 0-76
Total	115/73	1 (1-2) 1-3	461/57	8 (5-11) 4-15	1315/38	26.5 (20-34) 10-130

IQR: Interquartile range.

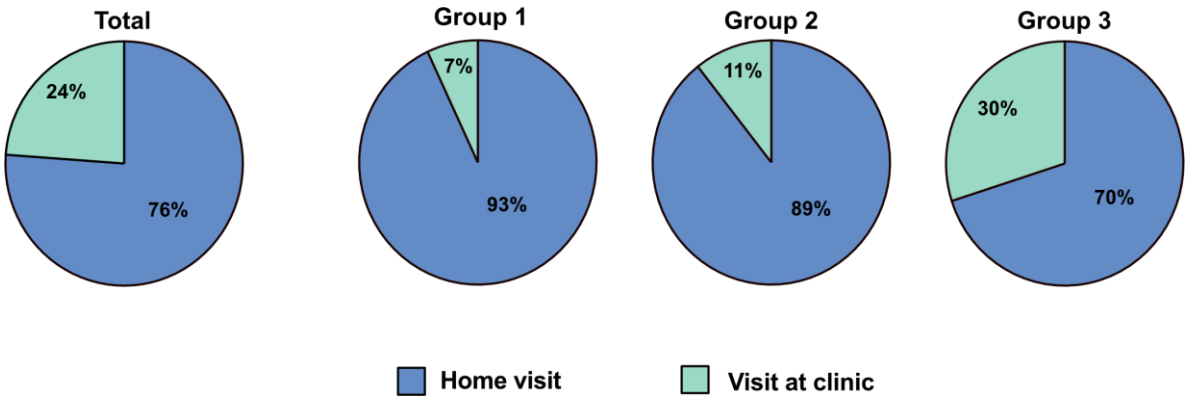

Figure 5. Visits by the neurorehabilitation team by location in total and per group.

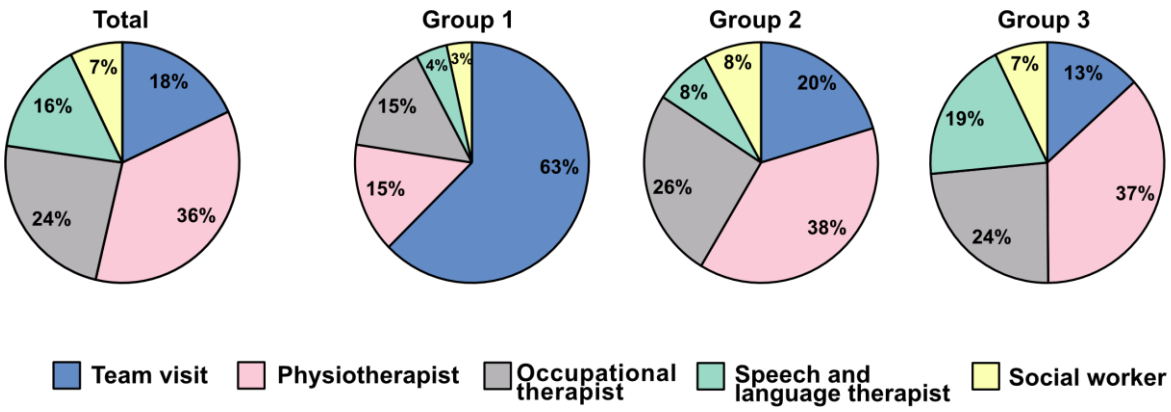

Figure 6. Visits by the neurorehabilitation team/profession in total and per group.

6.1.2 Outpatient care

A total of 11,154 contacts were registered for outpatient care during the study period. The number of contacts with outpatient care decreased during the course of the year. The dispersion of outpatient contacts during the first year after stroke by group are depicted in Figure 7.

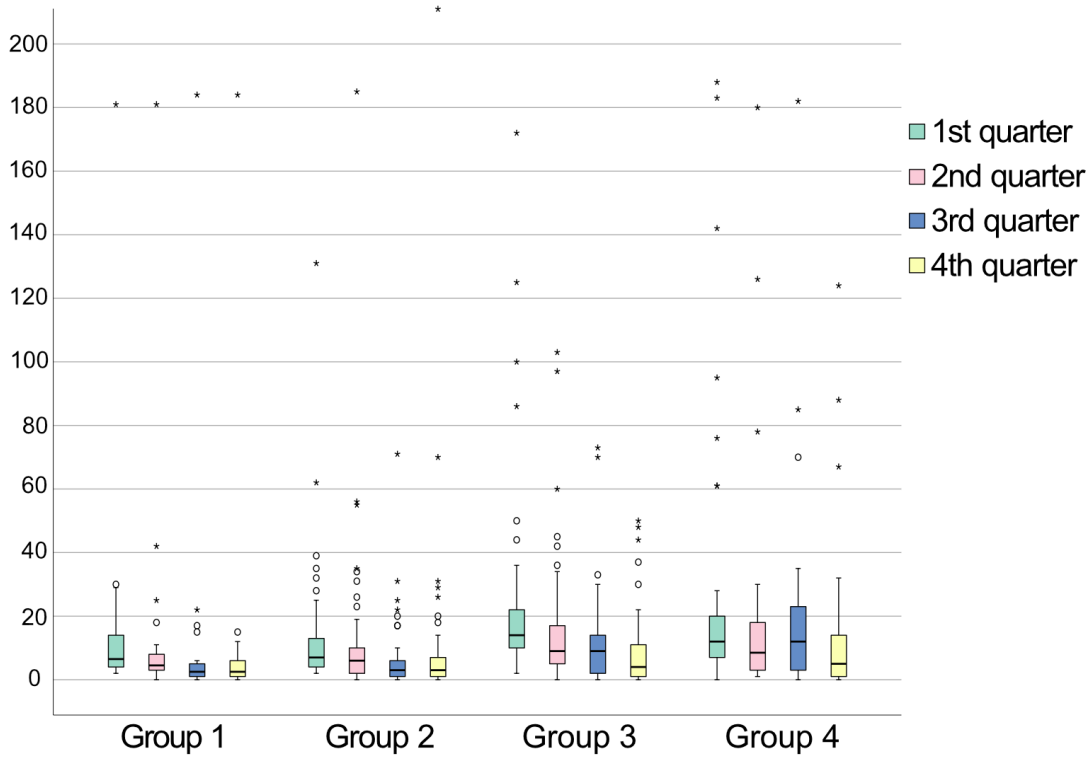

Figure 7. Dispersion of number of outpatient contacts during the first year after stroke by group.

6.1.3 Hospital inpatient care

A total of 86 participants, 168 recurrent hospitalizations accounting for 1099 inpatient hospital days were registered during the study period. Twenty-one (11%) participants had an acute hospitalization within 30 days from discharge and 41 participants (21%) within 90 days.

6.1.4 Healthcare utilization and associated factors

Multivariable linear regression models showed that female sex and length of initial hospital stay were associated with a higher number of visits with the neurorehabilitation team. Living alone, higher self-rated recovery, and being able to walk independently were associated with lower number of visits with the neurorehabilitation team. The adjusted coefficient of determination for the final multivariable linear regression was 0.357.

Female sex, use of home help services before stroke, initial length of hospital stay, and higher comorbidity were associated with a higher number of outpatient contacts. The adjusted coefficient of determination for the final multivariable linear regression was 0.278.

6.1.5 Outcomes

As depicted in Table 4, the median in IADL was 4 in group 1 and 2 respectively, whereas it was 1 in groups 3 and 4 respectively. The same pattern was seen regarding the BI, indicating that group 1 and 2 had less disability in comparison with groups 3 and 4. The median scores appeared to be lower in all SIS domains in groups 3 and 4 in comparison with groups 1 and 2.

At 3 months the median caregiver burden was 41 in groups 1 and 4, whereas it was 29.5 in group 2, and 38 in group 3. At 12 months the burden had decreased in group 1, from median 41 to 31, while the burden in group 4 had increased from median 41 to 43.5.

6.2 PERCEIVED QUALITY OF THE CARE TRANSITION - PAPER II

6.2.1 Perceived quality per item of the CTM-15

The proportions of participants who perceived low and high quality per item of the CTM-15 are reported in Figure 8. There was a variation in the reported proportions of low perceived quality per item, ranging from 10 to 57%. Thirty-eight percent of the participants reported low quality on the item stating that “I clearly understood the warning signs and symptoms I should watch out for to monitor my health condition”. Thirty-one percent reported low perceived quality in the items related to leaving the hospital: “I had a readable and easily understood written plan that described how all of my health care needs were going to be met”; “I had a good understanding of my health condition and what makes it better or worse”; and “I was confident I could actually do the things I needed to do to take care of my health”. Fifty-seven percent reported low quality in relation to the statement “I clearly understood the possible side-effects of each of my medications”.

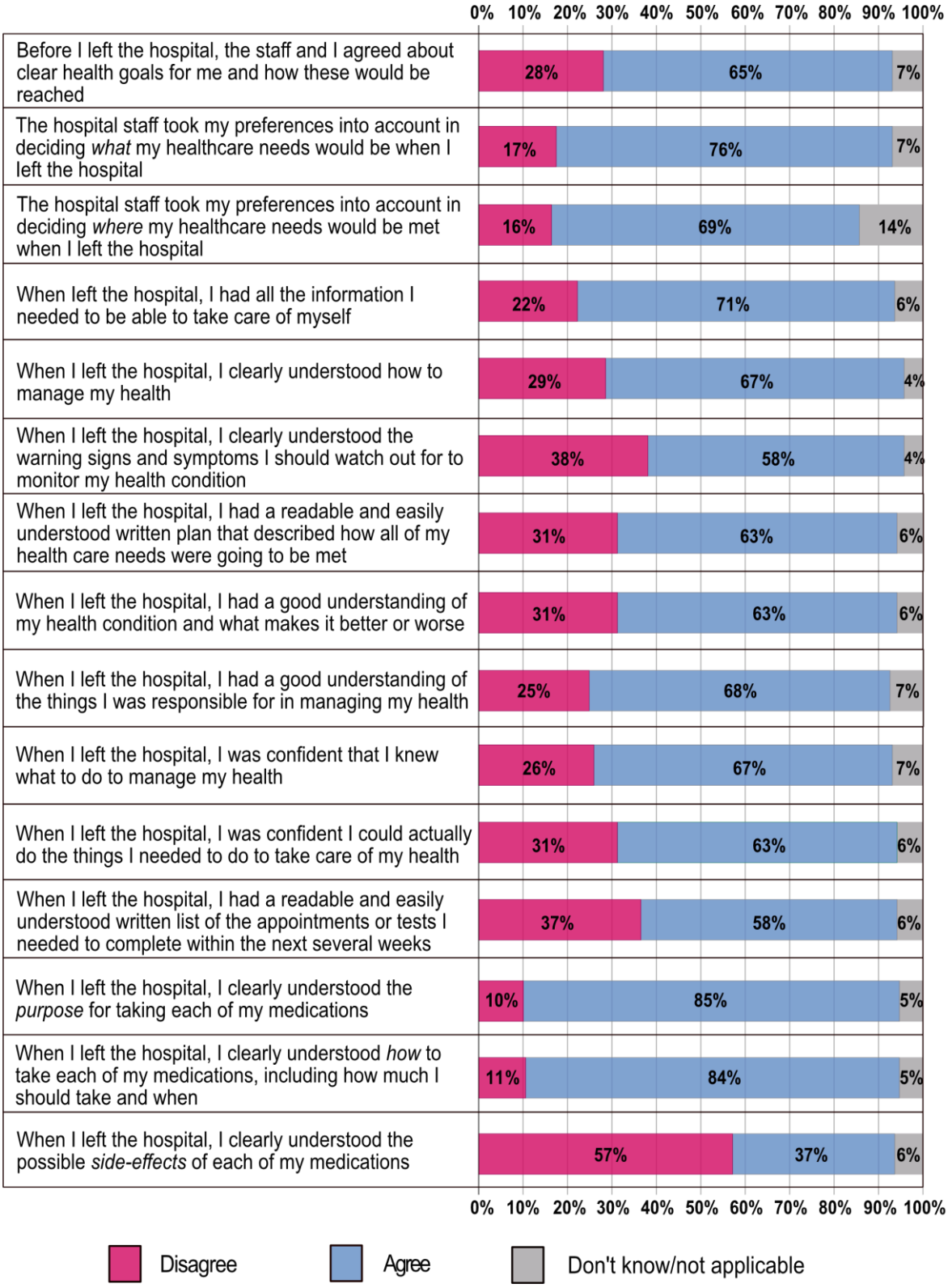

Figure 8. The proportions of participants disagreeing, agreeing and don´t know/or not applicable of the separate items of the Care Transition Measure.

6.2.2 Perceived overall quality of the care transition

The mean total score of the CTM-15 was 61.8. Participants with a very mild stroke reported a higher perceived quality of the care transition (mean 65.7) in comparison with those with a mild stroke (mean 58.3) and a moderate/severe stroke (mean 50.7), p= .021. Participants who were not able to walk reported a lower perceived quality (mean 54.2) in comparison to participants who walked with walking aid (mean 57.4), p= .006, and participants who walked independently (mean 66.9), p= .002. Participants who had home care services before stroke reported a lower perceived quality (mean 53.7) in comparison with participants who did not have any home care services before stroke p= .007. Participants receiving reperfusion therapy reported a higher perceived quality (mean 68.4) in comparison to participants who did not (mean 60.4), p= .05.

6.2.3 Factors associated with perceived quality of the care transition

The multivariable logistic regression analyses for the association of the independent variables and low perceived quality per item of the CTM-15 showed a variation of independent variables associated with each item of the scale. The final multiple linear regression model seen in Table 7, showed that walking with a walking aid and not being able to walk were associated with a lower perceived quality. The adjusted coefficient of determination for the final multivariable linear regression was 0.068.

Table 7. Final multiple linear regression model of associations between independent variables and the total score of the CTM-15.

CTM total score 0-100						
Independent variable	Unstandardized coefficients					Standardised
	β	95% CI			P-value	β
Constant	53.455					
Home help services before stroke onset	7.06	-0.57	-	14.69	0.070	0.135
Unable to walk/assistance and support	-11.34	-19.43	-	-3.25	0.006	-0.208
Walks with walking aid	-7.57	-14.68	-	-0.46	0.037	-0.162

6.3 THE CARE TRANSITION FROM THE PERSPECTIVE OF PEOPLE WITH STROKE, SIGNIFICANT OTHERS, AND HEALTHCARE PROFESSIONALS - PAPER III

In Paper III one core category "Perceptive dialogue for a coordinated transition", and two categories "Synthesis of parallel processes for common understanding" and "The forced transformation from passive attendant to uninformed agent", each with three subcategories resulted from the analysis, presented in Figure 9.

Figure 9. The core category, categories and subcategories of the findings in Paper III.

6.3.1 Perceptive dialogue for a coordinated transition

The core category a 'perceptive dialogue for coordinated transition' reflects the patients', significant others' and healthcare professionals' need for perceptive dialogue among each other. This entails a responsiveness for each other's specific situation and context during the care transition. A perceptive dialogue between stakeholders may both depend on and lead to a shared trust, mutual involvement, and the development of routines. The perceptive dialogue facilitates the synthesis of processes to form a common understanding of the transition as a whole. The common understanding embraces both the interpersonal understanding that facilitates a partnership between patients and healthcare professionals, as well as the common understanding between healthcare professionals within the team and across organizations to form an understanding of the transition process as a whole. On the other hand, a lack of perceptive dialogue between stakeholders' risks leading to a fragmented transition, where parallel processes will stay disconnected from each other. Without perceptive dialogue patients and significant others risk an unforeseen transition where patients are forced into a sudden and unsupported responsibility.

6.3.2 Synthesis of parallel processes for common understanding

The healthcare professionals described the care transition to comprise several parallel processes. These processes consisted of individual assessments, individual or team decisions regarding subsequent care, communication of decisions to patients, provision of information to out-of-hospital caregivers, and the receiving of information by out-of-hospital caregivers.

Creating links through dialogue

Healthcare professionals described how links, achieved through meeting each other and sharing information within and between organizations, facilitated well-functioning transitions. To be able to form the links between each other, several prerequisites such as spatial proximity,

formal and structured team meetings, and formal cross-organizational dialogue were identified. Having proximity to each other and formal ways of meeting facilitated dialogue that contributed to collaboration and knowledge about other professions' role. Dialogue facilitated a comprehensive understanding and synthetization of patients' needs, which enabled the team to make well-founded team decisions. On the other hand, healthcare professionals who did not have regular team meetings and opportunities for dialogue described the risk that decisions on subsequent care were made by individuals instead of unanimously across the team. Lack of team meetings also meant a hinderance in having to communicate information to other members of the team and an arbitrariness as to when, how, and what was communicated.

The healthcare professionals at hospital and in the neurorehabilitation teams described an absence of cross-organizational dialogue. The information between the organizations consisted of one-way communication by electronic referral from the hospital to the neurorehabilitation team. There was a lack of agreement as to when, how, or what information should be disseminated. The absence of a dialogue was described as generating preconceptions, misunderstandings, and mistrust about each other's ways of working. Both hospital healthcare professionals and the neurorehabilitation teams recognized that dialogue, feedback and collaboration between organization could improve patient care.

A path to decision based on (mis)trust

The path to a decision about a patient's discharge was either steered hierarchically or through a holistic process. Hierarchical decision-making meant that individual physicians made the decisions without dialogue with the team. This was described as generating mistrust around whether the team members' assessment of an individual was actually taken into account. On the other hand, in the holistic decision-making process, the team reached unanimous decision through dialogue.

Routines as safety nets

In order to reduce the risks of mistakes and give equal treatment to all, healthcare professionals described routines in terms of well-defined working methods and clear areas of responsibility to be of major importance. This was based on the enabling of time for development and maintenance of routines through staff continuity. Routines and structure were hard to maintain in units with high employee turnover.

6.3.3 The forced transformation from passive attendant to uninformed agent

The patients and significant others described themselves as passive during the period of hospitalization. The passivity was described as lack of involvement and dialogue and contributed to a sense of uncertainty and lack of control. However, after discharge the role changed from being a passive attendant to becoming an uninformed agent.

The unforeseen discharge

Patients and significant others experienced the discharge as forced and stressful, and with a sense of being pushed out. In some cases, patients did not have any discharge meetings, which led to a lack of understanding, a sense of uncertainty, and lack of control.

Healthcare professionals described late decisions about discharge and being forced to undertake practical and administrative duties as reasons why patients were overlooked. Patients who left the hospital without a discharge meeting or a planned follow-up described a feeling of insecurity. A prepared discharge with dialogue and a plan for follow-up, were described by patients as reducing the amount of discharge calls and visits to emergency care.

From passive to active

Patients and significant others experienced a lack of involvement and dialogue. The passive role during the hospital stay suddenly evolved into an active role after discharge. Instead, patients wished to be involved to a greater extent than was the case. Patients and significant others experienced that they were unprepared to self-manage at home, and had unanswered questions coming home after discharge.

The rookie with full responsibility

Patients and significant others described the need for support relating to coping with the illness and its treatment, but also with the practical issues of being newcomers in the healthcare context. Being a rookie made it difficult to know what to expect and ask for, which made it difficult to make proper demands on the healthcare system. Having a trustful healthcare professional to turn to with questions and having a planned follow-up visit was described as important in order to feel secure. The neurorehabilitation team was described as a valuable resource that could answer questions and provide a feeling of safety.

6.4 THE MANIFESTATION OF PARTICIPATION IN CO-DESIGN - PAPER IV

Four categories emerged of how participation manifested itself including the potential enablers and barriers to participation within the co-design process: “Composition of individuals for an adaptive climate”; “The balancing of roles and power”; Different perspectives as common ground for a shared understanding”; and “Leadership in an unpredictable and ever-adaptive process”. All together 9 subcategories were related to the categories as seen in Figure 10.

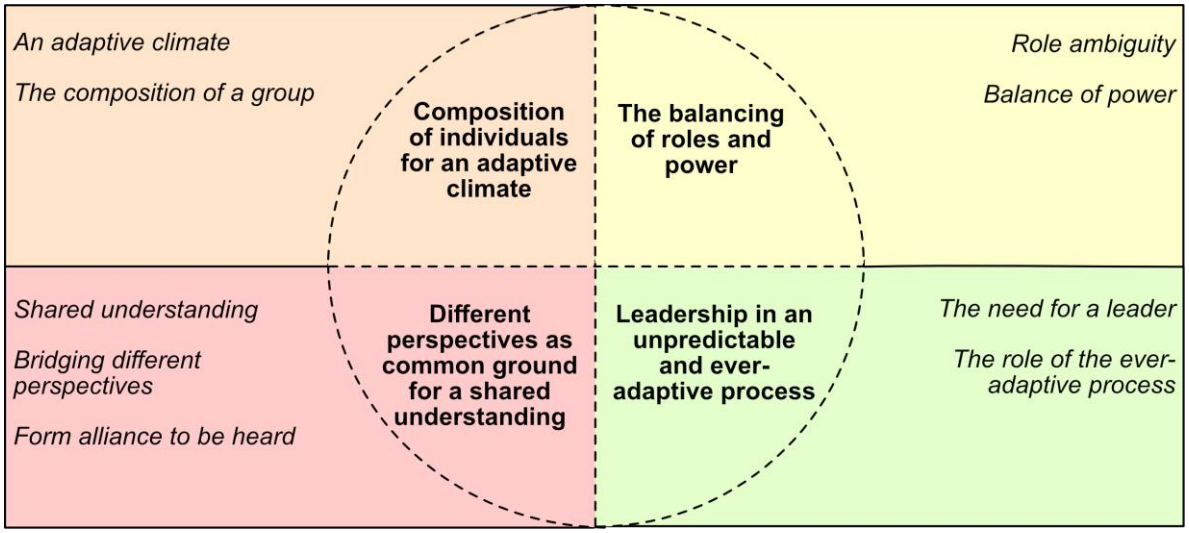

Figure 10. The 9 subcategories and 4 associated categories of the results.

6.4.1 Composition of individuals for an adaptive climate

Participation within the co-design process manifested itself depending on how the composition of individuals assumed an adaptive approach and created a permissive and inclusive climate. Participation was enabled by a collective engagement with responsiveness to the needs of fellow participants. The composition of individuals in each group was critical to how participation was either enabled or hindered. The forming of relationships affected the way participants felt comfortable to interact and participate. Factors such as personality, ability to act within a group, and skills related to the aim of the co-design process should be considered when composing a group of individuals.

6.4.2 The balancing of roles and power

There was an ambiguity around what roles the participants were expected to assume in the co-design process. The participants had difficulties combining their binary role as either patient/significant other or healthcare professional with their role as an equal member within the design team. People with stroke and the significant other described that limited knowledge made it difficult to contribute with more than their experience. Further, they had a view of themselves as inferior to the healthcare professionals. Some patients saw the professionals as experts and experienced that they as patients had less to contribute, which made the view of participation hierarchical. Healthcare professionals contrasted the experience-based perspective of the patients/significant other from one unique occasion to their own long-term experience of working within healthcare on a daily basis. These circumstances risked leading

to an unequal power balance and the cementing of traditional expert-novice roles, hindering equal participation.

6.4.3 Different perspectives as common ground for a shared understanding

One key aspect to enabling participation on equal terms was whether the participants managed to bridge their different perspectives and reach a common ground for shared understanding. A shared understanding enabled ownership of the co-design process and increased the motivation to contribute. An equal participation seemed to be enabled by a shared understanding of the purpose and aim of the process and how to jointly proceed, prioritize and execute the different steps of the co-design process. On the other hand, lack of shared understanding hindered workflow, generated frustration and sometimes led to the exclusion of persons who had difficulties understanding. The bridging of the experience-based perspective of the users and the perspective of healthcare professionals was described as difficult to achieve. The perception of the actual needs of the patients and significant others differed with difficulties in understanding each other's perspective. This led to difficulties in participation due to irritation, dissatisfaction, and a distance between participants.

6.4.4 Leadership in an unpredictable and ever-adaptive process

To process itself both enabled and hindered participation. The diversity of methods and assignments enabled a creative and open environment with variety and different modes to express, which benefited participation among the participants. The possibility to adapt and adjust along with the process, enabled participation. As minor conflicts and dissatisfaction arose, the possibility to adapt and revise the process was necessary. However, this was dependent on a continuous reflective approach from the researcher and facilitator to perceive and address changes needed to be made. On the other hand, the co-design process involved forced, unclear and difficult assignments which affected participation in a negative way. The confusion and insecurity that arose when participants had difficulties following the process hindered participation. Insecurity and stress within the group made participants focus less on interactions and participation among each other, instead prioritizing fulfilment of the tasks. The role of the facilitator was an important enabler for participation. The facilitator identified and remediated imbalances in participation and put strong incentives in listening to the patients and significant others. However, participation was hindered by the absence of a formal leader in each group. This together with the difficulties of the facilitator to provide a continuous and intense facilitation to meet the needs of all groups the leader role was of importance to facilitate an equal participation.

7 DISCUSSION

The present thesis intended to explore, describe and generate knowledge about the care transition from hospital to continued rehabilitation in the home for people with stroke, and further investigate the concept of participation in a co-design of a person-centred transition. The results generated from this thesis can hopefully lay ground for future person-centred care transitions.

7.1 SUMMARY AND DISCUSSION OF MAIN FINDINGS

The results revealed that the referral-based care transition mostly involved people having a mild stroke. Nevertheless, the care transition involved persons ranging from having had a very mild stroke to those having had a moderate/severe stroke. There was a large variation between the participants in the proportion of visits carried out with the neurorehabilitation team as well as use of other outpatient contacts during the 12-month study period. Overall, the number of visits with the neurorehabilitation team seemed to mirror the person's level of functioning and stroke severity.

There is room for improvement in the preparation for discharge and a need to enhance the support for self-management post discharge, especially for people with a moderate/severe stroke. From the perspective of people with stroke, significant others, and healthcare professionals, the care transition was described to consist of several parallel processes in need of synthetization and coordination in order to make well-founded decisions and provide coordinated transitions based on the actual needs of the person. The synthetization should be made through creating links between healthcare professionals within and between organizations. Patients and significant others described the care transition as a forced transformation from being a passive attendant, with a lack of involvement and/or dialogue about their care and rehabilitation, to being faced with a sudden and forced responsibility after discharge without enough support and preparation. The perceived absence of participation generated a feeling of uncertainty and lack of control. There is a need to create links and improve dialogue between patients/significant others and healthcare professionals in all aspects surrounding the care transition.

The manifestation of participation within a co-design process was shown to be affected by multifactorial inter-related links, such as the compositions of groups, the climate and adaptations among the participants, the balancing of power and roles, a shared understanding, leadership, and an adaptive and flexible process. Participation varied between individuals, groups, steps within the process, and topics of conversation.

7.1.1 Healthcare utilization and outcomes of the care transition

One of the intentions of this thesis was to describe and understand who the people are that receive the referral-based transition, what the model constitutes in terms of healthcare utilization, and describe the outcomes of patients and the potential burden of significant others. The majority of the participants who received the referral-based transition were people with a

mild stroke, and a majority of the visits were conducted in the participants' homes. This is in line with previous reports on discharge to home and in line with recommendations for post-discharge rehabilitation (62, 72). Although a majority had had a mild stroke, there was a broad variation in the sample regarding patient characteristics, disease-related data, and level of functioning. The varying consequences and needs after stroke are well-known (47, 48), as is the understanding that life after stroke encompasses a non-linear and dynamic process of recovering and adapting to a new life situation (189). As rehabilitation per definition (65) and as recommended in international guidelines and consensus (66-68) should be individualized, high demands are put on the design of actions to ensure the continuity and coordination of rehabilitation as patients transfer between the hospital and continued rehabilitation in the home. The span in stroke severity, disability, LOS and utilization of care and rehabilitation, within this thesis highlight that the conditions for provision of information and other type of support will differ depending on many inter-related factors. Hence, great demands are put on the organizations and involved healthcare professionals to be flexible in the provision of services and in offering an individual-based approach during the course of the care trajectory, i.e. to presume a person-centred approach as recommended in best practice guidelines for care transitions (62, 190). This is especially important in relation to the care transitions studied in this thesis, as the findings of Paper III indicate that there is no cross-organizational dialogue between healthcare professionals, which could complicate a person-centred approach.

Based on the skewed data of healthcare utilization and the categorization by number of visits with the neurorehabilitation team, the findings of this thesis demonstrated four diverse patterns for use of rehabilitation. The visits with the neurorehabilitation team ranged from some people having no visits to one person having 130 visits during the 12-month study period. The findings imply that there is room for flexibility in the provision of both short- and long-term efforts to meet individual needs, as essential in stroke rehabilitation (68).

Previously reported findings have shown that disease severity (191) and disability (192, 193) are the main drivers for healthcare utilization after stroke. Somewhat surprisingly, stroke severity was not associated with either the total visits with the neurorehabilitation team nor the total other outpatient contacts in Paper I. However, the descriptive statistics indicated that the number of visits with the neurorehabilitation team seemed to relate to patient characteristics, disease-related data and level of functioning. This further indicates the use of an individualized approach from the neurorehabilitation team, based on the need for rehabilitation. However, it is important to consider the lack of knowledge about the content of the visits, hence any far-reaching conclusion is difficult to make.

As all included participants received a referral to the neurorehabilitation team, this should indicate the need for continued rehabilitation or at least the need for follow-up after discharge from hospital. Despite this, 12% of participants had no visits with the neurorehabilitation team, even though being similar to participants with 1-3 visits regarding characteristics, disease-related data, and level of functioning. Out of the 22 participants who had no visits with the neurorehabilitation team, 18 had declined a visit, and for the remaining four, no reason was

found. The declining of visits from the neurorehabilitation team might have been due to not feeling the need for their services coming home after discharge. This is a likely scenario, considering their low total use of all healthcare during the 12-month study period, together with a high level of functioning and independence. However, there is a need to ensure that the non-visits were not related to the care transition process itself, especially as care transitions based on referrals have been connected to safety risks with information loss, incomplete referrals, and delayed follow-ups (194, 195). Further, inadequate discharge planning has been reported as a barrier to engaging in rehabilitation after discharge (196), and this, together with feelings such as "overwhelming" and "chaotic" (26), might make patients decline contact post-discharge. Additionally, the caregiver burden of the group with no visits and low levels of disability was found to be similar to the group with the greatest number of visits and the highest levels of disability. Even though the significant others in the groups were few in numbers and differed between the groups, one cannot completely ignore that the absence of visits with the neurorehabilitation team in connection to the transition might lead to an increased burden on the significant others. One possible explanation could be that the absence of contact with rehabilitation withdraws the option for support, information, and opportunity to pose questions, which might increase the burden on the significant other. Hence, even though the patients experience only subtle changes due to stroke and feel no need for visits with the neurorehabilitation team, the stroke might still affect the burden experienced by the significant other (197). Further, a lower caregiver burden has been reported when people with stroke receive continued rehabilitation after a coordinated discharge (198).

What could distinguish and explain the difference in visits is the higher proportion of individuals who were independent walkers in the group with no visits compared to the group with 1-3 visits. This seems to be a trend in the overall sample, as the proportion of people who were independent walkers is higher in the groups with a greater number of visits with the neurorehabilitation team. This was also supported by the findings of the multiple linear regression, where being an independent walker was associated with lower number of visits with the neurorehabilitation team. Further, it corresponds to findings from previous studies where walking disability has been reported to predict higher healthcare utilization (199) as well as having a clinical bearing, as walking disability is connected to dependency in ADL and participation in social activities, whereas rehabilitation is often focused on improving walking ability.

Of those who had at least one visit with the neurorehabilitation team, 52% had their first visit within one week from discharge, and 90% had their first visit within 14 days. This indicates a rather contiguous first visit with the neurorehabilitation team for a large majority of the participants, which could be a sign of good management continuity. Despite this, the 11% readmission rate within 30 days and 21% within 90 days are in line with previous studies of the stroke population, reporting a range between 6-24% all-cause 30-day readmission rates (200, 201). In this thesis we controlled for acute and non-acute readmissions, hence the numbers are no overestimation. The readmissions rates could be explained by the findings in Paper II, which suggest the need for enhanced preparation for discharge and information and

support for self-management post-discharge; for example, 57% of the participants in Paper II perceived a low quality and disagreed with clearly understanding the possible side-effects of each of their medications when leaving hospital. Combining this with the lack of medical expertise in the neurorehabilitation team, leaving patients with unanswered questions as reported in Paper III, could pose serious consequences for patients. Lack of information and knowledge about potential side-effects could render poor adherence, adverse events, and rehospitalizations (202). This is especially important in people with stroke where adherence to the medication for risk-factors is of utmost importance to prevent occurrence of a recurrent stroke. Hence, as the focus of the present thesis was on the care transition between hospital and the home, integration and coordination with other healthcare professionals, such as primary care physicians and districts nurses, is necessary. A systematic review of patients with diagnoses other than stroke found that increased patient capacity for self-management, multi-component interventions and involvement of more than two professions were the most effective components for reducing the risk of readmission within 30 days of discharge (96).

7.1.2 Perceived quality of the care transition

The mean total score of the CTM-15 was 61.8, which is one of the lowest reported scores using the CTM-15 in comparison with findings among patients discharged from general medicine, geriatric medicine, cancer, chronic obstructive pulmonary disease, congestive heart failure, acute coronary syndrome and diabetes (155, 203-206). The finding indicates that people with stroke are an especially vulnerable group in connection to care transitions, particularly people with a moderate/severe stroke who reported a 15-point lower score than people with a very mild stroke. One explanation for this might be the sudden onset of stroke and a short length of stay, with little time for preparation and identification of needs before discharge. Further, it could be explained by the lack of involvement of patients during the hospitalization as reported in Paper III. It should be noted that the comparison of perceived quality with other patient groups leaves room for some degree of uncertainty, as the studies originate from different part of the world and are conducted in different contexts and patient groups. Further, as the CTM-15 was sent out one-week post-discharge the perceived quality might be biased depending on whether the person had met the neurorehabilitation team or not, as perceived quality changes over time (207) and can be affected by the latest interaction with healthcare and/or healthcare professionals (208).

The complexity that the concept quality of care comprises, might be the reason for the low explanation rate (6.8%) of the variance of the total score of the CTM-15 in the final multiple linear regression model in Paper II. A previous Swedish study reported similar results with a 7% explanation rate of the variance when exploring the association of patient characteristics in relation to hospital care experience (209). Being unable to walk was the only independent variable associated with the total score of the CTM-15. As all of the independent variables were related to patient or clinical characteristics, it seems likely the variables have little associations with the perceived quality of the care transition, as measured by the CTM-15. This is not surprising, and is probably explained by the reason that perceived quality of the care transition

is associated with other factors such as discharge planning and routines, quality of communication, provision of information, and how care is coordinated, which corresponds to the findings in Paper III of this thesis and suggested by previous studies (24, 97, 102, 210). These factors need to be addressed in clinical care and in the design of future transitional care interventions.

7.1.3 The links between patients/significant others and healthcare professionals

People with stroke in Paper III expressed a lack of involvement and dialogue regarding all aspects of their care during the hospitalization which made them passive. Similar experiences were expressed by the significant others who described a passive role during the hospital stay without preparation for what would happen after discharge. Both patients and significant others expressed the wish and need to be involved in the early stages at hospital, and to be prepared on how to self-manage after discharge. In addition, 28% of the participants in Paper II perceived a low quality and disagreed with the statement "The staff and I agreed about clear health goals for me and how these would be reached". The lack of involvement and need for preparation before discharge from acute care is a commonly reported problem by people with stroke (57, 80, 81, 84). A Swedish study reported that 72-90% of patients with stroke perceived receiving information but fewer (15-47%) had actually participated in discharge planning, such as discussion about medications, needs and goals of care, and rehabilitation post discharge (64). In a related study of significant others by the same authors, about 80% perceived no participation in discussion about examinations/treatments, planning of care, or discussion about goals of care or treatment (63). Hence this is an important matter to consider in the attempt to improve the care transition process.

One could argue that patients and significant others who perceived lack of involvement in their own care might have been affected by the rather short LOS, as lack of time for healthcare professionals could hinder the involvement of patients, and perhaps especially the significant others. Healthcare professionals in Paper III reported time pressure as one reason why patients were overlooked. However, LOS did not seem to be associated with perceived quality in Paper II. This corresponds to the findings of Andrew and colleagues investigating influencing factors in discharge planning (211). Further, the mean length of stay in Paper III was eight days, which should be a reasonable enough time to be involved. Patients especially expressed a wish to be informed about procedures, get feedback on test results, and partake in decision-making, which is part of the care at the hospital, indicating that the lack of dialogue and participation were more related to if, how, and in what way the communication was conducted and the content of it, rather than clinical and contextual factors. This demonstrates the importance of inter-personal communication and dialogue as ground for forming a partnership, which is the foundation of PCC (122, 123, 212). Patients' and significant others' involvement in their own care is also a legal right and a way to strengthen empowerment and self-management skills (128, 129, 213, 214). Patients and significant others who are involved and have knowledge about their condition, secondary prevention, and medications may be more prepared for the

discharge and find it easier to bridge the gap in care transitions (210), as for example having control over procedures and subsequent care and rehabilitation after discharge (215).

Findings in Papers II and III propose a need for improved information, education, and self-management support. Information must be seen as something that is not only provided to patients; instead, it is important to ensure that the recipient of information understands and is able to assimilate the meaning of the information. Information should be shared in dialogue and focus on the understanding of information rather than the provision (216). Further, information needs to be reinforced and repeated (217). To be able to reinforce and repeat information, the need for cross-organizational dialogue needs to be in place in order to agree on what, when, and how information is provided to be able to ensure continuity in information across the care transition.

Approximately 30% of the participants in Paper II perceived low quality in and disagreed with items related to understanding and monitoring the health condition, and how to manage the own health after discharge. This leaves room for improvement as self-management skills and being able to monitor the health condition is related to modifiable risk factors that if managed in the right way, can prevent the risk of recurrent stroke (218). Further, skills in managing one's own health has been connected to better functional outcomes (219, 220), improved quality of life and self-efficacy in people with stroke (221). Interventions to support self-management in stroke have proven to show beneficial effects but further research is necessary to decide the most effective components and how to best deliver the interventions (221, 222). However, the evidence is often based on studies conducted in the community and there are further difficulties to compare the content of intervention to find the effective mechanisms. Some doubts have been raised regarding the appropriateness and timing of offering self-management interventions in the acute phase of stroke as patients might not be ready (223). Based on the findings in Paper III, patients and significant others already, during the acute phase, requested the need for support and guidance on how to cope with the illness, treatment, and practicalities, which is also supported by previous studies (18, 80, 82, 83). Further, the integration of self-management interventions have proved to be feasible and desired in the acute setting (224). But with regards to the short LOS, it is reasonable to believe that there is not enough time to assimilate and understand the excessive information that having a stroke might entail. This is an additional incentive for strengthening the cross-organizational coordination and dialogue between the hospital and neurorehabilitation team in order to provide linked and unified support for information and self-management adapted to the varying needs of people with stroke and the significant others.

7.1.4 The links between healthcare professionals and organizations

The lack of cross-organizational dialogue reported in Paper III is a frequently reported problem in relation to care transitions and has been described as hindering the possibility to coordinate care and rehabilitation and provide continuity for the patient and their significant others (13, 18, 20, 225, 226). Thus, interaction points between healthcare professionals at hospital and in the neurorehabilitation teams to meet in dialogue need to be established. There have been

numerous attempts to improve the coordination between hospital and the home but with varying results (23, 156). However, interventions that start at the hospital and continue in the home, with enhanced communication processes between organizations, have proven to be effective (210). One example is ESD, where a team is responsible for both the planning of discharge and the continued rehabilitation at home (72).

Having several disciplines involved in the care and rehabilitation of a patient will entail the need to synthesize assessment and interventions to be able to make holistic decisions based on the patient's needs, preferences, and resources. One interesting reflection is that healthcare professionals never talked about involving patients or significant others in the decision-making process within the team. Hence, information was gathered from the patient by each individual profession and at most synthesized in a team meeting but in the absence of the patient and/or significant other. Thereafter a decision about discharge was disseminated to the patients. This could explain the patients/significant others experiences of not being involved during the hospitalization.

7.1.5 Participation within a co-design process

In conformity with previous studies (109, 121, 227), the findings in Paper IV delineate the complexity of conducting a co-design process with multiple stakeholders. The concept of participation manifested itself differently in relation to the individual participants, the group composition and behaviours, the different steps and tasks within the process, as well as topics of conversation. Participation within the co-design process was affected by the climate among the participants, power relationships, the ambiguity around shifting roles during the process, the bridging of perspectives and seeking a common ground, and the leadership and content of the process.

One major hinder to equal participation was the imbalance in power between the participants. In order to be able to reach an equal participation between the participants it is necessary to value experience equally to any other knowledge within the process. The presence of epistemic injustice (228), where patients' and significant others' experiences sometimes were considered as anecdotal, is from my point of view the main obstacle to equal participation in the co-design process. The difficulties in achieving equal participation could have to do with the fact that the participatory design's focus is tacit knowledge which often is hard to formalize and describe (105). Perhaps (or probably) we, as professionals within healthcare are trained to focus on a more explicit kind of knowledge that can be defined, quantified and systemized, a view that may collide with the notion of knowledge within participatory design. The underlying meaning within co-design and PCC is closely related and the core of PCC must permeate the co-design process. Patients must be seen as experts and as equal partners in designing the new healthcare services. The findings in Paper IV and of others (121) reveal that more research is needed on how to best address imbalances in power within co-design processes.

The findings imply that participation is not a binary concept that can be asserted as existing or non-existing. This is important, as several frameworks used within participatory design assume

a hierarchical manner of grading levels of participation. The findings in Paper IV oppose this rather simplified view of participation, as others have done previously (117-119). Hence, merely conducting a co-design study will not automatically contribute to the participation of the involved participants. Instead, as stated by Andersen and colleagues, participation must be seen as a matter of concern (118). The findings in Paper IV support this point of view and propose that participation must be continuously evaluated, monitored and reflected on when conducting co-design. This is an important finding as the process of co-design in healthcare otherwise risks losing its meaning (112), becoming an empty word only, used in a tokenistic manner (111, 229).

7.1.6 Care transitions from a person-centred and integrated care perspective

Laying the foundation for future person-centred care transitions

Summarising the findings of the present thesis in relation to the concepts of PCC and integrated care, there are some overarching considerations to be made for the development of future care transitions.

From the perspective of the Rainbow model for integrated care, the findings outline on a micro level a need for improved clinical integration as patients and significant others experienced a lack and lack of involvement in the care transition process and a wish for dialogue about their care and support for self-management. In compliance with the definition of PCC in this thesis, the patients and significant others should be seen as experts and active participants in their own care and rehabilitation. This should begin at the hospital and should include a holistic and biopsychosocial approach, which is guided by the patient narrative and dialogue with healthcare professionals. Instead of healthcare professionals obtaining information from patients without providing anything back, as described in Paper III, the one-way communication must evolve into a perceptive dialogue, with a sharing of information and knowledge.

In addition to a perceptive dialogue between patients and different healthcare professionals, professional integration on a meso level where the parallel processes described in Paper III are synthesized is necessary for a coherent and coordinated care experience for the patient. There is also a need for cross-organizational dialogue which calls for a higher level of organizational integration. As of today, the degree of integration between the hospital and the neurorehabilitation team qualifies somewhere around the level of segregation or linkages, as it constitutes two autonomous organizations connecting through electronic referrals (140). Therefore, the coordination between these organizations must improve through increased cross-organizational dialogue. One example is the service model of ESD which includes that an interdisciplinary team prepares and coordinates the discharge and continues the rehabilitation in the home environment, which bridges the gap between hospital and the home (72). Other solutions to enhance cross-organizational dialogue are providing multiple modes of communication such as video-communication tools (230), recurrent face-to-face communication with agreements on guidelines and treatment plans (231), and a combination

of IT-based, person-based and written material (232). For organizational integration to facilitate PCC on a micro level, normative procedures as decentralizing decision-making and having policies and culture supporting the work are also of importance (233). Further, the functional integration, i.e. the workload of professionals and skill mix can be factors influencing the possibility to provide PCC on a micro level (234-236). Hence there is a need for vertical integration involving stakeholders on all levels, including managers and decision-makers for sanction and endorsement of PCC activities in the development of new care transitions (233, 235).

Such a co-design methodology involving stakeholders from all levels have the potential to develop solutions that align with legislation and policies for PCC and national stroke guidelines. However, it is a complex methodology in which barriers and facilitators for the participation of all stakeholders need to be considered.

7.1.7 Theoretical application of complexity theory

As described in the background, CAS is "a collective set of individual agents with freedom to act in ways that are not totally predictable, and whose actions are interconnected so that the action of one part changes the context for the other agents" (142).

If we extrapolate this definition to the findings of this thesis, the *agents* of our sample are the patients, significant others, and healthcare professionals at hospital and in the neurorehabilitation teams. These agents together constitute the complex adaptive system of this thesis, i.e. the care transition process between hospital and the home. The *connectivity* and *interactions* between these agents are the most important elements of the CAS as they are fundamental to how the system behaves (237). The behaviour, pattern and outcome of the interaction and connectivity is referred to as the *emergence*.

Based on the findings of this thesis, most prominently seen in Paper III, three important constellations of interactions were identified: 1) between patients/significant others and healthcare professionals; 2) between healthcare professionals at the hospital; and 3) between healthcare professional at hospital and the neurorehabilitation teams.

The behaviours, patterns, and outcome of the interactions influenced how the care transition was carried out, how it was experienced, and could perhaps be a factor that affected the resource use, health-related outcomes and perceived quality. Further, the interactions and connectivity between the participants of the co-design process influenced how participation manifested itself. Our findings revealed that patients and significant others experienced lack of involvement regarding all aspects of their care and that the healthcare professionals applied one-way communication through an electronic referral. These findings are a strong incentive for the future improvement of the care transition process as the emergence from the interactions will inform and change the behaviour of the agents and the system itself (141). The interaction needs to build on a perceptive dialogue and facilitate participation and focus on getting an understanding of each other's needs and preferences.

Applying the mindset of complexity theory to care transitions could help coordinate and integrate the efforts in relation to care transitions. As the agents of the current care transition are disconnected from each other and have almost no insight in each other's worlds, a sense of the whole is hard to achieve. Instead, interacting through dialogue could facilitate an understanding of other agents, but also the individual agent's own role in relation to the whole. This knowledge about other parts of the system might facilitate the understanding that "what I do in this step will have a consequence later on in another part of the system". Further, the potential *feedback-loops* this will generate will potentially lead to the *self-organization*, where the different agents learn from each other and continuously improve the care transition process based on emerging needs.

As the interaction between agents is also *dynamic* and behaves in a *non-linear* fashion, it contributes to an *unpredictability*. As people with stroke cope with the illness in different ways, have different needs, expectations, and resources, they will also act and experience the care transition in different ways. This will also change during the course of the transition. What is experienced as a need during the hospital stay might have changed when entering the context of the home. This implies the importance of tailoring the care transition to the needs of the individual, and that a needs assessment should be repeated. Hence, connecting back to the definition of integrated care, "*My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes"* (134) will be a cornerstone in providing care transitions based on the needs of the individual, i.e. enacting a person-centred approach.

Finally, the CAS is embedded in a wider context of *nested systems*, such as the different organizations of the hospital ward and the neurorehabilitation team, the hospital and primary care at the meso level, which in turn are nested with policies, regulations and laws at the macro level, that constantly interact with each other. Therefore, there is also need for interaction and connectiveness across the micro, meso, and macro level, i.e. vertical integration in order to be able to enhance the understanding and collaboration between levels in the system.

7.2 METHODOLOGICAL CONSIDERATIONS

This thesis has used a plurality of study design and methods. As a result, different assumptions need to be made regarding methodological considerations, as the methods are based on different epistemological grounds. This thesis has its bearing in pragmatism and has combined both quantitative and qualitative study designs to explore the aims of the thesis and as a means to understand the complexity that care transitions and participatory design processes entail.

7.2.1 Internal and external validity - Papers I and II

Observational study designs aims to observe (assess) different characteristics and their associations, instead of intervening experimentally as in experimental research designs (238). Further, it draws inferences from a sample of population where the studied variables are not under control by the researchers (239). In general, observational studies have two different focuses, partly to describe and assemble information in summary, distributions, and proportions, and partly to analyse and draw inferences and associations between variables (240). Due to the explorative nature of this thesis, our intention has weighed towards the descriptive focus, even though we have also explored inferences and associations.

Sample

To be able to interpret the findings in Papers I and II some potential systematic errors threatening internal validity and in the next step external validity need to be addressed. One major limitation is the risk of selection bias. Our intention was to include all patients diagnosed with a stroke and who received a referral to the neurorehabilitation team. Even though we had repeated information and instructions about the inclusion and exclusion criteria we cannot disregard the possible risk that healthcare professionals who recruited patients may have applied their own inclusion and exclusion criteria. Further, there were some indications of there being limited time to inform patients about the study due to late decisions about diagnoses and the discharge. Hence there are reason to believe that some patients were not asked to participate. This might especially be the case in relation to people with cognitive and communication problems as they need more time to be informed about the study. This might have contributed to an underrepresentation of people with cognitive and communication problems in our sample. This limits the external validity and provide difficulties in generalizing the findings to the whole stroke population. Further, we did not control for the number of participants declining participation or the number of patients treated for a stroke at the studied units; hence we are unaware of the proportions of people with stroke agreeing to participate in relation to the actual numbers of eligible patients. The above-mentioned factors might suggest a threat to external validity. However, the mean age and characteristics reflects the population as described in the Swedish national quality register (Riksstroke) (42) which might strengthen the external validity of the study.

Due to difficulties to diagnose, and a delayed confirmation of the diagnoses before discharge from hospital, some people were discharged with a stroke diagnosis that was later changed. These individuals were excluded upon awareness of the changed diagnosis. However, in Paper

II we included people who had not received a final stroke diagnosis and were classified and reported as stroke mimic. We did this since they had been discharged with a referral to the neurorehabilitation team and had been treated as a stroke diagnosis; hence the results of the CTM-15 should still reflect the quality of the preparation for discharge.

Measurements

To avoid unnecessary burden for patients and healthcare professionals, and to avoid intervening with routine care, we minimised the amount of baseline assessment during the hospitalization period. Instead, baseline data were mostly retrieved from medical records, except for the rating of self-perceived recovery from stroke, hence the lack of standardized assessments and tests with multiple assessors and sources might have contributed to informational bias and the misclassification of individuals. In order to reduce bias during the data extraction from medical records we used two reviewers who could discuss any difficulties interpreting the data. But as the source of data came from the assessments of different healthcare professionals, we have no knowledge about inter-rater reliability between healthcare professionals. Therefore, there might be differences in the way the data were assessed and reported in the medical records. On the other hand, this approach reflects the procedures of clinical practice.

The measurements used in this thesis were based on knowledge and experience about frequently reported measurements used in research and clinic with the stroke population. However, there are still some limitations regarding the measurements that need to be addressed. The use of BI as a measure of stroke severity has both advantages and disadvantages. An advantage is that BI is one of the most commonly used measurement in stroke research and clinical practice, and has been proven as a reliable and valid measurement in the stroke population (160-162). This strengthens the generalizability of our findings. However, as BI measures performance in ADL, it might not capture all aspects of disability. One alternative would have been to use the mRS scale that is said to capture global disability. However, as we lacked the mRS at baseline, the choice fell on the BI. The categorization of the BI, is previously used and recommended (164), but might have contributed to the low proportions of people with moderate/severe stroke. Further, the use of the categorized BI in the regression models could have contributed to loss of information, instead of using it as a continuous variable. This might explain the absence of stroke severity as a driver for healthcare utilization in Paper I.

The CTM-15 is the most commonly used measurement in relation to care transitions (241). However, there are some weaknesses when trying to interpret the total score of the measurement. To begin with the CTM-15 is said to measure perceived quality of the care transition. However, all 15 items relate to the preparation of discharge and do not recognize the time post-discharge. As care transitions per definition, and based on the results of this thesis needs to involve different levels or locations of care, the scale misses out on important aspects of the care transition. Further, the concept of quality is difficult to conceptualise in 15 items comprised in one measurement as the concept is complex and is affected by several inter-related factors (208, 242). Perhaps the CTM-15 should be seen as a measurement of preparation before discharge. In addition, there is an absence of reference values or cut-off points in the

literature on what can be considered a high-quality care transition, and there are no comparable studies in people with stroke where the CTM-15 was used as a measure. Therefore, as none previously done before, we deliberately chose to report the individual items of the CTM-15 to complement the somewhat difficult to interpret total score. This was done to enable us to gain a more detailed understanding about potential areas of improvement and should be seen as a strength of the present thesis. The choice to dichotomize the four-point Likert scale might have generated loss of information, especially in relation to the logistic regression conducted per item of the CTM-15. However, in order to gain an easier interpretation and overview of participants' responses per item, the dichotomization was beneficial, and contributed to the ability to understand potential areas of improvements regarding preparation for discharge, which is in line with the aims of the thesis.

The follow-up visits at 3 and 12 months were conducted in the participants' home, at the hospital, or any other convenient place chosen by the participant. The prospective data collection with face-to-face visits can be seen as a major strength of Paper I, as it potentially reduced the risk of incomplete data and further ensured the avoidance of misinterpretations of items in questionnaires by assisting with potential difficulties in interpretation of questionnaires. The follow-up visits were conducted by different researchers, so to avoid a variability in assessments and different interpretation of measurements, we used a standardized protocol with a predetermined order of questionnaires and performance-based tests. The different assessors discussed and agreed upon a standardized procedure for the execution of the visit and a common view on the rating and assessment of the different tests and questionnaires.

The use of categorization of variables in both Papers I and II could have possibly led to the loss of power when performing inferential statistics (243). However, the use of previously used cut-offs and standardized cut-off values might instead have facilitated generalizability and an easier interpretation.

One major weakness to consider is the lack of cognitive measure at baseline and at follow-up visit at three months. As cognitive deficits are common in people with stroke (244) and as this probably might influence how people perceive the care transition, receive information, and what type of support they might need in relation to the care transition, this is an important thing to recognize. Further, the lack of measurement of patients' health literacy is a major weakness, as this is could be a contributing factor to the outcome of care transitions and affect discharge instructions and the possibility to self-manage after discharge (245).

7.2.2 Trustworthiness - Papers III and IV

When appraising quality in qualitative methods, the concepts of rigour and trustworthiness are mentioned. Lincoln and Guba suggested four criteria in the pursuit of trustworthiness: credibility, dependability, confirmability, and transferability (246). The criteria of credibility refers to what extent the findings of the study can be trusted to correspond with and represent the original data and views and experiences of the participants (246). Hence, this is related to

all steps of the process and the alignment from research question, sampling, data collection, analysis, and results.

Both Papers III and IV used different sources of data in combination with a multiple stakeholder perspective. The different sources of data in Paper III (focus groups, individual interviews, and dyads) and Paper IV (observations, field-notes, recorded reflections, individual interviews and questionnaires) together with the different perspectives involved, i.e. people with stroke, significant others and healthcare professionals contributed to the gathering of rich data. This helped explore the aims of the papers in a rigorous way and should be seen as a strength of the present thesis.

The use of theoretical sampling in Paper III strengthened the rigour of the study as it gave an opportunity to explore upcoming topics or questions related to the study's aim. The pursuit for theoretical saturation (186), together with the constant comparative method generated a prolonged engagement in the field of study and generated rich data, which can be seen to strengthen the credibility and trustworthiness of the study (247). Further, the iterative process and constant comparative method strengthened credibility as it gave an opportunity to affirm and refine the emerging findings, in turn generating a deepened understanding of the care transition process. However, one limitation was the lack of involvement of decision makers and managers in the data collection, as some findings pointed towards organizational structures as a barrier to coordinated care transitions. But due to limitations in time and resources we had to limit the data collection to the clinical and professional level.

In Paper IV, the sample was limited to the participants who were involved in the co-design process. As the involved patients and significant others were underrepresented, this might have affected both the outcome of the co-design process and the findings in Paper IV and should be seen as a limitation. The use of different sources of data in this study generated richness. We might have gained a deepened understanding if all healthcare professionals had been interviewed instead of filling out a questionnaire. On the other hand, the use of questionnaire and interview enabled a variation in how participants could express themselves.

Different forms of triangulation were used in both Papers III and IV. Investigator triangulation was used during the analysis and interpretation of data. The different sources of data in Paper III (focus groups, individual interviews, and dyads) and Paper IV (observations, field-notes, recorded reflections, individual interviews, and questionnaires) together with the different perspectives involved, i.e. people with stroke, significant others, and healthcare professionals, enabled the validation of data through triangulation of sources. This further strengthened the credibility of the two papers.

Something to consider regarding Paper III is the constructivist view that knowledge and reality are socially constructed through processes and interactions (186). This means a rejection of the positivist view on researcher objectivity and the claim of scientific neutrality, and the approach we have applied to Paper III. This entails the position of the researcher as an evident part of the construction of theory. Instead the researcher is considered an active ingredient through all

steps of the research process. This view claims reflexivity from the researcher to be open one's stance, values, and role in the process. My own background, working within hospital setting, might have influenced my preconceptions about the care transition process in focus in Paper III. Further, the strong user-centred approach of patients and the significant other in Paper IV might have neglected the healthcare professionals' work-related experience. In Paper IV the observers of the co-design workshops were the same as those who conducted the analysis of data, which might have affected the interpretation of the data. However, we used a reflexive approach during the analysis in an attempt to avoid any preconceived assumptions.

Reflexivity was used through the whole all steps of the qualitative papers, through a continuous self-reflection about my own position and how that affected the different steps within Papers III and IV. Further, there was continuous discussion with the co-authors about our positions in relation to data and we constantly reminded ourselves to affirm that the analysis and findings were grounded in data, we not in preconceived assumptions. In Paper III, the constant comparative method and memo-writing was helpful to either affirm or refine the data, and continuously stay grounded in data.

Dependability and conformability refer to what extent the findings are consistent and could be repeatable by others and the extent to which there is an alignment between data and the findings. In both Papers III and IV the involved researchers discussed each step of the analysis and confirmed the findings in order to enhance conformability, although there is a possibility that mine and the other authors' backgrounds have influenced the analytic process. One further limitation is the lack of examples and description provided in order for the reader to follow examples on how the coding process was carried out and how the links between the steps aligned. Citations were provided to connect the data with the findings.

The transferability of the findings might be limited. In Paper III the findings are closely related to the context in which the data collection is performed. This makes transferability difficult to achieve. However, the intention with Paper III is not primarily to provide generalizable findings. To enable others to make assumptions about the transferability of the findings we provided detailed information about the context and the studied population. The context in Paper IV also has a large bearing on the results. We have tried to describe the context and the co-design process in detail to enable potential readers to assess the generalizability to another context.

7.3 ETHICAL CONSIDERATIONS

Patients experiencing a stroke as well as their significant others are in a vulnerable state. The recruitment of patients to our research project might have caused increased concern and contributed to stress upon discharge from the hospital. With a short LOS and a lot of procedures and things going on at hospital, additional information about participation in research might have led to minor confusion on the different types of information. Verbal and written information were given to the patients with opportunities for questions and contemplation. All participants provided a written consent before being included in the study. A reminder about

the study was sent out with the questionnaire one week after discharge, including contact details. A telephone call to make an appointment for the follow-up visits at three months was used as a reminder of the study, and the occasion was used to repeat information if necessary. At follow-up visits, patients were informed once again, and reminded that participation in the research was voluntary and could be interrupted at any point without further explanation.

The quantitative data collection could at times be burdensome for the persons with stroke, with regards to both energy and time. Especially demanding was the 12-month follow-up for people with a more severe stroke. Careful considerations were made to follow the patient's general condition and well-being. The structured interview had a standardized priority of included questionnaire and tests. Patients could end the follow-up at any time. In some cases where the follow-up had to be interrupted, an additional visit was scheduled, upon request of the participant, to complete remaining questionnaires.

The qualitative interviews with persons with stroke and significant others sometimes evoked reflections about the care and rehabilitation they might have received, which could provoke difficult feelings and thoughts. If this was the case, the option to discuss and reflect about this with the interviewer was offered. In these cases, the face-to-face follow-up visits and interview were a strength, by not leaving the people alone at a potential difficult time. The reserved time for interviews and follow-up visits was planned with a margin to prevent stressful situations.

The burden of health care professionals was also taken into consideration during recruitment and data collection. Interviews were made at a time and place for their convenience to avoid any adverse impact on workload.

To enable the participation in the co-design study, the employers of the participants received reimbursement for the time the participants were absent from work. Unfortunately, due to legal and policy restrictions no compensation could be offered to the participants who were retired.

The co-design process involved some ethical dilemmas. As conflicts and frustration were caused during the workshop series this had to be approached and reflected upon. The balance of power between the participants in the workshop must be given attention. In order to meet individual needs during the co-design process, we used a reflexive approach and adjusted the process to be able to facilitate participants' well-being and their participation within the process. Much efforts were put into enabling an open discussion and climate and making the participants feel comfortable to express their opinions and experiences.

7.4 CONCLUSIONS

This thesis has contributed with knowledge of the organization of the current stroke care trajectory in which the care transitions from hospital to continued rehabilitation in the home are included, with regards to resource utilization, patients and significant others outcome and how the care transitions are experienced. This knowledge is crucial in the development of new person-centred care transitions. Further, this thesis has contributed with knowledge of how participation in co-codesign process involving several different stakeholders can manifest itself and the different various factors that affect the individual's participation in such a process.

The findings highlight that the involvement of patients' and significant others needs to be enhanced during the different steps in the care transition process. Patients need to be more informed and prepared for the hospital discharge, with increased control over their situation. For the patients to be able to take care of their own health after discharge the dialogue and support for self-management need to be strengthened. In addition, the role of the significant others needs to be recognised. The involvement of significant others in dialogue could help avoid feelings of uncertainty and stress but also increase knowledge on how to best support the person with stroke.

The care transition consists of several parallel processes in need of synthetization and coordination for a common understanding about the care transition as a whole and that is based on patients' needs and preferences. This could be done by establishing forums with possibilities for patients, significant others and healthcare professionals to meet in dialogue.

The manifestation of participation in a co-design process is dependent on several inter-related factors, hence participation in a co-design process needs to be asserted continuous reflection, discussion and adaption in order to facilitate the unique knowledge and experience of the involved stakeholders.

In summary, the findings of this thesis can be part of the foundation in a future person-centred care transition and further contribute to developments and discussion within the field of participatory design.

7.5 CLINICAL IMPLICATIONS

The findings of this thesis have several clinical implications. To begin with the care and rehabilitation must be designed from the patient's perspective and not only from a professional and organizational perspective. We, as healthcare professionals need to ensure an understanding of the patient's situation after stroke. Thus, we must invest time and efforts for dialogue and exploration of patients' needs and preferences. This will improve the involvement of patients and hopefully contribute to an exchange of information, a mutual understanding and contribute to the individualisation of information and support during the care transition.

The information and preparation for discharge needs to be enhanced. The information and dialogue need to address procedures at hospital, information about the health condition and self-management as well as information and dialogue about discharge and preparations on what

to expect after discharge. Further, it is important to focus not only on the provision of information but on the understanding and assimilation of information through dialogue.

The findings further implicate a need to enhance the integration both within and between organizations. Synthetization of all parallel processes could enable a holistic decision-making process and the possibility to provide care and rehabilitation in a cohesive way. As this was dependent on creating links to meet in dialogue, organizations need to consider how to best incorporate and enable forums for a perceptive dialogue into their existing services.

The findings also have implications and relevance for managers of organizations to provide a permissive environment and resources to facilitate a person-centred approach and links between healthcare professionals both within and across organizations.

As the use of participatory design is expected from policy level, there is a need to consider the complex interlinked factors and a flexible approach in participatory design processes to facilitate its implementation.

7.6 FUTURE RESEARCH

- Future research should study how person-centred care transition can be developed and implemented in a co-design process with all involved stakeholders, as well as the perceived quality and patient and significant other outcome of such transitions.

- There is a need to further investigate how follow-up and rehabilitation correspond to the needs of patients in a short- and long-term perspective.

- As people with stroke often have complex healthcare needs it is important to study how rehabilitation and medical care services can be coordinated for an integrated care transition between hospital and home.

- It is important to study how municipality based health services such as home care services can be integrated in a person-centred care transition.

- Means for involvement and support of significant others in care transitions between hospital and home need to be developed and evaluated.

- There is a need to investigate how research and healthcare can evaluate the quality of care transition to include the whole care transition and not only preparations conducted during the hospital stay.

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”Ingenting får hända dig
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Allt måste hända dig
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- Bodil Malmsten, Det här är hjärtat.

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