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RETURN TO WORK:

Exploring paths toward work after spinal cord injury and designing a rehabilitation intervention

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Return to work: Exploring paths toward work after spinal cord injury and designing a rehabilitation intervention

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In memory of my mom

Du är det finaste jag vet

ABSTRACT

Introduction: Return to work (RTW) after spinal cord injury (SCI) often involves a complex and extended process for the person, due to consequences of the injury. There is limited evidence on how to support a person with SCI during the RTW process, and employment rates are low in Sweden, as well as internationally. It is important when developing a rehabilitation intervention for RTW after SCI, that the intervention derives from a contextually relevant evidence base, as well as from collaboration with persons with SCI.

Aim: The overall aim was to explore and generate knowledge about RTW for adults with SCI, in order to develop and evaluate the design and feasibility of a complex intervention that can serve as a complement to current RTW systems.

Methods: This thesis draws on the Medical Research Council's (MRC) guidance for developing and evaluating complex interventions. Study I was a follow-up study in which narrative interviews and participant observations were used to explore experiences of RTW in the context of everyday life, 7-11 years after SCI. In study II, a participatory approach drawing on photovoice methods was used to explore experiences of barriers and possibilities in RTW among working adults with SCI. In study III, constructive grounded theory and focus group interviews were used to generate knowledge on how professional stakeholders organize and experience the RTW process for the person with SCI. The findings in studies I-III in combination with research in the field and theoretical resources, constituted the evidence base for modelling ReWork-SCI, a person-centred, structured, and coordinated intervention process for RTW after SCI. The feasibility of ReWork-SCI and the study design for evaluating ReWork-SCI, with regard to adherence, acceptability, recruitment, retention, and use of outcome measures, was explored in study IV.

Findings: Studies I-III illustrate that the RTW process was experienced as fragmented by the person with SCI and difficult to navigate for the professional stakeholders. Moreover, findings show how the RTW process was situated in a person's everyday life. Further, tensions between intentions for fair support and possibilities to enable such, meant challenges in *when* and *how* a RTW process could be initiated and realized. Study IV shows that ReWork-SCI was feasible although modifications to the intervention, and the study design was necessary prior to a full-scale trial.

Conclusion: This thesis adds to the understanding of complexities in the RTW process after SCI. Supporting the person in untangling problematic dimensions of how RTW is situated in everyday life is a critical outset in the process. This thesis shows how a RTW coordinator based in the SCI rehabilitation team can collaborate with the person and provide coordination between stakeholders throughout the RTW process and how ReWork-SCI has the potential to guide when and how a RTW process after SCI can be made possible.

SVENSK SAMMANFATTNING

Introduktion: Återgång till arbete efter ryggmärgsskada (RMS) är ofta en komplex och lång process till följd av de omfattande konsekvenser en RMS innebär för personen. De finns begränsad evidens för hur stöd för återgång till arbete efter RMS bör utformas och sysselsättningsgraden är låg både i Sverige och internationellt. Vid utveckling av en intervention för arbetsåtergång är det viktigt att interventionen utgår från den kontext där den ska prövas och att utvecklingen sker i samarbete med personer med RMS.

Mål: Det övergripande målet var att undersöka och generera kunskap om återgång till arbete för vuxna med RMS, för att utveckla och utvärdera designen och genomförbarheten av en komplex intervention som kan fungera som ett komplement till nuvarande system för återgång till arbete.

Metoder: Avhandlingen utgår från Medical Research Council's (MRC) riktlinjer för att utveckla och utvärdera komplexa interventioner. Studie I var en uppföljande studie där narrativa intervjuer och deltagande observationer användes för att undersöka erfarenheter av arbetsrehabilitering i relation till personens vardagliga kontext 7–11 år efter RMS. I studie II, användes deltagande ansats och photovoice metoder för att undersöka erfarenheter av hinder och möjligheter för återgång till arbete bland personer med ryggmärgsskada som arbetar. I studie III användes konstruktiv grundad teori och fokusgruppintervjuer för att generera kunskap om hur professionella aktörer organiserar och erfar arbetsrehabiliteringsprocessen för personen med RMS. Resultaten av studie I-III, forskning inom fältet och teoretiska resurser formade kunskapsbasen för modellering av en personcentrerad, strukturerad och koordinerad interventionsprocess för arbetsåtergång efter RMS, ReWork-SCI. Genomförbarheten av ReWork-SCI och studiedesignen för att utvärdera ReWork-SCI, med avseende på följsamhet, acceptans, rekrytering, bibehållande och utfallsmått, prövades i studie IV.

Resultat: Studie I-III visar att arbetstrehabiliteringsprocessen upplevdes fragmenterad för personen med ryggmärgsskada och svårt att navigera för professionella aktörer. Resultaten visar på den plats arbetsåtergång har i personens vardagsliv. Spänningar mellan intentioner för rättvist stöd och möjligheter att erbjuda detta innebar svårigheter att utröna *när* arbetsrehabilitering kunde initieras och *hur* den kunde realiseras. Studie IV visar att ReWork-SCI var genomförbar men att modifiering av både interventionen och studiens design är nödvändig inför en fullskalig prövning.

Konklusion: Den här avhandlingen bidrar till kunskapen om den komplexitet som omger återgång till arbete efter RMS. Att stödja personen i att reda ut problematiska situationer i relation till dennes vardagsliv och kontext är en kritisk utgångspunkt i arbetsrehabiliteringsprocessen. Den här avhandlingen visar hur en koordinator baserad i ett multiprofessionellt RMS team kan samarbeta med personen och övriga aktörer genom arbetsrehabiliteringsprocessen och att ReWork-SCI har potential att ge guidning i förhållande till när och hur en arbetsrehabiliteringsprocess kan genomföras efter RMS.

LIST OF SCIENTIFIC PAPERS

I. Holmlund L, Guidetti S, Eriksson G, Asaba E. Return to work in the context of everyday life 7-11 years after spinal cord injury - a follow-up study. Disability and Rehabilitation. 2018;40(24):2875-2883.

II. Holmlund L, Hultling C, Asaba E. Mapping Out One's Own Paths Toward Work: Focus on Experiences of Return to Work After Spinal Cord Injury. Qualitative Health Research. 2018;28(13):2020-2032.

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IV. Holmlund L, Guidetti S, Hultling C, Seiger Å, Eriksson G, Asaba E. Evaluating the feasibility of ReWork-SCI: A person-centred intervention for return-to-work after spinal cord injury. In manuscript.

CONTENTS

1 Introduction 3
1.1 Theoretical Resources 4
1.1.1 An occupational perspective 4
1.1.2 Everyday life occupations 6
1.1.3 Participation in occupations in everyday life 7
1.2 Work 9
1.2.1 RTW after sickness absence 10
1.2.2 Sickness absence and RTW within in a Swedish socio-political setting 12
1.3 Spinal cord injury 15
1.3.1 Meaning of work in relation to everyday life after SCI 16
1.3.2 Determinants of employment and time to first job after SCI 17
1.4 Interventions to facilitate RTW 18
1.4.1 Interventions to facilitate RTW after SCI 19
1.5 Rationale of the thesis 20
1.6 Research aims 21
2 Methods 23
2.1 Development and evaluation of a complex intervention 24
2.1.1 Development of ReWork-SCI 24
2.2 Research approaches and methods 26
2.2.1 Narrative approach 26
2.2.2 Participatory approach and photovoice methodology 26
2.2.3 Constructivist grounded theory approach 27
2.2.4 Evaluation of the feasibility of a complex intervention 27
2.3 Participants 28
2.3.1 Sampling 28
2.3.2 Participants studies I-IV 28
2.4 Data generation 31
2.5 Data analyses 36
2.5.1 Analyses of qualitative data 36
2.5.2 Visual analysis 37
2.5.3 Analyses of quantitative data 37
3 Findings 39
3.1 Analysis of findings studies I-III 41
3.1.1 Negotiating work as part of a meaningful everyday life 42
3.1.2 Being as anyone else at work 42
3.1.3 Focusing on the person in a rule-based context 44
3.1.4 Navigating paths to meaningful engagement 44
3.2 Findings study IV 45
4 General Discussion 47
4.1 Actions in the RTW process as responses to everyday life situations 47

4.1.1 Understanding the situation as a starting point in the RTW process 48
4.2 Person-centredness and participation as a rights-based approach to RTW 49
4.2.1 Person-centredness as a component in the RTW process 50
4.3 The potential of implementing ReWork-SCI in a SCI rehabilitation unit 51
4.3.1 The coordination role in a SCI rehabilitation unit 52
4.3.2 Potentially active components of ReWork-SCI 53
4.4 Navigating the RTW process after SCI through societal landscapes 54
4.5 Methodological considerations 56
4.5.1 Aspects of trustworthiness 56
4.5.2 Using a participatory approach 58
4.5.3 Evaluating a complex intervention for RTW 59
4.5.4 Ethical considerations 61
4.6 Conclusions and implications of research 63
4.7 Future studies 65
5 Acknowledgements 67
6 References 71

LIST OF ABBREVIATIONS

ASIA	American Spinal Cord Association
AIS	ASIA Impairment Scale
CRPD	Convention on the Rights for Persons with Disabilities
COPM	Canadian Occupational Performance Measure
EQ5D	EuroQol Five Dimensions
EQ-thermometer	EuroQol thermometer
FIM	Functional Independence Measure
ICF	International Classification of Functioning, Disability and Health
MRC	Medical Research Council
RTW	Return to Work
RTW process	Return to Work process
SCI	Spinal Cord Injury
SOC-13	Sense of Coherence-13
SSIA	Swedish Social Insurance Agency
WEIS	Work Environment Impact Scale
WRI	Worker Role Interview

PROLOGUE

I remember, as a 10-year old, standing halfway from the hallway to the kitchen, still dressed in jacket and shoes, upset, declaring to my mother that "I will never go to university". Our teacher had told us that homework at the university consisted of reading books, whole books. I remembered my mother laughing, and saying "you will go, and it will be one of the best times in your life".

When I left Umeå as an occupational therapist several years later, my goal was to work in SCI rehabilitation. I was interested in the process of returning to, and recapturing, everyday life after trauma or illness, and how I as an occupational therapist could facilitate this. Entering the doors to the Rehab Station Stockholm and Spinalis SCI unit in 2003, I had the opportunity to gradually understand that process with support from experts, my colleagues, but foremost, persons living with SCI, many of them still in an early learning process themselves. In the meantime, I learnt that keys to how to navigate paths in everyday life after SCI were to be found in the stories told by the person beside me. Naturally, many stories stayed with me. I remember a young man, so brilliant, cool, and courageous, in a new and difficult situation. Facing everyday challenges with bravery and charm. Taking confident steps to an everyday life that reflected how he viewed himself and that was meaningful to him, with a relatively new occupational therapist to reason with. After things had settled, we repeatedly talked about future and work; he made jokes, changed the subject, and explained his thoughts on work and what mattered to him. Made me understand how this was an individual experience, but also situated. I especially remember a situation when the subject of work arose, and he said: "Maybe one day… but Lisa, how would you support me in this? Who would be able to support me in this?"

This story, along with many others, stayed with me. The question, however, remained unanswered. Who could support a person who had no employment to return to after injury, and no higher education to lean against? What story remained untold? What experiences and expectations remained unraveled? This was the point of departure for my research education and striving to explore paths toward work after SCI. Paths that I have navigated in collaboration with persons with SCI and the professional stakeholders with the responsibility to support them.

1 INTRODUCTION

A spinal cord injury (SCI) initially means a drastic shift in life (1) that often affects persons in their working ages (2). After injury the person is typically admitted to acute care for management, followed by extended medical rehabilitation (1, 3). Recapturing everyday life after SCI is a process where the person can gradually become familiar with their new situation (4-6) and return to embrace participation in occupations in their homes and communities (4, 5). Because of the role of work for meaningful participation in everyday life (7-11), and its importance to health and wellbeing (12) return to work (RTW) is often highlighted as a critical element in the rehabilitation process. Yet RTW after SCI is complex (7, 8, 13), and sometimes described as the final piece of a puzzle (7), due to the challenge of integrating work into a changed everyday life.

Return to work can be seen as a phenomena, including both a process and an outcome (14). In Sweden, work is viewed as an obligation, to work and be self-sufficient if able to, and as a right to improved life opportunities (15). Sweden has also signed and ratified the Convention on the Rights of Persons with Disabilities (CRPD). This implies a commitment to ensure equal rights for persons with disability, for example in regard to full participation and employment on the same terms as others (16). The RTW process includes multiple dimensions (17), systems and stakeholders (18, 19). In this thesis focus is on the person with SCI; the employer; health care professionals working in a SCI rehabilitation team; officers from the Swedish Social Insurance Agency (SSIA) and from the Swedish Public Employment Service. Despite political incentives and resources, employment rates for persons with SCI are low in Sweden (20, 21), as well as internationally (22).

Because RTW after SCI is complex, and because persons with SCI are marginalized in the labour market this thesis balances toward perspectives on work after SCI from a rights (16), and a process perspective (14). Moreover, an occupational perspective (23-25), knowledge on everyday life (26, 27), participation (28, 29), and person-centredness (30-32) are used as theoretical resources, so seeing work as one of many occupations in a person's day-to-day life is important (26). What a person does in his or her everyday life contributes to their being, belonging, and becoming (24), in an ongoing process, coordinated between the persons experience and context (26, 33).

In order to improve the RTW process after SCI, the Medical Research Councils (MRC) guidance for developing and evaluating complex interventions is used (34). Therefore, this thesis consists of three studies contributing to guiding principles and components as an evidence base for a person-centred intervention for RTW, ReWork-SCI. The feasibility of the intervention is evaluated in the fourth study. In this work, it has been important to incorporate the experience of persons with SCI and professional stakeholders, as well as to collaborate with them in the process. This is thought to contribute to authenticity and sustainability of interventions (35, 36).

1.1 THEORETICAL RESOURCES

1.1.1 An occupational perspective

Occupational therapy and occupational science is founded on an understanding of what persons do throughout their life and day-by-day, as an innate need, with significance for health and wellbeing (24). Situations where a person is deprived of occupations that have personal and social relevance, such as described in research on work after SCI (7-10), can impact negatively on experience of meaning, and on health (24, 37). In this thesis, the occupational perspective departure from the definition, "*a way of looking at or thinking about human doing"* (23 p. 8). Using this perspective in research implies opportunities to explore questions and generate knowledge in relation to what people do in their everyday lives (37). An occupational perspective can thus be used to understand occupations such as work and different stakeholders' actions and interactions in the RTW process.

This thesis derive from Wilcock's and Hocking's (24) understanding of occupation through the terms doing, being, belonging, and becoming. These terms are relevant to understanding the complexity of human occupation, and to understanding work as contributing to a sense of self (38), social participation (7, 10, 11), and growth (9, 11). Doing includes "*mental, physical, social, communal, spiritual, restful, active, obligatory, self-chosen, and paid or unpaid occupations*" (24 p. 135). Being is something personal, dependent on time for stillness and reflection, and founded in the person's inner self, spirit and personality. Being is contemplation of ideas and designing future plans. In this way, being is a way of making sense of everyday occupations. Belonging is the social aspect of occupation, the affiliation to others, places and things that can be related to feelings, such as connectedness, self, security and happiness. Becoming is the development or transformation in which individual and communities change and become different through what they do, such as achieving potential or realizing aspirations, and in this way, also creating communal or self-image (24).

Occupation has relevance on multiple levels (23). It can be conceptualized as experience, the way that persons engage in and experience doing (26, 39, 40). Attention has also been drawn to the necessity of looking at occupation as experience situated through context (e.g. 24-26, 41-43). Acknowledging the situated nature of occupation refers to "*how occupation is shaped, embedded and negotiated within, as well as how it contributes to the shaping of, social systems and structures*" (41 p. 58). Thus, situatedness refers to an inter-relationship between person and context (43). Context includes, for example, physical, social, cultural, and political forms (25). In this way, work cannot only be understood as an occupation experienced by the individual but as occupation situated in relation to multiple, and interacting, dimensions of environment.

Acknowledging a dynamic view of occupation (24), and how environment influences doing (32, 37, 44), is well described in occupational therapy and occupational science literature. However, an understanding of the situated nature of occupation draw on thoughts about situatedness grounded in transactionalism, based on philosopher John Dewey. A transactional

perspective on occupation was introduced in 2006 (25) and has since been outlined in a series of research articles (e.g. 33, 45-47) and books (e.g. 42, 48). The transactional perspective was introduced as a way of understanding occupation beyond a dualistic or individualistic perspective (25, 33) and implies potential of a complex understanding of how occupation occurs in coordination between person and context, and how occupation is always in process (25, 42, 45). This means that what a person does throughout their lives, for example in relation to work, is coordinated through their specific social, labour market, and societal context. The transactional perspective on occupation thus informs an understanding of doing in relation to the RTW process as something that cannot be viewed as static, but something always potentially in change. It also informs an understanding of doing in relation to work and the RTW process as inseparable from the context through which it occurs.

The distance from perspectives perceived as dualistic or individualistic (25) is motivated through a risk of seeing the individual as always being the authority on how occupations turn out, rather than understanding occupations as process located "*at the level of the situation of which the individual is an integral part*" (25 p. 91). Based on these understandings, a transactional perspective on occupation has informed critical perspectives in occupational science (49) and research targeting unemployment in relation to socio-political contexts (50-52). Using a critically informed perspective on occupation brings awareness of how occupation is shaped in relation to social structures, processes and practices, instead of framing challenges to occupation as a result only of factors within the individual (49). In addition to the critique to the dualistic perspective, the perspectives of possibilities (41) and choice (43) as embedded within, and shaped through, context have been relevant in synthesizing the findings of this thesis; for example, Rudman (41), argues that possibilities both shape, and contributes to the shaping of societal systems, and Galvaan (43), suggests that choice is mediated through a person situated in a particular social structure.

To summarize, this thesis derives from exploration of human occupation, through doing, being, belonging, and becoming (24). In the process of conducting this thesis and further framing, synthesizing, and discussing the research findings, a certain shift in the view of occupation has been seen as important. A shift from a perspective of occupation as experience (39, 40), deriving from something subjective and individual, to a perspective of occupation as a situated experience (25), in relation to, e.g. social, labour market, and societal contexts. This is seen as especially important in understanding the multidimensional RTW process (17, 18). I will argue that even if the rehabilitation intervention in this thesis is person-centred and based within healthcare, the RTW process needs to be understood and managed in relation to a broader societal context. This perspective is important in order to add to the understanding of the complexities of the RTW process, and in the endeavour to enhance possibilities of engagement in work contributing to health and wellbeing after SCI.

1.1.2 Everyday life occupations

When using an occupational perspective to explore RTW, understanding everyday life occupations is central. Everyday life occupations can be understood as what people do in their day-to-day lives. The everyday is the realm in which occupations are embedded and situated (26). In this way, the everyday frames an arena in which occupations, such as working, picking up children from school, or seeing a friend, occur. In line with a transactional perspective, Burkitt (53) suggests that the reality of everyday life is built through doing, or transactions. He argues that "*everyday life is related to all activities and is the sum of total of relations that constitute the human – and every human being – in terms of our collective and individual experience*" (53 p. 212). Somewhat differently, Hasselkus (27) emphasizes the regularity of everyday occupations, yet she suggests that this regularity does not necessarily encompass occupations that occur every day. Work constitutes a large proportion of everyday life for many adults. Yet when rhetorically asking "*what is your occupation?*" (p. 14) Christiansen and Townsend (37) argue for a perspective on everyday life that goes beyond paid work. A certain focus on one specific occupation, or creating boundaries between, for example, work, leisure, and rest, can limit the understanding of everyday life (39, 40). The perspective on everyday life occupation in this thesis can be understood through Hasselkus' (26, 27) and Burkitt's (53) fluid, or ongoing, description of day-to-day occupations. Moreover, this thesis embraces different forms of doing in everyday life (23), where meaningful engagement in everyday life, including work, is seen as essential for being, belonging, and becoming (24).

1.1.2.1 The rhythm of everyday life

In times of disruption in everyday life, such as after SCI, the everyday routines or the rhythm in everyday life become comprised (27, 51, 54). Everyday routines are characterized as regular or customary features of time use during the day (26, 54). Similar to Burkitt's (53) reasoning about the reality of the everyday, Clark (54) suggests that occupations can be characterized as building blocks through which routines are shaped in everyday life. Routines can therefore be understood as a sort of rhythm in everyday life (51). This rhythm, shaped by the person in their everyday life, can create regularity, stability, and predictability (26, 54). Hasselkus (26) notes that routine can mean the presence of familiarity, so although routine can be viewed as boring, implicating a certain 'stuckness' in everyday life, it can also be the means for stability, meaning, and construction of identity (26, 54). Returning to work after SCI can therefore be viewed as complex due to changed circumstances and routines, but can have a purpose of providing a new structure, identity and meaning (37).

Aldrich and Dicke (51) argue that negotiations in everyday routines can be viewed as responses to the person's abilities and possibilities to function in their situation; instead of attending to routines as ordinary, expected, or taken-for-granted, they draw attention to the uncertainty in everyday life when routines are disrupted. This is relevant in understanding

RTW after SCI because they suggest that there is a contingency between the person and the context in all aspects of everyday life (51), in relation to what a person needs, wants, or is obliged to do (24). In a similar way, Hasselkus (27) emphasizes that the complexities and singularities of everyday occupations sometimes become unnoticed or hidden, particularly if everyday life is referred to as something ordinary or mundane. In this thesis, it has been important to appreciate the richness and complexities of what a persons do in their day-to-day life (26, 27, 53), and to view work as intertwined in a rhythm of a person's everyday life (37, 51), and situated within a broader social and societal context (51).

1.1.3 Participation in occupations in everyday life

Similar to the perspective on occupation, participation is in this thesis seen as coordinated between person and context (28, 29). In supporting RTW, participation as a concept is relevant for several reasons. Basically, because engagement in occupations, such as work, can contribute to a person's health and wellbeing (24). Participation is also relevant from a rights-based perspective (16). Participation in occupations, such as work, on the same terms as others can mean inclusion, power, voice, and access to society (16, 55, 56). In this way, participation can mean influence in matters that are central to the person. In its preamble, the CRPD states that:

> Recognizing the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty (16 p. 2).

To situate the perspective used in this thesis, a short review of the development of participation will be presented. As a result of critique raised by the disability movement to a traditional view on disability as functional limitation (57) the World Health Organization, in 2001, introduced International Classification of Functioning, Disability and Health (ICF). In this framework, the inclusion of a participation component was novel and defined as "*involvement in a life situation*" (58 p.123). Thus, the influence of participation on health was emphasized and environmental factors were described as influential on activity and participation. The definition and conceptualization of participation held by the ICF was later critiqued due to the absence of a subjective dimension of participation. For example, Hemmingsson & Jonsson (59) pointed to the limitations of operationalizing participation as performance, and to the shortcomings of ICF in relation to subjective experience of meaning and autonomy. Several scholars aligned to the critique of the ICF (55, 60, 61), and exploration of participation from an experiential account are exemplified in research, (e.g. 62, 63). In research based on experiences of those living with physical disability participation was conceptualized as a complex and multidimensional construct deriving from dynamic

interplay between person and context (55, 60). Hammel et al. (55) frame participation as a set of core values, i.e. meaningful engagement; personal and societal responsibilities; having an impact and supporting others; social connection, inclusion and membership; access and opportunity; choice and control. Those values highlight that participation consists of balancing across individual, social, and societal levels (55). Aldrich and Heatwole Shank (28), and Lilja and Josephsson (29), advance this move from a subjective to a transactional perspective through emphasizing how participation is socially constructive, and a perspective of participation as phenomena, coordinated through context (28).

Understanding the gradual shifts in the conceptualization of participation, and how they derive from disability movement (57), is important to understand work as a possibility for meaningful engagement, contribution, and impact (24, 55); as well as, to understand work through dimensions of inclusion, power, voice, and access (16, 55). A socially constructive perspective on participation notes the importance of contextually situating the research project, and the importance of involving persons with SCI in the development of a rehabilitation intervention that concern them (16, 56, 57). To ensure that the experiences of persons with SCI are incorporated through collaboration has therefore been as an essential part of this thesis. This is a way to actively work with integrating the perspectives of those most intimately involved in social change and development of health care interventions (36, 64).

1.1.3.1 Person-centredness in research and practice

It is unlikely that a RTW intervention can be entirely successful or ethical without collaboration with the person involved. The Social Insurance Code (65) and the Health Care Act (66) both point to collaboration with the person as central in medical rehabilitation and in the RTW process, for example, the Health Care Act (66) emphasizes respect for the person's self-determination and integrity. To theoretically position the focus on the person's situation in healthcare interventions, the concept person-centredness is used in this thesis. There are multiple terms, such as patient, client, and person-centredness with somewhat different connotations in how to view a person in the healthcare system (30). The use of *person*-centredness is a conscious choice, grounded in an endeavour to highlight the experience, expertise, and situatedness of the person, and to minimize power relations (30). Yet the understanding and use of person-centredness in this thesis draw on several sources, e.g. a conceptual analysis of person-centredness by LePlege et al. (30), person-centred care by Ekman et al. (31, 67), and client-centred practice in occupational therapy (32). These resources all draw on thoughts from psychologist Carl Rogers. For the purpose of clarity, the term person-centred is used consistently, even if the referred research uses terms such as client-centred.

In their analysis, Leplege et al. (30) summarize person-centredness as a multidimensional concept with four principal meanings: i) addressing the person's specific and holistic

properties; ii) addressing the person's difficulties in everyday life; iii) person as expert: participation and empowerment; and iv) respect the person "behind" the impairment or the disease. In this thesis, these principles are seen as critical in RTW interventions for persons living with SCI. They are, together with storytelling as a basis for partnership, building blocks in how person-centredness is viewed in this thesis. Partnership is an essential part of client-centred practice in occupational therapy (32) as well as in the systematic routine for person-centred care presented by Ekman et al. (31, 67). Partnership is theorized to facilitate decision making (32), and to build trust through transparency and mutual sharing between the therapist and the person (68).

1.1.3.2 Narratives as part of a person-centred approach

In person-centred care, the person's narrated experience is a basis for initiating and maintaining partnership (31, 67). Narratives, sharing of experiences through stories, were therefore central in the development of the rehabilitation intervention in this thesis. Through storytelling the person shares what matters for them in their everyday lives (69, 70). Sharing one's narratives can also be a means of expressing identity (69). This may be of particular importance after illness or trauma, such as SCI, since opportunities for expressing identity through doing are initially limited. To open up for, and be attentive to, a person's narrative brings the person into focus and can illuminate stories that otherwise are untold (67, 69). Eliciting narratives can provide a means of understanding past experiences, making sense of the present, as well as provide guidance for the future (69, 71). In this way, narratives provide an opportunity, for example for health care professionals, to learn from and gain an understanding of a person's experiences through their stories. In a partnership, narratives become co-constructed and can imply possibilities for new understandings of future paths (69). This means that storytelling and mutual sharing of experiences provide a basis for collaboration (67, 69). This is important during the RTW process since the telling of stories can situate the person in relation to a broader context, and so function to understand and co-construct future possibilities.

1.2 WORK

A challenge in using an occupational perspective when exploring RTW is that occupation has several meanings and is sometimes used as synonymous to being engaged in work (24). As outlined earlier in this introduction occupation in this thesis refers to a range of occupations a person engages in throughout their lives and day-by-day. To avoid misinterpretations or mix-up in relation to employment the term occupation is carefully used in the separate research studies.

In this thesis employment, work, and job are used interchangeably and refers to paid or remunerative employment. ICF classifies remunerative employment as:

> "Engaging in all aspects of work, as an occupation, trade, profession or other form of employment, for payment as an employee, full or part time, or self-employed, such as seeking employment and getting a job, doing the required tasks of the job, attending to work on time as required, supervising other workers or being supervised, and performing tasks alone or in groups" (58 p. 165).

In 2017, the employment rate in Sweden for persons between 16 and 64 years was 78%. The employment rate for persons with disability in the same age group were 62%. Between 2013 and 2017 the employment rate for the entire population increased from 76% to 78%. However, the employment rate for persons with disability remained stable. For persons with disability who assesses that they have decreased work ability, the employment rate in 2017 was 55%. Within this group, 62% worked full-time (72). To the best of my knowledge, there are no recent studies on employment rates for persons with SCI in Sweden. Two studies report employment rates of 46 % (21) and 47 % (20). Levi et al. (21) reported that additionally 8% were self-employed. Internationally, an average employment rate after SCI is estimated to be 35 %, with a wide range of 3 to 80% (56). Employment rates are difficult to compare due to differences in definitions of employment and differences in the methods used. Yet the low employment rates for person with SCI point to an unequal situation on the labour market, and also, to a more difficult financial situation for those living with SCI (21). This is in contrast to the incentives of CRPD. In article 27 work and employment, the CRPD states that:

> States' parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities (16 p. 19).

To explore how support in the RTW process after SCI can be improved is relevant to enable fair opportunities on the labour market.

1.2.1 RTW after sickness absence

1.2.1.1 Return to work

In line with the conceptualization of Young et al. (14), RTW in this thesis is seen as *phenomena* including both *process* following sick leave and the eventual *outcome* of resuming employment. Therefore, RTW is sometimes used without a qualifier, such as process. Yet this thesis balances toward the perspective of RTW as a process, following the definition of Young et al. (14), who state:

> The RTW process is thought of as 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 (14 p. 559).

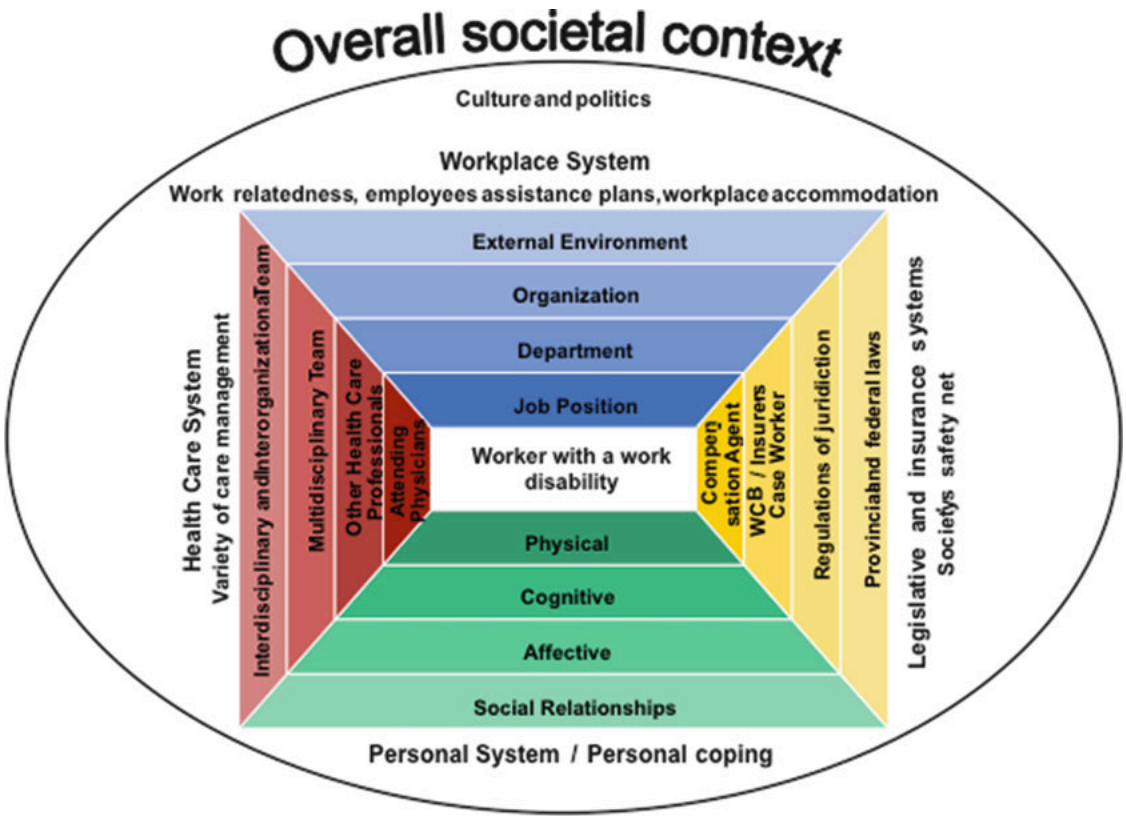
In this definition the complexity of the RTW process is captured by emphasizing the ongoing interactions between the person and the environment throughout the RTW process, and also by accentuating the multiple events, transitions, and phases that constitute this process. Young et al. (14) broadly divide the RTW process into four phases: off work, re-entry, maintenance, and advancement. These phases are described as non-linear, which means that the person may need to loop back to previous phases during the RTW process. Satisfactory outcomes of a RTW process do not necessarily mean paid work; it can also imply a final result of being off work. In their phase model, Chamberlain et al. (73) more distinctly present the possible outcomes of a RTW process. They describe that the process optimally concludes in an informed decision in regard to a return to the labour market or to a disability pension. In this way, Chamberlain et al. (73) point to how medical rehabilitation and vocational measures can overlap in the RTW process.

1.2.1.2 Sickness absence

Sickness absence can be defined as "*absence from work that is attributed to sickness by the employee and accepted as such by the employer*" (74 p. 420). For the purpose of clarity sickness absence is used consistently in this thesis when referring to both sickness absence and work disability as these terms are determined as interchangeable. Sickness absence is used even if the referred research uses work disability. Lederer et al. (17) in their scoping review assert that sickness absence is conceptualized from an individual, organizational, and societal dimension and thus point to a move from a biomedical perspective on sickness absence to a more holistic and multidimensional concept. They argue for a sickness absence as a relational concept "*resulting from the interaction of multiple dimensions that overlap and influence each other through different ecological levels*" (17 p. 258).

Lederer et al. (17) point to a lack of research focusing on sickness absence across dimensions. In a case management ecological model, Loisel et al. (18), try to facilitate such research through visualizing the arena of sickness absence and the multiple actors involved (Figure I). With this operational model, Loisel et al. (18) illustrate how RTW is situated within an arena of multiple integrating systems, such as personal, legislative and insurance, work place, and healthcare, and have an overarching societal context. Although stakeholders have shared interests, they stand to lose or gain on the RTW process (19). Through illustrating various systems, this model describes the potentiality of coordination between stakeholders. In this way, the model also clarifies the importance of situating research within the specific societal context in which RTW is intended. Implementation of interventions for RTW will depend on personal, legislative and insurance, healthcare, and work place systems, as illustrated in Figure 1. Understanding the specific characteristics of the socio-political context in which the intervention is situated is thus critical (34, 75).

Figure I The Arena in work disability prevention: a case management ecological model



Acknowledgement to: Loisel et al. (18), Prevention of work disability due to musculoskeletal disorders: The challenge of implementing evidence, with permission from Springer.

1.2.2 Sickness absence and RTW within in a Swedish socio-political setting

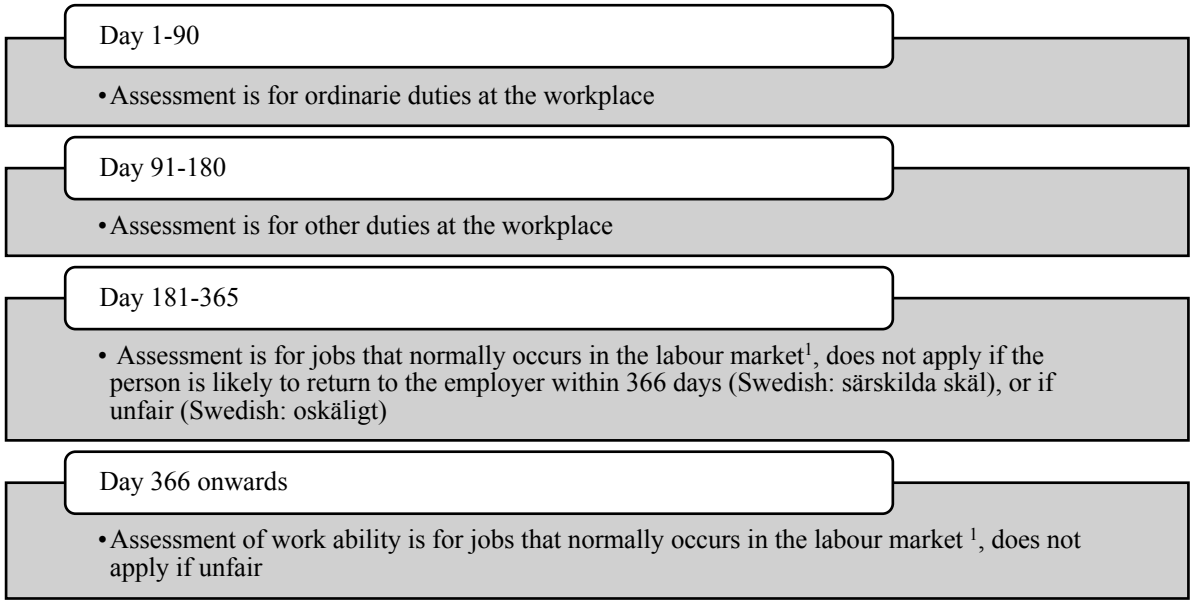
Within the socio-political system in Sweden emphasis is on workfare (Swedish: Arbetslinjen). Workfare provides a perspective of work as a right, but also work as an obligation for citizens that are able to work (15). In this thesis focus is on five main stakeholders involved in the RTW process after SCI: the person, the employer, the Swedish Social Insurance Agency (SSIA), the Swedish Public Employment Service, and the healthcare services, which in this thesis consist of the of the SCI rehabilitation team (i.e. physician, occupational therapist, social worker, physiotherapist, nurse, and, in some clinics, peer counsellor). The legal framework for the RTW process in Sweden is mainly governed by the Social Insurance Code (65), the Health Care Act (66), the Work Environment Act (76), and the Regulation of the labour market policy activities (77).

The SSIA is responsible for coordinating and monitoring measures for occupational rehabilitation (65). The SSIA should, in cooperation with the person and as soon as possible, clarify needs for, and take necessary steps in the RTW process. The SSIA should also promote cooperation between professional stakeholders. If occupational rehabilitation is needed, the SSIA is responsible for designing a rehabilitation plan. Similarly, the employer is

responsible for designing a plan within 30 days of sick leave if the person is assumed to be absent for more than 60 days. This is not necessary if, due to the person's medical conditions, it is clear that returning to work will not be possible. Both SSIA and the employer should continuously evaluate the RTW plans. The employer should also, together with the person, share information with the SSIA and take actions and provide for an efficient RTW process (65). The employer is also responsible for accommodation at the work place (76). Healthcare services are mainly responsible for medical care and rehabilitation, and for preventing, examining, and treating illness or injuries (66). The Swedish Public Employment Service is responsible for assessment, guidance, or preparatory measures for work, such as work trials (77).

Sickness absence is within the legislative and insurance system in Sweden understood from a medical perspective. Sickness certification has to relate to a diagnosis-disability-activity continuum without considerations to personal or societal dimension. Assessment of work ability is controlled by certain time limits, i.e. the rehabilitation chain (Figure II). Sick leave can be granted if work ability is decreased by at least one-quarter of the regular working hours. Sick leave can be granted on fixed sick leave grades, e.g. 25, 50, and 75%. These grades also apply to disability pension if work ability is permanently decreased. The sickness benefit is approximately 80% of the salary, but not more than 744 SEK a day. After 366 days, the benefit decreases to 75%, but not if the person has an illness defined as serious (65).

Figure II Time limits in the rehabilitation chain (65)



[1] If the individual is unemployed, assessment of work ability is for jobs that normally occurs in the labour market (Swedish: normalt förekommande arbete) starts from the beginning of sick leave. (65).

To summarise, sickness absence can be understood from a biomedical perspective, or from a multidimensional perspective, which is used in this thesis. The multiple systems and stakeholders involved in the RTW process complicates the process and cooperation among stakeholders (19, 78-81), both within and across systems (79, 80). For example, research shows how assessment of work ability needs to go beyond medical assessments (78, 82), which is contrary to legal frameworks for sickness absence (82). Research also points to a lack of routines among stakeholders (80, 82) and a lack of knowledge in regard to the expertise of other stakeholders involved in the process (78, 81). To improve work ability assessments, Sturesson et al. (78, 83) point to the necessity of team cooperation, and the possibility of using the competence of occupational therapists.

1.2.2.1 RTW coordination

Since 2006 agreements between the Swedish government and the Swedish Association of Local Authorities and Regions have been reached to increase incentives in the healthcare services for improved quality and efficiency in the sickness certification process (84). One central part of these agreements is to develop a RTW coordination role within healthcare (84, 85). The term 'RTW coordinator' is used in this thesis for the purpose of clarity in relation to international research, although rehab coordinator is commonly used in Sweden. Implementation of RTW coordination is most common in primary care, but also present in specialized care (85). The coordinating role is still loosely defined. Typically, framing of the role has varied between county councils, e.g. from administrative duties to being a coach and/ or organiser in regard to RTW processes at the unit. No specific education is required but commonly healthcare professions such as occupational therapists, physiotherapists, nurse, or social workers have taken on the role (86). A proposal for new legislation (85) suggests that early RTW coordination based in healthcare should offer individualised support and internal, as well as external, coordination. For example, mapping the needs of rehabilitation measures, coordination with other stakeholders, and statistical follow-up of patterns of sickness absence. According to the proposal (85), RTW coordination should be offered to those who consent to coordination, and as far as possible be made in consultation with the person. Thus, this proposal highlights the possibility of healthcare services coordinating RTW.

Research concerning the RTW coordinator role in Sweden described in independent and peer-reviewed research is limited. One study evaluates the coordinator role for persons who had suffered a stroke (87). Two study protocols show prospects for future research including RTW coordination to enhance RTW among patients with stress-related mental disorders (88), and to increase RTW among people on sick leave due to common mental disorders (89). In Stockholm county council, a standardized model for RTW coordination is evaluated in a report (90). The evaluation shows decreased duration of sick leave and decreased degree of sickness absence compared to the control group. The intervention was less effective for those with a combination of diagnoses, and also for those with a limited history of sickness absence and few healthcare contacts. The statistical differences is not demonstrated in the report (90).

Development of the RTW coordination role in Sweden is mainly situated within primary care settings, and focused on leading causes for sick leave, such as pain and mental disorders (84, 86). Practices within the county council aimed at specialised rehabilitation services, such as for persons with SCI, have received less focus.

1.3 SPINAL CORD INJURY

As this thesis focuses on RTW after SCI, understanding the characteristics of SCI and the rehabilitation process following SCI is essential. "*Spinal cord injury affects conduction of sensory and motor signals across the site(s) of lesion(s), as well as the autonomic nervous system*" (91 p. 536). SCI can be defined as tetraplegia, loss of function in the cervical segments of the spinal cord, or paraplegia, loss of function in the thoracic, lumbar or sacral segments of the spinal cord. Spinal cord injury can also be defined through completeness of injury. A complete injury means absence of signals in the lowest sacral segments, while an incomplete injury means preservation of any sensory and/or motor signals in the lowest sacral segments (91). The severity of SCI is classified according to American Spinal Injury Association (ASIA) Impairment Scale (AIS) (92). Paralysis is often the most commonly appearing change after injury and can imply a need for assistive devices such as a manual or electrical wheelchair, crutches etc. Depending on the level of injury, associated conditions, such as, neurogenic bladder dysfunction, autonomic dysreflexia, comprised respiratory function, and cardiovascular complications are common. In addition, chronic SCI means risk of secondary complications after SCI, for example, urinary tract infections, pneumonia, pressure soars, and charcot joints (1).

Spinal cord injury can broadly be divided into traumatic, non-traumatic, or congenital SCI, i.e. spina bifida. This thesis includes participants with SCI due both to traumatic and non-traumatic events. A global annual incidence for traumatic SCI rate is estimated at 23 cases per million (93). In the Stockholm region, the crude incidence rate for traumatic SCI is reported as 19 cases per million. During an 18-month period in the Stockholm region, 60% of cases were men, 58% were between 18 and 60 years of age, and 89% were between 18 and 75 years of age (94). Prevalence rates for traumatic SCI globally are reported as 250 to 960 per million (2). Global rates for prevalence and incidence for traumatic SCI are uncertain due to variation in methodologies and sites (i.e. national or county) (2), and likely also a failure to report (95). To the best of my knowledge there is no recent research reporting prevalence rates in Sweden for traumatic or non-traumatic SCI. Overall, there is less epidemiological research on non-traumatic SCI. The exiting data are assessed to be insufficient and the research of poor quality.

For the person affected, SCI means a life-course disruption (4, 96). Initially after SCI, everyday life drastically changes. Everyday life occupations, roles, and routines are discontinued (5) and the person can experience loss of control and power in relation to their bodies (4, 6), and in relations to others (4). Both the situation of being injured and the hospital

environment are unfamiliar (4, 6, 96). In the rehabilitation process the person gradually becomes familiar with, and recaptures control over the new body (4, 6), and decisions in regard to everyday life occupations (4). This process is embraced with uncertainties and step-by-step adjustments through doing in a new life situation (4, 6), even if doing means doing through or with support from others (97). For example, adjustments can mean learning new skills and translating them into everyday life occupations and routines (4). Re-establishing self is described as a critical part of the rehabilitation process. Persons with SCI often emphasize that they are not much different to before, or to others in the community (4, 96, 98). However, construction of identity after injury is affected not only through the person's view of self but also through their perception of how others view them (99).

Resilience in the rehabilitation process is strengthened through support from significant others, healthcare professionals, and peers (100). However, the support from healthcare professionals is gradually reduced (4). Research and guidance for clinical management and rehabilitation need to balance several questions, e.g. possibilities for neuroregeneration, management of acute SCI and associated conditions, as well as prevention and management of secondary complications (1). In addition, this needs to be balanced to physical training (1, 3) practice of new skills, applying skills to real world situations (4), and community participation (5). In this way there are many priorities, both for the person, as well as healthcare staff in the initial rehabilitation process. In optimal situations, acute care and rehabilitation is situated within a specialized SCI unit, and management and rehabilitation measures are based on evidence and individualized to the person (4).

Persons living with SCI have informed rehabilitation and society through actively advocating equal opportunities and rights, and advocating for themselves as experts on their own lives, thus being a self-evident element in designing solutions, interventions, and policies affecting them (56, 57). In addition, persons living with SCI are empowering each other in reclaiming everyday life after injury through, for example, non-profit organizations and peer counselling in rehabilitation settings (4). Translating this knowledge into rehabilitation structures is critical, and therefore participatory approaches (35, 36) to research within SCI rehabilitation are important.

1.3.1 Meaning of work in relation to everyday life after SCI

In exploring RTW after SCI, trying to grasp experiences of meaning in relation to work and everyday life is critical. The importance of research on RTW after SCI is often highlighted due to a perspective on work as important for social participation and wellbeing (7, 11, 12, 38). Yet the meaning of work after disability is also questioned due a debate on the meaning of work as normative (101, 102). Hammell (102) argues that priority of productive occupations is culturally bound and not always grounded in the experience of people whose lives have been disrupted or who have a disability. To close in on perspectives on meaning is therefore an important part in enhancing interventions for RTW.

In general, evidence suggests that work is positive for a person's physical and mental health and wellbeing. This is, for example, due to the importance of work for economic resources and the significance of work for psychosocial needs (12). Persons with disabilities' experiences of meaning of work (103), and the effect of work participation on health and wellbeing (12), is similar to persons in general. Persons with SCI seem to be satisfied with life as a whole (104, 105). However, increased satisfaction or quality of life is reported for persons with employment (104, 106, 107). Persons living with SCI point to the meaning of work for earning a living (7, 11), staying socially connected (7-11), and regularity in everyday life (7-9, 11). Moreover, work is experienced as significant for maintenance and construction of identity (7, 9, 10). For example, through meaningful engagement, and being able to contribute and be recognized at work (7, 8, 10).

Along with stories on meaning, returning to work is, in a study by Hay-Smith et al. (7), symbolised with a puzzle, meaning that work is a final piece of the puzzle to living a "normal" life after injury. This indicates that an everyday puzzle needs to be sorted out before work, as a final piece can fit (7, 13). Decisions about work are affected by numerous personal and contextual factors (13, 108). In line with Hay-Smith et al. (7), Fadyl and McPherson (13) point to competing responsibilities in everyday life, the extra effort work means after SCI, and the person's access to a suitable job, as elements that affect decisions about work. Due to the complexity of RTW, work after SCI has sometimes been described as optional (7, 13). Research on experiential accounts of work after SCI often target mixed groups (employed and unemployed), or persons participating in specific interventions. The possible dimensions of meaning between those in work and those outside the labour market are lacking.

1.3.2 Determinants of employment and time to first job after SCI

Factors affecting RTW outcomes after SCI are widely investigated (22, 109). This research has a purpose of predicting or understanding critical factors in relation to RTW after SCI and can therefore inform interventions (109). Within this research, there are numerous, and sometimes inconclusive, factors reported (109). Commonly, suitable pre-injury employment (110-113) and higher education (110-112, 114) are associated with employment after SCI. Educational level stands out as the most critical modifiable factor in relation to employment after SCI (22, 109). Research shows that both pre and post injury education correlates positively with RTW, and each year of education increases the probability of RTW (109). Furthermore, a higher level of independence (110, 111) and psychological resources (106) are associated with employment, but evidence in regard to psychological resources is less consistent (106).

Two tracks are identified in regards to return to first job after SCI; a fast track for those qualified to return due to higher education or suitable employment, and a slower track for those in need of further education or training (115). Younger persons are more likely to return to work (116), however, RTW is likely to be delayed for them due to lack of education or a

suitable job to return to (115). The average time for return to first job after SCI is estimated to be about five years (112, 115), with a range between three months and 20 years. By four years 50% of those who eventually returned to work had done so, and by 10 years 90% (112).

As is demonstrated above, research on factors affecting RTW often includes factors on an individual level. A broader contextual picture in regard to RTW is thus lacking. In this thesis it has been relevant to understand how factors can function to identify persons that are more vulnerable in a RTW process. For example, the challenging situation for younger adults who lack education or suitable employment to return to after SCI inspired the study preceding this thesis to exploration experiences of and expectations for work among young adults (8).

1.4 INTERVENTIONS TO FACILITATE RTW

In developing interventions for RTW it is of great importance to review and incorporate previous research within the area. Due to the magnitude of research evidence, this summary focus on systematic reviews concerning: *work place based interventions* (117-119); *characteristics of interventions that generally facilitate* RTW (118); and *RTW coordination* (117, 120, 121). This research mainly includes research targeting persons with musculoskeletal problems (117-121), mental disorders (119-121), and pain (117, 118).

Work place based interventions. Franche et al. (117) report strong evidence for work place based accommodations and contact between the employer and work place for reduced RTW duration. Further, they report moderate evidence for early contact with the employer and ergonomic work site visits for reduced RTW duration. Evidence for the sustainability of the above-mentioned effects was found to be insufficient. When updating the review by Franche et al. (117), Cullen et al. (118) found strong evidence for multi-domain interventions on reduced RTW duration, e.g. interventions that included two out of three of the following broad components: health-focused interventions, service coordination, and work modifications. In other words, multi-domain interventions were effective while evidence for separate components were mixed or insufficient. Van Vilsteren et al. (119) analysed evidence in regard to work place interventions to prevent sickness absence in sick-listed persons. They found moderate-quality evidence for reduced RTW duration for persons with musculoskeletal problems, yet in line with Franche et al. (117), they found low-quality evidence for the sustainability of this effect.

Characteristics of interventions that generally facilitate RTW. Hoefsmith et al. (122) studied components that generally facilitate RTW across populations and interventions. They found evidence for early interventions, i.e. interventions initiated before six weeks. Furthermore, they found multi-disciplinary interventions as effective across target groups, and that interventions following a certain structure, and activating interventions were effective for those with physical problems.

RTW coordination. Franche et al. (117) report moderate evidence for RTW coordination on reduced RTW duration. Similarly, Schandelmaier et al. (121) reported moderate-quality evidence for a relatively small increase of RTW after RTW coordination. The review by Schandelmaier et al. (121) is updated in a Cochrane review. In this review, Vogel et al. (120) found no evidence for the beneficial effect of RTW coordination.

1.4.1 Interventions to facilitate RTW after SCI

Evidence for interventions to facilitate RTW after SCI is still scarce (123, 124). The interventions given vary in being, for example, vocational, educational, multidisciplinary, and being based at hospital or in community settings. They also vary in, for example, start, duration, and frequency of intervention (124). Currently, research on RTW after SCI is dominated by two large, western countries. In the USA, Ottomanelli et al. (125, 126) have evaluated the effectiveness of supported employment versus regular treatment for veterans with SCI. To the best of my knowledge this is the only high-quality study evaluating RTW interventions after SCI. Supported employment refers to a number of services aiming toward competitive employment, such as job finding and on-the-job support. The intervention by Ottomanelli et al. (125) included individualised support provided by a counsellor. The services provided were mainly located in the community, and findings suggest that the intervention group were more likely to return to employment (125). In Australia, two research studies explore early RTW interventions for inpatients (127, 128) and community-based patients (128). Similar to Ottomanelli et al. (125) they emphasize an individualized support guided by a counsellor (127, 128). Hilton et al. (128) present practice guidelines including mapping, goal-setting, and job support. Middleton et al. (127) base their intervention on an individualised case management approach and includes elements such as motivational interviewing and career planning. Both interventions start early after injury, one to eight weeks after admission to acute care (127), and two to four weeks after admission to inpatient rehabilitation (128). They report promising results on patients' and staff experiences (127, 129), and RTW duration (128), yet they lack control groups.

In summary, when searching for evidence for RTW interventions, both in general and after SCI, there are a myriad of research, interventions, and intervention components on how to support persons on sick leave. This imposes challenges in evaluating evidence and in developing interventions. The majority of evidence regards conditions that represent the large proportion of sickness absentees, while evidence for interventions targeting other conditions is limited. Therefore, there is a need to broaden the evidence to different health conditions (119, 124) and also to different societal settings (75).

1.5 RATIONALE OF THE THESIS

Participation in meaningful occupations in everyday life is seen as an innate need and as fundamental for a person's well-being (24). Work often constitutes a large part of everyday life for an adult person and can provide an arena for meaningful engagement, contribution, and impact (16, 55), as well as, provide an important means to self-sufficiency (21). Work is experienced as meaningful after SCI (7-11), yet RTW is also described as a complex process due to competing demands of managing the new body and life situation (7, 8, 13). RTW involves a broad and multi-faceted research arena. Research to facilitate interventions for RTW internationally, as well as development of the RTW process in Sweden (84, 85) mainly focuses on the leading causes of sick leave. There is a lack of evidence about how to support RTW after SCI (123, 124), and research within this field is dominated by publications generated from a few countries (125, 127, 128). Because many persons with SCI remain outside the labour market after injury (20-22), it is important to expand the evidence base for RTW after SCI. Because the RTW process is closely embedded in local governances informing rehabilitation and employment support, it is important to carry out research in various country contexts.

When using occupation and participation as theoretical resources in exploring RTW it is essential to understand the persons experience and situatedness in the RTW process, and to include persons with SCI as research collaborators. Because RTW is coordinated between the person and multiple integrating systems (18), it is important to explore the RTW process in relation to a broader social, labour market, and societal context; for example, from a perspective of the multiple stakeholders involved and in relation to the specific setting and societal context to which the intervention is intended to be implemented (34, 75). It is also relevant to explore RTW processes over time, and from a perspective of those at greater risk in the RTW process, as well as from a perspective of those with working experience after SCI. This can generate important knowledge to inform and facilitate RTW.

This thesis is conducted through a systematic exploration of RTW experiences, actively involving persons living with SCI and professional stakeholders who are central in supporting RTW. The analyses in this thesis are situated in relation to specific policies, legal, and healthcare contexts in which the rehabilitation intervention is intended to be implemented. Collectively, this was seen as important for sustainability and authenticity in interventions.

1.6 RESEARCH AIMS

The overall aim was to explore and generate knowledge about RTW for adults with SCI, in order to develop and evaluate the design and feasibility of a complex intervention that can serve as a complement to current RTW systems.

The specific research aims were to:

- Explore experiences of RTW in the context of everyday life among adults 7–11 years after SCI (study I)
- Explore experiences of barriers and facilitators in RTW among working adults with SCI (study II)
- Generate knowledge about how professional stakeholders organize and experience the RTW process for the person with SCI (study III)
- Evaluate the feasibility of: *i*) ReWork-SCI with regard to adherence and acceptability, and *ii*) the study design for evaluating ReWork-SCI with regard to recruitment, retention, and use of outcome measures (study IV)

2 METHODS

This thesis builds on a combination of qualitative and quantitative methods. Drawing on guidance from the Medical Research Council (MRC) (34), the research was carried out through four consecutive studies. An integration of narrative, participatory, and constructive grounded theory approaches were used to identify an evidence base for developing an intervention for RTW after SCI. On the basis of this evidence base and literature within the field, a person-centred intervention for RTW after SCI, ReWork-SCI, was developed and evaluated in a feasibility study. In this way, the studies included were designed to logically build on each other and contribute to the overall aim of the thesis. Table I provides an overview of methods used in the thesis.

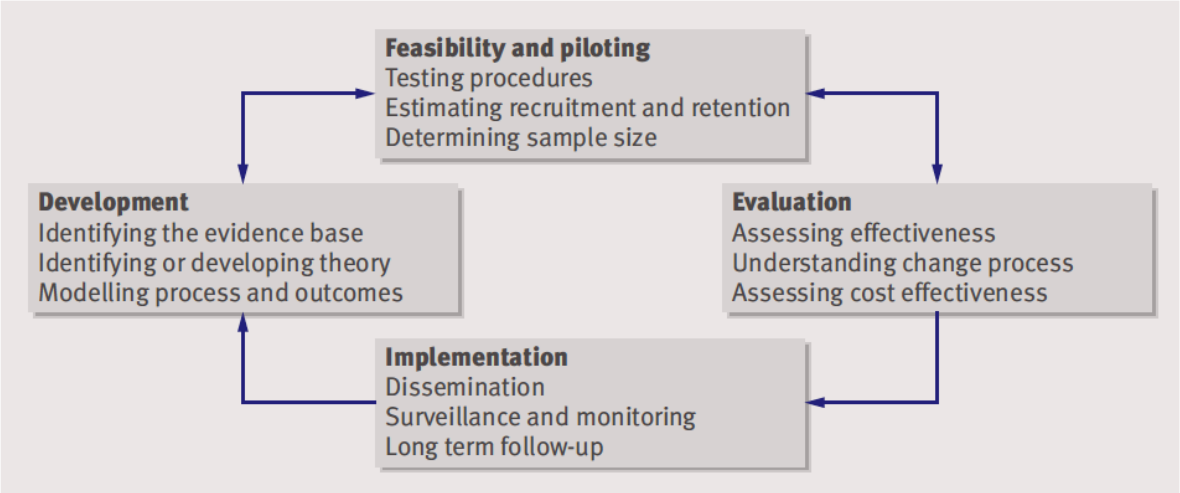
Table I Overview of methods in the four studies of the thesis

Study	**I**	**II**	**III**	**IV**
Aim	To explore experiences of RTW in the context of everyday life among adults 7-11 years after SCI	To explore experiences of barriers and facilitators in RTW among working adults with SCI	To generate knowledge about how professional stakeholders organize and experience the RTW process for the person with SCI	To evaluate the feasibility of: i) ReWork-SCI with regard to adherence and acceptability, and ii) the study design for evaluating ReWork-SCI with regard to recruitment, retention, and use of outcome measures
Design/ research approach	Narrative approach	Participatory approach	Constructive grounded theory approach	Single group, pre-post, feasibility study
Sampling	Purposive	Purposive	Purposive and theoretical	Consecutive
Participants	Persons with SCI	Persons with SCI	Professional stakeholders	Persons with SCI (Coordinators)
Participants, *n*	8	6	34	7 (2)
Data generation	Narrative interviews Observations	Photovoice sessions (pictures, and group discussions)	Focus group interviews	Demographic and vocational data Instruments Log books Semi-structured interviews
Data analysis	Thematic analysis of narratives	Thematic analysis of narratives and visual analysis	Constructivist grounded theory	Descriptive statistics and Wilcoxon signed-rank test Thematic analysis

2.1 DEVELOPMENT AND EVALUATION OF A COMPLEX INTERVENTION

Developing and evaluating ReWork-SCI followed the MRC guidance (34). Complex interventions consist of several interacting components, such as number and difficulty of behaviours required; number of interaction components; number of levels targeted; number and variability of outcome; and degree of flexibility or tailoring permitted (34). This framework was seen as relevant due to the complexity of RTW (14) and due to the multiple levels of systems and stakeholders involved (18). The process of development and evaluation of a complex intervention can be described in four non-linear phases, i.e. development, feasibility and piloting, evaluation, and implementation (Figure III). In this thesis, the authors followed the first two phases.

Figure III Development and evaluation process of complex interventions



Acknowledgement to: Craig et al. (34), Developing and evaluating complex interventions: the new Medical Research Council guidance, with permission from Peter Craig.

2.1.1 Development of ReWork-SCI

In the development phase of a complex intervention it is critical to identify an evidence base and to identify and develop theory (34). Identification of the evidence base for ReWork-SCI was carried out through a review of research regarding RTW after SCI and effective components to facilitate RTW. Identification of theory was related to occupation (24), and person-centredness (30-32). The theoretical resources and literature review are outlined in the introduction to this thesis and specified in Table II. In addition, it was deemed as necessary to generate knowledge in relation to gaps in the literature and the specific societal context and setting that the intervention targeted (34, 75). Studies I-III in this thesis generated knowledge on experiences of RTW in the context of everyday life after SCI and the RTW process after SCI, in Sweden. On the basis of the evidence base, modelling of the intervention was conducted in three steps.

Modelling process ReWork-SCI

1. **Identifying guiding principles and components**
   On the basis of the evidence base, a set of guiding principles and components for ReWork-SCI were identified (Table II).
2. **Modelling within the research group**
   On the basis of the guiding principles and components the research group modelled a preliminary RTW intervention.
3. **Modelling in collaboration with stakeholders**
   The preliminary RTW intervention was presented to stakeholders (persons with SCI, the SCI rehabilitation team, i.e. physician, social worker, occupational therapist, and officers at the SSIA and the Swedish Public Employment Service) in a workshop and further remodelled.

Table II Evidence base, guiding principles, and components for ReWork-SCI

Evidence base and theory	Guiding principles	Components
Studies I-III (and 8, 30, 31, 125-127)	Acknowledgment of the person's experiences, life situation and context	Person-centred approach and comprehensive mapping
Studies I and III (and 8, 122, 129, 130)	Early but timely actions	Initiation after acute medical care, person-centred and non-linear process
Studies III (and 122, 127)	Integration and rootedness in the multi-professional healthcare team	Structured intervention process Coordination based in healthcare
Studies I-III (and 118, 121, 122)	Systematic structure and coordination of multidisciplinary actions	
Studies I-II (and 4, 7, 8)	Support in finding strategies for everyday life with work	Person-centred goal setting and rehabilitation plan
Studies II-III	Support in finding strategies for dialogue at the workplace	Individualized information to employer Initiation of dialogue with employer Workplace assessment

ReWork-SCI consists of four phases and 15 steps. Each step is linked to a detailed component and key person/s. ReWork-SCI is presented in Appendix I, study IV. The purpose of ReWork-SCI was for a RTW coordinator to collaborate with the person with SCI in, i) designing a plan for RTW, and ii) finding strategies for an everyday life where paid work could be included after SCI. Development and evaluation of a complex intervention is a non-linear process (34), which means that literature was reviewed throughout the research project and that ReWork-SCI was clarified during training workshops for coordinators and during feasibility testing, in accordance to a dynamic approach (131). Coordinators participated in a training workshop to learn how to deliver the intervention.

2.2 RESEARCH APPROACHES AND METHODS

2.2.1 Narrative approach

Studies I and II used a narrative approach drawing on resources such as Polkinghorne (71, 132), Josephsson and Alsaker (70), and Asaba et al. (133). The narrative approach in this thesis refers to a sharing of experiences through stories. Stories are embedded in human actions (70, 71); through storytelling, the person makes sense of experience and uncertain situations, choices, and actions (69, 71). In eliciting stories in this thesis, the participants were asked to reflect on their everyday lives in relation to RTW and to reconnect to events and situations. In this way, narratives facilitated exploration of the participants' situations (134) and how meaning was enacted and constructed in relation to their everyday life (70). Narratives also facilitated an understanding of how negotiations and actions in everyday life were situated in relation to context (70). In study I, the stories built on previous interviews; in this way, narratives enabled the linking of previous events to their current situation (71, 132), as well as reasoning about future possibilities. In study II, stories were shared with other members in the photovoice group and focused around weekly themes and pictures. In this way, the stories could evolve, or be reframed in collaboration with others (133).

2.2.2 Participatory approach and photovoice methodology

In study, II a participatory approach and photovoice methodology was used. A participatory approach builds on a perspective of persons as experts on their own life situations (35), and mutual respect and equability between academia and community partners throughout the research project (35, 135). Participatory research methods are seen as suitable in the intersections between science, practice, and policy, and to target health disparities (135). Therefore, persons with SCI were seen as important partners in development of a rehabilitation intervention for RTW after SCI (136, 137). The use of photovoice methodology draw on resources such as Wang and Burris (64, 138) and Asaba et al. (133). Development of photovoice methodology is influenced by Freire's approach to critical education, feminist theory, and documentary photography (64, 133). Based on these theoretical resources the three main goals are identified as; *"(1) to enable people to record and reflect their communities strengths and concerns, (2) to promote a critical dialogue and knowledge about important community issues through large and small discussions of photographs, and (3) to reach policy makers*" p. 370 (64). Thus, the use of photovoice in study II meant that the photovoice members were seen as experts on their own lives and therefore could contribute with insights that others lack in this area. The use of photovoice meant creating a platform where the members could collectively reflect on their everyday life with work and their communities. In this process, documentation through pictures was seen as tool for empowerment and a catalyst for change (64, 133).

2.2.3 Constructivist grounded theory approach

In study III a constructivist grounded theory approach was used (139). This approach is developed by Charmaz (139) on the basis of grounded theory by Glaser and Strauss (140). Constructive grounded theory adopts methods for an inductive and comparative research approach, yet Charmaz (139) distance the approach from a mechanistic use of grounded theory. Instead, she points to the possibility of using the constructive grounded theory as flexible guidelines rather than strict rules. Charmaz (139) denotes that social reality is processual and constructed. Thus, she outlines a research approach that takes the researchers' position into account throughout the research process. This can foster reflexivity, rather than a perspective on the researcher as neutral or value-free. The aforementioned descriptions of constructive grounded theory were seen as suitable in relation to the aim of study III and the researchers' clinical and research background. It was also seen as a suitable to looking at a known problem, such as tensions in stakeholders' interactions in the RTW process, with a fresh perspective. This created possibilities to inform research direction, theory, and clinical practice (141).

2.2.4 Evaluation of the feasibility of a complex intervention

In study IV, the feasibility of ReWork-SCI and the study design for evaluating the intervention were evaluated. This was seen as important in order to evaluate procedures and to make decisions about the suitability of a full-scale trial (34, 142). Feasibility studies are small studies conducted in preparation for a full-scale trial (143). They can answer to if the intervention can be recommended for efficacy testing (144) and if the design is suitable (143). In this way, a feasibility build a foundation for a full-scale trial (145). A large number of elements can be included in feasibility testing (131, 143-145). In regard to a complex intervention it is important to test procedures, make estimations in regards to recruitment and to determine sample size (34), and to evaluate uncertainties in relation to the intervention and study design (34, 142). In study IV, feasibility testing focused on acceptability, adherence, recruitment, retention and evaluation of the outcome measures used (131, 143-145). Acceptability refers to how the intervention is received by deliverers and recipients of the intervention (144) and adherence refers to fidelity; how the intervention is followed by deliverers and recipients.

2.3 PARTICIPANTS

One ambition in this thesis was to explore, and build on, the experiences of the persons most intimately involved in the RTW process. Therefore, persons living with SCI, and professional stakeholders involved in the process, were asked to participate in studies I-IV. Recruitment was facilitated by collaboration with the SCI unit at the regional rehabilitation centre in Stockholm. In study III, professional stakeholders were also recruited through the regional SCI unit in Uppsala county, and governmental agencies in Gävle and Uppsala county. Study I was a follow-up study. Therefore, in study I, participants from the previous study (8) were contacted by the researcher for information and consent. In studies II and IV eligible persons were identified and contacted by professionals at the regional rehabilitation centre in Stockholm for information. Thereafter they were asked if they wanted to be contacted by the researcher for further information and consent. Demographic characteristics of participants in studies I, II, and IV are summarized in Table III.

In this thesis there is no distinction made between traumatic and non-traumatic SCI except for in study I. In the previous study (8), traumatic SCI was the criterion for eligibility. The decision to include both traumatic and non-traumatic SCI in studies II and IV was due to a perspective that the RTW process was likely to be similar, regardless of the etiology of the injury.

2.3.1 Sampling

In studies I-III, *purposive sampling* was used. This refers to a conscious search for participants to facilitate generation of knowledge in relation to the study aim (146). The researchers sought participants with a breath of expertise and experiences for example in relation to being employed or not, or in relation to gender, age, injury type, and severity of injury (studies I and II). In study III, the researchers sought a breath of experiences in relation to profession and role in the RTW process. In addition, *theoretical sampling* was used in study III. Theoretical sampling implies a conscious choice of participants in relation to the emerging analysis, to facilitate a deeper understanding or theory construction (139). In study IV, *consecutive sampling* was used. This meant a consecutive inclusion of eligible persons until a pre-determined sample was reached.

2.3.2 Participants studies I-IV

In study I, eight participants included in a previous study in 2008 (8) were asked to participate. Criteria for eligibility in the previous study were, 20-34 years of age, one to five years post injury, and not yet having returned to work. Criteria for exclusion were persons who had received clinical occupational therapy from the first author and persons who had a psychiatric diagnosis as defined in the Axis I and Axis II Diagnostic and Statistical Manual of Mental Disorders-IV. All persons that were invited to follow-up consented to participation.

The included participants represented diversity in injury type, severity of injury, and gender. At time of study I, six to seven years had passed since the previous study in 2008. One participant had part-time permanent employment, one had temporary employment, four were on sick leave, and two were excluded from the social insurance but not registered as unemployed. See Table III for demographic characteristics at time of inclusion.

In study II, the photovoice group consisted of six members. Criteria for eligibility were men and women aged 18 to 55 years, at least one-year post SCI, having returned to paid employment after SCI, and having had to make some form of adaptation relating to their work situation after injury. Seven members consented to participate but due to a new work assignment, one declined one week prior to the first photovoice session. The six members represented diversity in gender, type of injury, type of employment, and age, as well as in type of employment and paths to employment after injury. Two participants had returned to their previous employment, and four had changed employment after SCI. At time of injury they were employed within the county council, the municipality, the private sector, or were self-employed. See Table III for demographic characteristics at time of inclusion.

In study III, the recruited participants were professional stakeholders working within the RTW process after SCI. Eligibility criteria were, professional stakeholders with experience of working with RTW for persons with SCI. Due to employee turnover, recruitment from government agencies had to be adapted to wide experience of RTW. The participants were recruited from the SCI unit at the regional rehabilitation centres in Stockholm and Uppsala counties, or from governmental agencies in Stockholm, Uppsala, or Gävle county. In total 34 participants were recruited, representing healthcare professionals working in a SCI rehabilitation team (n=14), i.e. physicians (n=4), occupational therapists (n=3), physiotherapist (n=2), social workers (n=4), nurse (n=1), officers from the SSIA (n=5) and the Swedish Public Employment Service (n=10), and employers (n=5).

In study IV, enrolment of participants with SCI occurred in two consecutive phases. Eligibility criteria at recruitment were persons that: a) had sustained a traumatic or non-traumatic SCI, b) had undergone acute medical care, c) were between 18 and 65 years of age, d) were assessed by a physician to be ready for ReWork-SCI, e) had either permanent or temporary employment, f) wanted to return to work, and g) were able to communicate in English or in Swedish. Seven eligible persons in either daycare or outpatient care consented to participate in the study. A majority were single, three participants had children that were living at home. Four were employed in sedentary labour and three in manual labour. See Table III for demographic characteristics at time of inclusion.

In addition, one occupational therapist was recruited to be a coordinator in the study. Eligibility criteria were: a) being an occupational therapist or a social worker, and b) having expertise in SCI rehabilitation. Two occupational therapists and two social workers were invited to a three-day training workshop in October 2017. One of them was appointed to be a coordinator in the study. After the first coordinator terminated employment in May 2018 one additional occupational therapist was trained to deliver ReWork-SCI and assumed responsibility as a coordinator.

Table III Time of data collection, demographic characteristics at inclusion, studies I, II, IV

Study	I (*n*=8)	II (*n*=6)	IV (*n*=7)
Data collection, month and year	Nov 2014-Sept 2015	Sept 2015-Nov 2015	Oct 2017-Aug 2018
Age, *median (range)*	34 (27-41)	35 (28-52)	54 (33-62)
Gender, male/ female, *n*	6/2	3/3	5/2
Time since injury, <1/ 1-10 />10, *years*	0/6/2	0/6/0	6/1/0
Impairment, paraplegia / tetraplegia, *n*	4/4	3/3	4/3
Severity of SCI neurology[1], *n*			
C1-C8 AIS A, B, or C	4	3	1
T1-S5 AIS A, B, or C	2	3	4
AIS D any level	2	0	2
Higher education yes / no, *n*[2]	1/6	5/6	2/5
Employment, yes/no, *n*[3]	2/6	6/0	7/0

[1] According to AIS, American Spinal Association (ASIA) Impact Scale (91).

[2] Higher education here refers to a completed higher education, one person in study I was currently undertaking higher education.

[3] Employment here refers to being employed part-time or full-time; the participants in study IV were on sick leave at time of inclusion, one person in study I also had temporary employment.

2.4 DATA GENERATION

In study I, data generation was built on a combination of multiple interviews (n=14) and observations (n=4). This was seen as important for building report and to accomplish richness in data (132). Through a narrative approach stories in relation to everyday situations were elicited. This facilitated a deeper understanding of how RTW was situated in relation to everyday life and context for the individual. Each participant was interviewed one to three times at a place of their choice. This could be in their homes, at a workplace, or a coffee shop. One interview was carried out over the phone after agreement with the participant. The interviews lasted 45-120 minutes. The interview guide was based on the findings of the previous study (8) and conceptual areas related to, for example patterns of everyday life, follow-up on experience and expectations of RTW and support during the RTW process. Observations had a purpose of deepening the understanding of the participants' everyday life after injury, especially in relation to the theme, *finding meaningful occupation through one´s passions*. Observations were therefore supplementary to the interviews. In collaboration with some of the participants, the first author agreed on situations for observations that were related to emerging topics. The method for observations was inspired by "hanging out" (98, 147), which includes active participation in everyday situations. In study I this meant, for example eating together, making coffee, or visiting art or music studios. This allowed a natural interaction and deeper understanding of emerging topics. Each interview was digitally recorded and observations were recorded through field notes.

In study II, photovoice methods (64, 133) guided data generation. The members of the photovoice group met weekly over two months. Table IV gives an overview of activities and themes during each session. In an introductory orientation session, the researches guided the members of the photovoice group in photovoice methodology and procedures. This session was important to reconfirm consent and discuss ground rules for the group and ethics for the project. For example, the group decided how many pictures should be included each week and agreed on flexibility to facilitate participation for individual group members. Ground rules could change during the project through discussions in the group. The orientation session also included personal introductions of each member of the group. This led to discussions in relation to SCI and working life after SCI, and a decision on the first theme (Table IV). Between the sessions, members of the group took pictures in relation to the theme, using their smart phones. During the following weeks, sessions were opened with a review of discussions from the previous week, show and tell of pictures, and a general discussion of the topic of the day. Thereafter the group decided on the next week's theme (Table IV). The first and last authors functioned as facilitators. This meant being resources in regard to photovoice methodology, organization, and during sessions (64, 133). In this way, data consisted of both pictures and group discussions. Each session was digitally recorded and transcribed verbatim. After each session, observations of environment, discussions, actions and interactions in the group were documented through field notes.

Table IV Activities and themes during photovoice sessions

Photovoice session	***Activity*/ theme**
1	*Orientation session*
2	Barriers and solutions; focus on work
3	The social aspect of work after SCI
4	Experiences I'd like to share about work after SCI
5	My driving force in choosing work
6	To challenge the norm at work
7	*Analytic session*
8	How do I get work to work

In study III, a constructivist grounded theory approach guided data generation (139). Focus group interviews were considered a suitable method to explore the participants' experiences of the RTW process (148). Each focus group lasted about 90 minutes at the participants' workplaces or at the regional rehabilitation centre in Stockholm. Conceptual areas were the RTW process, coordination of resources, and paths toward work after SCI. Following purposive and theoretical coding, the focus groups were divided into five phases. The interview guide was reviewed between each phase.

In phase I, officers working at the Swedish Public Employment Service (*n*= 6) and the SSIA (*n*=3) facilitated a broad understanding in relation to the aim.

In phase II, all stakeholders were invited to two subsequent focus groups (*n*= 7+7) to share and discuss experiences in relation to, for example the RTW process and coordination. In these focus groups, pictures and stories generated in study II were used as triggers for discussion in addition to the interview guide.

Phases III-V aimed to generate a deepened understanding in relation to the emerging findings. In phase III the SCI rehabilitation team (*n*= 5) was interviewed to understand prerequisites to support a person with SCI in early rehabilitation. A deeper understanding was also sought regarding paths toward work for those in work and those lacking employment after SCI. Therefore, the last two phases included officers working in increased cooperation between the SSIA and the Swedish Public Employment Service (*n*=3), and employers (*n*= 4).

In study IV, data generation was conducted at baseline, at start of the intervention, and three and six months after start of intervention (Figure IV). The evaluation of the feasibility of ReWork-SCI was conducted through several methods of data generation. The researcher documented recruitment and retention in a log book. The coordinators registered contacts, the steps performed, and the time needed to perform steps in a log book. The acceptability of

ReWork-SCI was evaluated in semi-structured interviews, which were recorded digitally and lasted about 15-45 minutes. Injury related data and basic demographic data included age, gender, civil status, children, country of origin, cause of injury, severity of SCI neurology, and impairment type. Vocationally related data included educational background, occupational status, type of employment, sickness absence, work re-entry to paid employment (defined as >25% of pre-injury working hours), or work trial (defined as > 25% of pre-injury working hours with compensation from the SSIA or the Swedish Public Employment Service). The following outcome measures were used during the study:

Canadian Occupational Performance Measure (COPM) is a client-centred, semi-structured interview assessment that enables the person to identify and prioritize problem areas in everyday life. To support goal-setting, each defined problem area is scored between zero and ten guiding prioritizations of up to five areas, each of which is scored in regards to performance and satisfaction (0-10) (149, 150). Evidence supports responsiveness (151), and convergent and divergent validity (152) in use for persons in outpatient care. Reliability is moderate, and reproducibility is weak. Therefore, presenting mean scores instead of separate scores of problem areas is preferable (153).

Worker Role Interview (WRI) is developed on the basis of Model of Human Occupation (44) and is a semi-structured interview assessment designed to address psychosocial and environmental factors that impact RTW (154). WRI consists of six areas: personal causation, values, interests, roles, habits, and perception of the environment. Each item is rated from 1 to 4, indicating how factors support or interfere with RTW. Psychometric properties are shown to be valid across ages, diagnoses, and culture (155). Item 2, expectation of job success, is shown to be a predictor of job potential (156).

Work Environment Impact scale (WEIS) is developed on the basis of Model of Human Occupation (44). WEIS is designed to address the fit between environment and the person. It consists of 17 items rated from 1 to 4, relating to the person subjective experience of how work environment interferes with (1 and 2) or supports (3 and 4) work performance, satisfaction, and wellbeing (157). Testing of the Swedish version shows that psychometric properties were sound across diagnoses and occupations (158).

LiSat-11 assesses satisfaction with life as a whole and 10 domains of life. Satisfaction is graded 1 to 6, indicating 1, very dissatisfied to 6, very satisfied. Grades 1 to 4 are dichotomized as not satisfied, and 5 and 6 as satisfied (159). The global question alone, satisfaction with life as a whole, was chosen in this study. Validity of the dichotomy is shown (159).

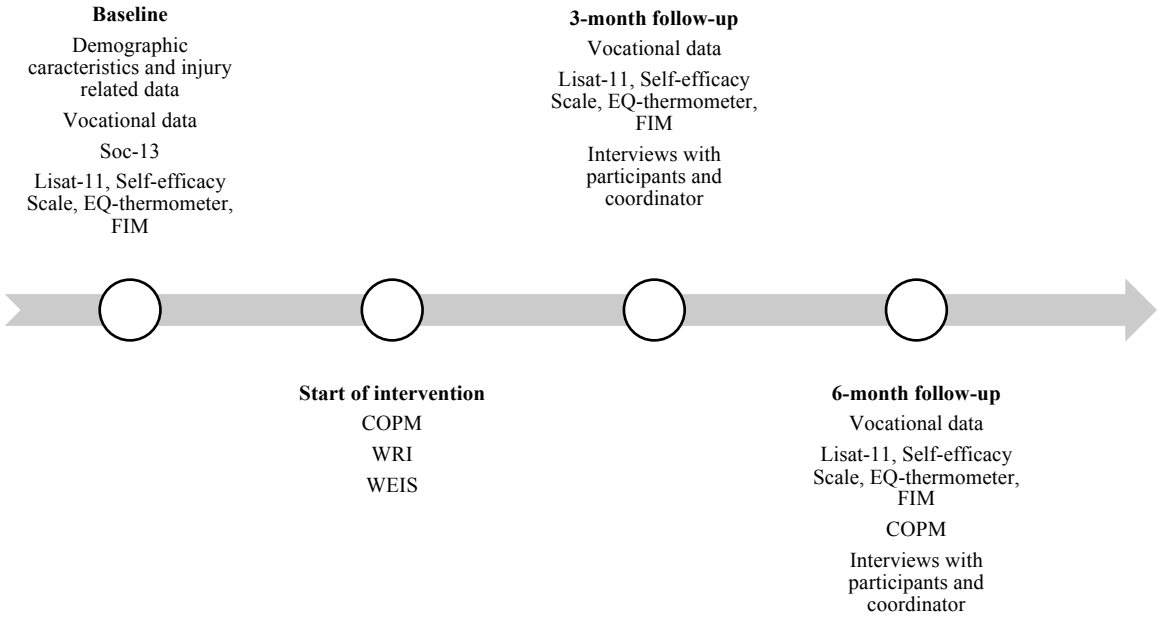
Self-efficacy Scale is developed based on Bandura's (160) theoretical framework on behavioural change. The scale originally consisted of 20 everyday life activities. Each item is scored on a 10-point rating scale. One equals "not being confident at all in my ability", and 10 "being very confident in my ability" (161). The items are further developed and in this study a set of 18 items were used.

EuroQol Five Dimensions (EQ5D) addresses health related quality of life. In this study, the EQ-thermometer was used. This means that the person rates their health state from zero, worst imaginable health state, to 100, best imaginable health state (162). Evidence suggests good psychometric properties of the EQ5D in a variety of conditions (163).

Sense of Coherence 13 items (SOC-13) addresses three elements, which are theorized to impact on a person's resources to cope with stressors and manage tensions, i.e. comprehensibility, manageability, and meaningfulness (164). The instrument consists of 13 items, each of which is rated between 1 and 7. The total score therefore ranges between 13 and 91 (165). SOC-13 is shown to be valid and reliable, and applicable across cultures (166).

Functional Independence Measure (FIM) is designed as an indicator of disability. FIM consists of six domains: self-care, sphincter control, mobility, locomotion, communication, and social cognition. These are divided into 18 motor and cognitive items, each scored from 1, total dependence, to 7, total independence (167). Motor items are shown to correlate well with functional status after SCI. However, increases in motor items are primarily shown between admission and discharge; only discrete changes are shown to occur up to a year, indicating a plateau effect. Moreover, a ceiling effect is shown for persons with paraplegia one year post discharge. The suitability of cognitive subscale for persons with SCI is also questioned due to a ceiling effect. (168).

Figure IV Timeline for data collection



The semi-structured interviews with the participants and the first coordinator were related to acceptability of ReWork-SCI. Each interview lasted about 15-45 minutes and was opened with a broad question to reflect on participation in the project and follow-up questions in

relation to the purpose and structure of Re-Work-SCI. The coordinators had the possibility to contact the first author for clarifications about ReWork-SCI (telephone or face-to-face meetings). In this way, a dynamic approach was used both to clarify and to modify components of ReWork-SCI during the course of the project (131). Adaptations made were logged by the researcher and documented as extensions to ReWork-SCI.

2.5 DATA ANALYSES

2.5.1 Analyses of qualitative data

The exploration of qualitative data, e.g. data generated through narrative (study I) and semi-structured interviews (study IV) participant observations (study I), photovoice sessions (study II), focus groups (study III), and field notes (studies I to III), followed two different methods for analysis. These were thematic analysis (71, 134, 169, 170) and a constructivist grounded theory approach (139). In studies I and III, data generation and initial analysis were integrated through listening to recordings or reading transcribed texts between interviews and observations. This guided further data collection. The software Atlas.ti (171) was used as a tool for organizing qualitative data in all studies. The Swedish language was used throughout data generation, transcription, and analysis. All quotes were translated independently by two authors. Thereafter, the translations were compared to each other. In situations of discrepancies, the authors discussed translation until consensus was reached.

In study I and II, a thematic analysis of narratives was used (71, 134). Analysis of narratives meant a paradigmatic and inductive approach to analyzing the data into themes. This approach was seen as suitable when analyzing narratives from several different persons (71). In this way, patterns in stories could be explored. Thematic analysis followed a systematic back and forward process between the data, codes, and emerging themes. Analysis started with reading through the texts to look for commonalities and differences that existed across stories and that were linked to the aim of the studies. Chunks of text were assigned a code, represented by a word or a short phrase that stayed close to the data. When referring to the same experience codes were merged and organized into themes. Codes and themes were continuously compared to each other and to the emerging data. In study II, themes were also compared to the themes in the visual analysis (see 2.5.2). In this way a coding system emerged (169, 170). The thematic analysis of narratives generated five main themes in studies I and II.

In study III, analysis was guided by constructive grounded theory (139). This meant a process of initial, focused, and theoretical coding and constant comparison between codes and data. Analysis was continuously facilitated by asking questions to the data. Similar to thematic analysis, initial coding meant labelling data, line-by-line or incident-with-incident, with a sentence or a short phrase that summarized the text. For example, *adaption to time limits*. This process was guided through asking questions such as "*what do the data suggest*?" (139 p. 116). Initial coding was characterized by openness and a swift move through the data, which directed further exploration and comparisons. Initial codes that were seen as analytically important were re-coded or summarized into focused codes. In this phase, questions like "*what are these codes getting at*" (139 p. 146) helped the understanding. Focused coding thus includes looking at larger segments of the data and advancing the conceptual understanding of the findings, for example, *timing as a paradox*. To further advance the conceptual understanding of the findings and in order to make the findings comprehensible and coherent theoretical coding was used. This process was partly guided by

theory (24, 41, 172) and contributed to an emergence of a core category and a temporal ordering of three main categories. Analyses were supported by memo writing and analytic discussions among the authors (139).

2.5.2 Visual analysis

In study II, visual analysis was performed in collaboration with the members of the photovoice group. Visual analysis followed Wang and Burris (64) and Asaba et al. (133) and was carried out during four sessions. Analysis started in the seventh photovoice session (Table IV), which included all members. The pictures taken during the project were printed and each member worked with their pictures. They were asked to choose the three pictures which for them were the most relevant. Each participant shared their choice of pictures and posted them on a wall along with a story explaining their choice. In addition, the group started a discussion on how pictures were related and gradually pictures were sorted thematically. Before the eighth session, the group could decide if they wanted to continue with analysis or an additional theme, if they found that something was lacking in their analysis. The members identified gaps in relation to their everyday solutions for work and decided to continue with an additional theme to fill this gap (Table IV). They also decided that three members should continue in two analytic sessions and that all members should gather for a fourth and final analytic session after this. This decision was based on an interest and possibility to continue for three participants, and time restraints for the others. Before the final analytic session, the first author had, after a request from the group, prepared short texts describing the themes. During this session, analysis concluded with merging pictures into a total of seven themes, and the texts were checked and modified to fit the intended meaning of each theme. Visual and thematic analysis supported each other although thematic analysis of the text contributed to an in-depth understanding and also meant merging the number of themes from seven to five.

2.5.3 Analyses of quantitative data

In study IV, descriptive statistics was used to present the quantitative data, i.e. demographic characteristics, information from log books, and outcomes at three and six-month follow-ups. To compare data between baseline and six-month follow-up, the Wilcoxon signed-rank test was used, with a p-value of 0.05 to determine statistical significance. This analysis was performed with the Statistical Package for the Social Sciences (SPSS version 25.0). COPM were analyzed using two different methods. On a group level, COPM were analyzed with Wilcoxon signed-rank test. However, on an individual level, COPM were analyzed in accordance to methods for analyzing COPM for clinically significant difference, i.e. >two-point difference in total mean score (150).

3 FINDINGS

Drawing on MRC guidance for developing and evaluating complex interventions (34), the four studies included in this thesis logically build on each other. The structure for presenting the findings is illustrated in Figure V. First, a summary of the main findings in studies I-III, followed by an analysis of findings in studies I-III, presented in four themes (Table V). These three studies contributed to guiding principles and components for ReWork-SCI (Table II). In the final part of this chapter, the main findings of study IV are presented. The terms person/s or participant/s in this section are used for persons living with SCI and professional stakeholder/s for professionals working with RTW.

Figure V Overview of presentation of the findings

In study I, the findings show how expectations and perceptions of possibilities for meaningful engagement in work can change after SCI. Some participants were engaged in paid work, but most had transitioned to a life that involved unpaid regular occupations or avocations that sprang from their passions and met the needs of flexibility in their everyday lives. The transition was characterized by constant negotiations of possibilities for work in relation to everyday life situations and context. Many still had hope for work, yet expressed concern in relation to everyday life challenges and priorities after injury, and possibilities for accommodation in the regular labour market. Moreover, they expressed concern in relation to possibilities for gaining meaningful employment with support from the Swedish Public Employment Service. Poor continuity in the RTW process, feelings of uncertainty, and that their life situation was neglected could mean resignation or finding their own solutions in paths toward work.

In study II, the findings were summarized by a picture of a staircase (Figure VI) and a picture of a gravel road (on the thesis cover). These pictures relate to how RTW and working life were shaped and understood among the members in the photovoice group. The double-edged meaning of a staircase (Figure VI) refers to the parallel stories of barriers in the RTW process, and in working life and a desire to find solutions in everyday life with work. The desire was grounded in an experience of work as viable and rewarding. To find sustainable

solutions for everyday life with work the members experienced having to map out their own paths toward work. The picture of a gravel road (on the thesis cover) referred to a perception of work as the only alternative after injury, and a wish for individualized paths toward work. The irregularities of the path and the tall pine trees on both sides represented challenges and the contextual barriers to navigating paths toward work. Consequently, this could mean that the person was left having finding their own solutions for work. Returning to work after SCI was a balancing act that required dialogue at the workplace, negotiations of contextual circumstances, and integrated strategies for sustainable everyday life with work.

Figure VI Double edge meaning of a staircase

Picture from study II, with permission from the photovoice member.

In study III, a core category, "mediating intentions and possibilities through contextual landscapes" was presented. The core category builds on conceptualization of how possibilities shape, and are shaped, in coordination between person and context (41), and relates to how intended and promoted paths toward work after SCI were contrasted to contextual challenges. The professional stakeholders experienced uncertainty when and how to support the person with SCI. The uncertainty was grounded in lack of structure and tools, for example, how to map a comprehensive picture of the persons situation. The uncertainty was also grounded in unclear allocation of responsibilities and a divide between dynamic and rule-based perspectives. The uncertainty and tensions could imply insufficient communication or absent cues between the stakeholders. The findings also illustrate possibilities for employers to support the person through an ongoing dialogue at work. However, paths toward work for those lacking a workplace to return to were unclear. The findings illustrate risks of unequal, delayed, and/or absent RTW processes, and point to a potential of early but timely actions in the RTW process, and direction through coordination, to create possibilities for work.

3.1 ANALYSIS OF FINDINGS STUDIES I-III

Thematic analyses (169, 170) were used to analyze findings in studies I-III in the thesis framework. The analysis is presents in four themes: *negotiating work as part of a meaningful everyday life, being as anyone else at work, focusing on the person in a rule-based context,* and *navigating paths within a fragmented support process* (Table V).

Table V Overview of study aims and themes, as well as themes in synthesis

Study	**Aim**	**Findings**	**Analysis of findings**
I	To explore experiences of RTW in the context of everyday life among adults 7-11 years after SCI	Negotiating the possibilities of working Hope for future work tempered with concern Education as a possible path to employment Paths towards RTW in the light of unmet support Unpaid occupations grounded in interest and competence	Negotiating work as part of a meaningful everyday life Being as anyone else at work Focusing on the person in a rule-based context Navigating paths within a fragmented support process
II	To explore experiences of barriers and facilitators in RTW among working adults with SCI	There is only one way Welcome back – or not To be like anyone else – or to be perceived as someone else Friction in the absence of clarity Finding integrated strategies for everyday life with work	
III	To generate knowledge about how professional stakeholders organize and experience the RTW process for the person with SCI	Core category: mediating intentions and possibilities through contextual landscapes Mapping ability for work – crucial but obscure Planning RTW – divide between dynamic and rule-based Work re-entry – unequal paths toward viable solutions	

3.1.1 Negotiating work as part of a meaningful everyday life

The findings illustrate stories of how the participants with SCI gradually establish new routines and come to terms with everyday life after injury (studies I and II). After several years the participants had found a stable foundation for everyday life, naturally different from the life they had lived before (study I). Facing changed body functions and an everyday life where activities required more time and energy implied a situation where the participants had to make priorities, for example in relation to family life and work. These stories illustrate complexities in how RTW was negotiated in relation to everyday life situations after SCI (study I). Initially after injury, the participants expressed hope for future work and an experience of work as meaningful and worthwhile. They sought an everyday life where work could be included. In this pursuit, work for some was non-negotiable while others expressed insecurity in regards to possibilities for work (studies I and II). In addition to how possibilities for work were negotiated through everyday life situations, possibilities were also negotiated in relation to possibilities for finding a sustainable and meaningful work situation in the regular labour market, for example, employment that accommodated their needs (study I).

Complex dimensions of everyday life and the RTW process after SCI were also reflected in the professional stakeholders' reasoning; for example, through their insecurity of readiness for work, and possibilities for work re-entry after SCI. Time needed for recovery and rehabilitation was juxtaposed to perceived benefits of early actions in the RTW process, such as sustaining motivation for work and maintaining contact with the workplace. Thus, timing became a paradox where early could be beneficial but also potentially harmful. Ambiguity with regards to timing was a barrier in the RTW process and implicated a situation where the person could remain stuck in the process due to continuous sick leave. Comprehensive mapping was seen as necessary, yet structure and tools for this were lacking in the early RTW process. The reliance of the sickness certification as a basis for decision and planning RTW caused tensions. The sickness certificate could only include medical explanations for a person's ability to work. This seemed to stifle an open dialogue among stakeholders. Instead of using existing resources within the SCI rehabilitation team to map a comprehensive picture, to nurture an open dialogue between stakeholders in the early RTW process, a one-dimensional (medical) picture was perceived to initiate and bring the RTW process forward (study III).

3.1.2 Being as anyone else at work

An experience of meaning in everyday life with work was rooted in a feeling of being able to contribute, having an impact, and sharing. Moreover, work contributed to personal development, regularity in everyday life, and self-reliance (studies I and II). Inherent in the descriptions of meaning was a wish to be as anyone else at work, in contrast to being perceived as someone else. Being as anyone else implied a desire to be able to do a good job

on the same terms as others; a situation where the individual's competence was in focus, while disability gained less attention. It also meant a wish to be a natural part of the workplace rhythm, thus being as anyone else in the workplace kitchen, by the coffee-machine, on the work trip, or at the conference (Figure VII, study II). Reasoning of meaning in everyday life with work was thus related to the participants' interest in and competence for work. Moreover, dimensions of meaning reflected the person's view of themselves in work and their view of what it meant to them to be a worker.

Figure VII Wheelchair entrance in comparison to a lavish main entrance

Picture from study II, with permission from the photovoice member.

For those not working, possibilities of adjustments and enactment of interests and identity through paid work were still unknown (study I). Those in work found that they contributed through their work, and mostly that they were welcomed and appreciated at their workplaces. Yet those in work also illustrated situations that left them with feelings of standing out in a negative way at work (study II). In situations when they felt that they couldn't contribute or did not feel welcomed, the meaning of being in work could shift and the person might change work (study II) or withdraw their efforts in the RTW process (study I). Nurturing hope for work could prevail through the person's perception of his/her possibilities for meaningful work in the regular labour market. Furthermore, feelings of hope could prevail through a concern of being placed in a position that did not suit them in regard to their competence and interest, for example, if seeking employment with support from the Swedish Public Employment Service (study I). The concern voiced by the participants was affirmed through similar concerns of the officers at the Swedish Public Employment Service. Officers experienced difficulties in finding suitable positions in regards to disability, but also in finding positions meaningful to the person (study III). In this way, paths toward a work

situation in keeping with the person's perception of meaning and self were unequal and uncertain (studies I, II, and III).

3.1.3 Focusing on the person in a rule-based context

The professional stakeholders unanimously expressed focus on the person as central to the RTW process and as something that was almost taken for granted. Yet, the possibility of keeping this focus was problematic due to existing frameworks for sickness absence. The SCI rehabilitation team questioned the need to conform to what they experienced as a linear and rigid 'one size fits all' system. This was exemplified in relation to time limits in the rehabilitation chain, the fixed sick leave grades, and a demand to evenly distribute part-time work during the week. Their wish for a more dynamic approach in the RTW process was, however, questioned by some officers at the SSIA who aspired to a more transparent and explicit process suitable for legal frameworks (study III). These tensions seemed to complicate communication and coordination between the professional stakeholders, and thereby risk delayed or absent RTW processes.

The participants who had returned to work (study II), or those wanting to proceed with education or unpaid occupations in an attempt to gain future employment (study I) shared the experience of rigidity and irregularities in the system for RTW. In their reasoning, they wished that the RTW process had a more individualized and dynamic approach. Furthermore, lack of a systematic RTW process meant a need for the participants to negotiate and navigate previously unfamiliar systems and contacts, and they shared feelings of uncertainty in regards to the RTW process and the professional stakeholders' responsibilities. This inevitably meant barriers to proceed. In situations of poor response from the different stakeholders, and when the person's everyday life situation was disregarded, a certain degree of resignation was identified in some of the participants' stories. This resignation was identified when participants withdrew their own efforts in the RTW process (study I) and contrasted to stories of mapping out one's own paths toward work (study II).

3.1.4 Navigating paths to meaningful engagement

In their pursuit of an everyday life that could include work, some participants found solutions for work through a supportive RTW process or through finding their own paths toward work (studies I and II). Others had transitioned to unpaid regular occupations or avocations, such as education or artwork (study I). Some central aspects were found in stories of returning to previous work, shifting to a new working position, or transitioning to unpaid regular occupations. For example, the participants had found strategies where their occupations were integrated to everyday life after injury. They had found a rhythm where the engagement could be given full attention when necessary, and yet, include considerations for consequences due to injury and prioritize occupations in everyday life as a whole (studies I

and II). Strategies were, for example, finding their own place at work for recovery and a certain flexibility during the day to allow for alterations such as short breaks for exercise or pressure relief (study II). For those not in paid work, it also meant a possibility to pause engagement when other priorities or consequences of the SCI prevailed (study I).

Possibilities of finding solutions in the regular labour market were uncertain for those lacking employment and also for the professional stakeholders. In search of a sustainable working life, it was important to maintain an open dialogue with the employer. This could contribute to a situation where employers gradually came to understand everyday life after injury and also how the employee preferred being met at the workplace, and their adjustment needs (studies II-III). For those not in work, the challenge was to find a workplace where such a solution could be realized. To find employment where adjustment needs were met was perceived as challenging. Moreover, to register as a jobseeker or to engage in education meant leaving the economic security of sickness benefits. The consequences due to injury, the economic risk, as well as an uncertain RTW process seemed to hamper hope and RTW initiatives (studies I and III). Locked-in effects could mean that cues from the healthcare services to the SSIA to proceed with the RTW process failed to materialize. Along with difficulties in finding actual positions that were meaningful and suitable to the person, the RTW process for those lacking a workplace to return to could be absent or delayed.

In summary, the main findings of studies I-III show how RTW is situated in everyday life for the person with SCI and how it is related to contextual landscapes. The findings contribute to illustrating the RTW process after SCI; a process experienced as fragmented by the persons with SCI and filled with tensions and challenges among professional stakeholders. This negatively impacts on the possibilities of designing a plan for RTW that is based on a comprehensive picture of the person's everyday life situation after injury, and that focuses on the person. This implies risks of delayed or absent processes, and inequalities in the RTW process. The synthesized findings of studies I-III contributed to guiding principles and components (Table II) to model a person-centred, structured, and coordinated intervention process, ReWork-SCI.

3.2 FINDINGS STUDY IV

The main findings of study IV show that ReWork-SCI and the study design for evaluating ReWork-SCI overall were feasible. However, certain flaws and contextual challenges were important to address prior to a full-scale trial. ReWork-SCI was *acceptable* to the coordinator and the participants. Four themes were identified through analysis: structure and sharing critical for timeliness; sharing the new situation with the employer and planning forward; coordination according to individual needs; and maintaining partnership and collaboration in a complex process. Sharing of experiences and information contributed to decision making and trust in the process. Although the initial mapping phase was extensive, this phase was seen as a course director for following phases. Potentially active components of ReWork-SCI

were identified as: a structured yet dynamic process; use of a person-centred approach; initiating a dialogue with the employer; and individualized coordination and support. The coordinator sometimes experienced uncertainty and loneliness in the process, and at times found it challenging to coordinate the other stakeholders. The participants and the coordinator experienced shared influence and flow in the process, yet the coordinating role was sometimes unclear to them, as well as to the SCI rehabilitation team. *Adherence* to ReWork-SCI was good. Overall, the coordinator strived to follow the steps for each participant. Challenges to adherence were mainly related to occasional cancellations, difficulties in organizing the SCI rehabilitation team, and follow-up. Follow-up varied in how it was conducted. Generally, it focused on practical matters for the person instead of following a person-centred structure and follow-up of goals and the RTW plan. This could mean insufficient revision of the RTW plan, for example, before a work trial.

All participants *accepted enrolment* and *agreed to follow-up*. At three-month follow-up all participants had a plan for RTW. At six-month follow-up five participants had returned to work, pursued a work trial, or had set a date for a work trial. Of those five, three were working part-time. The *outcome measures* overall showed low variance. On a group level there was a significant difference in the satisfaction component of the COPM. Individually COPM showed a clinically significant increase in the satisfaction component for three participants, while a clinically significant decrease was shown for one participant. One participant showed a clinically significant increase in the performance component. WRI item 11, daily routines (all participants), and WEIS item two, task demands (five of six participants), interfered with RTW/satisfaction of work performance. WRI item two, expectation of job success, and WEIS item 13, physical arrangements, differed between those in manual and sedentary labour, i.e. they were assessed as interfering with RTW/satisfaction in work performance for those in manual labour.

4 GENERAL DISCUSSION

This thesis focuses on RTW after SCI in order to generate knowledge on the development and evaluation of a rehabilitation intervention, ReWork-SCI. The findings in studies I-III illustrate that paths toward work after SCI are experienced as fragmented to persons living with SCI, and difficult to navigate for professional stakeholders. Uncertainty and lack of structure implies risks for unequal, delayed, and/or absent RTW processes for persons with SCI, especially for those lacking a work place to return to. This thesis generates knowledge about alternative paths in the RTW process after SCI, through a person-centred, structured, and coordinated approach that can operate in parallel to medical rehabilitation. This is an important effort to improve possibilities for fair support in the RTW process after SCI. The knowledge generated in this thesis can also add to the body of knowledge about RTW coordination in Sweden. Yet contextual challenges addressed in relation to the RTW process remain, and ReWork-SCI is still in an early development phase. On the basis of the theoretical framework and the findings presented in this thesis, the following are highlighted in the general discussion: *actions in the RTW process as responses to everyday life situations*; *participation and person-centredness as a rights-based approach to RTW*; *the potential of implementing ReWork-SCI in a SCI rehabilitation unit*; and *navigating the RTW process after SCI through societal landscapes*.

4.1 ACTIONS IN THE RTW PROCESS AS RESPONSES TO EVERYDAY LIFE SITUATIONS

The findings in studies I and II show how persons were negotiating everyday life situations after SCI. Previous research report similar findings, (e.g. 7, 8, 13). The findings show how managing the body along with priorities and responsibilities of everyday life were challenging to coordinate with an everyday life that also included work. It was evident in study I that the disruption after SCI was not an isolated event. In line with Nunnerley et al. (4) consequences of the injury were gradually incorporated when organizing the everyday, for example, through finding new strategies and routines. Therefore, strategies and possibilities for a new rhythm in everyday life is critical to understanding RTW after SCI.

Everyday situations include both problematic dimensions, as well as possibilities. Change in everyday life due to injury or illness requires attention, contemplation, and action (33). Studies I and II show how negotiating everyday situations was a continuous process that reflected how the persons with SCI made sense of their situation and how they perceived that their everyday life occupations contributed to being, belonging, and becoming (24). Furthermore, in line with research on identity (99), these two studies show that "*day-to-day negotiations of identities*" (99 p. 150), such as how working situations, or potential future working situations, contributed to identity construction were important in negotiating RTW. This was exemplified in stories of how the participants experienced their possibilities of contributing with their competencies and being viewed as anyone else at work. In addition,

possibilities for future work were negotiated in relation to context, such as families, labour market contexts, and societal structures; for example, through considerations of a potential economic risk if they could not find an adjusted part-time job. In this way, the participants experimented with possible outcomes of their actions through negotiating problematic situations (33, 47). The findings thus suggest that negotiating everyday situations after SCI was part of finding a new rhythm and meaningful occupation after injury; yet the experienced stability and hope for work that occurred several years after injury was not always a springboard to employment. The uncertainty that the participants felt in their current situations was present in their negotiations, and how they acted in the RTW process can be viewed as responses to their particular situation (33, 51). If work or possible future work was not perceived as contributing to experience of meaningful engagement, identity construction or self-sufficiency, paths toward work could be characterized by a certain hesitance.

Using a transactional lens in exploring the RTW process can therefore add to the understanding of complexities in RTW previously described in research (e.g. 7, 8, 13, 108); for example, Galvaan (43), argues that choices a person makes related to occupational engagement are co-constructed between the person as actor and social structures. In this way, using a transactional perspective provides an alternative understanding of choice that is contrary to a perspective of agency as something deriving solely from the individual. Similarly, Rudman (41, 172) argues for an understanding of possibilities as shaped, embedded and negotiated within social systems and structures. The absent or unfinished RTW processes described in studies I and III can therefore be viewed as responses to contextual challenges, such as fragmented support and lack of opportunities in the labour market, and/or economically unsafe solutions. A possible understanding of a person's paths toward work after SCI is therefore, a practical consciousness of possibilities of a working situation contributing to experience of meaning, identity construction, and/or self-sufficiency.

4.1.1 Understanding the situation as a starting point in the RTW process

Exploring negotiations of problematic situations can provide insights into how RTW interventions need to focus on the situatedness of the person through social, labour market, and societal systems. Fritz and Cutchin (33) state that interventions need to "*focus on the person-and-situation-as-a-whole*" (p. 7). In ReWork-SCI, a collaborative process of inquiry was initiated through attention to the personal narrative, and a structured mapping of problematic dimensions in everyday life with work. Supporting the person in finding an everyday life that can include work after SCI thus requires a broad perspective in rehabilitation beyond separate physical skills and activities. Moreover, RTW after SCI requires a perspective that reaches beyond the individual (25, 33, 49). In other words, the RTW process after SCI needs to include awareness of the contextual challenges. Trained occupational therapists and SCI rehabilitation teams are suitable actors (78, 81) in incorporating such a perspective, and in this way open up for a broad and inclusive dialogue as a starting point in the RTW process. The potential of involving the SCI rehabilitation team

and suggestions in how to navigate contextual challenges will be further elaborated on in the discussion.

4.2 PERSON-CENTREDNESS AND PARTICIPATION AS A RIGHTS-BASED APPROACH TO RTW

The findings in studies I and II illustrate the results of insufficient consideration of the person's experiences and situation in the RTW process after SCI. This could lead to resignation or having to map out one's own paths toward work. Study III indicates that a personalized support was taken for granted among professional stakeholders, but still difficult to achieve. In this thesis participation and person-centredness are used as theoretical resources to understand participation in work as a possibility for meaningful contribution and growth (24, 55), as well as inclusion, power, and access (16, 55). The need to acknowledge the person, and the person's rights in health-care is not new. Yet marginalization in the labour market for persons with SCI (20-22), and challenges to focus on the person highlighted in this thesis imply that these concepts are necessary to critically discuss and further develop.

To use a person-centred approach when aiming at a particular pursuit, such as RTW can appear paradoxical. Njelesani (101) argues that if a person-centred approach is not characterized with a certain reflexivity, there is a risk that the therapist promotes occupations that people in society are expected to do, and in this way narrow the range of occupational possibilities. As an example, there is a risk of RTW coordinators promoting work as something ideal and expected when meeting the person in clinical practice; and therefore risk de-emphasizing the needs of the person (101). Furthermore, in critique raised in relation to person-centredness and normalization of work (101, 102), the situation of persons with physical disability (101) and SCI (102) is exemplified to critically reflect on who controls and shapes engagement in occupations (101, 102). The findings in this thesis show multiple perspectives of persons' experiences of meaning in relation to RTW. The members of the photovoice group in study II experienced contributing through work as viable and rewarding, while most participants in study I had transitioned to unpaid occupations. Participants in study I were content about how this transition enabled flexibility in everyday life and possibilities to prioritize other occupations and manage the consequences of their injury. One evident interpretation is that meaning is an individual experience (26). Yet meaning and participation is also socially constructed (26, 28, 29). In line with Njelesani (101) and Hammell (102), the challenge is to understand if the different paths after SCI were grounded in the person's own choice, abilities, or possibilities. Reflexivity, as well as understanding the prerequisites for RTW after SCI are therefore important parts of a rights-based approach to RTW.

The low employment rates for persons living with SCI (20-22) along with the unclear, and sometimes absent, paths toward work illustrated in this thesis suggest that RTW after SCI is challenging to the person and maybe less expected in society. Therefore, it is necessary to

reflect on the potential consequences of being excluded from the labour market, such as lower income and a marginalized voice and platform in society. Work has a potential to permit self-sufficiency and social participation, work is therefore highlighted as a right, just as much for persons with disability as those without (16). To integrate a rights-based and a person-centred approach, ReWork-SCI was developed from a collaborative process, with an intention to enable fair support in the RTW process, regardless of whether the outcome is paid work or sick leave/disability pension. In this way, ReWork-SCI attempts to safeguard a process that acknowledges the person's interests and situation and offers possibilities to disentangle uncertainties in an everyday life with work after injury. The intention of ReWork-SCI is to understand the person's situation in order to be able to collaborate with and advocate for the persons in the RTW process. To continue exploring possibilities for participation in work after disability, as well as transitions to other meaningful occupations, is important to better understand the RTW process.

4.2.1 Person-centredness as a component in the RTW process

A personalized approach is a common element in RTW interventions after SCI (125, 127, 128), and emphasized in the Social Insurance Code (65), the Healthcare Act (66), as well as in documents regarding the RTW coordination role in Sweden (84). Yet *what* constitutes a personalized approach or *how* collaboration with the person should be implemented is not always specific. Moreover, a personalized approach is less explored and evaluated as a specific component in the RTW process. To identify how for example a person-centred approach can be implemented and evaluated in regard to RTW processes is therefore important in order to avoid it being taken for granted in frameworks and interventions (173, 174).

The person-centred approach in ReWork-SCI was supported by, for example, eliciting narratives (67, 69), sharing experiences and information between the coordinator and the person with SCI, and the use of COPM (150). The findings in study IV point to a potential of openness to the person's narrative to build partnership and trust between the person and the coordinator. In line with conceptualization and research related to person-centredness (e.g. 67, 68), the person-centred approach was seen as a means to facilitate trust and decision-making in ReWork-SCI. Maintenance of the partnership and a person-centred follow-up were more challenging. The RTW process after SCI is often extensive; research shows that an average time for return to first employment is about five years (112, 115). Therefore, continuous follow-up in the RTW process after SCI is critical. The findings show that follow-up in ReWork-SCI focused more on problem solving than following the structure of COPM and the revision of set goals. In line with Wressle et al. (175), the participants in study IV felt that they were actively participating in the rehabilitation process and goal-setting. However, contrary to Wressle et al. (175), the participants had difficulties in recalling problem areas in COPM and goals set at three-month follow-up. Even if they experienced a flow throughout the RTW process, they also described that they were alone in managing uncertainties in

relation to everyday life with work. Supporting persons in finding strategies for everyday life and work was an important part of ReWork-SCI. Therefore, person-centredness as a component in ReWork-SCI needs to be improved. For example, the researcher needs to be more aware of challenges in using COPM and improve training related to the person-centred approach. In addition, improved transparency and active participation in the RTW process might be facilitated by use of digital health solutions, where the goals set are more accessible to the persons with SCI throughout the RTW process (176).

4.3 THE POTENTIAL OF IMPLEMENTING REWORK-SCI IN A SCI REHABILITATION UNIT

Studies I and II illustrate experiences of a fragmented RTW process, and study III points to challenges in navigating and coordinating paths in the RTW process. This indicates that a more structured and coordinated RTW process is important after SCI. Evidence in regard to RTW coordination is still uncertain (120, 121) and evaluation of RTW coordination both internationally (120, 121) and nationally (90) is mainly focused on the leading causes for sick leave. A proposal for new legislation suggests implementing RTW coordination broadly into healthcare services in Sweden (85). In the light of this, it is important to discuss the potential of implementing support for RTW within the rehabilitation setting, as well as the potential challenges in doing so.

A person with SCI typically has lifelong loss of motor and sensory function, and associated conditions (1) and spends an extended period in the healthcare services during acute care and medical rehabilitation. Studies I and III show uncertainty in relation to *when* to initiate a RTW process after SCI. Study III shows that sickness certification is provided by the physician at the SCI unit during in-patient rehabilitation. This means that several months can pass before sickness certification is provided by the physician in primary healthcare. In some rehabilitation settings, such as in Stockholm and Uppsala, sickness certification can be provided continuously for the person with SCI. It is therefore imperative to develop support for RTW in the rehabilitation setting. Furthermore, the proposal for new legislation for RTW coordination in Sweden builds on identification of persons in particular need of personalized support (85). Persons with SCI are, due to their injury, at risk of long-term sickness absence (112, 115). Those who lack higher education (110-112, 114) or a suitable job to return to (110-113) are at an even greater risk. In addition, evaluation of RTW coordination in the Stockholm region showed that coordination for persons with complex conditions and high care consumption was less effective. It was suggested that multi-professional team efforts can be important for such patient-groups (90). This is in line with previous studies that point to the strength of including multi-professional competence in the RTW process (78, 83, 177).

On the basis of this discussion, it is imperative to improve RTW support and explore possibilities of RTW coordination where the person with SCI is situated, and where sickness certification is provided. Absence of RTW support such as RTW coordination in

rehabilitation settings can imply a delay in the RTW process. In line with evidence for multi-domain interventions to facilitate RTW (118), study IV points to the potential of implementing ReWork-SCI to design an individualized plan for RTW. Study IV also points to the potential of offering person-centred support in the RTW process parallel to medical rehabilitation. Members of the SCI rehabilitation team are experienced in understanding the problematic dimensions arising after SCI and are specialized in understanding the consequences that follow the injury and in collaborating with the person in managing those consequences. Finding paths to parallel processes, in line with ReWork-SCI, are therefore important for timeliness after a substantial life disruption such as SCI.

4.3.1 The coordination role in a SCI rehabilitation unit

Study IV illustrates the potential of a RTW coordinator as part of the SCI rehabilitation team to balance the RTW process with medical rehabilitation. The findings in studies I-IV also point to a need beyond mere coordination between stakeholders in the RTW process after SCI. RTW coordinators typically have higher education (86), however, type of education or competence needed is not specified in the proposal for new legislation for RTW coordination (85). ReWork-SCI follows a person-centred, structured, and coordinated RTW process and the intervention is grounded in theoretical resources relating to occupation (24) and person-centredness (30-32). There is a potential risk with implementing RTW coordination broadly if the competence of the coordinator is not grounded in knowledge of, for example, medical rehabilitation, insurance medicine, and theories and tools useful in the RTW process. In ReWork-SCI occupational therapists or social workers are suggested as potential coordinators in a SCI rehabilitation unit due to their educational background. Sturesson et al. (78) suggests that occupational therapists have competence in assessing work situations. The findings of this thesis point to the potential of occupational therapists in collaborating with the person during the RTW process. The occupational therapist is trained in understanding how a person experiences and makes sense of everyday life and accompanying them in finding new strategies in everyday life (26).

In study IV, challenges to implement the RTW coordination role were mainly contextual, such as difficulties in organizing the SCI rehabilitation team and other professional stakeholders, and challenges aligned to the new and additional role of being a coordinator. In line with this, success factors in implementation RTW coordination are determined as, for example, management support, explicit roles and routines, and cooperation with the multi-professional team (86). When implementing RTW coordination in a SCI rehabilitation unit, it is relevant that implementation is initiated from, or in collaboration with, the management in the unit, and that the role and routines of the RTW coordinator are carefully considered. Moreover, it is seen as important that the coordinators are offered continuous support, for example in relation to insurance medicine and the RTW process. This approach is found to be an important part of implementing RTW coordination in healthcare (86).

4.3.2 Potentially active components of ReWork-SCI

Evidence related to separate components to facilitate RTW is still varied or insufficient (118), and mostly targets the leading causes of sick-leave, such as musculoskeletal problems or mental disorders (119). The uncertain evidence and lack of research in regard to the SCI population (123, 124) points to a need to continue to evaluate RTW components for this population. Study IV indicates that coordination based in the SCI rehabilitation unit, a non-linear structure initiated through person-centred approach and mapping, and dialogue with the employer as potentially active components in ReWork-SCI. A few of these components have already been discussed. In this section, the non-linear *structure* and the *dialogue with the employer* in ReWork-SCI will be highlighted.

Study III illustrates ambiguity in regard to *how* to support a person in the RTW process after SCI. The structure of ReWork-SCI, consisting of 15 steps, can appear linear and meticulous but had a purpose of detailing the necessary steps for an individualized RTW process. Hoefsmit et al. (122) point to the effect of interventions following a certain schedule. In line with Hoefsmit et al. (122), study IV suggests that following ReWork-SCI could facilitate the coordinator's work. The coordinator experienced increased difficulties when deviating from the steps; for example, if initial mapping was insufficient, this could negatively affect the dialogue with the employer. Yet due to the multi-dimensional nature of RTW (14, 17), ReWork-SCI needed to allow a dynamic process. Therefore, it was possible to loop-back in ReWork-SCI, and some steps were flexible or possible to merge. These possibilities were used in the process, and further developed through a dynamic research approach (131). The persons with SCI expressed how they experienced flow in the process and trusted that they could pause the process if necessary. Therefore, a possible interpretation is that the structure facilitated a flow that could direct the person and the coordinator in how to proceed in the RTW process. The structured process had the potential to guide what was necessary in the specific situation, and plan for the future.

In studies II and III we found that an ongoing dialogue with the employer had the potential to facilitate integration of strategies for an everyday life with work. Franche et al. (117) and van Vilsteren et al. (119) point to the effect of workplace-based interventions, such as contact between healthcare services and the employers, on reduced duration to work (117). Yet evidence for the sustainability of this effect is still insufficient (117, 119). In Sweden the employer has substantial responsibilities in the RTW process (65, 76). However, Ståhl et al. (82) point to a lack of coordination between healthcare services and employers, and a risk of employers not completing their responsibilities. To improve coordination Björk et al. (88) highlight a need to evaluate the RTW coordinator role in involving the employer in the RTW process. Studies II and III give insights to the employers' role and potential challenges to carry out that role during the RTW process. Persons with SCI often live with substantial functional limitations. Due to the small populations it is likely that the employer lacks knowledge about what it means to live with SCI. Sturesson et al. (78) point to the competence of an occupational therapist to analyze work conditions. In addition, study IV points to how the RTW coordinator could support the person with SCI and the employer in the RTW

process through sharing information and initiating a dialogue about work after SCI. The participants expressed the strength of having a third party that could address what living with SCI meant to them. This initial dialogue meant a possibility to untangle uncertainties related to the person's life situation, work environment and work tasks. Furthermore, this meeting showed potential in detailing the RTW plan, which sometimes meant that coordination meetings with all stakeholders were not required. Instead, communicating by telephone or through a sickness certificate could be sufficient. Supporting an initial dialogue with the employer, although time-consuming to the coordinator, appears to be an important part of coordinating RTW after SCI. This might provide support to the employer in completing their responsibilities in the RTW process and empower the person with SCI and their employer in maintaining a continuous dialogue.

4.4 NAVIGATING THE RTW PROCESS AFTER SCI THROUGH SOCIETAL LANDSCAPES

Study III illustrates how professional stakeholders mediate between intentions and possibilities for RTW after SCI in relation to labour market and societal contexts. Tensions between the person's needs in the RTW process and the problem of fitting those needs to the labour market and legislative system are previously highlighted (e.g. 78, 82); for example, related to the strict time-limits of the rehabilitation chain (82), and to the medical assessment of work ability applied within the SSIA (78, 82). The structure and coordination in ReWork-SCI seemed to untangle some uncertainties in the RTW process. We found that the comprehensive mapping could potentially bridge certain discrepancies and open up for a degree of dynamic actions in the RTW process. Yet, one important finding in this thesis was also that realistic paths toward work were lacking for those at greater risk in the RTW process. Even though the authors believe that shorter RTW duration can be a possible outcome of ReWork-SCI in a future full-scale trial, it is possible that RTW coordination is not enough for persons who lack education or a work place to return to after SCI, if challenges in the societal context are not addressed.

Ståhl et al. (82) point to a gap between the sickness insurance and labour market contexts, and state that reintegration to the labour market can be a Sisyphean task. For persons with disability the situation in the labour market is delicate and a lower proportion of persons with disability are employed (72). The members of the photovoice group highlighted their wish to be as anyone else at the workplace. Yet studies I and II raised questions of what is normal, valued, and promoted in the labour market. For example, persons with disability typically need some adaptations such as reduced working hours or accommodations at work (72). The employers' awareness of these needs was limited and to ask for and acquire accommodations could be challenging, not least in a new working position. Furthermore, in study III, officers at the Swedish Public Employment Service stated the necessity in delicate cases to evaluate work ability in a work place environment and highlighted the Swedish Public Employment Service's competence in doing such. This was contrasted to a potential economic risk if

proceeding to the Swedish Public Employment Service, and also to difficulties of doing so when ability to work was still uncertain. The abovementioned tensions could mean that cues from healthcare services to the SSIA were absent and that the person became stuck in the process due to continuous sick leave. It could also mean that the person received disability pension without fair opportunities of a work trial. It is therefore important to acknowledge how contextual factors are part of shaping opportunities for inclusion (178). It is imperative to evaluate how a fair assessment of a person's abilities and possibilities in the labour market can be conducted, and how paths toward paid work can be improved for those lacking employment after SCI, for example, through reflections of the norm of being able-bodied and working full-time, along with recognizing the contribution that can be made by persons with SCI to the labour market.

Currently, paths through support from increased cooperation between the SSIA and the Swedish Public Employment Service seem to be the most suitable path for persons with SCI who lack employment options after SCI and whose work ability is uncertain, since this path can proceed for one year with retained sickness benefit. For persons whose workability are more certain, but who are in need of support to find paid employment, special introduction and follow-up support can be an option. This support is based on supported employment, which is shown to be effective for veterans with SCI (125, 179). Based on the findings it is thus of utmost importance that action-oriented services are person-centred. Another possible path for persons with SCI is education. Education is the number one factor contributing to employment after SCI (22, 109). Each year of education contributes positively to employment (109). Education is highlighted as a possible path to meaningful employment after SCI from the perspective of young adults who lacked a work place to return to after SCI (8). Participants in study I described how attending courses was viable and that participating in education opened up a safe environment in which to evaluate one's abilities. This was due to the flexibility education could offer, for example through studying at home and dividing the workload over the day or week. In this way, education was viable and a path that could potentially lead to future employment. Yet several participants hesitated, or had abandoned plans, to pursue formal or higher education. It is therefore important to consider education as an option in the RTW process, especially for young adults. Individualized paths can be initiated through a coordinated RTW process based in healthcare services.

4.5 METHODOLOGICAL CONSIDERATIONS

This research project includes both strengths and weaknesses in how it is designed and conducted. The main strength of this thesis is the use of MRC guidance (34) in the step-by-step development and evaluation of a rehabilitation intervention. The combination of research approaches and methods facilitated the generation of knowledge of *when* and *how* a RTW intervention can be possible after SCI. After modifications, the effect of ReWork-SCI can be evaluated in a full-scale trial. In this section, *aspects of trustworthiness* in studies I-IV will be discussed, together with reflections of *using a participatory approach* in this thesis, as well as considerations of *evaluating a complex intervention for RTW*.

4.5.1 Aspects of trustworthiness

Studies I-III logically built on, and contributed to, each other. While this was a methodological strength, the small sample size was a limitation in studies I, II, and IV. In evaluating qualitative research Williams and Morrow (180) refer to integrity of data and balance between meaning and research interpretations. They argue that trustworthiness in qualitative research goes beyond sample size. Instead, integrity of data includes aspects of *rich data* and *thick descriptions* (180, 181), and *detailed descriptions of the research process*. Balance between meaning and research interpretations implies *reflexivity in the research process (147, 180)*. These aspects will be discussed in this section.

4.5.1.1 Rich data and thick descriptions

A challenge in this research process was to gather rich data and to analyze and present data beyond mere descriptions of the findings (180). The combination of interviews and observations in study II, visual and text data in study II, and multiple stakeholder perspectives in study III, along with the prolonged engagement in each study (see Table III), were examples of strategies to achieve rich data. Alternating data collection and analysis in studies I and III, as well as the collaborative research process spanning eight weeks in study II contributed to rich data and thick descriptions. An important question is when data collection should end due to no new information being added, and richness and complexity is presented through findings, i.e. saturation (180). Williams and Morrow (180) argue that saturation is complex and almost impossible to achieve due to the diversity of human experience. In each study of this thesis, the researchers have made decisions in relation to inclusion and data collection, based on the study aim and method used. Because study I was a follow-up study the sample size was predetermined. In study II, the number of sessions was predetermined at time of inclusion. It is possible that larger samples might have contributed to thicker descriptions.

The stepwise research process in this thesis was important in gaining thick descriptions. This approach contributed to possibilities to develop research questions between studies, to draw

on previous findings, as well as to discuss findings in relation to each other. For example, study I implied a fragmented support and constant negotiations of everyday life situations, and highlighted challenges to proceed with safe solutions for work. In study II, the everyday negotiations were confirmed and visualized by the members in the photovoice group. Yet study II also gave new insight on possible solutions for work. Study III pointed to an awareness of the challenges described in studies I and II and intent for individualized support for solutions for work, but also to specific challenges of mediating between intentions and legal frameworks in the RTW process. This exemplifies how the stepwise contribution of each study and also synthesizing of findings contributed to thick descriptions.

4.5.1.2 Detailed descriptions of the research process

Williams and Morrow (180) point to the importance of *detailed descriptions of the research process*. This can, for example, refer to grounding methodology in theory (70, 139). In this thesis, a combination of a narrative approach (study I), participatory approach drawing on photovoice methodology (study II), and constructive grounded theory (study III) was used. Using these approaches meant understanding stories as means of making sense of everyday life situations (69), a perspective of persons with SCI as experts and collaborators in changes that concern them (35, 36, 64), and understanding research as construction (139). The different approaches implied challenges; for example, using different approaches meant a lack of in-depth knowledge about the approach when entering the research process. Moreover, it meant that experiences gained in the research process were not possible to confirm in a second study. Yet a combination of approaches also meant opportunities to approach research questions with different lenses, which was seen as a strength of this thesis.

There were limitations in each study in regard to methods used. For example, while thematic analysis of narrative is a possible method in a narrative study (71), using narrative analysis and for example presenting findings through cases or vignettes might have contributed to a richer description of data in study I. In study II, dissemination of the findings through an exhibition is still not completed. Further, grounded theory aims at theory construction (139, 141), while in study III a final theory is not presented. To manage challenges and flaws in the research process the authors attempted to present the methods used and the research process in as much detail as possible, and to critically discuss any methodological limitations. In this way, the reader can follow the research processes and form an opinion on the choices made. For example, the use of thematic analysis was motivated through the benefits of using the same method in the follow-up study as in the previous study (8). Moreover, although study III did not present a complete theory construction, the analysis contributed to a conceptual understanding. Charmaz (139) states that analysis consists of at least two phases, initial and focused coding. In study III, theoretical coding was used, although it is possible to advance theory construction in future research.

4.5.1.3 Reflexivity in the research process

Reflexivity in all types of research is critical (180). Williams and Morrow (180) refer to reflexivity as a ***balance between meaning and research interpretations***. I will briefly relate how reflexivity has been central during this research process. Entering this research process as an occupational therapist with clinical experiences from a SCI rehabilitation unit implied both strengths, based on experiences of the research area, and weaknesses, due to possible pre-understandings. In an early phase of data collection in study I, I was inspired by *Gazing anew: the shift from a clinical gaze to an ethnographic lens* by Lawlor (147). In this article, Lawlor (147) argues that reconfiguration of the clinical gaze to a researcher stance is a complex process. Especially, Lawlor's (147) reflections of acts of being present, socially connected, self-conscious, and reflexive was important when I started the research process. The experiences brought from clinical encounters and knowledge in the field had to be balanced to a researcher stance, and I had to find new ways of acting, observing, and asking questions. I was further inspired by readings of Corbin and Buckle (182), who argued for a researcher's role in "*the space between*" (p. 60). They suggested that whether a researcher comes from an insider or an outsider position, with the strength and weaknesses this brings, the researcher, based on his/her position, can only occupy the space between. This was important in understanding my position during the research process. Charmaz's (139) take on constructive grounded theory was another important resource in helping to further adopt a researcher stance. These sources helped to bring clinical legacy to the research area (147) but also to consciously identify and reflect upon my own pre-understandings related to the research questions and the data.

4.5.2 Using a participatory approach

The use of a participatory approach drawing on photovoice methods was an important methodological choice in this thesis. The necessity to involve persons with disability in change that concerns them has long been pursued by the disability movement (56, 57) and is stated in the CRPD (16). Hammell (137) points to the paradox of promoting a person-centred perspective without collaborating with service users in development of interventions. In line with this, Bloom et al. (183) point to the importance of involving persons with SCI to ensure authenticity in RTW interventions. Using a participatory approach, drawing on photovoice methods, was therefore a strength in this thesis. Study II was conducted in collaboration with six persons working after SCI in a research process that continued over two months. The members of the photovoice group gradually developed their knowledge of the method and assumed ownership in the research process. The members were active in the visual analysis, which is in line with photovoice methods (133) and the findings contributed with important knowledge of personalized paths to help find viable solutions for everyday life with work. In this way, study II made an important contribution, both methodologically and in development of ReWork-SCI.

Two prominent methodological limitations in study II will be discussed: *framing the research question* and *dissemination in a community context*. An important element of the photovoice methodology is to include service users in designing research questions (64, 184). In study II the researchers framed the research question and persons with SCI were asked to collaborate with the researchers in a later phase. A more suitable way to establish equity would be to engage in collaboration with a community partner in an early research process. Yet this can be challenging to achieve depending on the origin of the research project and also due to the burden of participation, i.e. the risk of participation is overwhelming for the participants due to other responsibilities (185). Furthermore, dissemination in a community context is an important part of photovoice (64, 133). Photos and text are chosen by the members of the photovoice group in preparation for an exhibition, yet an exhibition has still not been accomplished at time of writing. Even if the researcher intended to pursue dissemination in the community context and the participants were positive to contribute to an exhibition, both participants and researchers had limited time to pursue exhibition planning. An important experience is therefore to carefully reflect upon the burden of participation and discuss this with members at the start of a photovoice study, and also to calculate the time and resources needed for an exhibition in an early phase of a photovoice project.

4.5.3 Evaluating a complex intervention for RTW

To evaluate the feasibility of ReWork-SCI and the study design, the authors choose to use a pre-post test, single group, design. There are a large number of elements that can be included in feasibility testing (131, 143-145) and no precise guidance is available for non-randomized feasibility studies. Since ReWork-SCI is in an early development phase, there were a number of uncertainties around implementation of the intervention in clinical practice, for example, whether the structure of ReWork-SCI was possible to follow and acceptable to clinicians and persons with SCI. There was also uncertainty with regard to recruitment. Therefore, the focus in study IV was on adherence, acceptability, recruitment, retention, and evaluation of outcomes used.

The main strength of study IV was the combined approach of evaluation methods, such as log books held by the coordinators and researcher, interviews with participants and coordinators, and the use of a variety of outcome measures. The combined data gave important information of strengths and weaknesses that need to be addressed in preparation to, and during a full-scale trial. For example, analysis of log books showed that follow-up was unclear and varied in content, timing, and regularity. During interviews, the coordinator stated that the first part of the ReWork-SCI was clear, yet follow-up was uncertain. Similarly, the participants expressed a gradual loss of contact with healthcare professionals and difficulties in recalling the set goals. Follow-up with COPM was not performed with all participants before six months. Instead the researcher did those evaluations. This can be seen as a major limitation. At the same time, these findings are critical to making adaptations to ReWork-SCI and the study design before proceeding to a full-scale trial, for example, through a more clearly

defined process and through improved training in regard to person-centred follow-up. The dynamic approach used in this study created possibilities to adapt and clarify follow-up during the interventions (131). Methodological limitations mainly concerned *sample size*, and the *outcome measure used*.

4.5.3.1 Sample size

The authors decided on a sample of six to eight participants. When the first coordinator terminated employment, seven participants were recruited. Due to the fact that the predetermined sample size was reached, and because of uncertainty around recruitment of a new coordinator, the authors decided to stop recruitment at that point. The small sample meant that it was not possible to calculate sample size for a future full-scale randomized trial which was a limitation of this study (143). It also implied limitations related to evaluation of outcomes described in the next section. The strength of including few participants was the possibility of following the participants closely during the research process, and for the coordinator to have enough time to familiarize with the intervention.

4.5.3.2 Evaluating outcome measures in a RTW intervention

Evaluating outcome measures in study IV had a purpose of understanding if they were suitable in a future full-scale trial, and to determine which outcomes were suitable as primary and secondary measures. The challenges of measuring RTW have been previously discussed (183, 186). There are numerous measures and definitions of outcomes (183, 186) and the choice of outcome measures is difficult. The choice of instruments in this thesis was grounded in the psychometric properties of the instruments, the theoretical underpinnings of the instruments, the use of instrument in the specific population, and the researchers' experiences. In addition to instruments used, the authors chose to measure frequency, i.e. number of persons returning to paid work or work trial (part-time or full-time).

The vocational outcomes measures and COPM showed a certain variance between baseline and six-month follow-up. These outcomes target specific components in the intervention, such as RTW and problematic dimensions in everyday life. In addition, COPM is theoretically grounded in a person-centred approach (150). These outcomes, in combination with log books, and interviews, provided important insights to the person-centred approach, the RTW process, and follow-up. Therefore, these outcomes are probably suitable as primary outcomes in a full-scale trial. FIM, Self-efficacy Scale, EQ-thermometer, and Lisat-11 (global question) showed no significant difference between baseline and six-month follow-up. It is possible that a larger sample would have shown a variance but on the basis of this study it was difficult to know if a variance can be expected in a future full-scale trial. FIM is shown to plateau after discharge, which implies that it is not a suitable outcome measure for out-patients (168). Moreover, even if psychometric properties overall are sound for the chosen

instruments, it is uncertain if the chosen instruments could capture the potential effect of ReWork-SCI. For example, the content of FIM and the Self-efficacy Scale suggest that they may be more useful as a description of the sample. In addition, the Spinal Cord Independence Measure (SCIM) is shown to be more sensitive to functional changes after SCI (187). Therefore, FIM could be exchanged to SCIM if translated to Swedish. Lisat-11 shows that all participants were non-satisfied with life as a whole after three and six months. This is likely more related to their overall life situations than to the intervention. However, these results imply a need to consider the person's psychosocial situation further in a full-scale trial. WRI and WEIS were used at the start of the intervention. They target specific components in the intervention and give important insights both to participants' experiences and situations, and may be useful in predicting job potential (156). The coordinator experienced WRI and WEIS as useful in the initial mapping. WRI and WEIS can be suitable either as secondary outcome measures or purely as clinical assessments.

4.5.4 Ethical considerations

The research in this thesis was conducted in accordance to the Helsinki Declaration (188). Risks, burden, and benefits were carefully considered prior and during each study. Information about the study and possibilities to end participation at any point was shared through verbal and written information to each participant before consent. In studies II and IV, eligible persons were informed by a healthcare professional that was not connected to the research project. Thereafter they were asked if they wanted further information from the researcher. This was seen as important to avoid the person experiencing pressure when asked to participate.

In generating qualitative data, there was a risk of causing anxiety for the person. In study I, several years had passed since injury, and contacts with professional stakeholders were less frequent. In study II the participants were relatively newly injured. The subject of everyday life with work could thus be sensitive. This was carefully considered during data generation through information about the study aim and considerations of signs of discomfort during the interviews. All participants were informed that contact with a social worker or physician could be offered. Although observations were seen as important in study I, they could provoke feelings of being exposed. Furthermore, including several interviews and observations were time consuming to the participants. Therefore, observations were used sparingly and as a complement to interviews.

In studies II and III it was seen as important that the participants felt comfortable in the group and with the discussions. The facilitators thus had an important role in managing potential tensions within the groups. It was seen as especially important to avoid tensions due to power imbalance in the multidisciplinary focus groups. A participatory research study drawing on photovoice raises several ethical dilemmas, for example, in relation to burden of participation and dissemination of pictures (185). Ethical dilemmas were continuously discussed and

managed in the group. For example, there was a mutual decision about not including pictures in which the participants or other persons were identifiable in the research article. Nash and Murray (185) state that it is important to apply a flexible approach to participatory research, rather than a "one-size-fits-all", therefore it was seen as important to discuss ground rules so that rules were adapted to the members in the photovoice group.

In addition, due to that the SCI population is small, confidentiality was carefully considered throughout the project. The participants were informed that no information was shared by the researchers to professional stakeholders. Moreover, in the research articles individual demographic characteristics that may identify participants were presented in terms of a group, and the findings presented in themes and with pseudonyms. This was seen as of utmost importance to avoid risk of persons being recognized. In studies II and III it was important that pictures, stories, and discussions shared within the groups also stayed within the group. This was discussed continuously in study II and prior to each focus group interview.

Although careful modelling in collaboration with stakeholders took place, there were uncertainties about how ReWork-SCI could be implemented and received in a clinical setting. Therefore, in study IV, the participants were informed that ReWork-SCI was complementary to the regular rehabilitation program at the clinic and that if they chose to end their participation it would not affect their ordinary rehabilitation. The potential risks of proceeding with ReWork-SCI were continuously discussed with the RTW coordinator and the research team, and consent was reconfirmed verbally before each occasion for data collection.

As exemplified above, potential risks, and aspects of confidentiality, were continuously considered. Measures to minimize risks were implemented throughout the research project. The benefits of increased knowledge in regards to RTW after SCI and development of a rehabilitation intervention were assessed to outweigh the risks. Ethical approval was obtained from the Regional Ethical Review Board in Stockholm for studies I-III (reg. no 2014/2035-31), and study IV (reg. no 2017/1361-31).

4.6 CONCLUSIONS AND IMPLICATIONS OF RESEARCH

This thesis contributes to an understanding of how a person's negotiations of problematic everyday situations in relation to social, labour market, and societal context is a continuous process in RTW after SCI. Through negations of everyday life situations, the person makes sense of their experiences and can eventually find a new rhythm. How a person acts in the RTW process can be seen as a response to how they perceive their situation/or a possible future (working) situation, contributing to meaning, identity construction, and self-sufficiency. *It is critical to collaborate with the person in mapping a comprehensive picture of his/her unique situation and in untangling uncertainties related to everyday life and work. Specialized healthcare professionals in the SCI rehabilitation team are seen as suitable partners in the collaborative inquiry. Mapping a comprehensive picture can function as a starting point for an open dialogue between stakeholders and incorporating multiple perspectives of the RTW process.*

This thesis contributes to illustrate possibilities for collaboration with persons living with SCI when developing a complex RTW intervention. Through this collaboration, a perspective of work as viable and rewarding after SCI emerged. Among the persons who shared experiences there was a powerful desire to be like anyone else at the workplace and to contribute on the basis of competence and on the same terms as others. *Interventions for RTW after SCI need to derive from the persons involved. This is important for authenticity and sustainability in solutions. A person-centred approach has an intention to safeguard a fair RTW process, that acknowledges the person's situation, and that can be pursued regardless of an outcome of paid work or disability pension. Increased labour market participation for persons with SCI can function to raise awareness of diversity and accessibility and in continuing a necessary dialogue about normalization in the labour market, such as full-time work.*

This thesis shows how the RTW process was experienced as fragmented to the persons with SCI and difficult to navigate for the professional stakeholders involved. The professional stakeholders experienced mediating between their intentions of a fair RTW process and possibilities for RTW within contextual landscapes. Uncertainties and tensions implied risk of unequal, delayed, and/or absent RTW processes. *ReWork-SCI has a potential to facilitate collaboration among stakeholders and designing a RTW plan. Potentially active components in a RTW intervention after SCI are coordination based in the SCI rehabilitation unit, a non-linear structure initiated through a person-centred approach and mapping, and dialogue with the employer.*

This thesis aligns to the development of RTW coordination in Sweden. The fragmented RTW process for persons with SCI and challenges to navigate in the RTW process imply a need for improved coordination. Persons with SCI are at risk in regard to RTW, and spend extended time in acute care and medical rehabilitation. Sickness certification is provided by the physician at the rehabilitation centre. *To enable early and specialized support it is critical that coordination is based within the SCI rehabilitation unit. Coordination needs to be carried out in collaboration with the person, the SCI rehabilitation team, and other*

stakeholders. Coordinators need to have relevant higher education and be trained and supported in their role as coordinator. The county council, and management at the SCI rehabilitation unit, has an important role in supporting this.

This thesis illustrates inequalities in RTW after SCI. Persons lacking education and persons lacking a suitable job to return to are at greater risk of being excluded from the labour market. Abilities to work after SCI can be uncertain, and it is necessary to evaluate concrete possibilities in a working situation. Paths that explore abilities and opportunities for work for this group are unclear and can be economically unsafe. *It is important to work toward an economically safe and equal RTW process where abilities for work can be explored. Through ReWork-SCI, decision for a suitable path for this group may be recommended. Timely cues from healthcare services, individualized support from the Swedish Public Employment Service, and increased possibilities for formal or higher education may be critical in improving opportunities on the labour market for this group. It is imperative that action-oriented services derive from the person's situation, competence, and interests.*

4.7 FUTURE STUDIES

This thesis illustrates that ReWork-SCI is feasible. To further evaluate the effect of ReWork-SCI in a full-scale randomized trial will be important to determine the effect of the intervention and thus contribute to the evidence base for RTW after SCI. Before evaluating the potential effect of the intervention in a full-scale randomized trial, revisions to recruitment, involvement of the SCI rehabilitation team, and training of RTW coordinators are necessary.

RTW interventions, such as ReWork-SCI, are typically multidimensional. In order to better understand the different dimensions, it is important to further develop and evaluate potentially active components, such as person-centredness and collaboration between healthcare and employers. Digital health solutions can be an important tool in this endeavor, to improve goal-setting and for continuity and sustainability in RTW.

This thesis brings to the surface the potential of introducing a coordinator role in a SCI rehabilitation unit to facilitate the design of a RTW plan and potentially decrease duration. Development of a coordinator role in rehabilitation settings in Sweden is in an early phase and evidence for RTW coordination is still varied. It is important to further develop and evaluate the effect of the RTW coordinator role, as well as qualifications and support needed, and content of the role.

This thesis adds to the understanding of complex negations of everyday situations as part of the individual RTW process. Longitudinal studies exploring the person's situatedness in the RTW process can contribute to a better understanding of their experiences and transitions during an RTW process, which can inform medical rehabilitation and future RTW practices.

This thesis highlights the need to acknowledge the person during a RTW process. It is critical to include persons with SCI in further development and evaluation of RTW interventions after SCI. This is seen as especially critical in research situated in the intersection of research, practice, and policy.

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