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REWORK-STROKE – CONTENT AND EXPERIENCES OF A PERSON-CENTRED REHABILITATION PROGRAMME FOR RETURN TO WORK AFTER STROKE

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ReWork-Stroke – Content and experiences of a person-centred rehabilitation programme for return to work after stroke

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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I would like to dedicate this thesis to you, all the persons that have had a stroke. To you, who are struggling to return to former activities and to find new meaningful activities in life. To you, who are dealing with so many challenges in your “new” daily life, challenges that we others´ can´t fully understand.

I would like to thank you, who have shared your experiences and knowledge in such a generous way, and given me energy, power and courage to continue this work. It is for you that I have kept on working and finalizing this thesis.



And,

To my family with love

ABSTRACT

The process of return to work (RTW) after stroke is complex, less than half of those having stroke in working ages RTW. Guidelines targeting RTW in Sweden is lacking.

The overall aim was to enhance the knowledge regarding rehabilitation for return to work after stroke and to explore how the person-centred rehabilitation programme ReWork-Stroke was translated into practice, for people who worked before their stroke, as well as the experiences of the involved stakeholders. Additionally, the aim was to explore changes in work potential and work performance while participating in the rehabilitation programme.

Methods: Study I used a descriptive case study design to explore and describe the core elements of the ReWork-Stroke programme as they were documented by the coordinators, and their experiences of providing the programme to people who had had a stroke. The two interviews with the coordinators and their logbooks were analysed using content analysis. Study II applied a grounded theory approach in order to explore and describe how people that had had a stroke experienced the RTW process while participating in a person-centred rehabilitation programme focusing on RTW. Seven persons with mild or moderate stroke were interviewed twice at their work place during their work-trial. Study III was inspired by grounded theory aiming to explore and describe how co-workers and managers experienced the RTW process involving a colleague who had had stroke and participated in a person-centred rehabilitation programme focusing on RTW including a work-trial. Sixteen interviews were conducted with seven co-workers and four managers during the work-trial of a colleague who had had stroke. Study IV used a mixed method approach with an explanatory sequential design in order to explore changes in work potential and work performance while participating in a person-centred rehabilitation programme for people who worked before their stroke.

Results: Time use, place and format for elements in the programme varied between clients. Core elements identified were: make aware of consequences of stroke; provide information to stakeholders; use of strategies to handle work tasks; assessments, goalsetting and evaluation of work ability; planning/follow up of work trial. The coordinators experienced their role to build an alliance between stakeholders and to give support and guidance during the RTW process. Knowledge of stroke, strategies and a straightforward communication facilitated the possibility to adapt to the situation for the persons that had had stroke. The co-workers and managers experienced various challenges; the emotional challenge of being a supportive co-worker or manager, the challenging experience of having too much responsibility and the challenge of being supportive despite lack of knowledge. Changes in work potential and work performance varied among the participants and were mostly in a positive direction. Various strategies were used by the coordinators in cooperation with those involved at the work place to handle the different needs.

Conclusion: The ReWork-Stroke programme included various elements adapted to the needs of the individuals. The involvement of the coordinator seemed to facilitate the RTW process and collaboration among the different stakeholders. Establishing a commitment between the employer and all involved stakeholders was of importance.

Key words: occupational therapy, rehabilitation, return-to-work, ReWork-Stroke, stroke experiences, work place, person-centredness, coordinator

SAMMANFATTNING

Introduktion: Processen att återgå i arbete efter stroke är komplex. Färre än hälften av de som får stroke i yrkesverksam ålder återgår i arbete. Riktlinjer saknas gällande arbetslivsinriktad rehabilitering i Sverige.

Det övergripande syftet var att öka kunskapen kring arbetslivsinriktad rehabilitering efter stroke och att utforska hur det personcentrerade rehabiliteringsprogrammet ReWork-Stroke fungerade i praktiken för personerna som arbetade innan de fick stroke och hur det upplevdes av olika aktörer. Syftet var även att undersöka förändringar i arbetspotential och arbetsutförande under tiden som personerna deltog i rehabiliteringsprogrammet.

Metod: I studie I användes en beskrivande fallstudiedesign för att utforska och beskriva huvuddelarna i programmet ReWork-Stroke såsom det dokumenterats av koordinatorena samt deras upplevelser av att utföra programmet. De två intervjuerna med koordinatorena samt deras loggböcker analyserades med innehållsanalys. I studie II användes grundad teori för att utforska och beskriva hur sju personer med mild eller måttlig stroke upplevde processen för återgång i arbete när de deltog i rehabiliteringsprogrammet. Individuella intervjuer gjordes vid två tillfällen på deras respektive arbetsplatser. Studie III var inspirerad av grundad teori och syftet var att utforska och beskriva hur arbetskamrater och chefer upplevde processen för återgång i arbete gällande sin kollega som efter stroke deltog i rehabiliteringsprogrammet. Sexton intervjuer gjordes med sju arbetskamrater samt fyra chefer under tiden som kollegan deltog i programmet. I studie IV användes mixad metod för att utforska förändringar i arbetspotential och arbetsutförande under deltagandet i rehabiliteringsprogrammet hos personer som arbetade före stroke.

Resultat: Insatserna i programmet varierade mellan deltagarna gällande tidsåtgång, sättet rehabiliteringen utfördes på samt vilka insatser som utfördes och var. Huvudinnehållet var att medvetandegöra konsekvenserna av stroke, ge information till olika aktörer, göra bedömningar, ge förslag på samt utvärdera strategier och arbetsförmåga, sätta mål samt planera för arbetsåtergång. Koordinatorerna såg betydelsen av att vara en sammanhållande länk och bilda en allians mellan de olika aktörerna där koordinatorena gav stöd och guidning under processen för arbetsåtergång. Kunskap om stroke och strategier samt tydlig kommunikation underlättade möjligheterna att anpassa sig till den nya situationen enligt både personerna som hade haft stroke och deras arbetskamrater och chefer. Arbetskamrater och chefer upplevde olika utmaningar under arbetsträningen som den känslomässiga utmaningen att vara stödjande trots bristande kunskap samt att ha för mycket ansvar. Förändringarna gällande arbetspotential och arbetsutförande varierade mellan deltagarna men var i huvudsak positiva. Individuella strategier användes av koordinatorena i samarbete med de olika aktörerna för att hantera behoven.

Konklusion: I programmet ReWork-Stroke ingick flera olika delar som anpassades till deltagarnas behov. Koordinatorns engagemang förefaller ha underlättat processen för återgång i arbete och samarbetet mellan olika aktörer. Att bygga upp ett engagemang hos arbetsgivare/chef och övriga inblandade är viktigt för samarbetet och för en fungerande arbetsåtergångsprocess.

Nyckelord: arbetsterapi, arbetsrehabilitering, återgång i arbete, ReWork-Stroke, stroke, upplevelser, arbetsplats, personcentrering, koordinator

LIST OF SCIENTIFIC PAPERS

- I. Johansson, U., Öst Nilsson, A., Hellman, T., Hansen Falkdal, A., von Koch, L., & Eriksson, G. The ReWork-Stroke programme – Content and experiences from the coordinator perspective. (In manuscript)
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- III. Öst Nilsson, A., Eriksson, G., Asaba, E., Johansson, U., & Hellman, T. (2019). Being a co-worker or a manager of a colleague returning to work after stroke: A challenge facilitated by cooperation and flexibility. *Scandinavian Journal of Occupational Therapy*.
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- IV. Öst Nilsson, A., Johansson, U., Ekbladh, E., Bernspång, B., Hellman, T., & Eriksson, G. The return to work process after stroke – Changes in work potential and work performance while participating in a person-centred rehabilitation programme. (In manuscript)

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LIST OF ABBREVIATIONS

AWC	Assessment of Work Characteristics
AWP	Assessment of Work Performance
ADL	Activities of Daily Living
FSS	Fatigue Severity Scale
GP	General Practitioner
GT	Grounded Theory
ICF	International Classification of Functioning, Disability and Health
MOHO	Model of Human Occupation
MRC	Medical Research Council
OT	Occupational Therapist
RTW	Return to work
RTW process	Return to work process
SIS	Stroke Impact Scale
SSIA	Swedish Social Insurance Agency
TIDieR	Template for Intervention Description and Replication
WHO	World Health Organization
WRI	Worker Role Interview

1 PERSONAL INTRODUCTION

During my 20 years working as an occupational therapist (OT) I have been amazed by peoples´ driving forces and the power people can muster to handle different challenges in daily life. As an OT I have met people in their homes, at specialized rehabilitation units, in daycare units and so on in order to find out important activities and tasks for them for focus on during rehabilitation. I´m so thankful for having the opportunity to share all these moments and situations, to be a part of peoples´ lives and to hear about their dreams and goals, something that many of us take for granted when daily activities works without interruptions. I have learned so much from these people and from these meetings, about what is important and meaningful in life. Through these meetings I have also had the opportunity to work with wonderful colleagues in different professions, with different personalities and ideas. I have seen and understood the value of working in teams, with our client in the center, where every person is important and can contribute with their unique perspective and knowledge. Together we have made change, change in daily life, in our clients´ lives and in our lives. Together through collaboration in our teams encouraged by our clients we have found solutions to overcome problematic situations and reached goals. Together we can make change, now and in the future. These changes that we initiate and shape together in our clinical practice can be expressed and put on paper in research. Through research we can give the words we hear and express in clinical practice a voice. Through research we can make our experiences visible for other people in the society. By combining practice and research we can make change, now and in the future, together.

Through my research I have also got the opportunity to share experiences, goals and dreams, but in other environments and places than I´m used to be in. However, in some way the circle is now completed. During the 90´s I also visited workplaces, but as an OT belonging to a team at a rehabilitation unit, and not as a researcher. Some of my questions concerning the complex process of returning to work were raised at that time, and now, many years later, some questions got an answer while others´ did not. My curiosity and my wish to make change for people, with people, has been my driving force through these years within the research field. The same driving force that got me into the field of occupational therapy. To make change, meaningful change, together in our daily life of daily activities.

A poem about research, occupational therapy and life itself

Jag tar små steg på bearbetningens trappa

Sakta, sakta binder jag förståelsens krans

Väver insiktens matta

Dagar och nätter passerar

Steg för steg, förstår jag allt mer

Vissa frågor förblir obesvarade

När livet går vidare

Steg för steg

2 BACKGROUND

2.1 WORK AND THE IMPORTANCE OF WORK AS A HUMAN OCCUPATION

Work and returning to work after stroke is the focus of this thesis. Work is essential in peoples' lives, improves psychosocial wellbeing (Waddell & Burton, 2006; Wei, Liu, & Fong, 2016), and is important for developing a person's self-esteem and social status (Baldwin & Brusco, 2011). The noun work is defined in many different ways. In Merriam-Webster, Dictionary (n.d.) the definition for work is "*an activity in which one exerts strength or faculties to do or perform something*". In the International Classification of Functioning, Disability, and Health (ICF) work is defined as: "*engaging in all aspects of work, as an occupation, trade, profession or other for employment, for payment or when payment is not provided, as an employee, full-time or part-time, or self-employed...*" (World Health Organization [WHO], 2001, p. 171, d850). Both of these definitions mainly concern paid employment which is also the goal for the persons that want to return to work (RTW) that are presented in this thesis. A broader definition of work can even include duties that are not paid, such as household chores. However, a person's identity is closely connected to work (Taylor, 2017) and the social context is of central value when considering worker identities, orientations and commitments to work (Coutu, Coté, & Baril, 2013).

Within occupational therapy literature, work is framed as one of several human occupations and the concept of occupation is central. Occupations concern what we do in everyday life. Human occupation is, in the Model of Human Occupation (MOHO), defined as: "*the doing of work, play or activities of daily living within a temporal, physical and sociocultural context that characterizes much of human life*" (Kielhofner, 2008, p. 5). Another way to frame occupation is the everyday things that people do and that are considered to be those things that provide a person with meaning and identity (American Occupational Therapy Association [AOTA], 2017). The MOHO is chosen as the theoretical underpinning in this research to assist in the reasoning on how occupations such as work but also other everyday occupations are motivated, patterned, and performed (Kielhofner, 2008) among people that are in the process of returning to work after stroke. Work is seen as one of many productive occupations and includes both paid and unpaid work. The undertaking of occupations in this model is divided into three levels: participation in occupations, which refers to the overall engagement in work or other occupations; performance of occupations, which refers to the doing of the specific tasks to accomplish the actual occupation; and the skills, which are the actions needed for the performance of the occupation. The performance of, for example, a work task is dependent upon the interaction between the individual's characteristics, the demands of the actual work task, and the work environment where the performance takes place. In this thesis the engagement in work (participation level) as well as the actual performance of work tasks (performance and skills level) are considered and supported.

2.1.1 The importance of being engaged in work after stroke

For many of those having a stroke while they are of working age, the primary goal is to RTW (Edwards, Kapoor, Linkewich, & Swartz, 2018; Westerlind, Persson, & Sunnerhagen, 2017) and returning to work was an essential indicator on recovery for young persons with stroke (Alaszewski, Alaszewski, Potter, & Penhale, 2007). Being motivated to RTW was one of the inclusion criteria in the studies constituting this research. For a person who has had a stroke, it can be central to reconstruct the occupational identity (Walder & Molineux, 2017) by enabling engagement in meaningful and purposeful occupations (Clark, 1993; Fisher, 1998; Townsend & Polatajko, 2013) such as resuming work. Work can be therapeutic and have positive health effects both for people with disabilities (Waddell & Burton, 2006) and for those without (Coutu et al., 2013).

Being outside the work force has been described as the hardest thing in life and as a psychological distress (Stone, 2003). Employment after stroke promotes life satisfaction and wellbeing (Wei et al., 2016), and is considered to be a very important predictor for quality of life (Donker-Cools, Wind, & Frings-Dresen, 2015; van Velzen, van Bennekom, Edelaar, Sluiter, & Frings-Dresen, 2009), and higher health-related quality of life was scored among persons with stroke who worked compared to a non-working group (Westerlind et al., 2017). Work satisfaction has also been found to increase with the amount of hours of paid work a week in a sample where only half of the participants returned to the same level of working hours as before the stroke (van der Kemp et al., 2017). This variation among individuals and the different preconditions are important to capture in the RTW process.

2.2 PERSON-CENTREDNESS IN RETURN TO WORK PROCESSES

Person-centredness is a philosophy for organising and delivering healthcare that sees the persons using the service as equal partners, working together with the professionals to reach the best outcome. In occupational therapy the concept client-centredness is commonly used, implicating that occupational therapists in practice should demonstrate respect for their clients, involve them in decision making, be aware of their experiences and knowledge, and meet their needs (Townsend & Polatajko, 2007), which corresponds to the practice of being person-centred (Jesus, Bright, Kayes, & Cott, 2016). Both concepts build on Rogers' ideas about client-centred practice (Rogers, 1951). In this thesis, using a person-centred approach in the ReWork-Stroke programme was a self-evident choice as it has been found that setting person-centred goals, making individual-specific plans for the RTW process, including adaptations of work tasks and working hours, was effective (Ntsiea, Van Aswegen, Lord, & Olorunju, 2015; Trexler, Trexler, Malec, Klyce, & Parrott, 2010). In a conceptual analysis of person-centredness, Leplege and colleagues (2007) identified four different interpretations or meanings of the concept addressing the person's specific properties and context, his/her needs and difficulties. Central is also respecting the person as expert on his/her own conditions. All these meanings are relevant and of importance in RTW processes and also guided the development of the core elements in the ReWork-Stroke programme. Partnership with the client, which is the foundation in the programme, is emphasized in person-centred care

(Ekman et al., 2011) and occupational therapy (Townsend & Polatajko, 2013) where the client's story is seen as a point of departure for the future collaboration in the rehabilitation process. Furthermore, client-centred practice (Townsend & Polatajko, 2007) is a collaborative approach in which the clients also can be groups, agencies etc. In this thesis, the client/person-centred approach also included all involved at the work place.

2.3 THE CONCEPT AND DIMENSIONS OF WORK (DIS) ABILITY

The concept of work ability has physical, psychological and social dimensions (Ludvigsson, Svensson, & Alexandersson, 2006) and has several definitions that can diverge between fields such as medicine and law (Bostrom, Holmgren, Sluiter, Hagberg, & Grimby-Ekman, 2016). Loisel and colleagues (2014) defined work inability as: "*occurring when a worker is unable to stay at work or return to work because of an injury or disease*" (p. ix). In earlier literature, work ability has been viewed from a biomedical perspective, i.e. as a condition related to impairment, or from an insurance perspective, i.e. the legal and financial consequences as compensation after work disability due to impairment (Lederer, Loisel, Rivard, & Champagne, 2014). Over the last decades, a more multifactorial view on disability has emerged and, in accordance with that, work disability cannot be seen only as an individual condition but also within a social and societal context. According to a scoping review by Lederer and colleagues (2014), it now seems to be a consensus that work (dis)ability is a: "*relational concept resulting from the interaction between multiple dimensions that are influencing each other through different ecological levels*" (p. 242). In the shift from focusing work disability to considering work ability, there is a need to reflect on several factors, i.e. the congruence and balance between the individuals' resources and the demands in the work that influence work ability (Ilmarinen, Ilmarinen, Huuhtanen, Louhevaara, & Nasman, 2015). The complexity and content of work ability is visualized and described in the Work ability house (Figure 1). The Work ability house comprises four floors that contain different components: 1) health and functional capacity (constituting the basis for work ability), 2) education, competence, occupational skills, 3) attitudes to and motivation for work, and 4) work content, work organisation, working climate and management. Work ability is, according to Ilmarinen and colleagues (2015), influenced by how these different floors/components are sustained and how supportive they are to each other. In accordance with Ilmarinen the work ability can be improved or reduced by organisational factors in the work context as well as the psychosocial working climate and the private life (Bostrom et al., 2016). Viewing work ability as a relational concept with all these components fits well with the perspective used in this thesis and approaches that have been proposed in research on interventions focusing on RTW after stroke (Donker-Cools, Daams, Wind, & Frings-Dresen, 2016).

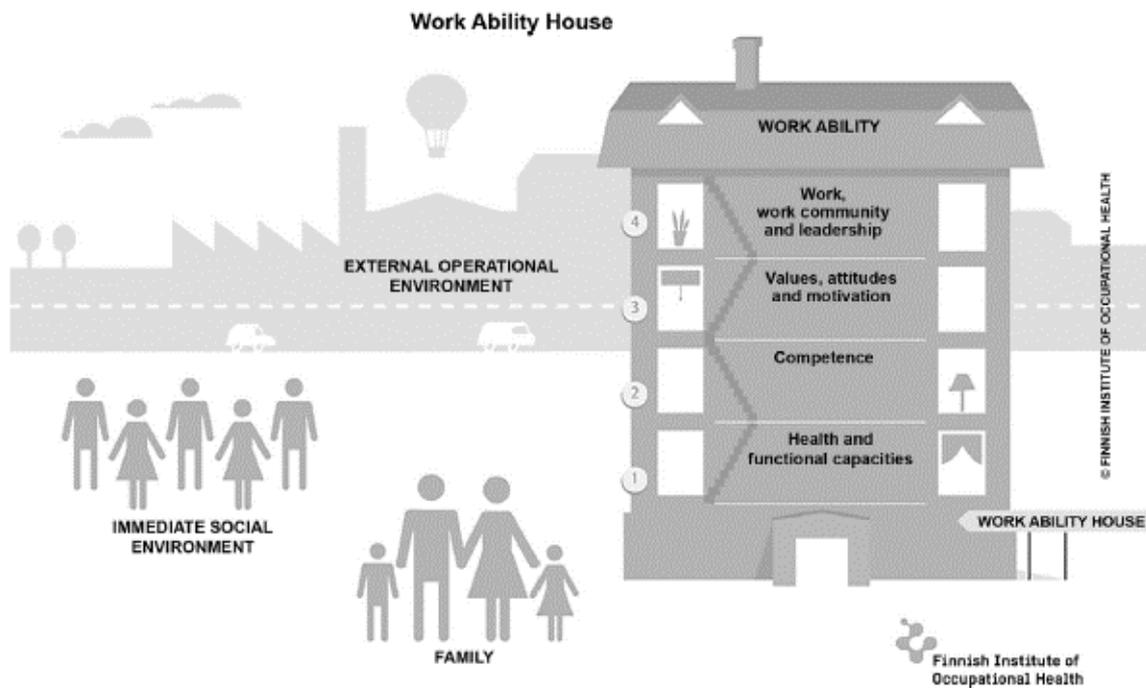


Figure 1. The Work Ability House according to © Finnish Institute of Occupational Health.

There are several factors that need to be considered to understand how and why a person functions in the way he/she does in the work situation. Work ability can be affected by personal factors, environmental factors at work and in private life, as well as past experiences and expectations for a future working life. Consequently, in assessments of work ability a combination of several instruments is needed (Sandqvist & Ekbladh, 2017). In this thesis, assessments based on the Model of Human Occupation were used. In study IV the participant's work performance, i.e. how efficient and appropriate he/she performed work tasks and their psychosocial work potential was assessed.

2.4 RETURN TO WORK AND THE RETURN TO WORK PROCESS

The concept of RTW has been utilized both as an outcome measure of disability regarding the status of working or not working, and as the process of returning to work (Schultz, Stowell, Feuerstein, & Gatchel, 2007). In this thesis RTW is seen, in accordance with Young and colleagues (2005), as a developmental and dynamic process: *“encompassing a series of events, transitions and phases and includes interactions with other individuals and the environment. The process begins at the onset of work disability and concludes when a satisfactory long-term outcome has been achieved”* (p. 559). This definition indicates that an outcome of the process can be both returning to work and not returning to work.

The process of returning to work for persons with disabilities is complex and has numerous challenges due to legal, administrative, social, political, and cultural aspects. The complexity of the process is captured by Loisel and colleagues (2005) in the Sherbrooke model (Figure 2), where the different stakeholders involved in the arena of work disability are identified. It puts the worker in the centre and depicts four influential systems of her/his work situation: the personal system, the healthcare system, the work place system, and the compensation

system. This model is used as a theoretical point of departure in this research project. These systems/stakeholders have different roles and responsibilities in the RTW process and the actual societal context can influence how the stakeholders fulfil their responsibilities.

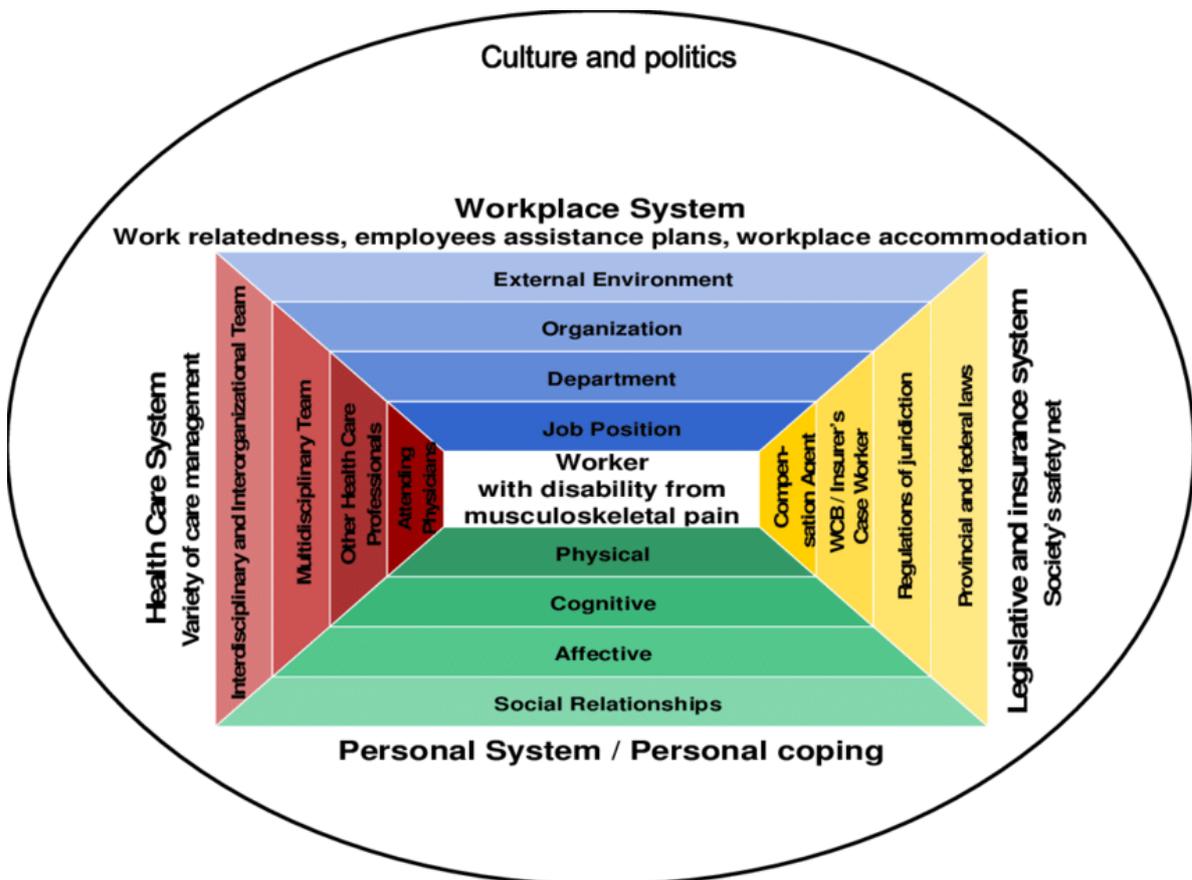


Figure 2. The Sherbrooke model. Reused form: Loisel P, Bushbinder R, Hazard R, Keller R. Prevention of work disability due to musculoskeletal disorders: the challenge of implementing evidence. *J Occup Rehabil* 2005; Dec;15 (4):507-24 with permission from Springer Nature.

Vocational rehabilitation involves many different stakeholders whose objective is to enable people with health problems to return to and remain in work (Waddell, Burton, & Kendall, 2008). Vocational rehabilitation in Sweden is based on five stakeholders: the individual and the employer, and three governmental agencies comprising Healthcare, the Swedish Social Insurance Agency (SSIA), and the Swedish Public Employment Services. These stakeholders share the responsibility to support persons on sickness absence in their RTW. The employer has the main responsibility to take measures to facilitate the RTW process according to the Swedish Working Environment Act (SFS 1977:1160). Healthcare involved in the RTW process after stroke is typically multi-disciplinary teams specialized in medical rehabilitation. Primary healthcare services with more generalized services and physicians can also be involved in the RTW process. The SSIA's main responsibility is to determine if an individual has the right to receive sick leave compensation and to coordinate rehabilitation resources for individuals who are on sick leave. The Swedish Public Employment Services become involved for persons who are unemployed or at risk of unemployment.

During the process of RTW, the different stakeholders are involved at different time points (Hellman, Bergström, Eriksson, Hansen Falkdal, & Johansson, 2016). A lack of continuity has been pointed out by persons with stroke who have experienced an RTW process. They were unsure of who actually was responsible and for what, and felt that no one took full responsibility for the complete process (Hellman et al., 2016; Vestling, Ramel, & Iwarsson, 2013). This situation has been one of the underpinnings of the research presented in this thesis.

In Sweden, a recent agreement between the Government and the Swedish Association of Local Authorities and Regions was reached where the role of healthcare in work related rehabilitation was explored (SKL, 2019). The agreement imposed that the support and interventions from healthcare should be developed and improved for persons on sick leave and who had difficulties in returning to work. It was also proposed that more responsibility and resources were given to healthcare for handling RTW issues. According to the proposal, which has recently been implemented in some county councils: 1) an assessment support will be implemented in healthcare to identify needs of RTW interventions early in the process, and estimate when collaboration with employers should be initiated, 2) healthcare should routinely include actions for returning people to work, 3) increased support to employers was emphasized, and 4) more resources to improve follow-up and evaluations of RTW interventions should be provided.

2.5 STROKE AND CONSEQUENCES OF STROKE

Stroke is one of the leading diseases worldwide (WHO, 2018). In Sweden, 25,800 people had a stroke 2017 (Socialstyrelsen, 2018b). The incidence of stroke has in recent years increased in younger people nationally (Medin, Nordlund, & Ekberg, 2004; Rosengren et al., 2013) and also internationally (Rolfs et al., 2013; Sultan & Elkind, 2012; Wei et al., 2016).

Approximately one-fifth of strokes in Sweden occur in persons of working age (Lallukka et al., 2018). Stroke often leads to decreased functioning in everyday life due to impairments, activity limitations, and participation restrictions. Common symptoms after a stroke are sensory impairment or paralysis/weakness, often on one side of the body. Other symptoms can be related to speech and eyesight (WHO, 2016) and to more “hidden” symptoms such as fatigue (Lerdal et al., 2009) that is experienced by about 80% of people that had had stroke (Alaszewski et al., 2007), cognitive and emotional changes such as depression (Carlsson, Moller, & Blomstrand, 2004; Lerdal et al., 2011), and lack of awareness of disabilities (Ekstam, Uppgard, Kottorp, & Tham, 2007). Approximately two-thirds live with an ongoing disability after stroke (WHO, 2016). Returning to life as it was before stroke can be a long-term struggle (Socialstyrelsen, 2018a). Restrictions in participation in everyday life and in performing daily activities still are common three years after stroke (Riksstroke, 2018). Work disability is one major consequence (Arwert et al., 2017).

2.6 RETURN TO WORK AFTER STROKE

In Sweden, more than 50% of people of working age do not RTW after their stroke (Riksstroke, 2016). The percentage of people who do RTW after stroke varies a lot between studies, probably due to different follow-up periods, varying study samples, and also different definitions of work and stroke (van der Kemp et al., 2017). In a review on working-age people after stroke (Daniel, Wolfe, Busch, & McKeivitt, 2009) 70 studies reported great variations in proportions (0-100%) that had returned to work, with a mean RTW rate of 44%. Returning to work after stroke often takes time and the RTW rate can increase over time up to four years after onset (Edwards et al., 2018). In a recent study (Westerlind et al., 2017) persons continued to RTW for more than three years after stroke. At one year post-stroke, 48.3% of persons had RTW while at follow-up six years post stroke this figure had increased to 74.7%.

2.6.1 Predictors for not returning to work after stroke

There are several predictors for not returning to work after stroke. Sick leave prior to stroke, severe stroke (Wozniak & Kittner, 2002), and a more severe disability are risk factors for not RTW (Westerlind et al., 2017), as well as aphasia and attention dysfunction (Tanaka, Toyonaga, & Hashimoto, 2014). There are significantly lower RTW rates for persons with cognitive impairment and depression after stroke compared to those without these consequences (Fride et al., 2015). Post-stroke fatigue appears to be a strong determinant for not returning to paid work (Andersen, Christensen, Kirkevold, & Johnsen, 2012) and was rated as the greatest barrier for returning to work within the first year of stroke (Ntsiea et al., 2015). Cognitive functions and especially psychomotor speed and executive function (Edwards et al., 2018) and neurological status, as well as functional independence are strongly related to RTW for persons of working age with stroke (Edwards et al., 2018; Treger, Shames, Giaquinto, & Ring, 2007).

2.6.2 Predictors for returning to work after stroke

Persons who have had RTW support, and who valued work as important, have shown to be more likely to RTW (Lindstrom, Roding, & Sundelin, 2009) as well as people with higher self-efficacy (van der Kemp et al., 2017). Predictive factors for RTW after stroke are younger age, high education, and being a white-collar worker (Treger et al., 2007). However, there has been a lack of consensus concerning predictive factors for RTW for persons with mild to moderate stroke, especially personal and neuropsychological factors. Global cognitive function at two months post-stroke has turned out to be an independent predictor for RTW one year after stroke and should be considered during rehabilitation (van der Kemp et al., 2017).

2.7 EXPERIENCES OF THE RETURN TO WORK PROCESS

In this thesis the process of RTW after stroke is in focus where experiences from different perspectives has been captured. The RTW process after stroke in younger persons can

generate mixed feelings, including both trust and fear of the future work situation (Vestling et al., 2013). People have also reported experiences of lack of support in the process of RTW after stroke (Culler, Wang, Byers, & Trierweiler, 2011; Gilworth, Phil, Cert, Sansam, & Kent, 2009) and in handling the consequences of stroke at work (Gilworth et al., 2009; Vestling et al., 2013), as well as a lack of assistance from vocational specialists (Vestling et al., 2013). The main factors that were experienced as facilitating RTW after stroke were a supportive employer (Culler et al., 2011), strong self-motivation (Gilworth et al., 2009; Vestling et al., 2013) and modifications at the work place (Culler et al., 2011; Gilworth et al., 2009; Vestling et al., 2013). Employers face complex practical and emotional issues during the RTW process for people who has had stroke and may lack knowledge and experience of assisting people in RTW process. Advice and support from clinicians knowledgeable in rehabilitation after stroke are welcomed as the quality of support networks varies. Close cooperation between the individual, health/rehabilitation professionals, and supportive employers is experienced as being of great importance for RTW (Coole, Radford, Grant, & Terry, 2013). A recent meta-analysis by Schwarz and co-workers (2018) confirmed these findings. They identified three fundamental factors for RTW: adaptiveness for both the person who had had stroke and the work place, the experience of purposefulness in the work situation for the person who had had stroke enhancing motivation, and also an openness for cooperation between stakeholders. To find work and work rehabilitation purposeful was underlined as the driving force for the frequently demanding process of RTW.

2.8 COMPLEX INTERVENTIONS IN REHABILITATION TO WORK

In this thesis, the Medical Research Council (MRC) guidelines (Craig et al., 2008), for developing and evaluating complex interventions have been used. Complex interventions are described as comprising multiple components that interact to produce change (Craig et al., 2013). What makes an interaction complex is a) the number and difficulties of behaviours required when delivering or receiving the intervention, b) the number of interacting components within the interventions, c) the number of organization or group levels targeted, and d) the number and variation in outcomes and degree of flexibility or tailoring of the intervention permitted (Craig et al., 2013). The process of developing and evaluating a complex intervention has several non-linear phases. These are the development, feasibility/piloting, evaluation, and implementation phases. In the process of developing the ReWork-Stroke programme, the existing evidence (Coole et al., 2013; Culler et al., 2011; Radford & Walker, 2008) and the gaps in knowledge were identified. Thereafter new knowledge was developed and added (Hellman et al., 2016) and from there the theoretical base for the ReWork-Stroke programme was delineated. In the MRC guidelines (Craig et al., 2013) it is proposed that a series of studies may be required to refine the design of an intervention before conducting a full-scale evaluation. In this thesis, the four studies were conducted to explore the ReWork-Stroke programme from different perspectives to generate knowledge on the experiences of the programme, how it was conducted in practice, and the changes it brought about to be able to develop and refine the programme further and to continue the evaluation process.

2.9 PROGRAMMES FOR RETURN TO WORK AFTER STROKE

There are more RTW programmes designed for people with traumatic brain injuries than there are for people who had had stroke. There are also relatively few rehabilitation programmes for RTW after stroke that have been evaluated: one in South Africa (Ntsiea et al., 2015), one in the United States (Trexler et al., 2010) and also one in the United Kingdom (Grant, 2015). All three programmes used a case coordinator approach focusing on coordination of services and early initiated intervention. The programme in the United Kingdom is found to be feasible and an evaluation is ongoing. The other two programmes have demonstrated positive results compared to rehabilitation as usual. The Swedish National Board of Health and Welfare continuously update National Guidelines for Stroke Care (Socialstyrelsen, 2018a) but guidelines for RTW are lacking in that document.

In this thesis the involvement of the work place and the frequent visits by the coordinators were core activities in the ReWork-Stroke programme. There is an agreement in the literature that the work place is an important arena for action including all people involved in the individual's work situation when promoting RTW regardless of diagnoses or work disability (Donker-Cools et al., 2016; Ekberg, Eklund, & Hensing, 2015). In a review of evidence for effective interventions focusing on RTW for people with acquired brain injuries, including stroke there was strong evidence for work-directed interventions, such as adaptation of work tasks combined with coaching and educational activities. Also, training in work-related and social skills, and coping skills, as well as providing emotional support were related to a positive outcome in the RTW process. Another significant component were involvement of employers and co-workers (Donker-Cools et al., 2016).

2.9.1 Coordinators in return to work

During recent years, the use of rehabilitation coordinators in healthcare in Sweden has increased (Hansen Falkdal, A., Hörnqvist Bylund, S., Edlund C., Janlert, U., & Bernspång, B., 2013), mainly in primary healthcare but also within hospital care, and mainly as coordination between stakeholders in the RTW process has been poor. Professionals in healthcare can include occupational therapists, physiotherapists, and social workers (Hansen Falkdal et al., 2013) but no specified education is required, even if courses are now available. The role of a rehabilitation coordinator differs between county councils. Their ideal assignment is, according to Hansen Falkdal and colleagues (2013), to organise statistical follow-up in the area of sickness absence, to be a support for insurance medicine issues, provide knowledge and advice to general practitioners when issuing medical certificates, be a coach to clients, conduct assessments, formulate rehabilitation plans, and to further collaborate with external stakeholders such as SSIA, the Swedish Public Employment Services, and employers. Being a "spider in the net" in their complex role requires personal skills and qualities (Bohatko-Naismith, James, Guest, & Rivett, 2015), such as excellent communication and organizational skills, as well as being empathic and supportive. The rehabilitation coordinators implemented in primary healthcare are required to have a generic competence with regard to diagnoses and consequences of various illnesses. The coordinators in the

ReWork-Stroke programme were deliberately recruited clinicians who worked in parallel in specialized brain injury rehabilitation teams, as competence in stroke was seen as a prerequisite to coordinate RTW for people with stroke (Hellman et al., 2016). These coordinators' assignments also differed as they predominantly met the persons who had had stroke at their work place and provided the ReWork-Stroke programme.

The ReWork-Stroke programme emanated from an overview of existing knowledge as recommended in the guidelines of the MRC (Craig et al., 2008). The development of the ReWork-Stroke programme was initiated in 2012 as a result of the shortage of guidelines and programmes for RTW after stroke in Sweden. The programme was modelled based on what all involved stakeholders in RTW expressed was necessary to provide in a programme for RTW after stroke (Hellman et al., 2016). It has a person-centred approach, includes a preparation phase of varying length, as well as a phase of work trial, and is coordinated by occupational therapists skilled in rehabilitation. The ReWork-Stroke programme is presented in the Method section of this thesis.

2.10 RATIONALE

Work is central in our society, and fulfils a fundamental and valued role in everyday life for people. Being a worker has a symbolic meaning as it implies having an identity as a professional as well as participating in society and, through that, being socially accepted. Furthermore, it is of economic significance both to the individual and to society. More than half of persons of working age do not RTW after their stroke.

Many stakeholders are involved in the RTW process for people on sickness absence. The stakeholders have different perspectives and knowledge, which can be counterproductive to their collaboration and to the continuity of the RTW process. Knowledge of stroke and its consequences is lacking among employers and they have therefore requested support in the RTW processes. In addition, people who have had stroke experience a lack of support in the RTW process.

There are few evaluated evidence-based programmes for rehabilitation to work after stroke internationally, and Swedish guidelines are lacking.

Coordinators are implemented internationally and in Sweden to support RTW processes. Using coordinators in RTW programmes for people who have had stroke has been effective internationally, but has not yet been tried out in Sweden.

3 RESEARCH AIMS

The overall aim was to enhance the knowledge regarding rehabilitation for return to work after stroke and to explore how the person-centred rehabilitation programme ReWork-Stroke was translated into practice, for people that worked before their stroke as well as the experiences of the involved stakeholders. Additionally, the aim was to explore changes in work potential and work performance while participating in the rehabilitation programme.

The specific aims were:

- I. To explore and describe the core elements of the ReWork-Stroke programme as they were documented by the coordinators, and the coordinators' experiences of providing the programme to people who have had a stroke.
- II. To explore and describe how people that had had a stroke experience the RTW process while participating in a person-centred rehabilitation programme focusing on RTW.
- III. To explore and describe how co-workers and managers experience the RTW process involving a colleague with stroke participating in a person-centred rehabilitation programme that focuses on RTW.
- IV. To explore changes in work potential and work performance while participating in a person-centred rehabilitation programme for people who worked before their stroke.

4 METHODS

4.1 DESIGN

In order to enhance knowledge about rehabilitation for RTW after stroke various methods have been used in this thesis, including both qualitative and quantitative approaches. The four studies intend to capture the different stakeholders' perspectives as described in the Sherbrooke model (Loisel et al., 2005). Study I focuses on the perspective of the healthcare system, study II the perspective of the worker, study III the perspective of the work place system, and study IV the personal system. An overview of the methods and studies used are given in Table 1.

Table 1. Overview of the methods and studies.

	Study I	Study II	Study III	Study IV
Study design	Descriptive case-study	Qualitative, explorative	Qualitative, explorative	Mixed methods
Data collection (when, in time, and occasions)	Interviews: 12 and 18 months after start of the ReWork-Stroke programme Logbooks: continually written during the ReWork-Stroke programme	Interviews on two occasions: 2-3 weeks and 10-12 weeks after start of work trial for the person who had had stroke	Interviews on two occasions: 2-3 weeks and 10-12 weeks after start of work trial for the managers and co-workers of the colleague who had had stroke	Assessments; before and after three months of work trial Logbooks; continually written during the ReWork-Stroke programme
Data collection (methods and instruments)	Semi-structured interviews with two coordinators Logbooks written by the coordinators	Semi-structured interviews with persons who had had stroke	Semi-structured interviews with co-workers and managers – either individually or in pairs	Worker Role Interview Assessment of Work Performance Stroke Impact Scale Fatigue Severity Scale-7 Logbooks written by the coordinators
Methods of data analysis	Descriptive statistics Deductive qualitative content analysis	Constant comparative analysis	Constant comparative analysis	Descriptive statistics Deductive qualitative content analysis

4.2 PARTICIPANTS

The samples included in this thesis have all been involved directly or indirectly in the ReWork-Stroke programme. They were representing various perspectives in the RTW process in order to increase the understanding of how the programme was experienced from their unique points of view. An overview of the characteristics of the participants is given in Table 2.

Table 2. Demographic characteristics of the participants

	Study 1	Study 2	Study 3	Study 4
Participants	Coordinators of the ReWork-Stroke programme	Persons who had had stroke and participated in ReWork-Stroke programme	Co-workers and managers of colleagues who participated in ReWork-Stroke programme	Persons who had had stroke and participated in ReWork-Stroke programme
Gender M/F	-/2	5/2	7/4	7/3
Age, years mean (range)		52 (40-57)		51 (40-57)
Severity of stroke (mild/moderate)		5/2		7/3
Months between stroke onset and inclusion, mean (range)		7.9 (4.5-14)		9.1 (4.5-19)

4.2.1 The coordinators

The sample in study I consisted of the two coordinators conducting the ReWork-Stroke programme. They had professional backgrounds as occupational therapists and both had extensive experience of rehabilitation after stroke (25 and 14 years, respectively) and of vocational rehabilitation. They worked clinically in outreach brain injury rehabilitation teams.

4.2.2 Persons who had had stroke

Eligible for inclusion were persons who had had stroke that were 1) referred for rehabilitation to specialized brain injury rehabilitation units in two cities in Sweden, 2) 20-63 years of age, 3) worked before stroke, 4) wanted to return to work, 5) estimated by the rehabilitation team to be in RTW phase, 6) had the ability to communicate in Swedish. Exclusion criteria: Diagnosed with dementia, neurological or psychiatric disorders.

The sample in study II consisted of the first seven participants included in the project. All of them were in the phase to prepare for and start work trial, and were employed within the fields of education, healthcare, manufacturing or transport.

The sample in study IV consisted of 10 participants and the time from inclusion to start of work trial ranged between three and 8.5 months. Six of the participants had fatigue, both at baseline and after three months of work trial.

4.2.3 Co-workers and managers

In study III, the sample consisted of seven co-workers and four managers of the persons who had had stroke that constituted the sample in study II. These 11 participants worked at the work places where their colleague who had had stroke performed their work trial. Ten of these participants had worked together with their colleague for between six and 16 years, while one of the managers did not have any work history with his colleague who had had stroke. The amount of employees at the work places ranged between six and 100. Eligible for inclusion were co-workers and managers of a colleague who had had stroke and who was participating in the ReWork-Stroke programme for RTW after stroke. The person who had had stroke was asked to choose a co-worker or a manager with insight into the RTW process, and with whom he/she had a trustful relationship, to be approached for inclusion in study III.

4.3 STUDY CONTEXT

4.3.1 The ReWork-Stroke programme

The ReWork-Stroke programme is a person-centred rehabilitation programme targeting RTW after stroke. The programme was provided and coordinated by two occupational therapists working at different outreach brain injury rehabilitation units in Sweden. The main goals of the ReWork-Stroke programme are the following:

- Make the client aware of consequences after stroke in work situations and everyday life.
- Test different strategies to handle consequences after stroke in the work situation as well as activities to resume in everyday life.
- Analyse demands in work tasks in relation to stroke consequences and work environment, advise the client on performance of work tasks and the employer on choice of work tasks.
- Inform and explain about rules for being sick-listed and rules of the RTW process.
- Inform employers about consequences of stroke in general and in specific work situations for his/her employee.

- Provide tools, e.g. assessments or checklists, to employers for evaluation of work capacity.
- Inform officers from the Swedish Social Insurance Agency (SSIA) about the consequences of stroke in work situations and discuss how they can be dealt with.
- Together with the client and involved stakeholders, make plans for work trial, follow up regularly throughout the RTW process, and negotiate work re-entry.

The programme consisted of a phase of planning for RTW and a period of work trial. The planning phase included individual meetings with the client to discuss the consequences of stroke, what these might imply in a work situation, strategies that might be implemented to handle these new challenges at the work place, and preparation for visiting the work place and meeting the employer in order to capture and address questions in the specific work context. An individual plan was formed in collaboration with the person who had had stroke, the employer, and the social insurance officer. The period of work trial (three months) was based on the individual plan for work tasks and working hours that was compiled during the planning phase of the programme. The second phase, the work trial, contained continuous collaboration with the person who had had stroke and the other stakeholders involved, such as co-workers, managers, and employers, mainly based on visits by the coordinators to the specific work place every second week. Further, the coordinator had contact with the social insurance officer and the responsible general practitioner to exchange information during the individual RTW process. The visits and follow-ups at the work place included giving individual advice to the person that had had stroke and to the available co-workers/managers. Strategies were discussed about how to handle the consequences of stroke in the unique work context, as well as exchange of information between the stakeholders. The plan for RTW decided on before the work trial was followed and revised when needed in discussions at the work place, e.g. working hours might be increased and work tasks changed.

4.4 DATA COLLECTION

4.4.1 Interviews

All interviews conducted in studies I-III were semi-structured with open-ended questions formulated in interview guides. The interview guides for studies II and III were piloted before data collection, and resulted in minor changes of the guide. However, these changes were about formulations to increase the clarity of the questions, and less about the content.

The interviews in study I were conducted with the two coordinators together in order to stimulate reflections and discussions, similar to the reasoning behind the focus group methodology (Ivanoff & Hultberg, 2006), about the ReWork-Stroke programme and its content. The interviews focused on their experiences of delivering ReWork-Stroke and their reflections about its content. In study II, interviews with each participant were conducted on two occasions, and all 14 interviews were conducted individually. The first interview focused

on their experiences of the programme, their collaboration with the coordinator, and how they formed the individual plan for work trial. The second interview was conducted to explore the RTW process over time and to follow up questions from the first interview. In addition, to the interview guide, individual questions for each specific participant were formulated based on the stories told in the first interview. This action was taken in line with the grounded theory (GT) approach to further explore the area of interest as new parts of the RTW process turned up (Charmaz, 2014) as well as the analysis running in parallel with the data collection.

In study III, the majority of the 16 interviews with the co-workers and managers were conducted individually. Two interviews were conducted in pairs: one with two co-workers and one with a co-worker and a manager. The focus of these interviews was about their role when working with a colleague who participated in the ReWork-Stroke programme, and about their experiences of the programme and their collaboration with the coordinator. In this study the transcripts from the first interview were not analysed before the second interview. Instead, the first interview was carefully listened to in order to further develop the interview guide to gather rich data (Charmaz, 2014). When listening to the first interview, it became evident that two managers did not have much insight into the RTW process of their colleagues. In these cases, two co-workers working more closely to the colleagues were interviewed, which is in line with the theoretical sampling of GT (Charmaz, 2014).

4.4.2 Logbooks

Logbooks were written by the coordinators for each person that had had stroke and completed the programme (n=13). These logbooks intended to describe the core elements for each participant, i.e. contacts and actions taken, involved stakeholders, time spent, etc. In total, the logbooks consisted of about 100 pages of text. In study I the logbooks were used to explore and describe the core elements of the ReWork-Stroke programme and how, when, where, and in collaboration with whom, the programme had been provided. In study IV the logbooks were used to give examples of elements provided in order to enable change in work potential and work performance.

4.4.3 Assessments

The assessments used in study IV are presented below. The Worker Role Interview (WRI) and the Assessment of Work Performance (AWP) were conducted at baseline and again after three months of work trial, by occupational therapists from the Swedish Public Employment Office. The Fatigue Severity Scale (FSS) and The Stroke Impact Scale (SIS) were administrated by the coordinators at baseline and again after three months of work trial.

Work potential. WRI was used for measuring work potential. The aim of the WRI is to identify both psychological and environmental factors that can influence a person's ability to RTW after illness or injury. It contains items that can predict RTW and is suitable in vocational rehabilitation to identify individual needs (Ekbladh, Thorell, & Haglund, 2010). A semi-structured interview guide was used to collect data on three content areas: Motivational factors, Lifestyle factors, and Environmental factors. After the interview, a rating scale was

used where the therapist scored the client's answers on 16 items corresponding to the content areas. A Likert-scale was used where 1=strongly interferes, 2=interferes, 3=supports, and 4=strongly supports RTW. Different aspects of utility, validity, and reliability have been tested (Ekbladh, Haglund, & Thorell, 2004; Ekbladh et al., 2010; Forsyth et al., 2006; Yngve & Ekbladh, 2015).

Work performance. AWP is a performance based assessment of a client's work skills in relation to how appropriate and efficiently work tasks are performed for measuring work performance in the domains of motor, process and communication, and interaction. The performance of the structured work tasks is scored on a Likert scale with four alternatives where 1=Incompetent performance, 2=Limited performance, 3=Questionable performance, and 4=Competent performance. AWP is a valid (Fan, Taylor, Ekbladh, Hemmingsson, & Sandqvist, 2013; Karlsson, Liedberg, & Sandqvist, 2018; Sandqvist, Bjork, Gullberg, Henriksson, & Gerdle, 2009) and reliable instrument for assessing work performance (Fan et al., 2013). The assessment was performed in a constructed environment where two selected work tasks were used.

Perceived impact of stroke. The Stroke Impact Scale (SIS) version 3.0 (Duncan, Bode, Min Lai, & Perera, 2003) was used to measure the perceived impact of stroke. The SIS is a self-rated assessment consisting of 59 items divided into eight domains: strength, hand function, mobility, activities of daily living (ADL) and instrumental ADL (IADL), emotion, communication, memory and social participation. Each item was scored by the person who had had stroke on a five-point rating scale. The aggregated domain scores in SIS range from 0-100 and the higher score, the less the impact. In studies the SIS has shown to be valid and reliable (Duncan et al., 1999; Edwards & O'Connell, 2003), sensitive to change, and is frequently used (Tse, Douglas, Lentin, & Carey, 2013).

Fatigue. The self-report instrument Fatigue Severity Scale (FSS-7) (Lerdal & Kottorp, 2011) was used in study IV to assess fatigue. FSS has seven items and a seven graded scale from 1 (strong disagreement) to 7 (strong agreement). The mean score of 4 is the cut-off score for fatigue post stroke (Lerdal & Kottorp, 2011). FSS is a reliable instrument and simple to use in order to quantify fatigue (Valko, Bassetti, Bloch, Held, & Baumann, 2008).

4.5 DATA ANALYSES

4.5.1 Descriptive case-study analysis (study I)

Study I has a case-study design, including two data sources, semi-structured interviews, and logbooks containing documentation from the coordinators. In the process of describing the programme, the Template for Intervention Description and Replication (TIDieR) (Hoffmann et al., 2014) was used as an inspiration. The TIDieR checklist was developed with the intention of improving reporting of interventions.

A deductive qualitative content analysis (Graneheim & Lundman, 2004) has been used in the analysis both of logbooks and interviews. In the analysis of logbooks, the focus has been on

the procedure of the programme, and in the interviews on the coordinators' experiences of providing the ReWork-Stroke programme. Furthermore, descriptive statistics have been used to analyse the logbooks concerning number of actions taken by the coordinator, amount of collaboration, and time required for these efforts. The analysis started by organising the text according to eight predetermined categories from the goals of the programme given in the method section, after which meaning units for each category were identified and organised into codes. Codes from different logbooks were compared according to similarities and differences, and collapsed into five categories representing the core elements of the programme. The analysis of the interviews resulted in an additional category.

4.5.2 Grounded theory analysis (studies II and III)

In the analysis in studies II and III a constant comparative approach, inspired by the principles of grounded theory (Glaser & Strauss, 1967) was used. To gain a deeper understanding of the RTW process after stroke, from the perspective of persons who had had stroke (study II) and their co-workers and managers (study III), the grounded theory (GT) approach and guidelines for analysis described by Charmaz (2014) was applied.

All interviews were successively listened to with the purpose of obtaining an overview of the data as the first step in the analysing process. The initial step in the coding process was open coding close to the data through line-by-line. The next step in the analysis was focused coding, where an analytical comparison of the first codes from each interview was conducted. The codes were then compiled into subcategories. Later, a comparison between all the interviews was performed and different patterns emerged. From these patterns the final categories appeared. During the analysing process, each step was discussed with the last author, and the upcoming results discussed with all authors. Memos were captured at the time of each interview in both studies concerning the researchers' observations during and in connection to each interview, as well as during the analysing phase to take the analysing process further.

4.5.3 Mixed methods analysis (study IV)

In study IV, a mixed method approach was applied consisting of quantitative and qualitative data from assessments and the logbooks. An integration of two data sources was conducted in this study by using the explanatory sequential design, which meant that the quantitative method was given priority (Creswell & Plano Clark, 2017; Hadi, Alldred, Closs, & Briggs, 2013). First, descriptive statistics were used to describe and visualise characteristics of the sample regarding perceived impact of stroke (SIS) and fatigue severity (FSS), while WRI and AWP were used to assess changes over time in work potential and work performance. Secondly, the logbooks regarding the programme for the included 10 participants were analysed. The deductive qualitative content analysis followed the same procedure as in study I. However, in this study the text was organized according to the content areas of Motivation, Lifestyle and Environment in the WRI, and the Motor and Process domains in AWP.

5 RESULTS

The main results of the studies, including the perspectives of the stakeholders, representing different systems in the RTW process (Loisel et al., 2005), will be presented in this section. First, the findings from the exploration of the ReWork-Stroke programme, i.e. the healthcare systems and in this case the coordinators perspective (study I) will be presented. Thereafter the experiences of taking part in the programme will be presented from the perspectives of the persons who had had stroke, i.e. the personal system (study II), their employers/managers and co-workers, i.e. the work place system (study III), and the coordinators providing the programme, i.e. the healthcare system (study I). Finally, the measured changes in work potential and work performance while participating in the ReWork-Stroke programme and examples of elements provided in the programme (study IV) will be presented, constituting the personal system perspective.

5.1 THE REWORK-STROKE PROGRAMME – CONTENT FROM THE COORDINATOR PERSPECTIVE

The results in study I constitutes the core elements from the logbooks documented by the coordinators, including their actions; where, when, how and the amount of time spent delivering the programme, as well as their experiences of providing the programme to persons who had had stroke. The core elements that were identified in the programme were: Make the client aware of the consequences of stroke for working life; Inform stakeholders about the consequences of stroke; Suggest and evaluate use of strategies; Assessments, goal-setting and evaluation of work ability at the work place; and Planning and follow-up of work trial. In addition, another core element emerged from the analyses of the interviews with the coordinators: The role of the coordinator - building an alliance to create a team -.

The length of the ReWork-Stroke programme ranged between 12 and 36 weeks, including a preparation phase and three months of work trial mainly delivered at the specific work place of each client. The majority of the contact with the client, co-workers and manager were face to face, while the majority of contact with other involved stakeholders (SSIA, GP) was by mail or phone. The mean number of occasions when the coordinator interacted with the client and/or other stakeholders regarding the clients' RTW process was 22.4 (range = 12-36). Contacts made by the coordinator to inform other stakeholders not attending meetings ranged between two and 14 with the mean aggregated duration of those contacts for each person being 4.6 hours. The number of times when the coordinator met the client, the employer and/or co-worker at the work place varied between two and 10, and the mean aggregated duration of these meetings per person was 11.3 hours.

The coordinators used their time, both before and during the work trial, to make the client aware of the consequences of stroke for working life. Changes after stroke, such as reduced ability to perform work tasks, were discussed in connection to possible ways to handle difficulties in everyday life and working life. The coordinators also gave advice for balancing working life and activities during free time and how to plan for sleep and rest. The logbooks

revealed plans based on the clients' abilities and the demands at the work place, made in collaboration before the start of the work trial, as well as a plan for how the client wanted to present his/her consequences of stroke to other stakeholders. The coordinators experienced that cognitive consequences were difficult for the clients to understand but by trying different work tasks, and through discussions, the limitations became more evident.

Suggestions and evaluation of the use of strategies to overcome difficulties in work situations was recurrent during the programme. Cooperation and exchange of knowledge and experience between the different stakeholders occurred when discussing different strategies. The co-workers were instrumental in supporting the client in the implementation of strategies to manage different work tasks. The evaluation of the applied strategies was made in cooperation with those involved. Different assessments, such as the Assessment of Work Characteristics (AWC) and AWP, were used by the coordinators in collaboration with the client and the manager/co-worker as one part of the evaluation of the client's ability to perform work tasks. The AWC was seen as a valuable tool as it contributed knowledge concerning the demands in different work tasks and was a base for choosing work tasks. Evaluations were continuously made at the work place in real work situations.

The coordinators stressed two important cornerstones in the programme; one was the Planning and follow-up of work trial. The planning of the work trial was described as challenging but also as a very important phase where the coordinators aimed to capture different wishes and viewpoints among the stakeholders, and to formulate a detailed plan for RTW. The role of the coordinator was complex and building an alliance to create a team was the other cornerstone in the programme. The coordinator facilitated communication and collaboration, and raised different perspectives to reach a shared understanding built on trust. Their main focus was to collaborate with and provide support to the client and to facilitate communication among the stakeholders concerning more sensitive questions.

During the RTW process there was negotiation between the SSIA and the employer about how to proceed, where the coordinators described themselves as having an important role in contributing with their knowledge and experience of performing work tasks despite consequences of stroke. The follow-up was often initiated by the coordinators and was detailed concerning progress, content, time, and need for adjustments in the specific work situation.

5.2 EXPERIENCES OF BEING INVOLVED IN THE REWORK-STROKE PROGRAMME FROM THE PERSPECTIVE OF PERSONS WHO HAD HAD STROKE, MANAGERS/CO-WORKERS AND COORDINATORS

The interviews contributed with different perspectives and experiences from participating in the ReWork-Stroke programme, having a colleague participating in the programme, and from coordinators in the programme. These experiences have been summarized within the following categories: Handling a changed situation both emotionally and practically; Reaching individual solutions through participation and flexibility; and Communication and collaboration for moving forward.

5.2.1 Handling a changed situation both emotionally and practically

Findings from studies II and III identified that feelings of insecurity and of feeling like a novice were experienced during the RTW process. There were no paths to follow as the situation was new and unfamiliar. During the RTW process, co-workers and managers were struggling with the fact that their colleague who had had stroke was changed because of it. This situation was emotionally challenging to handle because of having to establish a new relationship. The persons who had had stroke also struggled to adjust to their new situation, to find out what was and was not possible at work according to their limitations after the stroke (study II). The coordinators (study I) described that this was often a time-consuming process for the persons that had had stroke. An emotional reaction of loneliness and insecurity during the RTW process were expressed in this new and “changed” situation by the persons that had had stroke, as well as by their co-workers and managers (studies II and III). During these processes, the coordinator was very important and was described as a person who was standing by their side. By their recurrent visits to work places, collaboration was facilitated and a trustful relationship was built.

The way back to work was experienced in different ways by the participants. In some cases the co-workers and managers and the coordinators described a more challenging situation as time passed during the work trial, as more difficulties within the work situation became visible (studies I and III). Also the fact that co-workers and managers in some cases expressed a different view of the progress of the work trial compared to their colleague who had had stroke was challenging, and created more insecurity, especially when the work trial did not work out so well (study III). In other cases, more hope was expressed during the way back to work as the work trial progressed more smoothly (studies II and III). However, an increased amount of stress was expressed, both among the co-workers/managers and the persons who had had stroke, when the work trial began to come to an end and aspects of salary and possibilities of extended work trial were discussed (studies II and III).

In study II the persons who had had stroke had their main focus on their own situation at work; the present challenges and about what would happen next during the work trial, while in study III the thoughts of the managers/co-workers were divided between how to handle their own work situation and the work situation of their colleague. Co-workers and managers were balancing their own work load while struggling to be supportive to their colleague during the work trial. This situation of being “in between” working with two processes was sometimes demanding and a pressure to handle. While concentrating on their own work tasks they had many thoughts about how to handle the situation of their colleague. They expressed that they were prepared to step in and change direction if the present work tasks of their colleague who had had stroke did not work out. The co-workers and managers expressed feelings of concern and empathy in their role, to be responsive and present for their colleague (study III).

In cases where the co-workers experienced that managers did not take responsibility in the RTW process, they expressed that their contact with the person who had had stroke (study

III) could be difficult and demanding. The lack of support and unclear leadership created insecurity, a struggle to be accountable without enough mandate or competence to handle the situation. In these cases, the person who had had stroke also experienced a lack of support from the same manager, which created a stressful situation and insecurity in how to proceed in the RTW process (study II). The participants in studies II and III expressed the importance of having the coordinator as a supporting link in the RTW process on different levels. When they lacked knowledge and experience about the situation the coordinators contributed with various aspects of information and support. The participants appreciated the opportunity to exchange ideas with the coordinator, whom they experienced as very knowledgeable. This collaboration contributed a security about how to proceed in the RTW process (studies II and III).

5.2.2 Reaching individual solutions through participation and flexibility

The importance of meeting(s) at the specific work place was highlighted in order to understand the specific work situation; the work tasks and the context (studies I, II and III). The co-workers and managers described it as a challenge to really capture and understand the consequences of stroke in daily work (study III). Advice about how to handle the consequences of stroke, as for example fatigue, aphasia, and memory impairment in the different work situations, was asked for (studies II and III). This was described by the coordinators as an important and frequently occurring element of their collaboration with co-workers and managers (study I). The work trial very much consisted of trying different work tasks and working hours in order to find suitable solutions. Discussions about work tasks were facilitated by meetings at the work place (studies I, II and III). Support from the coordinators was, in these above-mentioned cases, highly appreciated, and brought hope for the future in being able to find a suitable pathway (studies II and III). The coordinators' contributions were examples of strategies, adaptations and aids to try out and to use in the specific work situation where there were difficulties in, for example, reading, writing, and balancing a limited amount of energy. Their knowledge and experience from similar situations about how to proceed gave more clarity to the RTW process (studies I, II and III). The coordinators also valued the propositions from co-workers and managers concerning useful strategies based on their knowledge (study I). The co-workers and managers were concerned to find a suitable work situation that was possible to manage and good for the health of their colleague (study III). For some this took time, and the need for an extended work trial was raised and argued for by the coordinator, and, after discussions, also approved by the SSIA (studies II and III).

5.2.3 Communication and collaboration for moving forward

The importance of having the opportunity to express one's own wishes and thoughts during the RTW process and be listened to, were raised by the persons that had had stroke. Various approaches were used to discuss the work situation, from participating in more formal meetings, to informal talks during work performance (study II). However, when the manager was not that engaged, and absent at work, participants lacked the possibility to contribute

with their opinions regarding their work trial (study II). Being straightforward even about difficult questions was highlighted as important (studies I, II and III) giving structure and common ground for the RTW process.

The evaluation of how the work trial proceeded served as a base for moving forward (studies II and III). However, communicating about how the work trial proceeded was not always easy. In cases where participants had difficulties during their work trial and the progress was not as expected, the co-workers and managers experienced it as hard to be direct and clear about it (study III). Participants also sometimes experienced that they did not get enough feedback from co-workers and managers during the process of RTW, which led to insecurity about their efforts at work, not knowing if they were on the right track or not (study II). In these situations, the coordinator was a good support in the communication necessary to help and facilitate the discussions (studies II and III). Among participants, the support of the coordinator was highlighted as valuable in communication with others in, for example, meetings and in preparations about what to bring up at meetings (study II). The support made participants more secure when they had difficulties in expressing themselves because of, for example, fatigue or inattention (study II).

5.3 CHANGES IN WORK POTENTIAL AND WORK PERFORMANCE

In study IV, changes in work potential and work performance while participating in the ReWork-Stroke programme were explored by use of assessments and logbooks written by the coordinators during the programme. The main results were that the majority of the changes during the three months of work trial were positive. The logbooks informed about various actions taken by the coordinator to support the RTW process and to deal with consequences of stroke in the work situation.

5.3.1 Work potential

At baseline, many of the items concerning work potential were found to be supportive for RTW within the areas: Motivational factors, Lifestyle factors and Environmental factors, and many of these items remained supportive at the three-month follow-up. Most changes, from interfering to supportive, were within Environmental factors, where 11 changes occurred, which was more than in the Motivational factors where there were eight, and in Lifestyle factors where there were three changes. The negative changes amounted to three in each of the areas.

Concerning the Motivational factors, all items were assessed as supportive at baseline for four of the participants and at three-month follow-up there were eight positive and three negative changes. The area of Motivational factors had the most interfering items at follow-up of the three factors constituting WRI. The item “Pursues interest”, i.e. the person’s abilities to seize possibilities to make his or her life stimulating and meaningful, was the most interfering item (n = 3) at follow-up. According to the logbooks, discussions were held both before the start of the work trial and during the work trial, concerning the reduced ability to work and aspects connected to motivation. Different strategies were suggested and used to

handle different consequences of stroke, for example fatigue at work, to overcome difficult situations.

Concerning the Lifestyle factors, all but two participants had all their items rated as supportive at baseline. However, a negative change from supporting to interfering occurred at the item “Adapts routine to minimize difficulties” for two participants, and on the item “Daily routine” for one participant. In the logbooks, actions regarding Lifestyle factors were described as balancing activities in life. Coping strategies for handling the balance between activities in and outside work were proposed by the coordinators. The importance of rest and sleep routines were ventilated within the new “work” situation.

Within the area of Environmental factors the most positive changes were on the items “Perception of work setting” and “Perception of co-worker” with four changes respectively. There was also one negative change each for different participants on the items “Perception of family and peers”, “boss” and “co-workers”. The logbooks revealed that the planning for and the evaluation of RTW occurred in collaboration between the participant, the coordinator, and the colleagues at work. This planning concerned discussions on, for example, finding suitable work tasks, the demand of support needed, and advice regarding distribution of working hours. This collaboration at the work place differed among the participants where for some the manager was absent and in some cases the collaboration went more smoothly.

5.3.2 Work performance

Within work performance, regarding both motor and process domains, there were mainly positive changes, from an incompetent to a competent performance. In total there were 22 positive changes, spread across all the motor items, where a competent performance was reached on 20 items, but there were also three negative changes. Within the process items there were 24 positive changes, spread across all items, where a competent performance was reached on 17 items, but there were also five negative changes. Three of the 10 participants had three or more changes to a competent performance within the motor items. On the process items, four of the 10 participants had three or more changes to a competent performance.

Concerning the motor domain, several actions were taken by the coordinator as suggesting different strategies to overcome difficulties. There was collaboration at the work place concerning how to choose work tasks, and discussions were held about, for example, the participant’s physical ability connected to breaks and control of pace. The schedule was also adjusted based on these discussions concerning working hours and the need for sometimes having a day off in between work days. Many of the strategies linked to the process domain were suggested and used for handling memory deficits, fatigue, and poor concentration. Different kinds of reminders, such as tape-recorders and to-do-lists, were used for structuring the work situation and remembering what to do. Also, the possibility of working in a quieter environment was used as a strategy to handle earlier mentioned difficulties.

6 GENERAL DISCUSSION

The perspective of this thesis was grounded in occupational therapy theory, the Sherbrooke model of the return to work process (Loisel et al., 2005), and the Work Ability House (Ilmarinen, 2009). The goal for the research was to enhance knowledge regarding rehabilitation for RTW after stroke from different perspectives. Throughout the studies there has been a predominant focus on both individual aspects of the person who had had stroke (studies II and IV) as well as system-oriented aspects in the complex RTW process, such as the views and experiences from various stakeholders, and their collaboration within this process (studies I, II and III). The findings from this thesis are, however, grounded in occupational therapy, and the Legislative and insurance system in the Sherbrooke model has not been in the foreground. This is, of course, an important aspect that influences the RTW process as well, but it often lies outside the control of the person who had had stroke, as well as the occupational therapist providing the rehabilitation programme, such as the ReWork-Stroke programme. This thesis might be seen as a useful contribution to the occupational therapy knowledge base but can perhaps also be of interest for other professionals working both within and outside healthcare, as the area of interest includes various stakeholders.

In this section the main findings from the empirical studies in the thesis will be discussed. This discussion will be outlined by following the Personal system, the Healthcare system, and the Work place system that is outlined in the Sherbrooke model. Initially, the influence of the individuals' preconditions on RTW will be discussed as well as the need for a person-centred approach in rehabilitation. Thereafter, the role of the coordinator in the ReWork-Stroke programme will be in focus, followed by the importance of involving the work place stakeholders in the RTW process. In addition, the complex process of RTW will be discussed in reference to the ReWork-Stroke programme connected to the Sherbrooke model, MOHO and the Work Ability House, as well as in the section about the importance of including all stakeholders representing the systems from the Sherbrooke model.

The discussion will then continue with a section concerning methodological and ethical considerations, and conclude with a summary of clinical implications together with suggestions for future research.

6.1 THE PERSONAL SYSTEM

The findings in studies II and IV elucidated a considerable variation in individual preconditions related to consequences after stroke that are important for the RTW process. The individual preconditions and consequences have also been brought up by the coordinators (study I) and managers and co-workers (study III). These findings thus support the importance of a person-centred approach in a rehabilitation programme such as ReWork-Stroke. The individual consequences and the person-centred approach will be discussed in the following.

6.1.1 The influence of the individuals' preconditions on return to work

Findings from study IV revealed that there was a variation regarding consequences after stroke between the participants. Of the ten participants in study IV, three had a moderate stroke while the remaining participants had a mild stroke. Combinations of consequences after stroke varied within the sample. About one-third of the participants perceived memory problems, difficulties with concentration, physical weakness in one or more body parts, and vision or aphasic problems. The variation of consequences after stroke was also evident in study II as the participants needed strategies to handle various difficulties. Some needed support to increase the awareness of their difficulties, others needed strategies to handle memory impairment. These are all important consequences to consider, as earlier studies have found cognitive impairments and depression (Fride et al., 2015) as well as aphasia and impaired attention to be hindrances for RTW (Tanaka et al., 2014). Six of the participants in study IV perceived severe fatigue at the time of inclusion, as well as after the three months of work trial. Fatigue has also been reported to be a barrier for RTW (Andersen et al., 2012; Donker-Cools, Schouten, Wind, & Frings-Dresen, 2018; Ntsiea et al., 2015) and a common symptom after stroke, as well as emotional changes (Carlsson et al., 2004). Concerning work potential and work performance there were also differences between the participants, and the changes over time differed. This variation among the participants occurred both within the motor and process items on the AWP and within the content areas of motivation, lifestyle and environment on WRI.

Based on the findings from the present thesis and previous literature it is evident that a rehabilitation programme focusing on RTW needs to consider and handle these consequences of cognitive and physical impairments after stroke when planning and testing different work tasks. According to the findings in this thesis, there are a lot of strategies that can be tested and used to overcome these limitations when performing activities, an approach which is also recommended by Palstam and colleagues (2018). However these limitations need to be seen and understood in the specific work context and everyday life in order to perceive the uniqueness of each participant's situation. In this thesis it also became evident that both managers and co-workers (study III) and the persons who had had stroke (study II) struggled with this understanding. The coordinator played a significant role in increasing this understanding (studies I, II, III and IV) through the use of different strategies in order to move forward in the RTW process.

6.1.2 The need for a person-centred approach

In this thesis, across all studies, it became evident that the individual consequences after stroke varied among the participants. These differences impact on the RTW process as described in the previous section. The consequences of stroke among the participants also entailed different challenges due to the individual's type of profession, for example education, healthcare or manufacturing, and influenced the planning of the work trial phase of the programme (studies I, II, III and IV). Furthermore, the work context concerning both organizational factors, and how available and dedicated the staff was, also served as

influencing factors during the RTW process. Summarizing these findings it might be concluded that various aspects, which can have different influences for the individual, are important to consider in the RTW process and a person-centred approach is needed. These findings are also supported by Palstam and colleagues (2018) who highlighted the importance of individually tailored rehabilitation.

The ReWork-Stroke programme was designed using a person-centred approach (Ekman et al., 2011) and the need for that is supported in study I. The content in the logbooks (study I), as well as the descriptions from the interviews in study II, highlight the importance of analysing the individual work situations in order to find usable strategies and aids to handle consequences due to both physical and cognitive impairments. This reasoning indicates a need to see each person in her/his unique environment and work context to fully understand the complex situation of the performance of work, i.e. the actual occupational performance depends on the interaction between a person's characteristics, the demands of the occupation, and the environment described in the MOHO (Taylor, 2017). The importance of incorporating the perspective and desires of the client is highlighted, and this should preferably be done by working in partnership with the client during healthcare/rehabilitation, as recommended in the person-centred care described by Ekman and colleagues (2011) where the client's story is a point of departure.

The strategies that are used according to the findings in this research (studies I, II, III and IV) were adjusted to the needs of the specific person, to overcome difficult situations within the specific work context/situation. That is in line with Jesus and colleagues (2016) description of a person-centred approach that concludes that interventions shall be based on clients' needs, preferences and experiences. However, these preferences were not always that easy to use as the persons who had had stroke (study II) expressed experiences of uncertainty at the beginning of the process, which has been expressed previously among people returning to work after stroke (Coole et al., 2013; Vestling et al., 2013). Also, the co-workers and managers in study III struggled with feelings of uncertainty during this phase concerning how to support their colleague based on limited knowledge, which has previously been found (Dunstan & Maceachen, 2014). The coordinators found it important on these occasions to increase the understanding about the 'new' situation for the persons who had had a stroke (study I) concerning the consequences of stroke in connection to the specific work task and context. This increased understanding and awareness could then facilitate the planning of RTW.

According to the findings in this thesis (studies I, II, III and IV), the coordinators were a valuable support both for the persons that had had stroke and their co-workers and managers during the RTW process. Being supportive in the social context of a person/client is in line with the reasoning regarding the view of who can be the client in client-centred practice. Townsend and colleagues (Townsend & Polatajko, 2007) consider that the client also includes groups or persons significant to the person who is in focus for interventions in occupational therapy. While conducting the ReWork-Stroke programme it became obvious

that a client- or person-centred approach to those involved at the work place was a prerequisite (study I) for work trial to function properly.

6.2 THE HEALTHCARE SYSTEM

The ReWork-Stroke programme in this thesis is situated within the healthcare system, with the coordinators working at specialist brain injury rehabilitation units. The coordinators played a significant role in conducting the ReWork-Stroke programme. Study I focuses explicitly on how the coordinators have translated the programme into practice and their experiences of providing the programme. The role of the coordinator has also been brought up by the persons who had had stroke (study II) and stakeholders at the work place (study III). These findings will be discussed in the following.

6.2.1 The role of the coordinator in the ReWork-Stroke programme

The experiences from the interviews of the coordinators as well as from the logbooks (study I) revealed that the coordinators had a complex and multifaceted role in the ReWork-Stroke programme. They contributed with a wide range of ‘elements’ in ReWork-Stroke such as giving support, exchanging ideas, and discussing challenges with the stakeholders. The focus for the coordinator was to enable the person who had had stroke to find ways to practice, and to develop work skills together with finding routines in daily life, to make it possible to reclaim his/her worker role. The coordinator, skilled and experienced within occupational therapy, analysed the individual’s present capacity to perform different work tasks at his/her specific work place, i.e. analysis of the performance level of occupations (Kielhofner, 2007), which was a cornerstone in the programme. Discussion about which work tasks to choose according to the consequences of stroke, and the availability at the work place, were held in cooperation with the person who had had stroke and his/her colleagues, which was also performed in an earlier study using occupational therapists as coordinators (Grant, 2015), with the goal to provide knowledge and understanding in this challenging situation.

Based on the findings in this thesis, an occupational therapist with competence in vocational rehabilitation and experience of rehabilitation of persons that have had stroke was appropriate considering the different tasks, skills and competences required in the role as a coordinator in the ReWork-Stroke programme. That this competence was required was quite expected when putting it in relation to the needs of the stakeholders involved in the RTW process. Previous research has showed that, for example, advice and support are asked for by employers as they may lack knowledge in supporting people in a RTW process (Coole et al., 2013). Supporting the employer is an important task for the coordinators as it is known that a supportive employer facilitates the RTW process (Culler et al., 2011).

The need to communicate and raise different issues, even sensitive ones during the RTW process is, however, raised both by the persons that had had stroke (study II) and their co-workers and managers (study III), and in these situations the coordinator played an important role. The coordinator had continuous contact with the persons that had had stroke and they had developed a trustful relationship in the preparation phase of the programme. At the work

place a structure and a plan was created that contributed to a transparency between the client, the coordinator, and the co-workers/managers. Based on the relationship with the client, the coordinator could bring up questions or could facilitate other stakeholders to speak about what they experienced as sensitive during the work trial. The value of creating a sense of transparency in relation to clients during intervention has previously been underlined by Ranner and colleagues (2018) which is in line with the findings in this thesis, where the programme they participated in made their own RTW process transparent. This was also brought up by the coordinators who spoke of creating an alliance with the involved stakeholders (study I) during the RTW process.

These findings could be interpreted as the coordinators having had an important role in facilitating the communication between the person who had had a stroke and his/her colleagues in order to increase the understanding for the individual situation of the client. This is in line with previous research in which RTW coordinators have identified communication skills as essential qualities in their complex role (Bohatko-Naismith et al., 2015).

The findings from this thesis revealed, both in the logbooks and in the interviews (study I), that the coordinators' role was also much about coordinating different stakeholders in a wider sense. The coordination involved organizing, initiating and arranging suitable meetings that could facilitate communication, as well as conducting phone calls with the SSIA and doctors who could have difficulty attending meetings. This collaborative function has also been described as important in earlier research concerning RTW where the role of the RTW coordinators has been highlighted as central (Bohatko-Naismith et al., 2015; Gardner, Pransky, Shaw, Hong, & Loisel, 2010; Pransky, Shaw, Loisel, Hong, & Desorcey, 2010; Shaw, Hong, Pransky, & Loisel, 2008). In Sweden the support from healthcare in the RTW process is planned to expand, and the role of coordinators is proposed to be permanent. Today the primary tasks for a coordinator in healthcare is to be a contact, support and coach for the patient, intern coordinator, and to cooperate with other stakeholders in society. The coordinators in this research, beside their coordination role, also have a more clinical role working as advisory occupational therapists out in the field at different work places and are more specialized concerning acquired brain injuries. In general, the use of occupational therapists in multidisciplinary rehabilitation focusing on RTW has shown favourable results. The effects of occupational therapy in terms of employment and amount of sick leave days have shown good results at follow-up studies (Desiron, de Rijk, Van Hoof, & Donceel, 2011), where work place interventions was one beneficial method (Lambeek, van Mechelen, Knol, Loisel, & Anema, 2010).

The role of the coordinator very much consisted of finding new ways to perform work tasks due to the changed situation after the stroke, in cooperation with the stakeholders. In some cases this process did not necessitate many meetings or arrangements for the coordinator, while in other cases more time and support was needed, as the process of RTW was more complex and demanding. The need for education in handling the complex role of being a

RTW coordinator has been raised in earlier studies (Bohatko-Naismith et al., 2015), as has the need for mentorship (Pransky et al., 2010), and an extensive training programme has been asked for (Bohatko-Naismith et al., 2015) that includes, for example, ethical aspects (Pransky et al., 2010). Hansen Falkdal and colleagues (2015) found in a literature study that the coordinator is in need of relevant education, suitable individual qualifications, knowledge of judgements and organisatory and community capability.

In the present research, the coordinators have described situations of ethical dilemmas and used different skills to handle these. Perhaps the coordinators' extensive experiences and knowledge of working with vocational rehabilitation and people with acquired brain injuries has contributed to a range of strategies to use when more sensitive questions arose, and therefore these situations might not have been raised as emotional challenges in study I in the same way as in earlier research. In literature, some RTW coordinators have also described their role as emotionally challenging as it was necessary to be able to create a strong relationship with the injured worker, and other stakeholders, while also trying to have an emotional distance in order to be professional and objective (Bohatko-Naismith et al., 2015).

6.3 THE WORK PLACE SYSTEM

The ReWork-Stroke programme consists of two parts: a planning phase and a period of work trial. The findings in this thesis identified the involvement of the work place as an important feature in several ways. Being at the work place was highlighted in order to understand the specific work situation; the work tasks and the context (studies I, II and III). The co-workers and managers particularly described that it was a challenge to really capture and understand the consequences of stroke in daily work (study III), and that was also described by the persons who had had a stroke (study II). The period of work trial created possibilities to increase the understanding of the person's actual ability to perform tasks at the specific work place. Furthermore, the coordinators expressed that meeting the person in his/her real work environment enabled them to discuss relevant strategies (study I). In this section, the importance of involving the work place stakeholders in the rehabilitation, and the mutual importance of being at the work place, will be discussed.

6.3.1 The mutual importance of being at the work place

This situation of being in the process of RTW after stroke was something new and unfamiliar for both the persons who had had stroke (study II) as well as for the co-workers and managers (study III) and is not so well explored in earlier literature. Information about the RTW process and about the consequences after stroke connected to work has been asked for (Gilworth et al., 2009; Vestling et al., 2013). The coordinators in this study had been involved in the processes of RTW before, supporting other persons who had had stroke and could therefore also contribute with knowledge and experience into this process (study I), which was much appreciated (studies II and III). During the process of RTW, feelings of insecurity were described by the persons who had had stroke and also by their co-workers and managers. The 'new' situation at work is expressed as difficult to understand and therefore

also difficult to handle. The support from the coordinator during the RTW process turned out to be important in several ways for both groups. This is in line with earlier research indicating the lack of, and need for, support during the process of RTW, both by persons who had had stroke (Culler et al., 2011; Gilworth et al., 2009; Vestling et al., 2013) and by employers (Coole et al., 2013). Assistance from vocational specialists during the RTW process has been wanted (Vestling et al., 2013). The coordinators in this research highlighted the importance of collaborating and sharing knowledge at the work place (study I). The persons who had had stroke and their colleagues could contribute with their knowledge and experience concerning their specific work place, work tasks, and work situations while the coordinators gave valuable information based on their experiences within vocational rehabilitation after stroke. The importance of sharing knowledge and experiences between the client and the occupational therapist was found to be an essential condition throughout the client-centred ADL-intervention to enable agency in daily occupations for persons with stroke (Ranner, von Koch, Guidetti, & Tham, 2016). The sharing was reciprocal; the occupational therapist shared their professional knowledge and the client shared their experiences of their new everyday life situation after stroke and changes they wanted for the future, and occupations they wished to resume. A good relationship was the base for this sharing and a starting point for an interaction within the intervention. In this thesis, the interaction between the client and the coordinator throughout the rehabilitation programme had many similarities with what was described in the ADL-intervention (Ranner et al., 2016). There was a reciprocal sharing of experiences of the vulnerable situation in the RTW process, and professional knowledge on how to initiate work trial, try out work tasks and strategies etc. between the coordinator and the client with stroke. In addition to what Ranner and colleagues (2016) described, in this thesis the sharing also included those involved at the work place. In study III, the knowledge sharing among the stakeholders involved seemed to be very important to increase and broaden the understanding about the 'whole work situation' from different perspectives in order to move forward in the process to RTW, but has not been described before in the context of RTW after stroke. Based on the findings in this thesis and previous literature it is important to involve the work place stakeholders in the RTW process.

Previous research has highlighted the differences in experienced support from stakeholders in the RTW process where some had positive experiences while others experienced lack of clarity, inflexibility, as well as lack of coordination (Holmlund, Hulting & Asaba, 2018). In this thesis the recurrent visits to the work places by the coordinators facilitated cooperation among the stakeholders and enabled the communication concerning various aspects that turned up during the process of RTW. It also gave possibilities to understand the complex work situation for every individual concerning work tasks and contextual factors, as well as the specific needs for adaptations and alternative strategies to overcome difficulties at work. The benefits of adaptations at the work place according to the specific demands of the individual have also been raised in earlier studies (Franche, Baril, Shaw, Nicholas, & Loisel, 2005; Shaw et al., 2008). A key feature in this research was the opportunity to test different work tasks at the work place. Through that, the client could get an increased understanding

about his/her own situation and ability and also benefit from support from the coordinator in the 'real' context of work. The consequences of stroke could give different difficulties in various work tasks, and this was visualized and highlighted by the visits. The performance of 'real tasks' that are important and meaningful for the individual in the specific environment, is highlighted in the National Board of Health and Welfare Guidelines for Stroke Care (2018) as a high evidence level for task-specific training, and is in line with the findings in the present research.

6.4 THE COMPLEX PROCESS OF RETURN TO WORK

Based on the findings in this thesis, taken the different perspectives into consideration (studies I, II and III) it is evident that the RTW process is complex and multifaceted. It involves many stakeholders having various perspectives, and is influenced by individual, organizational, and legal aspects. This thesis has its theoretical grounding in the MOHO (Taylor, 2017), the Sherbrooke model (Loisel et al., 2005), and the Work Ability House (Ilmarinen, 2009). The combination of using all three models has been beneficial in deepening the understanding of the RTW process and enhancing the knowledge of rehabilitation for RTW after stroke. This section will focus on how the RTW process might be understood based on the theoretical models used in this thesis and, moreover, about the importance of including all stakeholders and the representing systems from the Sherbrooke model in the RTW process.

6.4.1 The ReWork-Stroke programme connected to the Sherbrooke model, MOHO and the Work Ability House

The findings in this research (studies I, II, III and IV) confirm the complexity of the RTW process where various stakeholders are important and can contribute with knowledge and experience in different ways to facilitate the RTW process, which is in line with the Sherbrooke model (Loisel et al., 2005). According to the findings in this thesis (studies I, II, III and IV) the multidimensional view on the RTW process (and the collaboration between stakeholders), as described by Loisel, is crucial. A rigorous mapping of the individuals' unique situation at the work place has been performed by the coordinators, in cooperation with other stakeholders. This was made in order to understand the consequences of stroke for the specific work task in its environment, which is in line with the occupational perspective in MOHO (Taylor, 2017), as well as to strive for a shared understanding. The unique needs, interests and potential of the persons who had had stroke have been considered (Townsend & Polatajko, 2007). This reasoning above is in line with the occupational perspective in MOHO (Taylor, 2017), as well as the view on person-centredness by Townsend (2007). By using this approach, to meet the individual in her/his unique work environment, various aspects within the Work Ability House (Ilmarinen, 2009) have been captured and raised. For example, responsibility and roles among co-workers and managers in contact with the person who had had stroke has been discussed, as well as the individual values and motivation of the person who had had stroke. Further aspects concerning the competence, health and functional capacity of the person that had had stroke has been discussed in connection to work tasks.

This means that the coordinators in the ReWork-Stroke programme are addressing ‘all four floors’ in the Work Ability House during the RTW process when analysing the activities performed by the persons in the specific environment, when making plans according to the upcoming needs, and when working with individual based strategies (as well as during the evaluation). In addition, some strategies used by the coordinators focus on factors/aspects within the environment of ‘the house’ such as involving the family in the process of RTW, cooperation with companies concerning technical aids, and with user organizations. These strategies (and tasks) are included in the occupational perspective within occupational therapy where different ways of coping are used to deal with the difficulties in performing occupations (Taylor, 2017). By this reasoning, according to the findings in this research (studies I, II, III and IV), the coordinators are working with many aspects of work ability in the RTW process, both on an individual level meeting the person in his/her work context but also on a more organizational level involving stakeholders like co-workers, managers, social insurance officers etc. In conclusion, by combining and using these three models (Sherbrooke, MOHO and Work Ability House), a deeper understanding of the complex process of RTW, and the multidimensional factors that can influence work ability during the process, have been facilitated.

6.4.2 The importance of including all stakeholders representing the systems from the Sherbrooke model

According to the findings in this thesis (studies I, II, III and IV) it is important to include different perspectives to get a broader understanding of the RTW process, as different stakeholders can contribute with their unique views and knowledge. The perspective of co-workers and managers (study III) gave, for example, insight into their emotional challenges of being a colleague during the RTW process. Their knowledge about the work place and work tasks, as well as their experience of knowing beforehand the person who had had a stroke, gave valuable information from their point of view. The main focus in this research is not the legislative system within the Sherbrook model. However, the regulations about RTW within this system influence, for example, the length of work trial, which has turned out to be an important issue in some cases in this research. The rules can be difficult to understand from different points of view, and negotiation can be required, which was the fact in this research. In these situations, the value of the coordinators was raised as their knowledge and experience could increase the understanding of the need for an extended work trial. The challenges of handling the different views and perspectives among stakeholders have, in earlier research, also been raised as difficult (Franche et al., 2005). For example, the SSIA has been described as having a more reductionistic view concerning work ability than the more holistic view taken by healthcare (Stahl, Svensson, Petersson, & Ekberg, 2009).

7 METHODOLOGICAL CONSIDERATIONS

7.1 DESIGN

In this research, the aim was to build knowledge regarding rehabilitation for return to work after stroke, and the ReWork-Stroke programme. The persons who had had a stroke are at the centre of this programme; however, it is known that the process of RTW is complex and therefore there was a need to use a variety of methods in order to be able to capture different perspectives of the process. The use of both quantitative and qualitative methods and different data sources are recommended when trying out complex interventions (Craig et al., 2008), such as ReWork-Stroke. Two of the studies in this thesis (studies II and IV) explored the situation of the persons who had had a stroke but with various methods. In study II the experiences of participating in the programme were explored using a GT approach (Charmaz, 2014), and in study IV their work potential and work performance was explored by using a mixed-method approach (Creswell & Plano Clark, 2017). These two studies complemented each other and validated the findings of one another. The perspective of the coordinators was explored in a case study design (Yin, 2014) in study I, and the co-workers' and managers' perspectives with a qualitative approach in study III. The combination of various research methods also permitted the use of various data sources.

To develop and evaluate an intervention is a time-consuming process. This ReWork-Stroke programme has been developed through different steps (Craig et al., 2008; Hellman et al., 2016). During this research, the programme was translated into clinical practice by two occupational therapists. Applying a case study design in study I enabled a thorough description and understanding of how the ReWork-Stroke programme had actually been translated into practice. Such knowledge about a certain programme is valuable but seldom well described in research (Stetler et al., 2006). Many interventions found to be effective in research projects fail to translate into meaningful outcomes across multiple contexts. In this research, the content of the ReWork-Stroke programme is described, as well as the different steps and considerations that were handled and experienced by the participants during this research. The knowledge gained can increase the understanding of being in the process of return to work, both from the perspective of providing the programme, as well as from the perspective of participating in it as a person who has had stroke or as a colleague. A RTW-programme explored from all these perspectives has not been described in such detail before.

7.2 SAMPLING

The participants included in the sample in studies II and IV were all persons who had had stroke and belonged to one of two brain injury rehabilitation units in Sweden. The ReWork-Stroke programme was then provided by coordinators in two different cities, which can be considered as a strength of this research. The distribution of participants between the two clinics was equal, and the experience of the coordinators described in the logbooks was similar.

The participants were first asked by the coordinators if they wanted to be a part of the project or not and, if they were interested, a researcher called them to ask about their consent to participate, inform about the project, and answer questions if there were any. Through this procedure the participants had the possibility to talk to two different people about the project, and raise questions, which was perhaps beneficial. Even if the participants did not want to be included in the project, they knew that they would get support in the RTW process, i.e. usual care/rehabilitation, although not in the same structured way as in the research project. One inclusion criterion in this research was that the person should be able to speak and understand Swedish, which is a point for reflection at a time when so many people in our society do not speak or understand Swedish.

The persons who had had a stroke and were included in this sample were motivated at inclusion and wanted to RTW, which could be of importance for the findings in this research as motivation has shown to be a predictor for successful RTW (Ekbladh et al., 2010). While participating in the ReWork-Stroke programme, some participants dropped out because of having a further stroke or another illness.

The participants in study III were chosen by the person who had had a stroke, which might have influenced the inclusion of the participants and therefore also the findings. It may have been difficult for the co-worker/manager to say no to being interviewed. Most of them had had a long relationship with their colleague before the colleague had the stroke and this may have influenced the participants' acceptance to being interviewed. If the manager had chosen a co-worker or a manager for the interview, it may have been another person.

7.3 DATA COLLECTION

The methods used in this research and the procedure for data collection were suitable for capturing knowledge concerning the different aims of the studies, as well as getting a broader understanding and knowledge regarding rehabilitation for return to work after stroke and the ReWork-Stroke programme. As study I included logbooks completed by the coordinators as well as interviews with them, this gave complementary information about the core elements of the programme and of the experiences of conducting it. Knowledge was gained concerning how unique the different processes were for each participant, and about the different factors dealt with and their importance during the RTW process. The logbooks also contributed with insight into how the consequences of stroke influenced the performance of work tasks in the specific work situation and what challenges this entailed. Furthermore, knowledge was gained concerning occupational therapy practice and how different methods and strategies were used according to the individual needs in each situation.

In studies II and III semi-structured interviews were conducted mainly at the participants' work places. As the purpose of the interviews was to capture experiences and processes concerning RTW connected to the specific work context and work place, it was beneficial for both parties to meet at the work place, and it made the interviews more focused on the work situations. For the interviewer, these meetings gave additional information about the

participants' work situation, both concerning work tasks and the environment and context. The participants had the possibility to show their work place and work tasks and sometimes colleagues at work were introduced. This information altogether contributed to an increased understanding about the participant's work situation.

One challenging aspect of the interview process was that the interviews with both the persons who had had stroke and their co-worker and managers were conducted during the same time frame and often at the same visit at the work place. This meant that a change in focus and perspective was needed from one interview to another.

The assessments used in study IV contributed valuable knowledge concerning the variation between the participants, which was useful in order to understand the consequences of stroke for each individual and to make person-centred plans for the work trial. By doing repeated assessments, the changes during the process of RTW were also captured and the understanding about changes for each individual and how these differed between participants was increased. Work performance was assessed with a standardized and valid tool (AWP), and gave valuable information concerning the motor and process areas of each participant. However, it was not used at the participants' work places or on work tasks connected to their work. Therefore the results did not contribute with specific knowledge and understanding of the unique work situation of the participants, which has been recommended by Karlsson and colleagues (2018). However, the assessment was conducted by assessors from the Swedish Public Employment Services, which was a strength in this research as this organisation had experience of doing these assessments and was also 'neutral' in relation to the participants.

7.4 DATA ANALYSES

Different methods for data analysis were used within this thesis, depending on which data that was collected and the methodology used for each study.

The data collection (interviews) was ongoing in parallel for studies II and III but the analysis of each study was conducted one after the other. This was a deliberate choice as it could have been difficult to separate the various perspectives of persons who had had a stroke and the perspective of managers/co-workers if conducting the analyses at the same time. Both studies were inspired by a qualitative grounded theory approach but the data collection in study III was not conducted in parallel with the analysis as described in grounded theory (Charmaz, 2014) due to the reasoning mentioned above. The analysis in study II began in conjunction with the first interview and then continued during the data collection. In both studies, the first interview with each participant was carefully listened to and the content made the basis for developing questions for the second (follow-up) interview.

In study III both co-workers and managers were included. According to their different roles and responsibilities it was difficult to decide how to deal with the data, if the co-workers and managers should be two groups according to their different roles when analysing the interviews. However, there were also similar experiences described and therefore the data from the findings ended up being presenting together.

In studies I and IV the material from the same logbooks was used but analysed differently according to the different aims of the studies. In study I, the focus during the analysing process was on where, when and how the ReWork-Stroke programme was delivered and how the core elements of the programmes were provided in practice. In study IV, the analysis of the logbooks focused on the concepts work potential and work performance, and on what content in the logbooks regarding these was related to changes during the programme. In study I, findings from the logbooks were combined with the findings in the interviews with the coordinators. This design was chosen as it was expected that the understanding of the quantitative result could be increased by the qualitative data. Using a deductive approach in analysis of qualitative interview data, as here in the structured logbooks, might entail losing some information that could increase the understanding and the experiences of the provision of the programme. This choice was led by the aim of the study to explore and describe the core elements of the programme. The focus was not to find new elements (Dahlgren, Emmelin, Winkvist, & Lindhgren, 2007).

In study IV, analyses of information from assessments and logbooks focusing on work potential and work performance was conducted using a mixed method with the intention to increase the understanding of the quantitative data (Creswell & Plano Clark, 2017). The logbooks contributed with examples on the actions taken by the coordinators specifically targeted towards work performance and work potential to increase aspects of work ability.

The choice of analysing data on an individual level is in line with the person-centred approach of the programme and the analysis focused on potential individual changes during the work trial. Another argument for the chosen analysis was the small number of participants in the studies.

Several steps were taken to ascertain the trustworthiness of the results in all qualitative analysis of this thesis (Graneheim & Lundman, 2004). The researchers first read the transcribed interviews and the logbooks repeatedly to get a thorough understanding of the text. During the analysis the researchers went back and forth between the emerging findings and the original text to make sure that the findings were in accordance with the text. The researchers have been working in pairs through the analysis in studies II and III, making an ongoing discussion possible in the interpretation of the findings. All researchers were involved in discussions in of the upcoming results in the different studies and thereby trustworthiness was established. In study III the trustworthiness was also validated by discussing the results with people skilled in brain injury rehabilitation. Further, in study III the five researchers worked interactively during the analysis process. To ensure credibility, triangulation of data sources have been used. Using data from different methods, in study I from interviews and logbooks, increased the possibility to verify particular details that have been identified through one of the sources, with the other (Shenton, 2004). To strengthen transferability the researchers have strived for giving a detailed presentation of the participants as well as the findings.

7.5 GENERALIZATION

In this research the purpose is not to generalize the findings, as the included sample of participants is quite small. However, perhaps some of the more generic thoughts and aspects concerning the ReWork-Stroke programme and its findings could be used in other settings as the purpose of the programme is not to be used in specific settings, rather in work places in general.

8 ETHICAL CONSIDERATIONS

All participants in studies II and III have been interviewed at their different work places, a decision that was made by themselves; thus the interviews were conducted in a familiar environment. The period in which the first interviews were conducted was, to some extent, vulnerable for the persons who had had a stroke. They were in the early phase of the RTW process without knowing what the future would bring concerning their possibilities to RTW. Also, their managers and co-workers were in the phase of not knowing what was to come concerning their future relationship with their colleague at work. According to these circumstances, the interviews were conducted during a 'sensitive' time concerning ongoing processes. However, the aim of this research was to capture experiences from this early phase of RTW, as well as from three months later. In advance it was difficult to know how the interview would turn out and what kind of emotions it might bring up. In some cases the interview might have raised emotions that were difficult to handle, but the persons who had had a stroke (study II) already had ongoing contact with the coordinator, who also had a team within healthcare to talk to. Some of the participants in study III also had contact with the coordinator in the project while supporting their colleague. All participants were informed that they could withdraw from the project at any time and that it was okay not to answer questions that they did not want to during the interview. Several participants (in both studies) also mentioned, in connection to the interviews, that they were happy to share their knowledge and experiences with the hope/aim to help others in similar situations as themselves.

During the research several assessments were filled out by the participants (study IV) and they were also observed by the occupational therapists from the Swedish Public Employment Services when performing tasks (AWP). These situations could have contributed to feelings of insecurity; additionally, the assessments took some time and could affect the alertness of the participants dealing with fatigue. However, they were informed about the purpose and content of these assessments at the beginning of the project and made aware that they could withdraw if they wanted to. The coordinator was also available for participants if they had questions concerning the assessment.

9 CLINICAL IMPLICATIONS

The empirical findings in this thesis contribute to knowledge concerning experiences of being in the process of return to work after stroke while participating in the ReWork-Stroke programme. Experiences from the different perspectives of persons who had had a stroke, their managers and co-workers, as well as the coordinators providing the programme have been explored. Different challenges within work situations are described as well as strategies that are used to overcome these. Taken together, these findings provide important knowledge that can be implemented in occupational therapy practice and in vocational rehabilitation.

The findings in this thesis highlight the importance of applying a person-centred approach to a rehabilitation programme focusing on RTW. The findings indicate that this is an appropriate approach because of the individuals' various work tasks and working environments, the unique consequences after stroke, and the stakeholders involved in the process. The coordinators providing the ReWork-Stroke programme in the RTW process need to thoroughly map out all individual preconditions in order to be able to plan and support the person who had had a stroke.

In addition to the clinical implications of applying a person-centred approach, the benefits of being at the work place is evident. The findings indicate that mapping out the individuals' occupational performance and skills in the real/actual work environment contribute to a relevant and realistic plan for the forthcoming rehabilitation period. Being at the work place is of high importance as the same consequences after a stroke might bring various limitations in occupational performance, depending on the work tasks, and necessitate various strategies to increase work ability.

The findings also indicate that in order to form individual plans for the work trial phase of the programme, a reciprocal knowledge sharing and collaboration with the person who had had a stroke and the work place stakeholders (managers and co-workers) is crucial. Such knowledge sharing brings clarity to the process and a mutual plan to work towards.

When providing a rehabilitation programme that focuses on RTW, such as the ReWork-Stroke programme, it is important to be aware of the situation of those indirectly involved. The findings indicate that co-workers might have a difficult and sometimes vaguely defined role when there is a lack of clarity regarding responsibility and time allocated for being a 'supportive' colleague to the person who had had a stroke. It is clear that co-workers and managers are important in the RTW process, and therefore it is vital to also consider their situation in this kind of programme.

To summarize the clinical implications that have been identified based on the unified findings in this thesis, it might be recommended that rehabilitation focusing on RTW needs to include the co-workers and managers at the work place as well in a structured way. Furthermore, rehabilitation needs to be situated in their real working environment to have access to relevant work tasks and situations. Finally, despite the fact that various consequences after stroke still

remain, there can be hope for the future by "*creating possibilities for work ability through shared knowledge and flexibility in the RTW process.*"

10 FUTURE STUDIES

According to the findings in this thesis the ReWork-Stroke programme has been beneficial in several ways for different stakeholders. However, some of the participants would probably benefit from having support from the coordinator in a prolonged programme where necessary. Longer follow-up periods have previously been recommended as RTW after stroke can take a long time and different obstacles can occur as time goes on. An individualisation in the length of the programme based on the need for support was obvious in this project and needs to be tested. Further a long-term follow-up using both qualitative and quantitative data would be valuable.

Study I included information on estimated time throughout the ReWork-Stroke programme for different elements provided to the different stakeholders. This gave a tentative appreciation of resources for provision of a programme focusing on return to work. Performing a health economic evaluation would be of interest and could give more thorough information and knowledge about the costs involved. After refinement of the programme based on the findings in this thesis, the effect of the ReWork-Stroke programme needs to be evaluated in comparison to the usual methods of rehabilitation targeting RTW after stroke.

During the different studies it became obvious that information on consequences of stroke and how these could be dealt with was limited among persons who had had stroke, their co-workers and managers, and the social insurance officers. Information booklets on, for example, fatigue, memory problems, and simultaneous capacity could be used to resolve this limited knowledge and could be distributed in a more structured way to the different stakeholders. A website could be another way of distributing information to and between those involved in the programme.

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