
Changes in Occupational Patterns after Disability
—A private, a domestic, or a working life triage—
**Exploring individual experiences through the lens of qualitative
methods**

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LIST OF PAPERS

- Paper I** Relatives' experiences of family members' eating difficulties. Johansson A.E.M, Johansson U. *Scandinavian Journal of Occupational Therapy*. 2009;16: 25-32
- Paper II** Disability pension and everyday life: A period of transition and subjective aspects of future occupational life. Johansson A.E.M, Johansson U. *Work*. 2011;40:375-84
- Paper III** Participation in the workforce after a traumatic brain injury: A matter of control. Johansson A.E.M, Haugstad T, Berg M, Johansson U. (Submitted)

SUMMARY

The aim of the research presented in this dissertation is to explore individuals' experiences regarding everyday occupations and adaptation to a changed life situation after disability. The aftermath of a severe illness or trauma changes human beings' ability to keep up with their former capabilities and endurance. Physical capacity and occupational patterns are altered: self-care and moving around in-doors and around one's neighbourhood often requires more time to perform, and new habits and roles are created during this period of adaptation. In caring for a family member, relatives take on tasks that are new to them, and they could suffer from symptoms of burnout. Adaptation to the activities of daily life could be a stressful period for the individual as well as for the relatives. Support from the family network and the work environment might be of assistance in the process of adapting to a current life situation. The question of how individuals as well as relatives change their habits and roles after disability, and how this influences their future occupational life, has not often been studied. This research gap, with the incentive to gain knowledge about individual experiences of returning to work with a disability pension or after having had a traumatic brain injury formed the topics for this dissertation. Qualitative methods were chosen for analysis with the intent of displaying the participants' experiences from a number of perspectives. In gathering data for three separate studies, nine informal caregivers of family members with eating and swallowing difficulties, fourteen people with neuropsychological or musculoskeletal diseases having a disability pension and eight men recovering from a traumatic brain injury agreed to participate and were individually interviewed. The findings revealed implications for extended supportive interventions of counselling characteristics with the intention of enhancing the individuals' ability to control their everyday occupations from a balanced point of view between what they have to do and what they want to do. Being the agents of their everyday domestic tasks as well as work routines could increase the individuals' beliefs in their own skills. The conclusion drawn from the findings in this dissertation is that balancing activities after disability several of the participants chose to downsize at least one of the domains of home labour, leisure activities, or working hours in order to meet their capacity and endurance.

1 INTRODUCTION

When people try to regain mastery of everyday life after severe injuries leading to permanent decline in physical or cognitive function, they often experience changes in their occupational capacity (1). Going about ones' occupational life with a disability is often a process of alteration of daily routines and activities. There are few studies on peoples' adaptation to habits and roles with the aim of returning to work after acquiring a disability. This project aims to add to the knowledge of how people adapt their occupational patterns after disability. When physical and cognitive capacity and occupational patterns are often altered, new habits and roles are created during a period of adaptation. Orientation to normality is a strenuous endeavour, in which people need support and guidance (2, 3), while others managing quite well due to former learned skills in handling life events in general (4, 5).

Guidetti (2) found in her study of people who have suffered from stroke that it takes energy to become accustomed to the "new" body and to regain independence in self-care. Staying home, disconnected from working life, can create feelings of loneliness and social exclusion (6, 7). After being disabled, it often takes more time to perform self-care and to move around at home and in the neighbourhood. As a consequence, one needs to re-organize family life and to recapture a new structure in daily life. This is usually a stressful period after discharge from the rehabilitation hospital. The physical environment, with home and the workplace in mind, is found to be important for the meaning of actions during the rehabilitation phase (3). Human beings construct their occupational identity and develop through purposeful and meaningful activities. The degree of success in occupational adaptation varies over time (8). The process of how people change their habits and roles after disability and how this influences their future occupational life is a topic for future research. This research aims to explore individuals' experiences regarding everyday occupations and adaptation to a changed life situation after disability. The concepts of occupation need therefore to be clarified as well as perspectives of the individuals' subjective meaning of participation.

2 BACKGROUND

To introducing this dissertation, a review of the relevance of occupation as well as perceived health is necessary and appropriate. Early in the process of shaping the principles of occupational therapy (OT), meaningful and purposeful activities were stressed, while environmental influence was noted to be significant for inspiration and the meaning of doing¹. First of all, self-maintenance and domestic chores, caring for home and family, and the prospect of learning a traditional occupation enable one to earn one's living, and that concept dominated the workshops. The individual's distribution of occupations² over time was a recurrent theme in rehabilitation program; the individual's own perspective should be considered. Thus, OT embodies theoretical assumptions about human beings' perception of autonomy, creativity, and responsibility, focusing on meaningful and purposeful activities (11, 12), not to mention that individuals are "inherently active and capable of developing" (13, 14).

2.1 Everyday occupations

2.1.1 Perspectives on occupation

Just over a decade ago, a worldwide interest in developing and explaining the concept of occupation was sparked. An emphasis on broadening the understanding of its core concept, and on consolidating a practice exercise with an academic and scientific entity (15, 16), launched a search for a definition of the very concept of occupation. In 2005 this subject was given further attention in the way "the relationship between occupation, health, and wellbeing, and the influences that shape occupation" p. 2 (15) was manifested by The World Federation of Occupational Therapy.

Furthermore, occupation as a core concept in occupational theory entails several unique components for each individual. On a daily basis, particularly in the rehabilitation process, people's occupational values and performance highlight the variety of activities they perform and the time they spend to perform them, but this information is not sufficient. In the field of OT, the conceptualization of the core concept has taken the matter a step further. The definition that "people's health requires a balance of activity and rest and that people take responsibility to

¹ The word *doing* is selected to convey the sense of performing, producing, or causing. The drive to action, transformed into the ability to "do", is fundamental to ego development and adaptation, p. 305-6: 9.

Fidler GS, Fidler JW. Doing and becoming: Purposeful action and self-actualization. *American Journal of Occupational Therapy*. 1978;32(5):305-10.

² An activity or set of activities that is performed with some consistency or regularity, that brings structure, and is given meaning by individuals and a culture, p. 19: 10. Polatajko HD, J. Stewart, D. Cantin, N. Amoroso, B. Purdie, L. Zimmerman, D. Specifying the domain of concern: Occupation as core. . In: Townsend EAP, Helene J., editor. *Enabling Occupation II: advancing an occupational therapy vision for health, well-being, & justice through occupation*. Ottawa, Ontario: CAOT Publications ACE; 2007. p. 13-36.

decide matters concerning him-/herself” (13, 14) opens up the issue for broader reflection. The concept of “occupational beings” is articulated (17), and is understood as “a way of looking at or thinking about human doing”. Recently, senior lecturers expanded the issue into a suite of studies with the overall aim of providing an extended view on occupation and allied synonyms, which were examined (18, 19) and summarised as follows: “occupation is being directed by the character and life situation of the individual” p. 90 (18). As in a previous statement, here Polatajko highlights the actual purpose and meaning of occupation, embraced by performance that will enable OT scientists and practitioners to uncover a diversity of aspects of occupation and its relation to health and well-being (20). The following actions are given as examples of the different purposes of the chosen activities: *sewing a button on a purchased shirt with the purpose of mending or designing and manufacturing a series of shirts with the objective of economic viability*. Evidently, activity and occupation embrace all kinds of actions. In this dissertation, “activity” and “occupation” are used interchangeably.

Other trends in research focusing on an extended understanding of the patient’s involvement, particularly in outlining the effect of rehabilitation, are under investigation (21). Various other ways of collecting data, mainly notations on participants’ transfer process from one occupation to another, could give gainful information about the occupations in place, and how and with whom the occupations are carried out (22). One other study (23) looked at the complexity of actions woven into an occupation. Findings revealed that disturbances and interruptions of different intensity interfered with performance. Evidently, the pattern of an occupation is about sequencing and performing daily activities, and is defined by Erlandsson and Eklund as: “a complex interplay of action sequences, building up main, hidden, and unexpected occupations” p.4 (22). Examples of main occupations are repetitive tasks such as “preparing dinner”, hidden occupations such as “going through the mail”, and tasks that are not known beforehand, for instance, “chasing a runaway dog”. The method for registering patterns of daily occupation has been further investigated. One other method used is the time-geographical method (24-27), which introduces the concept an occupational pattern while raising two theoretical topics: “parallel activities” and “occupational project” (24). According to these, activities are sometimes performed parallel to each other during different kinds of projects. Projects are unique to each individual and are at the same time comparable to other individual projects. Occupations do not just appear in temporal order but also in an environmental arena. Thus, mastery³ of everyday occupations and the adaptation to a changed life situation after disability have been adopted as definitions for

³ Competent occupational functioning 28. Schkade JK, Schultz S. Occupational adaptation: toward a holistic approach for contemporary practice, Part 1. The American journal of occupational therapy : official publication of the American Occupational Therapy Association. 1992;46(9):829-37.

occupational patterns, namely that patterns “are regular and predictable human occupation ways of doing, and occur when human beings organise activities and occupations” p. 4 (24). The fundamental principles encapsulate any issue or task, mirroring that person’s mind and having a meaning and purpose to the performer. The complexity of how individuals make use of their time sequencing activities is being studied from several perspectives, one of which is frequently addressed in clinical work: the aspect of balancing activities.

2.1.2 A global classification on health

At the turn of the century, the World Health Organisation (WHO) undertook an essential and fundamental task to draw up guidelines for a global discussion about health and health-related issues, obtaining five domains (29) to reach a comprehensive understanding about human beings’ health conditions. The domains included in the International Classification of Functioning, Disability, and Health, (ICF) (29) are body function, body structure, activity, participation, and contextual factors. Of these, activity and participation are of greatest interest in this dissertation.

In accordance with the declaration, the ICF definition of activity is “the execution of a task or action”, whereby two qualifiers characterize the actions of an individual. The qualifier “capacity” embraces what a person can do, while the qualifier “performance”, significant for this act of doing, involves what a person actually does. Further, an individual performing everyday activities in an environmental context could be due to the concept of participation, which is described as “involvement in a life situation”. Contextual factors embrace two components: environmental factors and personal factors. Environmental factors are further classified into two levels—individual and societal—accentuating that they are “external to the individual”. Personal factors are “the particular background of an individual’s life and living, and ... not part of a health condition or health states”. Furthermore, personal factors are not classified in ICF (29).

The concept of participation according to ICF is highly recognized, since participation or involvement in an activity shared with others is an important component of engagement in everyday life (30). The signalled interest in how people perform activities in reciprocity with their environment draws the researchers’ attention to how that bearing might affect the participants’ ability to enjoy social companionship. However, individual experience and participation as described in ICF are considered underexplored (31) as three perspectives were found to be lacking. The first perspective not classified is the subjective experience of meaning in a social-environmental context (31). The second issue is that of the importance of self-determination and autonomy for well-being. Thirdly, a one-dimensional view on environmental factors, such as facilitators or barriers for participation, was also omitted. A few studies (32, 33) brought extra knowledge to

this understanding when school-children's experience of involvement (32) was questioned, and: a self-reported dimension of experience, which revealed features such as concentration, control, involvement, and motivation appeared to be significant for participation. The research concludes that an "increased subjective experience of involvement gives better psychological health and well-being" (32).

Another team of researchers (33) highlighted one other dimension by assessing the clients' satisfaction and enjoyment in doing by administering a self-rated questionnaire. Addressing the dimension just highlighted (32), the question: "What difference does the dimension reveal or is it more likely a position of an ideological dissonance?" challenged me. The dimension addressed by Haglund and Fältman were: (1) performance (what a person does) was mentioned to encompass another perspective, namely "performance without assistance", (2) capacity (what a person can do) holds one other perspective, which is understood as "capacity with assistance", (3) and the last one displayed is a token for the clients' voice, which is considered significant in developing a deeper understanding of the individual experience of participation (33). Evidently, participation has multifaceted perspectives that need to be taken into account when surveying individual commitment and questioning the influence environmental barriers have on performance.

Hence, in light of the assumption about a missing qualifier in ICF, other features ought to be considered in an individual's experience. Expressing a broader meaning and alternate definitions of occupation is necessary in understanding meaning and purpose in the context of the individual's interests and motivations. However, in the view of the ICF, one could argue that the qualifiers of capacity and performance are items that are not specifically obtained by an individual experience of participation, and as such, aiming at expressing and describing individual experiences is not enough; intrapersonal mechanisms for guiding performance and other subtle instruments for comprehension are needed. While preserving the paradigmatic traditions of OT in addressing humans' interests, values, and roles, the ICF classification does not give a complete image of individuals' participation, and thus more comprehensive aspects will shed light on these topics. Consequently, environmental factors from a socio-cultural aspect should contribute to a discussion about perspectives on the individual's behalf and about choice of daily occupations. That needs to be further investigated.

2.1.3 Performance and everyday occupations

In drawing on the complex and multi-faceted cognitive and functional capacities needed in performing an everyday activity and with concern to human beings' minds and interests, when living with some kind of difficulty individuals have to reorganize and recreate their habits and roles. However, individuals could

experience a loss in habits and/or roles due to fragile health following severe illness or injury. The subjective components of changes in occupation due to such losses can cause lack of motivation in choosing suitable activities (8). In short, motivation is understood such that human beings hold an innate “urge to explore and master the environment” p. 573 (11). As everyone has a unique palette of characteristics, control over choices of activities as well as performance will naturally vary from case to case. That might affect an individual’s understanding, anticipation, and motivation for alterations (8) based on the assumption that “occupation is patterned by habituation” p. 68 (8), while frequent replication of habits is internalized into former roles, or new ones are created and added to the repertoire of roles (6). The following citation expresses the components of performance capacity:

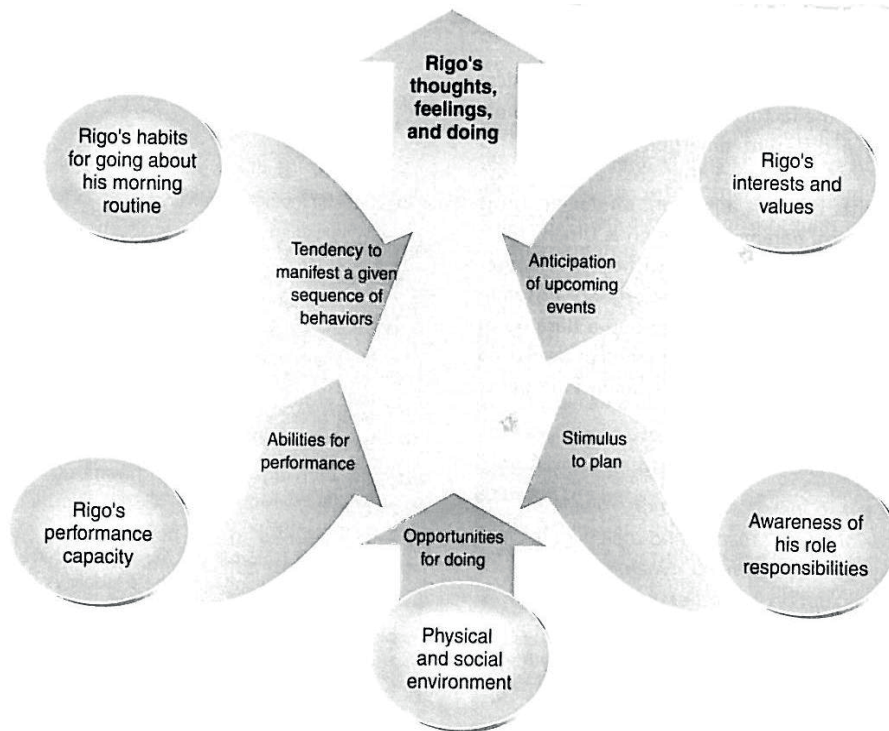
“Our performance depends on our being composed of musculoskeletal, neurological, cardiopulmonary, and other body systems. The capacity to perform also depends on cognitive abilities such as memory. When we do things, we exercise these capacities” p. 81 (34).

This theoretical assumption about the necessary bodily features could be supported by looking at Rigo’s daily morning routine. See Figure 1 to visualise an average activity of daily living (ADL).

Figure 1 conceptualizes a dialectic process between the individual, the task, and the environment. Rigo’s volition in going about his morning routine, as usual, motivates him, guided by his values and habits; he adapts his skills to his current situation. His interests and habits are valuable assets. Rigo evaluates his preferences in relation to what is required of him in a particular task. Thus, his awareness of capacity and effectiveness are important for his actions. Rigo reevaluates his interest and alertness; the completion of the activity protrudes as all elements collaborate in this special context (35). On behalf of the reader’s reflection on Rigo’s morning routine, this activity can be transformed into far more complex everyday situations, for example driving a car in busy morning traffic, or experiencing the aftermath of a severe brain injury.

The present dissertation comprises the experiences of individuals with long-standing disabilities due to brain injuries and musculoskeletal and psychological disorders. The consequences of a brain lesion include various deficits of the structural brain. While clients with neurological disorders mostly have focal cognitive deficits, those with a traumatic brain injury (TBI) usually have multifocal cognitive deficits, including executive dysfunctions such as planning and shifting from one task to another (36, 37). Adapting to the various consequences of a brain injury challenge the former identity and routines, which might cause stress to the individual and further reduce their health-related quality of life (38-40).

Figure 1. Heterarchical contributions of volition, habituation, performance capacity, and environment to an occupation. Model of Human Occupation, Theory and Application. 4th Ed, p. 25 . Kielhofner G. © 2008 Lippincott Williams & Wilkins.



In addition, changes in identity influence everyday life (41). Likewise, similar reflections of losing self-dependency were found in a descriptive study covering a wide range of diseases (42), although the reported life-changes were not always perceived as negative. Performing ordinary activities on a daily or weekly basis could be challenging even several years after the onset of brain injury. In a study of patients with stroke, an important issue was dependency on personal care, specifically with toileting during the first few months post stroke; these experiences were found to influence distress and well-being even two to five years later (43). Individuals on average three years post-stroke were less satisfied with their achievements in domestic labour (40). In a cohort study, long-time affliction of executive function among patients with traumatic brain injury as found to have consequences in both private and work life several years post-injury (44). The perception of managing everyday tasks among brain trauma patients on sick leave was more frequently expressed with negative rather than positive

feelings (45). Moreover, struggling with everyday use of technical devices influenced work ability (46). Concerning complex symptoms from a TBI (44, 47), in particular, the symptoms of both cognitive and physical deficits were found to dominate in relation to the severity of symptoms at three-months post-injury (48), and the severity of depression was found to have a noticeable effect on social participation (49).

2.1.4 Participation in the workforce

Other aspects that influence on individual basis and community are the resulting economic and social consequences, and evidently, these require further research. Being off work is a multi-faceted dilemma as in Table I, allowances are allotted pending return to work (RTW) as well as financial support to people awaiting an old age retirement pension. It is important to note that old age retirement pensions are based on three dimensions in Norway and Sweden, there might be differences in individual income, education, and work opportunities. These dimensions are pension-qualifying salary, occupational retirement provision, and individual savings. Consequently, people with low combined income will receive a low retirement pension. In case of early retirement the proportional share of disability allowance will also be low. Additionally, the sick-leave process for leaving the workforce may enforce both social and financial constraints (50). Inequalities related to socioeconomic status were explored in a Swedish study among a sick-listed population (51). No gender differences were found, and in relation to low socioeconomic status, and in addition, in manual work, workers' status as skilled or non-skilled, male or female was not significantly correlated to being on sick leave. On the contrary, young females in manual labour reported a lower socioeconomic status compared to male workmates (51). In Table I, sickness absence and disability pension allowances for people aged 18 up to the general retirement age in Norway and Sweden are 67 and 65, respectively (52, 53). Additionally, it is appropriate to mention that individuals with impairment and reduced capacity who do not meet requirements for an old age pension can benefit from the personal assistance system for important needs in daily life activities.

Many studies (in particular, those referring to specific diseases) reveal factors as well as consequences of long-lasting sickness absence that hinder or promote an individual's RTW. In particular, when recovering from a brain injury, cognitive and behavioural difficulties might influence the RTW process negatively (54), which could be the only determinant factor (55). However, the influence of severe TBI symptoms on RTW was also investigated (56). Young people who were unemployed at the time of a TBI, were poorly educated, or were blue-collar workers are less likely to find jobs after recovery. Furthermore, a severe loss of consciousness at admission to intensive care and a long hospital stay indicated low work sustainability (56). The influence that the environment might have on

Table I. A selection of benefits from social insurance services in Norway and Sweden.

	<u>Norway</u> (% compensation of work income)	<u>Sweden</u> (% compensation of work income)
Governmental allowances		
Sickness absence certification	12 months Full compensation up to 6 x G (G = basic amount NKR 88370 per year)	12 months Around 80%
Extended sickness benefit		Approximately one and a half years, around 75%
Work assessment allowance (AAP), for example <ul style="list-style-type: none"> • workplace training • education 	3 years Around 66% An extended period if necessary through arrangements leading to return to work	
Workplace training	The employer is responsible for work adjustment and rehabilitation as long as a job position exists.	The employer is responsible for work adjustment and rehabilitation as long as a job position exists.
Activity compensation		Age 18 < 30 Not able to work full time for at least one year due to work disability
Disability pension	Age 18 < 67 Minimum 1/2 lasting work disability	Age 30 < 65 1/1, 3/4, 1/2, 1/4 lasting work disability
Benefit for care of closely related persons	At terminal care of a family member either at hospital or at home a close relative is entitled to compensation for 60 weekdays	Having a work position the employee is entitled to leave from work, and the relative is entitled to 80% compensation for 100 days
Handicap/disability allowance	Age > 16 Functional impairment or illness lasting more than one year, and in need of help in day to day life NKR 13 836, per year, or have additional expenses NKR 7716, per year	Age 19 – 65; Functional impairment or illness lasting more than one year, and in need of help in day to day life, or have additional expenses; approximately SEK 12654, per year

the absentees' belief in the re-entry to work process or sustained employment is in the spotlight. Individuals with musculoskeletal disorders described that demands at work could negatively interfere with their quality of health. However, individuals' work planning options and environmental adjustments could contribute to their overall well-being (57). In addition, a population survey of 15- to 75-year-old blue- and white-collar workers found no gender differences regarding perceived health as related to sense of coherence (58). However, having a work position is significant for a positive sense of self-confidence (42). Young male jobseekers on long-term sick leave who were diagnosed with psychological and musculoskeletal disorders were found to be more likely to be employed compared to females (59).

The national treasury's extraordinary expenditures for disability pension (d.p.) raised questions about work ability pending people back to the workforce. Among individuals on "resting disability pension", the assumption is that there are people with residual work ability who, due to several years of recreation have increased their capacity (60). However, one other study found that the judgement of a d.p. is based on other criteria, such as age or unemployment instead of medical conditions (61). Being middle aged could indeed have an effect on individuals' prospects for a RTW passage.

Apparently, individuals' experiences are multifaceted, as are their thoughts about what factors most influence their work ability (62). Similar findings were put forward, such as subjective rating of work ability described by individuals suffering from chronic diseases, and low belief in a possible RTW (63). People's re-entry to work after sick leave is more likely related to their social network and social capital than criteria based on education and experience.

In a Danish cohort study (64) was established to look for factors that positively influence work sustainability among individuals with stroke and a significant correlation between the size of the company and the likelihood for RTW was found. Evidently, positive associations between former extensive work experiences and RTW were revealed in a Norwegian study among individuals with musculoskeletal or psychological disorders; consequently, low work experience indicated a low RTW (65). In any case, contributions from work opportunities embodied a diversity of factors. From the individual's point of view, being on sick leave involves feelings of discomfort and inconvenience (66), and of losing control due to being cut off from the work market (42). That is not always the case, however; women were slightly more likely to experience the sick leave period as a time for recuperating (67).

As inconveniences are concerned, one out of five participants of a study population expressed negative experiences from encounters with officials. Of these, one-third said these encounters could negatively influence their RTW

processes (66). Positive encounters with actors were one of several facilitators in a long-term, involved process. Furthermore, feelings of being respected by social insurance office staff could increase the individual's belief in his or her own work ability (66, 68). In addition, the absentees would welcome continuity and balanced rehabilitation plans (68), because they nourished feelings of frustration and anxiety about what the future would bring, especially during long periods without any contact with officials or health care institutions (69). Most certainly, positive encounters with healthcare providers who listen to and respect the individual have a positive effect (68, 69). To assist in the process of returning to work, telephonic interviews revealed that individual tailored rehabilitation plans could improve the participant's balance activities and work demands (68). Individual self-rated work ability (70) and thoughts and feelings about future occupational life (62) are essential ingredients in the course of a RTW process.

Getting back to "normal" is, for the average person, a difficult life-long process. As a whole, that is a burdensome task on the family system, but especially for parents and spouses (7, 71-73). Women, in accordance with traditions and social roles, have often taken on the responsibility for domestic labour for the sake of their families' well-being (74, 75). The burden of being an informal caregiver is often a great stressor (74, 76, 77); caregivers often take on responsibilities they are not prepared, which can cause depressive symptoms (71, 78, 79). Another area of concern is the informal caregivers' feelings of being bound by their obligations and faithfulness, in particular resulting in a shortage of time for their own activities (80, 81). This negatively affects their integrity and independence (82). Studies have shown that a low level of well-being among informal caregivers depends both on their state of health before their family member was taken ill, and on how well they are able to adjust to the new situation (79). A caregiver's negative experience of workload could no doubt increase his or her level of the perceived burden (73). However, individuals' intra-personal mechanisms can guide their understanding of life events (5, 28, 83).

Patients who have had a stroke or TBI often suffer from eating difficulties. Approximately 50% of patients who have had a stroke experience difficulty in eating and transporting food to their mouths, moulding the food, and swallowing (84-86). In populations with an increasing proportion of elderly people, illness dramatically affects individuals' lives. In hospitals, medical professionals see that patients are well provided for. When discharged from the hospital, however, patients are most often cared for by their elderly partners, which can cause dysfunction in the home (87). A number of the informal caregivers' problems have been drawn to researchers' attention. Thus, the needs for information and support have been identified and a few studies have been performed. However, over time, interest for how informal caregivers arrange and sequence their everyday activities is sparse. Numerous studies have been performed revealing the everyday life among people in an old age retirement process and a few years

after. The process is described as a multi-factorial process due to the individual meaning ingrained in the occupations, and it is therefore difficult to give an overarching view (88). However, research on current life situations after the disability retirement process is sparse. Disability pensioners' daily life activities and thoughts about future working life have not yet been explored. Studies reveal that in Scandinavia, nearly 50% of individuals who suffered a TBI return to work (39, 89, 90). Thus, we focused our concerns on regarding former inpatients returning to work, specifically those persons discharged from rehabilitation units at Sunnaas Rehabilitation Hospital.

My position in studying the objectives in question is supported by an energetic approach that requires creativity and a reflective and responsive attitude. Theoretical foundations intertwined with clinical experience pave the way for observing individuals' experiences of their everyday lives, whether they were taken ill by disease or injury or were relatives caring for their family members' well-being and rehabilitation. Although any analysis encapsulated in the researcher's pre-understanding, is included, qualitative methods invite a scientific understanding. On that note, in this dissertation, my understanding derives from the codes of ethics through which the participants are autonomous, responsible for actions taken and with the potentials to increase their performance and participation.

Addressing the difficulties experienced by individuals with acquired disabilities, theoretical frameworks will focus on the control of daily life occupations. Changes in parameters, such as conceptualizing occupation and balancing activities, can be seen in the changes in occupational patterns that take place after disability, and parameters related to participation and well-being will be reconsidered. In that vein, the following paragraphs provide some of the theory behind the assorted concepts above. In addition, underlining the objectives, the topic will be considered from the individuals' perspectives that control their everyday activities. Throughout the dissertation, reference literature and articles were searched using databases such as the Amed and allied OVID databases, and Pubmed. The databases were systematically searched using free-text keywords. Google Scholar and various reference lists were also searched.

2.2 Conceptual framework

To understand the experiences of mastering everyday occupations after disability, a tentative reflection is needed. A broadly scoped literature review on the perspectives of occupation will serve as a base for further communication about individuals' engagement in occupations. To that end, the theories of occupational adaptation, balancing activities, and sense of coherence are presented.

2.2.1 Occupational Adaptation

Through a lifetime people adjust to their present circumstances differently. Schkade and Schultz provide the rehabilitation process with the Occupational Adaptation theory, obtaining the important consideration that former learned functional skill is assimilated to current ability after disability (28, 83). The basic ideology of the theory is to guide the individual's way forward after disability in controlling his/her everyday occupations (4, 28, 83). The transference of an individual's desires and demands encourage them to deal with their capacity. However, two basic assumptions should be mentioned. First, occupational adaptation is a usual procedure, not necessarily related to disability, that helps the patient to become more adaptive before beginning training that is directed specifically to the patient's adaptive process. Secondly, the patient's desires and goal-setting guide the training and later on in the process the patient's response to an intervention can be evaluated in relation to that person's desired goal.

An occupational perspective on adaptation might help an individual visualize the way forward, recapturing the ability to understand performance in a life situation (9). Occupational adaptation is the construction of a positive occupational identity⁴ achieving occupational competence over time in one's environment. Occupational adaptation is the consequence of one's culture and a lived life experience of participation. Over time, persons construct their occupational identity and competence through on-going participation in domestic and working life. The degree of success in occupational adaptation is reflected in the identities everyone constructs, and the extent of competency in enacting activities varies over time. Individuals change and develop habits and roles through their occupations (8), while previous preferences for activities are of great importance after illness (92, 93). Goal-setting can be a helpful guide in establishing new activities and roles (92, 93). In an observational study, participants' positive score of self-esteem in relation to skill mastery was considered an effect of self-evaluation. The participants' own goal-setting and assessment of the outcome motivated them (94). However, most people will at one time or another experience some hindrance in occupational adaptation, requiring the rebuilding of occupational identity and competence (8), a matter that is highly important for individuals after disability.

This basic foundation suggests that people create their own habits and roles, and that the components of their needs and desires are a driving force. That is most apparent in ordinary life, and also after being sick or indisposed due to disability. In this respect, the individual's own progress proposes decisive action in taking

⁴ A mirror image of the individual's occupations 91. Rudman DL, Dennhardt S. Shaping knowledge regarding occupation: Examining the cultural underpinnings of the evolving concept of occupational identity. *Aust Occup Ther J.* 2008;55(3):153-62.

control over daily life activities. The meaning and purposefulness that the individual experiences through adaptation can be understood from the person's occupational identity. Hence, meaning and identity play a significant role in the adaptation process (95).

A reasonable number of studies from several disciplines have employed the theory of occupational adaptation to clarify individuals' adaption process after severe illness. Among others, studies on elderly people with chronic pain (96), adolescents with knee or upper limb amputation (94), further RTW processes after TBI (97), and living with post-traumatic stress disorders (98) or carers' perspective on occupational adaptation (99) have been conducted. Klinger (100) explicated the rehabilitation process of clients who had a TBI addressing the understanding of their new identities as a prerequisite for successful occupational adaptation. Likewise, one other study (101) focusing on individuals who had a TBI and their alterations in everyday occupations as well as their adaptation to current life showed that one effect of a severe illness might be a struggle to maintain a previous identity or create a "new" one. Further, activities the person used to do, now performed in familiar settings, are suitable training objectives for overcoming shortcomings. My understanding is that researches employing the occupational adaption process related to the musculoskeletal system (op cit) do mainly cover individuals' former skills as they are adapted to current physical training program and goal-setting. Although, studies related to brain injuries show the participants' acceptance to changed occupational identities (op cit), while improved self-esteem and satisfaction are mentioned. Therefore, it would be purposeful to study the occupational adaptation process in sample populations with a wide range of disabilities.

2.2.2 Balancing activities

One topic of interest in this dissertation is individuals' mastery of changes in occupational patterns. Supported by human beings' innate urge to explore and master the environment, the significance of the ability to balance activities in relation to capacity and energy ought to be considered. The meaning of "activity balance", however, is in some settings comparable to occupational balance or even "work-life balance", and can be understood from different perspectives (102-104). From the early days of OT history, the importance of activity/occupation to be purposeful and meaningful (92, 105) was proposed, and this laid the foundations for OT to view humans as competent, capable, self-directed persons (106). These special implications have been the core of the discipline through the decades since then (30, 107). Furthermore, meaningful occupations enhance the possibility of balancing activities with manageability and control (108), while other aspects focus on the distribution and number of activities and how energy consuming each one is (30). Balancing activities—regarding the individuals' control over the distribution of daily occupations—have

been shown special interest (109, 110). However, the value and commitment experienced by individuals in their daily and work activities are not easily observed (30). Through an exposé of various perspectives, Westhorp (111) summarizes elements in occupational performance that could influence the notion of balance. For instance, Westhorp notes that the amount of time and energy and the desired outcomes of activities change from one day to another, as does the sensation of flow, and acknowledging this fluctuation can further the individual's understanding of workload and ability to modify, reflect on, and control his/her actions. The changeability of activity preferences and roles, time use, and energy over a lifecycle promotes researchers to delve into the matter of balance, exploring the fluctuation of three dimensions—Exacting, Flowing, and Calming—displayed in an experiential model of occupational balance (112). In their experiential model, Jonsson and Persson (112) assume that people's sensible use of time changes throughout their lives. The researchers give three domains to explore: "exacting" and "flowing" refer to high challenging experiences, and "calming" is a low challenge experience necessary for rest and restitution p.69 (112). Accordingly, the distribution of interest, roles, time, energy, lifecycle, and more is mainly individualized. Thus, in order to make persons' manageability and control over their pattern of occupations comprehensible, other methods for investigation, presumably everyday narratives about commitment and the meaning of performance, ought to be considered.

There is no consensus on the definition of balance. However, Erlandsson and Håkansson (113) assert that an individual aspect is incorporated into the concept. Different people experience a specific workload differently. They point out the assumption "that balance or imbalance is related to what you are doing and how you experience your occupations rather than the proportion of time spent doing certain things" p. 116 (113). Likewise, in exploring individual experiences of occupations, Jonsson (114) clears the way for a new direction: not solely a distinctive way of thinking about occupation in the traditional way, sequencing occupations by subject, but also connecting the categories of occupation with well-being. Jonsson invites us to unveil categories in order to discuss "occupational patterns distinguished in the data that might promote or restrict well-being" p. 7 (114). In this assumption, a person's experience of balance or imbalance should carry a context of self-reported well-being and belief in one's own skills, and concern for revealing individuals' experiences regarding changes in occupational patterns.

In people's evaluation of occupations, the model of lifestyle balance (103) in five dimensions in relation to well-being was of particular interest. The five dimensions incorporate factors through which occupation organizes time and energy, resulting in an improved personal identity with feelings of being engaged, challenged, and competent. However, different understandings of balancing activities are circulating. In the course of daily activities, some are desirable (tasks

one wants to do) but others are not (tasks one needs or has to do) (115); an ordering of priorities is needed to balance one's abilities and one's time consumption (116, 117). Thus, the importance of individual experience of meaningful occupations should be considered when discussing the understanding of balancing activities. In a recently published article that adopted the model of lifestyle balance for analysis, intrapersonal thinking and communication when performing a self-directed occupation can form the conception of a meaningful activity (118). The significance exposed by the distribution of activities in the balance model was extensively studied by an international team of researchers (119). An additional adjunctive dimension was revealed, namely the negative effect that financial strain has on well-being. Thus, the above dimensions of sufficient challenge, meaningful activities, time use, and financial security are found to be important for an ordinary life balance (103, 119). Task challenge and task familiarity, as well as various task alternatives, inspire individual control. In any case, the question about balancing activities is somewhat problematic in that individuals value tasks differently (120).

2.2.3 Perspectives on a health-disease continuum

In general, the rehabilitation process is based on a biological-medical understanding of health. Through the last decades of the 20st century, there was a call for an extended model of disease, combining psychological and sociological aspects into a so-called biopsychosocial model (121). In disciplines, such as OT that consider additional perspectives from the individuals' view, complementary aspects are required. Moreover, the relationship between occupational performance and health is complex (122). Study results (109) cautiously imply that perceived well-being is related to patterns of daily occupations. Nevertheless, occupation and health are stressed as dually important (104, 123). Creativity and engagement in activities plays an important role. Thus, the individual's inner drive and skills are reflected in his/her action and performance, through which *being* is the next step in the *doing-being-becoming*⁵ triad (93). Domains embodied by the ICF classification, performance and participation, could broaden the knowledge of both social and cultural features and add worthwhile components to the biomedical model of disease. Thus, it is necessary to have a holistic approach embodying bio-psycho-social features, the definition of which is that individuals are understood as independent and responsible beings with a will to act, while their mind and body interact with the environment (9).

Understanding the relationship between occupation and health leads further to a discussion about perceived health. Successful medical methods have raised the

⁵ Actions, the actual sequence of doing, give meaning to the individual in the sense of "being". The influence "being" has on people's health and well-being is stressed. "Being" is understood as "becoming" in the light of an environmental context 93. Wilcock AA. Reflections on doing, being and becoming*. Ibid. 1999;46(1):1-11.

question and consequently encouraged discussions on the individuals' aspects of wellbeing. The health-disease continuum (124), recently extensively discussed by Nordby, Rønning and Tellnes (125), includes personal factors as well as the individuals' own beliefs and perceptions. Nordenfelt (124) set the stage for developing a theory on subjective health in relation to illness expressed by the affected individual or a significant family member. Goal-directed desires are important for that person's ability, and likewise for their perceived positive health. On the other side of the health – disease continuum, disability is strongly related to hindrances, not least from the environment. According to Nordenfelt, an individual who perceives balance or "equilibrium" is levelling ability and disability (124).

Absence of disease or sickness does not give a complete picture of total health (126, 127). However, a healthy life is comprehensible only through interpreting the individual's perceived health. Personal perceptions of contentment and happiness are the effects of handling life situations. Within the concept of Nature-Culture-Health Interplay, (NaCuHel), the importance of individuals' choices of activities influences perceptions of good health. Likewise, the concept indulges individuals' creativity in developing other personal features, which could facilitate communal growth through participation in activity groups (128). A sense of belonging is stressed as a marker for increased self-esteem and competence (129, 130). Thus, the hallmark of the NaCuHel concept combines environment and culture, which must be considered fruitful for a sense of well-being. The ability to transfer newly learned skills to other fields gives individuals a feeling of subjective good health (129, 131).

2.2.4 The concept of Sense of Coherence

One other theory connecting people's understanding of performance and health is the Sense of Coherence (SOC) (127). A counterweight to the medical dimension of disease and pathogenesis is the salutogenic—a positive view of understanding health—way of thinking about and controlling adaptation over one's own recovery process after traumatic events or disorders. The salutogenic model was outlined by Antonovsky (127). The fundamental ideology of the salutogenic theory accentuates the importance that someone's life experience has in a current situation. The influence social context has on the persons' thinking about and handling of situations should also be acknowledged. Thus, salutogenesis is a theory of individual thinking about subjective health in a positive sense (132). The theory comprises three central components: comprehensibility, manageability, and meaningfulness. For instance, determinants such as ego identity, coping strategy, commitment, and preventive health orientation are considered important for an individual's understanding and progress in managing his or her life as a whole (132). Thus, comprehensibility comprises the ability to perceive and understand internal as well as external stimuli. Manageability is, to a large extent,

about the individual's motivation reflected in their ability to control and structure the adaptation process (127). A key feature, meaningfulness, is the individual's positive approach when handling internal as well as external elements of disturbance. In this way, participation and independent agency are stimulators in coping strategies (132, 133). Various studies have been performed and a few illuminating examples are addressed here. Individuals with a low SOC tend to be more vulnerable. In a Swedish population study, a high SOC was associated with good self-rated health, while a low SOC was associated with poor self-rated health, symptoms of tension, and treatment for depression or chronic disease. White-collar workers, entrepreneurs, and young adults underline that social factors and living conditions tend to have a beneficial impact on their high level of SOC (58). However, in order to reveal a possible linear process between level of SOC and health, patients with rheumatic arthritis answered questions about their strategies in controlling their everyday life. The final results reveal that in individuals' ability to perform ADL activities, low education and poor health status correlated with a low level of SOC (134). A sample of individuals with chronic musculoskeletal pain participated in another study, where a correlation between perceived good health and high SOC was found (135). Informal caregivers' level of burden is also related to the SOC level. A high level of SOC was protective against worrisome feelings (136). Yet, in a Finnish study, meaningful activities constituted approximately one-third of the variation on depression (137). Of notice, no gender differences were found in a Swedish survey about circulatory deficits and psychological distress related to SOC (58).

2.3 The rationale of significance underpinning the overall aim

In summarizing the background, questions related to activity and participation are raised. Establishing new activities and roles after a disability involves a period of adaptation. Considering the findings about the diversity of factors related to balancing activities and the observations about the missing qualifier of individual experience in relation to ICF, this dissertation was born with the objective to explore participants' experiences regarding controlling and balancing activities. Thus, personal factors, such as well-being, belief in one's own skills, and environmental impulses, are important for participation in a life situation. Furthermore, research on difficulties with eating, in particular when speaking of relatives' experiences of assisted feeding, is sparse. Research conducted with concern for disability pensioners' everyday lives after being awarded a d.p. and their views on returning to work has not been explored previously. Likewise, the individual endeavour to come to terms with a changed life situation, as well as work after a TBI, is not frequently investigated.

Finally, a structured understanding of the objectives under consideration is required in research findings. Thus, calling upon individual experiences requires methods that are sensitive to people's life stories. In light of these objectives,

gathering data through communication is appropriate for qualitative analysis through structured sequencing and abstraction of the text (138).

3 RESEARCH OBJECTIVE

The overall aim of this dissertation is to explore individuals' experiences regarding everyday occupations and adaptation to a changed life situation after disability. The perspective is portrayed from several angles by looking into everyday occupations at home as well as at work after disability. The specific aims of the three studies are:

- | | |
|-----------|--|
| Paper I | To describe relatives' experiences of family members' eating and swallowing disorders in their everyday life |
| Paper II | To explore and describe everyday life experiences among people with a disability pension and their expectations of future occupational life |
| Paper III | To explore individual experiences in developing a mastery of daily activities and roles after a traumatic brain injury with the objective of returning to work |

Thus, individuals suffering from illness or injury as well as relatives' experiences of everyday life and roles after disability came into the searchlight. In order to describe and explore individual experiences to gain a deeper understanding of facilitators and hindrances in performing activities of daily living, the support of conceptual frameworks is required. In order to define the overall mastery of activities, instead of only performance activities and time use, parameters beyond observational ones ought to be considered. Listening to people's narratives about their living conditions and current life situations requires one-on-one communication. To grasp the inner meaning of someone's narrative requires careful methods for categorizing data.

4 MATERIALS AND METHODS

For this dissertation, three independent studies were performed. The first and second studies, reproduced in Papers I and II, were conducted in central Sweden, while the third study, presented in Paper III, was conducted at Sunnaas Rehabilitation Hospital in Norway. All data collected in the first study were considered confidential, as required by the Personal Data Act (1998:204) issued by the Swedish Data Inspection Board. The second study was approved by the Regional Board of Ethics, Uppsala University, dnr. 2005:167. Similarly, the third study was approved by the Regional Ethical Committee for Medical Research and the Data Inspectorate in Norway, nr. 2011/925b. However, considering the research questions in this dissertation aim to explore individuals' experiences regarding the occupations of everyday life and the adaptation to a changed life situation after disability, three qualitative methods were found to be useful in providing a structured method of analysing the data for further interpretation. Therefore, data were sampled from individual interviews and analysed qualitatively. See Table II for an overview of materials and methods.

4.1 Study context

4.1.1 Study 1

In a population with an increasing proportion of elderly people, illness dramatically affects the lives of more and more individuals. In the hospitals, medical professionals see that patients are well provided for. In general, in the residents' own homes, the welfare system provides home health care (139). Among upper middle age and old age couples, it is often the case that individuals are cared for by their elderly partners. It is nearly inevitable that one family member's serious disease will affect the whole family, including couples' mutual everyday activities (7, 72, 73, 87).

4.1.2 Study 2

In Sweden, the number of working-age people entitled to a d.p. increased dramatically at the turn of the century. The pending early retirees that went temporarily back to work so as to have their work ability assessed were promised that they would not lose their compensation entitlement (52). Workforce and healthcare authorities were concerned about how many people on a d.p. could possibly return to work. Assessments of clients' medical or physical status are often missing from the data files at the Social Insurance Offices (50), so such information could hardly contribute to the question of work ability. The region under consideration in the present study had, at that time, a considerable proportion of inhabitants registered with a d.p.

Table II. An overview of materials and methods

Paper	Aim of the study	Study/ Context	Data sampling	Participants	Data analysis
I	To describe relatives' experiences of family members' eating and swallowing disorders in their everyday life	1 Sweden	A strategic sample	Nine participants: seven female spouses, and one male and one female parent of grown children	A constant comparative analysis
II	To explore and describe everyday life experiences among people with a disability pension and their expectations of future occupational life	2 Sweden	A purposeful sample	Fourteen men and women; ten participants on a full-time d.p. and four participants on a partial d.p. while working part time	A latent content analysis
III	To explore individual experiences in developing a mastery of daily activities and roles after a TBI with the objective of returning to work	3 Norway	A purposeful sample	Eight men	The grounded theory method

4.1.3 Study 3

In Norway, the Ministry of Labour and Social Affairs (NOU 2000:27) proposes that all individuals, including persons with impairments, immigrants, and persons with other special needs, should have access to a working life (140). Known nationally as the IA Agreement, NOU 2000:27 emphasizes the following key points as especially important for individuals' re-entry to the workforce: the individual's work-rehabilitation plan ought to be followed up on, the employer's responsibility must be stressed, early interventions must be proposed, and the employee's residual work ability should be taken into account.

4.2 Participants

All participants considered men and women in the midst of their lives to be hardworking, responsible people. The participants in Study 1 had leading positions as caregivers, and two had even changed their working careers to become personal assistants to their husbands; however, four participants with a previous prosperous working life were, at the time of their partners' diagnosis, old age pensioners with aspirations for an active life with their families. Unfortunately, their family member was taken ill with severe long lasting symptoms from a stroke, TBI, or neurological diseases. Over several years, the family members' difficulties had increased and thereby the participants' hope for de-escalation of their workload would not be reality. In Study 2, the participants discussed their years-long struggle to remain in the workforce. Meanwhile, the difficulties from musculoskeletal disorders, psychological illnesses, a stroke, or brain injuries had escalated and reduced their work ability. The participants had poor education—they had at the most passed 9th grade—and in their early teens they joined the workforce in manual work. The situation was quite different for the participants in Study 3; they had not fully recovered from their TBI and still hoped for full recovery. The participants were academically skilled, holding positions in administration and economy, although a few had industrial occupations. In any case, modern industrial work requires high education, especially in data processing. Additionally, it should be mentioned that the population in this dissertation each participant has contributed with his-/her special experience separately. See Table III, for information about demographic data.

Table III. Demographic information about the participants

Full or part time d.p. or old-age retirement	n=19	Unknown	Musculoskeletal disorders			Psychological/ neuropsychological disorders, Study 2			TBI Study 3				
		Study 1	Study 2										
		1/1	1/1	1/2	1/1	1/2	1/1	1/2	1/1	1/2			
		M F	M F	M F	M F	M F	M F	M F	M				
		0	4	2	3	0	3	2	3	1	0	1	0
Full/part /temporary time; work position	n=16	Unknown	Musculoskeletal disorders			Psychological/ neuropsychological disorders, Study 2			TBI Study 3				
		Study 1	Study 2										
		M F	M F	M F	M F	M F	M F	M F	M F				
		1	4	0	3	1	0	7	0				
White collar worker		Study 1	Study 2			Study 3							
		M F	M F	M F	M F	M F	M F	M F	M F				
		unknown	unknown	2	2	5							
Blue collar worker		Study 1	Study 2			Study 3							
		M F	M F	M F	M F	M F	M F	M F	M F				
		unknown	unknown	3	7	3							
Single		Study 1	Study 2			Study 3							
		Not cohabitating with the disabled											
		M F	M F	M F	M F	M F	M F	M F	M F				
		1	2	2	2	5							
Family		Study 1	Study 2			Study 3							
		Cohabitating with the disabled											
		M F	M F	M F	M F	M F	M F	M F	M F				
		0	6	3	7	3							
Age at time of interview		Study 1	Study 2			Study 3							
		≤45	46-60	61<	≤45	46-60	61<	≤45	46-60	61<			
		0	3	6	0	14	0	3	5	0			
Time of experience of injury/ difficulty	yrs	Study 1	Study 2			Study 3							
		Years since disorder											
		Years with a d.p.											
		Years since injury (first interview)											
		<3	3-15		<3	3-15		<1	1-1½	1½<			
	n	1	8		1	13		1	5	2			
Total	31	14/17	Unknown	Musculoskeletal disorders			Psychological/ neuropsychological disorders, Study 2			TBI Study 3			
			Study 1	Study 2									
			M F	M F	M F	M F	M F	M F	M F	M F			
			1	8	2	6	3	3	8				

4.3 Recruiting procedures

4.3.1 Study 1

A strategic sample of relatives could not be drafted from the medical records, despite assistance from the social service offices. As a result, a snowball sampling was employed, a procedure recommended in cases that necessitate rich information from key subjects (141), in which the subjects introduce the study to one another by word of mouth. Accordingly, a research colleague of mine informed the first participant about the study. The second participant was then introduced by a team-leader at the local municipal service. The speech pathologist of the second participant's husband subsequently asked the next participants with the hospital's verbal and written consent and so on. In all, nine individuals—seven female spouses and one male and one female parent of grown children—participated.

4.3.2 Study 2

In 2005, when the project "Sjukersättning: väg med skäl" ["Disability pension: a multidimensional issue"] was launched in Gävleborg county, a northern region of Sweden, approximately 13000 subjects received full-time or partial d.p. benefits. Among these, 8700 subjects were 30- to 60- years of age and matched the inclusion criteria. The criteria was as follows: people with mental retardation were excluded due to their special needs, including modified workplaces, as considered by Swedish law and regulations; likewise, people that were prison sentenced or forensic judged were excluded. A team of researchers from the regional health care services in collaboration with the Regional Insurance Office was established to recruit participants. A random sample of sixty subjects with an equal distribution of gender and age on a full- or part-time d.p. was drafted. The draftees were informed about the study and asked to participate in writing, and with a telephone reminder, 14 individuals (five men and nine women: ten participants on a full-time d.p. and four on a partial d.p while working part-time) agreed with written consent to participate. Accordingly, the medical difficulties expressed by the participants represented two out of three categories in line with norms used by The Swedish Social Insurance Agency, namely musculoskeletal and psychological/neuropsychological disorders. See Table III.

4.3.3 Study 3

The third study was the only one in which participants were drafted from medical records. So as not to interfere with the interviewing or analysing process, the second author, a neurologist, performed the recruiting procedure, which was conducted twice, as a result of the consideration of inclusion and exclusion criteria. Nine men decided to participate and were invited to a first interview.

During this interview, however, it became clear that one participant did not meet the inclusion criteria. Another participant on a d.p. participated in only the first interview. In total, eleven (9+3) male and four (2+2) female 30- to 60-year-olds were asked to participate, and were informed verbally and in writing about the study. If, in any case, the letter of participation were not returned within a fortnight one telephone reminder was made.

4.4 Qualitative methods chosen for data analysis

The overall aim of this dissertation is to explore individuals' experiences regarding everyday occupations and adaptation to a changed life situation after disability. It is generally held that a qualitative method is typically employed in order to broaden or even deepen knowledge about areas not frequently studied with the purpose of adding something not easily quantified (142). One other, highly significant aspect of adopting qualitative methods is related to these methods' ability to provide understanding and reveal the inner meaning of data (143). With this assumption, Jackson, Drummond and Camara (144) discuss Stakes' suggestions for qualitative study designs and data analysis methods, noting that such methods are mainly used when the objective is to understand rather than explore, highlighting the researcher's use of self instead of impersonalization of self, and expressing that knowledge is discovered rather than constructed, p. 37 (145). In order to grasp comprehensive image of the research questions, several procedures for data sampling could be used. Data from texts, narratives, and photos are suitable whenever the illustration of meaning is the focus. Such an approach requires an engaged and structured professional approach utilizing qualitative methods, p. 130-2 (146). This sort of approach, in which researchers bridle their own pre-understandings and allow findings to crystallize, strengthens the trustworthiness of the findings (146), though some skills in research and a therapeutic relationship will go far in gaining a scientific reasoning (138). The body of knowledge encompasses a "conscious use of self", p. 11 (147) as one of the professional tools advocating a therapeutic relationship. A qualitative research approach will invite rapport and encourage sharing from experience. As the research questions in this dissertation aim to explore individuals' experiences regarding the occupations of everyday life and the adaptation to a changed life situation after disability, with the goal of developing knowledge about individuals in a specific life situation, three qualitative methods were found to be useful in providing a structured way for analysing the data from individual interviews for further interpretation.

A different qualitative method was employed for each paper. Paper I makes use of the constant comparative method described by Bogdan and Biklen (148), Paper II carried out the latent content analysis represented by Graneheim and Lundman (149), and Paper III employs the grounded theory, GT method (146, 150). All three methods sequenced transcribed text in similar ways. The most basic and

significant element in qualitative analysis is the stepwise process of narrowing a text into meaning units, which are subsequently sequenced into segments called codes or categories. These categories, themes and even sub-themes are then eventually labelled. See Figure 2, Qualitative analysis guide of transcribed individual interviews. A comprehensive understanding of the methods used may be gained by way of a full review of these methods' principles in each of the three individual studies. There are, however, a few additional characteristic elements that distinguish these methods.

4.4.1 A constant comparative analysis

In the first study, the constant comparative analysis (148) originally formulated by Glaser and Strauss (150) was chosen in order to shed light on the complex meaning of the participants' experiences. The scope of meaning, according to this method, is as follows:

“meaning is not something that can be found in the open; it is expressed indirectly through actions, words, or other kinds of human productions and, as a consequence, the meaning of human occupation needs to be interpreted to enhance our understanding”, p. 525 (151).

The process of analysis used in Paper I was inspired by the researches of Tham and Borell (152) and supplemented by other studies (77, 153, 154). The data were compared both for each interview and between the interviews, as described below. The constant comparative method permitted the analysis of a number of various perspectives and covered both similar and divergent elements. According to Nayar, “The constant comparative analysis is a hallmark” (155) process of qualitative analysis. Paper I used the constant comparative analysis described by Bogdan and Biklen (148) as a template for the generation of themes and subthemes. This approach involves the comparison of similarities and differences over a spectrum of aspects. In the constant comparative method (150), significantly, the gathering of data and the analysing of that data represent a parallel process. In the first study, however, all interviews were conducted and transcribed before the actual analysis began. Thus, an expanded description of how the method was carried out would be appropriate. The second interview in Paper I, the one directly after the test interview, was chosen as the starting point as a result of its voluminous and informative content. In the initial stage, each paragraph or paragraph segment that contained separate information was categorized and assigned a three-digit code. A chart of categories was manually

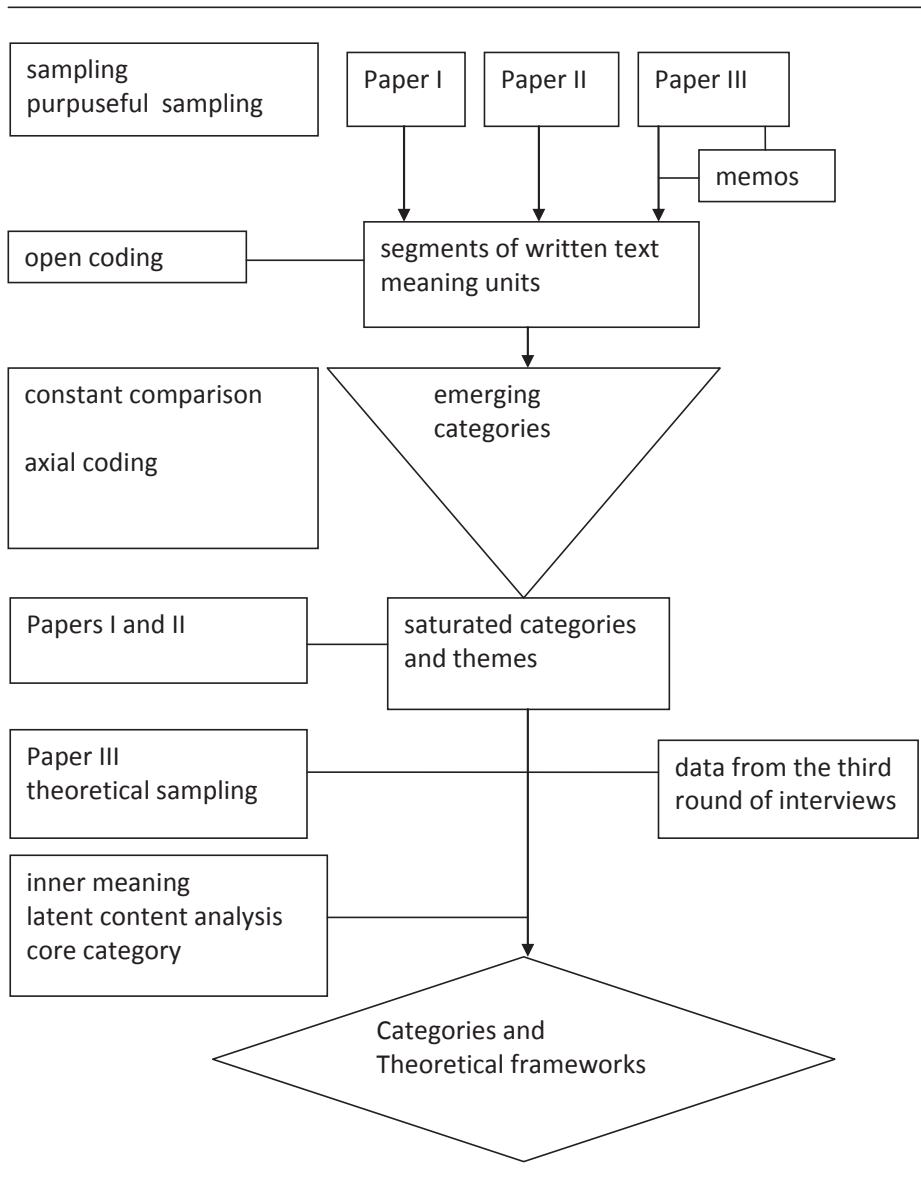


Figure 2. Qualitative analysis guide of transcribed individual interviews

drawn on a sheet of stationery. Any new information that was not previously mentioned underwent the same procedure.

4.4.2 A latent content analysis

The second study aimed to explore and describe participants' everyday occupations and thoughts regarding the future of persons living with disabilities. To this end, the study used a content analysis method (149) that offered a structured way of sequencing written text. In addition, in Paper II, a tableau of possible categories proved helpful when writing temporary reports. The tableau was useful in organizing and sequencing categories in pursuit of a pattern of leading themes. The data were analysed and key elements within the objective employed three overarching domains: work ability, rehabilitation, and future occupational life (see Table IV).

Table IV. Key elements within the project "Disability pension: a multidimensional issue"

Work ability	Rehabilitation	Future occupational life
Tasks should be "in time" to meet any individual's strengths and weaknesses	A desire to alter one's situation for prospective outcomes	Feelings of a here-and-now aspect
There is a cost of energy loss when attending work-related or leisure time activities	Self-awareness and responsibility for own rehabilitation	A desire to return to work but not having the strength required
Being busy with activities gives daily and weekly routines		Attitudes of homebound feelings
Leaving a work position too early is a burden of sorrow		A desire to increase working hours

The second study served a second purpose in addition to the objective of Paper II: to uncover useful complementary information of interest in designing a survey, which subsequently was sent to a larger portion of inhabitants on disability allowances. Therefore, in order to meet the criteria to describe a variety of perspectives, Paper II adopted a content analysis in order to work out an overall perspective of the objective and examined the findings by means of in-depth comprehension (149). However, because the purpose was not solely to describe

the participants' experiences, the analysis was transferred to a latent level, and thereby the content was given a richer meaning.

4.4.3 The grounded theory method

In the third study, the grounded theory (GT) method, originally formulated by Glaser and Strauss (150), was employed. In order to enlighten a change over time in mastering daily life activities, three individual interviews were conducted over a six-month period. However, one note must be addressed regarding the constant comparison procedure: the same procedure used in Paper I was adopted for conducting the initial stages of analysis and codes were sequenced into clusters of categories. However, in Paper III the consideration clause *an ongoing struggle through day and night* was found useful to define what the data was about and was considered fruitful for the analysis process. Through the constant comparison of similarities and differences and the use of GT (150), the interviews revealed consistent themes.

Furthermore, in Paper III, one of the most complex interviews was chosen as a starting point for the mind-mapping procedure. The complexities derived from the many different codes, and the going back-and-forth through the codes to cluster them into groups of a conjunctive nature proved an exceedingly difficult challenge. A chart of codes was created and a word processing program was employed, but with the utmost delinquency. The codes were eventually called into question, and at this point similarities and differences were sought, clustered and labelled into categories.

A few more elements need be mentioned with respect to GT. Firstly, this method necessitates the writing of memos that serve as protocols for the thorough grounding of data in order to obtain an overview of ideas concerning emerging categories. Memo-writing is a significant shorthand tool that combines sampling and writing and thus strengthens credibility, p. 84-5 (146). A thorough grounding of data helps researchers to avoid misleading clues and deceptive inferences. Secondly, the regimen for theoretical sampling should be obtained for testing categories that had emerged during the first analysis process. Moreover, the combination of constant comparative analysis and theoretical sampling represents a way forward in the generation of a theory, p. 102 (150). Thus, in the early stages, the initial sequencing of data into categories requires adherence to data sampling in order to obtain an accurate image of perspectives. Emerging findings will illuminate and lead to the development of nascent categories. Additional perspectives may also emerge to further address the objective in question (146). At this stage, with the attention of theoretical sampling, the three last interviews in the third round of interview sessions became productive as, for instance, the emerging categories were addressed to and discussed by the participants.

Moreover, the process of generating a theory begins with the collapsing of several categories into a single core category. The deeper understanding that emerges in examination of the core category will then add information to the theoretical understanding. The forefathers of GT (150) identify two possible outcomes of this process: a substantive theory, which places the findings in a certain, specific context; or, on the contrary, a formal theory that is understood to be of interest, generally. The idea that people with similar experiences can identify themselves with certain outcomes implies that a formal theory can be of universal interest (155). Suddaby (156) concurs with this, noting that GT is designed for interpreting the reality of interpersonal relationships in generally applicable way, rather than exploring individuality. That viewpoint substantiates the use of GT in the third paper regarding; mastery of daily activities and roles after a TBI with the objective of returning to work, intentionally contributing knowledge to rehabilitation programmes regarding the support given to patients in similar conditions.

4.5 Trustworthiness

The rigor of qualitative research is understood by the merit of its truth-value (149, 157). The characteristic components of trustworthiness include credibility, dependability, transferability, and confirmability. It is important to note that the values required depend on the particular type of study (158). Moreover, each of the values mentioned can be applied in several different stages of the research process. See Table V, The consideration of trustworthiness.

4.5.1 Credibility: An issue of communication

Credibility, in particular, addresses the question of communication between the researcher and the reader. Thus, the consistency should present a trustworthy review that covers the sampling of data, the process, and the final product of data analysis (159).

Accordingly, in Paper I, the original questions were tested by way of a test interview. Implications from the test interview revealed a need to re-write the guide, and thus domains of concern were formulated. The method of interviewing with a semi-structured guide covering only a few areas was successful in that participants felt free to share their personal experiences regarding the topics. As a result of the success, this design and interviewing technique was adopted for Paper II. An extended procedure in which the gathering of data ran parallel to the analysis employed in Paper III. This helped to deepen the areas under consideration. See Table VI, Interview guides.

My own pre-understanding of the matters in question and my developed skills in interviewing proved to be reassuring. Still, the question arose: was there enough

Table V. The consideration of trustworthiness

P Sample	Interview-context	Interview-guide	Interviewing, transcribing, analysing Pre-understanding	Analysing process	Findings
I Strategic: Snow-ball sampling	A homelike setting or in the participants' home	A test interview led to a review of the guide and four main areas of importance were crystallised	First author	Interviewing, transcribing, analysing Pre-understanding	Themes and sub-themes
II Purposeful: Variability in age, gender, full time/part time disability pension	A homelike setting or in the participants' home	Four main areas	First author	Conducted after the completion of the data sampling	Themes and sub-themes
III Purposeful in line with inclusion and exclusion criteria Two drafts	A homelike setting or at the participants' work place	A semi-structured guide, which was reviewed parallel to the analysis process Three sessions	First author	Memo-writing Analysis parallel to the data sampling	Categories and core category
Credibility Transferability	Credibility Transferability	Credibility	Credibility Dependability	Credibility Dependability Confirmability	Credibility Dependability Transferability

time for each interview to develop with respect to depth and to the aspects covered? With respect to the objectives and conditions of these studies, the attention directed at each participant was indeed satisfactory. Furthermore, in order to keep an open mind as a researcher in the interviewing and analysing process, I received no medical history or any other knowledge about participants' private lives beforehand. The participants' pre-medical history and life situations were kept private. It was their decision only what to reveal during the interview sessions.

The entire research process was, in fact, subject to scrutiny regarding credibility. The methods were precisely chosen for the unique abilities of each method to achieve the aims of each individual paper. For example, the very first intension in designing the second study was to identify issues that could serve as a starting point for designing a questionnaire survey. As such, a manifest content analysis method would be well matched to the research question. As the work proceeded, a latent content analysis was found to correspond with an expanded understanding of the objective under consideration. Thus, the original design was compliant with the research question with an augmented analysis.

4.5.2 Dependability: An issue of consistency of methods for gathering data

Dependability, or consistency, addresses whether or not the methods for gathering data are sufficiently trustworthy. The collection of data in Paper III can be clearly distinguished from the procedures of the first two papers because the participants in Papers I and II were interviewed only once, while, in Paper III, data sampling was conducted three separate times at regular intervals of three months with each of the participants. Notably, the study included two drafts of participants. In order to ensure the stability of the sampled data, the participants of each draft were interviewed separately. There was, however, some overlap at the conclusion of the first draft and the beginning of second, but such a minor aberration did not affect the interviewer's focus. Separate interviews and ample time in between for transcription and analysis greatly strengthened the dependability of this interview method.

4.5.3 Transferability: An issue of fittingness to other samples

Transferability refers to the question of fittingness with respect to other groups in similar positions. Qualitative research findings are not meant to be generalized. If such generalizations are attempted, important data will likely be neglected. Instead, researchers can ensure transferability by clearly detailing information concerning the participants and the study's context so as to allow for their findings to be developed and compared with other findings under similar circumstances (157). In actuality, whether or not certain findings can be applied to a comparable group of individuals in a similar situation is a question up to the

readers' judgement and interpretation (157). Such a difficult question can be eased whenever the sample of participants is clearly described. In developing inclusion and exclusion criteria for the studies in this dissertation, despite differences in the data-gathering processes the common goal of creating groups of experienced participants capable of addressing the objectives of the respective studies was sought.

4.5.4 Confirmability: An issue of presentation

Additionally, an issue of presentation to in pursuit trustworthiness is the procedure of keeping a journal or writing memos. Continual memo writing throughout the collection and analyse of data in the third study proved an outstanding way of bolstering confirmability, helping the researcher maintain distance and objectivity from emerging elements and proving beneficial in identifying patterns in the categories.

Table VI. Interview guides

Study 1	Study 2	Study 3
<p><i>Test interview</i></p> <ul style="list-style-type: none"> • Events • Tasks • Emotions <p><i>Following interviews</i></p> <ul style="list-style-type: none"> • Hours daily spent on food preparation and feeding, • Family members' need and assistance, • Leisure and time on their own, • Socializing with family and friends 	<p><i>Main theme</i></p> <ul style="list-style-type: none"> • Past, present conditions, • Future expectations <p><u>Past:</u></p> <ul style="list-style-type: none"> • Circumstances awarded a d.p. <p><u>Present:</u></p> <ul style="list-style-type: none"> • everyday life • work situations • leisure activities • family relations • economic situation <p><u>Future:</u> work ability</p>	<p><i>Main theme</i></p> <ul style="list-style-type: none"> • Facilitators and obstacles in everyday activities, including those related to return to work, • The balance in everyday activities, • The individual's future occupational life <p><i>Example of questions</i></p> <ul style="list-style-type: none"> • What do you usually do from early morning until late? • Tell me about your thoughts, and the purpose of having a job or position? • If you do have a job position, How would you describe your work assignment? • How would you express what the meaning of work is to you? • What, if any, hindrances or barriers do you experience when talking about returning to work? Could you describe what the concept <i>life balance</i> means to you? • Where do you see yourself in five years?

5 SYNOPSIS OF THE FINDINGS

This section presents a summary of the studies' main findings. In addition to that which is discussed at length in Paper I, the analysis revealed that informal caregivers set aside their own interests in favour of the family members' interests and care. The informal caregivers' loss of time for personal activities is therefore given special attention. The fact that a lengthy period had passed since the participants of Paper II had been granted a d.p. presented an opening for Paper III. In Paper III, the findings suggest a core category for addressing the participants' motives and actions.

5.1 Paper I

5.1.1 Relatives' experiences of family members' eating difficulties

Paper I endeavoured to describe relatives' experiences of family members' eating and swallowing disorders in their everyday lives. Three central themes emerged: *the relative as provider of the next of kin's health and well-being*, *the relative's sensitive attitudes towards the next of kin's change in appearance*, and *the relative's adaptation to the new situation*. Food preparation skills were also crucial, as more time was spent on cooking than was previously the case. Combined with circumstantial eating, food preparation dominated working hours. The caregivers' agendas revealed a shortage of time for their own physical training and personal interests. The increased time demands of household chores and caring procedures altered caregivers' own occupational patterns. The participants also expressed emotional reactions to their relatives' eating behaviours. In particular, the loss of good, proper eating and the lack of affinity during meals caused feelings of sadness. Strategies like dinner arrangements and shared responsibility guided the participants in adapting to this new situation.

From the moment the first participant of the very first interview, the test interview of Study 1, answered the posed questions, it was clear that the informal caregivers' own activities were not thoroughly realized. The informal caregivers' perspectives had not been awakened to their own lack of opportunities for meaningful activities. By employing a back-and-forth process of analysis with the aim of describing and exploring women's knowledge of their own activities when caring for partners, one major theme was identified: *the consideration for partners' needs influenced the informal care-givers' own activities*. Utterances like the following supported this theme:

"He walks really slowly. And besides, we live in an old house and there is all that to take care of. I do not have time to walk with him at his speed and then go for a walk on my own. If I had time to do that, I would be so tired,

and I would rather sit down for a while. This absorbs everything. It's just how it is."

In addition to the many other impacts that caring for family members has on a caregiver, these care-giving women could not follow their own doctors' orders concerning physical training or rehabilitation. When not caring for their partners, they were busy with domestic chores. Family and friends did not visit as often as they once did. However, it should be added that women whose partners stayed in nursing homes also struggled to take part in meaningful activities and make friends of their own.

In spite of the negligence for their own preferences displayed by these women, those living with partners often found a way to continue spending free time together by adapting to their partner's present capacity:

"We try to get the best out of our everyday life and do what we used to do, but differently, so to say."

This quote above could be a slogan or mantra for committed and motivated individuals who are responding to occupational adaptation by developing skills that lead to engagement in occupation and participation in social life.

5.2 Paper II

5.2.1 Disability pension and everyday life: A period of transition and subjective aspects of future occupational life

The aim of Paper II was to explore and describe everyday life experiences among those with a d.p. and their expectations for occupational life in the future. The analysis suggested three themes: *strategies for handling the situation*, *adaptations to remaining functional capacity*, and *expectations for future occupational life*. Initially, departing from the workforce entailed a period of emotional discomfort. Structures for participation and performance helped individuals to cope with this discomfort, and to rectify and balance their lives. The study concluded that participants with a full-time d.p. reconciled themselves to their situation, revising their conception of the consequences of being an early pensioner, while those participants who worked part-time saw their future role as that of a worker. Thus, present employment promotes the notion of a future career. Another important factor related to work capacity was the need for a balance between the paid work and the domestic work reported by disability pensioners working part-time.

5.3 Conclusion of Paper I and Paper II

The findings of the first and second studies revealed themes that addressed various perspectives of adaptation to a changed life situation. Several years had passed since the family member had become ill or the participants had been awarded a d.p. Thus, the participants offered a somewhat process-like account of their experience. The findings illustrated what a life situation could be like after disability or early retirement. A changed life situation was not only experienced by the disabled or retired individual, but by his or her family member(s) as well. The informal caregivers subordinated their own activities and interests to those of the person they cared for. In the second study, time had passed since the participants were granted a d.p. That was seen as a limitation, with the purpose of following up with research of experience early in a vocational rehabilitation period. That prompted the design of a third study.

5.4 Paper III

5.4.1 Participation in the workforce after a traumatic brain injury: A matter of control

Paper III explores individuals' experience of developing a mastery of daily activities and roles after a TBI, with the final objective of returning to work. Four categories emerged during research: *facing up to the adversity of a working life, pending time while accepting the slow rate of recovery, reducing activities to match current abilities, and attaining an adequate everyday life.*

The participants experienced the period of time covered in Paper III—approximately one to two years post-TBI—as a time of testing their own ability and endurance. Participants were constantly attempting to achieve their former capacity. Consequently, the motivation to return to work was imaged through the adaptation of domestic work to the standards of paid work, which seemed important for the participants' re-entry to the workplace and subsequent attainment of a higher degree of participation. Few participants considered turning to education for alternative work so as to become more desirable in the work market. Rather, they hoped to find more promising options in line with their ability and endurance. Still, two years after injury, participants were uncertain of how their abilities compared with workplace expectations. They felt they would do better as time progressed. One single core category emerged from the four mentioned above: *a desire for control: focusing on high-priority issues.* Further reflection on the core category offered up a deeper understanding of this desire for control. The decisions of public players and employers regarding the level of work ability distressed the participants because they felt they had not yet reached their optimal level of recovery. Eventually, the core category was discussed with respect to the participants' motivation and actions in order to develop their

highest performance levels and encourage increased participation in their domestic and working lives.

5.5 Summary of Papers I, II and III

Thus, the findings of all three papers revealed the participants' high degree of dedication to their commitments. Paper II, in particular, probed the participants' childhoods for evidence of attitudes of addiction that may have worked to exhaust the participants. As illustrated in Paper I, a few women even abandoned their own careers to provide for the health of their husbands, and thus took up tasks that were previously unfamiliar to them. In all the studies, findings indicated that participants voluntarily changed careers and living accommodations in order to match their current work ability and endurance. The fact that so many participants were therefore forced to leave their social networks behind might help explain why these participants became less outgoing.

6 DISCUSSION

6.1 Discussion of findings

The overall aim of this dissertation is to explore individuals' experiences regarding everyday occupations and adaptation to a changed life situation after disability. Here, the most relevant findings are given special attention. They draw the picture of lonely endeavours and feelings of uncertainty in balancing activities; involvement in future occupational life activities; and adaptation to current life situations. The view of mastering everyday occupations and elements related to a lifestyle balance will be considered. In accordance with that view, the effects that a social-cultural approach might have on well-being will be explored.

6.1.1 A lonely endeavour: Nurturing feelings of uncertainty

This section refers to the participants' ongoing struggle with a sample of daily activities extracted from the themes: *caring for the-next-of kin's well-being* (P I), *striving to handle a changed life situation* (P II), *moderating activities to match current abilities* (P III), *attaining an adequate everyday life* (P III), and *pending time while accepting the slow rate of recovery* (P III). A deduction of the findings offers the suggestion that the participants' narratives gave similar experiences about finding a satisfactory operating daily life after their own or a family member's disability. The participants had to rely on their own appraisals. In considering their life situations after disability or after being awarded a d.p., the participants, in general, endeavoured to come to terms with unfamiliar occupational situations and issues without relying on professional judgement, which was illuminated in balancing activities.

6.1.1.1 Balancing activities: A socio-cultural view

Among other topics, one in particular stressed by the participants in Paper I was their engagement as providers of their family members' well-being, which stretched them to their limits. Similar and comparable are the experiences of the participants in Papers II and III, although a number of them had an excess of time to spend; still, one can argue that their frustration over a lost ordinary working life like they used to have gave them feelings of desolation. The participants' experiences as discussed in Paper I covered a period when people would normally enjoy the benefits of a prosperous and laborious working life. Neither did the participants on an early retirement (P II) or those (P III) with back-into-work prospects benefit the fruits of time off work, because the outside world might emphasise their low contribution to the workforce. The current societal norm is to exchange paid occupations for the enjoyment of an active retirement age. For the participants' respective life-stages, one could argue that the portions of high challenging experiences increased. Quite the opposite would be expected: that

domain of high challenging experiences would diminish as they moved forward to an early or constitutional retirement age. Addressing the middle-aged and elderly participants, studies have described the transition from leaving a productive life in becoming an old age pensioner as a process of exchanging roles (160, 161). Moreover, the retirement process could reflect an absurd situation in that occupations that are less pretentious and challenging to the performer; free time might turn into unpleasantness (162).

Changing habits and roles, mainly shown in the participants' choices of activities, became fundamental for a discussion about strategies and routines; daily hours spent on household tasks was especially important. The participants, those of Paper III in particular, did not believe that household labour provided sufficient structure for a whole day. The participants on a d.p. (P II) showed sensitive attitudes about permanent exclusion from the labour market. These participants went through a vacuum-like period until they found other meaningful and purposeful activities to attend to. Even so, the participants who had had a TBI (P III) and were on sick leave for several months pointed to feelings of uneasiness and insufficient satisfaction due to their desire to do what was normal for them and what they felt others were doing. Quite the opposite, the round-the-clock commitment described by the participants in Paper I—tied by their obligations—gave them minimal of time for activities of their own. The results revealed the shortcomings of the participants' expectations in keeping up with current norms of social inclusion in family relationships on a day-to-day basis, and with opportunities to participate actively in social life. This subject was brought up by participants in all three studies. However, after several years of searching for solutions, other forms for communion and togetherness were tested, in particular concerning the participants in Paper I and for a few in Paper II. It was too early in the transfer process in Paper III to draw final conclusions about participants being accustomed to changed situations. One can argue that, in Scandinavian countries in particular, the government eases family situations with daily childcare, which encourages both parents to take on work positions. Shared child-care as well as domestic labour facilitates the integration of women into the work force. However, equal payment between genders is still an issue. To this day it is the men who contribute most to the family economically. However, the traditional line of thinking about female domestic labour and responsibility for their family's well-being was echoed (P I) in the changing of work careers in favour for their family member's needs. In a few cases, becoming a personal assistant to care for a family member became their second professional career. In addition, the male participants in Papers II and III worried more about financial strain due to poor income. Therefore, their first option was to remain in the workforce.

In Paper I, in particular, the participants were keen on keeping up with family holiday traditions. Cooking and housekeeping have long been women's

contributions to family domestic labour, and elderly women have likewise been the guardians of their families' health, while the men have supported the household economically and through home maintenance (163). Thus, a social system that promotes family togetherness has sustained Western culture. Not surprisingly, the relationship nurtured by women is reflected in their cooking skills. The female participants in Paper I continued to participate in what they considered their contribution to family life. In addition to this, the expectations that these women met for their family members could prove an overwhelming effort. Providing their families with traditional food while thinking of nutrition from a biological and medical perspective could prove a cultural dilemma (164, 165). The conclusion about relatives' experiences of providing food and feeding (P I) was that the participants experienced a double burden: along with providing and preparing food, they had become responsible for their family members' care and concerns as well. As far as the men in Papers II and III were concerned, the main predicament was the difficulty to make ends meet financially. Other concerns for participants included shortcomings in providing their children with what children normally need; school trips and family vacations were mentioned.

With respect to the participants' narratives, a traditional social system with shared responsibility for household labour is disrupted after disability, whether the person has taken ill or is a relative of one who is ill. In addition to customary habits, the participants in Paper I stressed that gardening, financial affairs, and vehicle maintenance were added to their traditional tasks. The participants in Papers II and III shared housework or were less meticulous about housekeeping than they had once been. Thinking about what changing habits does to individuals' roles or, more importantly, identities, is a matter of conceptualizing occupational identity. This could be understood as a mirror image of that person's occupations (91). The concept of identity is understood via several parameters (166). Many aspects should be considered, for example, with whom and why people do what they do. Thus, meaning ought to be envisioned through the lenses of each individual's culture, history, and social norms, a theme further discussed in the next section.

Communication about individual commitment and occupational identity, or more likely individual interactions with surrounding elements, revealed certain key ideas, such as that a socio-cultural heritage is passed on for generations, influencing human beings' activities and choices of activities (107). A Western cultural tradition underlines that people identify themselves through their occupations, which provide meaning to the individuals. The authors did not only mean professional occupations, but also a number of daily lifestyle activities, such as physical training, maintenance, and other subjects of aesthetic and artistic value (91, 107, 167). In particular, individuals' heritage and culture indirectly affect their desires, feelings, and thoughts through their activity commitments. Thus, a

person's identity stems from his or her engagement in various occupations. All these factors reflect a person's identity (8). After all, in daily activities, cultural and social norms play a vital role in individuals' interests and routines.

Thus, in the light of this dissertation's aim, the individuals' voice is focused as follows. Taking into account the influence of culture and society, the meaning of occupation would include not just the single act of doing, but also cultural and social norms carried on by tradition.

6.1.2 Involvement in future occupational life activities: The meaning of work

Findings about future occupational life included *facing up to the adversity of a working life* (P III), *future occupational life expectations* (P II), and *a desire for control: focusing on high-priority issues* (P III). Uncertainty about one's capacity for a future working life was stressed by the participants (P III) who had had a TBI. The participants working part-time while on a partial d.p. (P II) were no exception; they, too, had found alternative ways of modifying daily life activities. However, the question of sustaining the workforce remains unanswered.

Uncertainty about work ability worried the disability pensioners (P II) whenever re-entry to work was brought up. The concern was their importance in the workforce as well as environmental issues. Research about disability pensioners' thoughts on returning to work is not frequently conducted, but there have been a few studies. In one (168), researchers found that people who had been off work for several years with back pain experienced negative effects on self-confidence and worried about their work ability. In addition, re-entry into work required special arrangements, for instance, environmental adjustments or reduced working hours (168). Two men and 15 women with musculoskeletal disorders who were on resting disability pensions and working part-time participated in a qualitative study about adaptation patterns in returning to work. Adjustments at the workplace and adjustments in working hours to match the individuals' work abilities were leading themes (169). Accordingly, there are a number of individual conditions that might ease individuals back into the workforce. For instance, driving one's own vehicle made a person four times more likely to stay in the workforce (170). Similar experiences with driving one's own vehicle were shared among the participants in Papers I and III. The relatives in Paper I said it was difficult for them to go to the grocery store and buy food for dinner when they had no driver's license. The majority of the participants in Paper III were dependent on transportation to their work-places. One participant could have had increased working hours if he had not been dependant on public transportation.

Other plausible explanations might arise from the participants' comprehension of the meaning of work. Thoughts about future occupational lives were shared by the participants in the second and third studies. In Paper II, one notable factor was

that the disability pensioners working part-time saw themselves as workers in the future. In Paper III, participants were asked, “How would you express what the meaning of work is to you?” A conventional understanding is that a job provides an income, and that tasks provide daily structure (171, 172). However, the findings in this dissertation show that individuals’ thoughts and experiences in paid as well as un-paid work are in reciprocity with society as a whole. Examples of that include feelings of competence and satisfaction upon completion of assignments, specifically for participants in Paper I, whereby the relatives took on new tasks. With time, they addressed themselves as experts on their family members’ care and well-being. In the third study (P III) in particular, the participants indicated a desire for societal togetherness in enacting former skills.

In order to reach a deeper comprehension of the participants’ experiences controlling their everyday lives, a reflection on having a work position would be significant. A considerable number participants frequently brought up their desires for living a “normal” life. In Scandinavian countries, in particular, the general opinion is that citizens should experience equality and welfare. The code of equality is especially widespread; everyone should benefit from health- and welfare programmes to provide for individuals living a normal life. Of course, it is significant that individuals themselves contribute on an equal basis, namely doing their utmost to stay healthy through physical fitness and nourished food. Furthermore, Samaritan principals in caring for each other and voluntary work contribute to the community. Additionally, the norm of reciprocity, giving back to society through being active in the work market, taking on voluntary work, or helping others in need, is a token for social community and social participation.

The most obvious expressions about reciprocity were made by the participants in Paper II, who talked about the effect that their upbringing had on their beliefs about paying their utmost attention to and making their best efforts at performing tasks. A participant in the Paper II study said:

“It’s because you’re born that way; it’s ingrained in you that you’re supposed to work and be able to take care of your family and all that.”

A participant in Paper III felt that being off work did not permit him to do what men his age normally do. Another participant (P III) pointed out a sort of social reciprocity that allowed for giving back by participating in permanent work. Such a statement echoes norms about welfare equity. However, there is a major sticking point: a choice about economic and social prosperity covers a socially cohesive thinking built on models of democratic virtues requiring all residents to do their share. It could be perfectly justifiable to say, without making any exceptions, that the participants in this dissertation proved their civil duties. The meaning of work addresses a socio-cultural heritage in which children and young adults are brought up to earn their living and pay attention to their supervisors in appreciation for

employers' as well as customers' satisfaction. That is consistent with employer-employee attitude findings in other studies (173, 174). Participants returning to work spoke of being responsive to expectations about being busy and focused (169). Similarly, an autobiographic analysis focuses on influences from the past related to the present in meaningful activities and places (175). A crucial point is the individual's capacity to transfer lived experience into new circumstances. That hypothesis is based on the assumption that every influence of a person's past—the places they lived, the schools they attended, the workplaces, interests, and activities they took part in—is integrated as they face new places and challenges. Clearly such a transfer mode mirrored the findings in this dissertation: one pivotal aspect is an individual component to consider when addressing RTW.

6.1.3. Adaptation to current life situations: Sustaining autonomy

According to the present findings the participants modified their lives by taking up activities similar to what they had done previously. The results from Paper I reveal the participants' desires to keep up their former fundamental occupational identity and autonomy. Examples are their strategies to free themselves from duties that could be done by others. One other eminent example is the participants' respect and compassion not just for themselves, but also for the family members in their care. In particular, the family member's habits and traditions were fundamental in the preparation of hot meals ready for feeding. This helped them to sustain their occupational identity as well as autonomy. In Paper II the participants' found activities to match their current energy reservoirs with societal closeness as the driving force. Indeed, the individuals' application of adaptation accentuated the participants' reflective thinking. The participants' in Paper III were concerned with their mastering or controlling their abilities to go about their daily occupations, since they had not reached their desired level of autonomy from an occupational view. Similar findings are revealed in another study, in which people were found to have decreased work identity after experiencing a brain injury (6). Nayar and Stanley (95) search for a deeper understanding of the findings in order to explore the individuals' processes in gaining meaningful outcomes. Thus, summarizing the findings of this fairly modest view illuminates one distinctive feature: the participants' push for *sustaining autonomy*. Autonomy refers to the code of ethics imprinted in human beings, "having the capability to take responsibility to decide matters concerning him/herself" p.6 (14). Thus, *sustaining autonomy* embodies occupational adaptation.

In sustaining autonomy, the findings accentuate the participants' desire to be their own agents for adjustment. The participants in this dissertation made it clear that they were not quite satisfied with their capacity to meet their obligations. One possible option for handling this discomfort was to ask for information about prognoses and rehabilitation (P I). One other frequent request, as far as the

findings in Paper III are concerned, was for updated strategies and techniques to enable them to control activities by time and place. Another study (176) implied similar information in that the participants accentuated how important supportive and understanding employers and colleagues were to their satisfaction with re-entry into work. Also, frequent contact with the rehabilitation team made them feel confident. Furthermore, the findings revealed individual factors, such as being one's own driving force, finding balance in activities, and creating helpful habits in line with their ability to adjust and be flexible (176). Additionally, the participants stressed a need for information about mastering a balanced everyday life as well as awareness of individual resources for reordering their activities (172).

In sustaining autonomy, the findings also reveal the participants' urge to find an acceptable life situation. Former preferred and engaging activities in private and working life can be adapted to accommodate challenges while still allowing the individual to attain contentment (177). Participants' recognized that their home and work activities were not balanced, particularly in Papers II and III. In one interview article (178), OT students explored to what extent work-life balance could be influenced by the respondent's work transition through voluntary occupational changes. It could be argued that occupational transition is a determinant of fulfillment due to rethinking what mattered most in life and adjusting preferences in changed work careers and places. In a recent study (179), Scandinavian men and women considered a work-life balance to be a determinant for health. The findings in this dissertation could be mirrored from a work-life perspective as follows. The majority of the participants in Paper I had retired from paid work, while just a few kept working while caring for their family members. For participants in Papers II and III, current life situations could be perceived as slightly different in that the research question was about re-entry to work after a d.p. or a TBI. Thus, they were of working age and thereby seen as possible future workers. Findings from the present studies, regardless of how participants' life situations had changed, revealed a discrepancy between what they wanted to achieve and what they could manage, because of inadequate capacity and the energy cost.

The findings of Papers I and II took into account a fair length of time after illness, giving the majority of the participants time to adapt to their altered life situations. Quite often, participants saw themselves as the person they were before the brain injury (176). The findings stressed that participants needed more time to perform tasks, especially at work. Other intriguing matters were that the employees did not tell their employer about their shortcomings (180). In a review encompassing 16 articles and three theses, the conclusion was that after a TBI, the changes in the individuals' occupational identity formed a barrier when it came to activities they used to do (180). However, transitioning to a new situation seemed to elevate the participants to a higher degree of contentment. That becomes possible (referring to the findings in Papers I and II) as the participants internalize

newly learned activities into habits and roles. Thus, their occupational identity changes regarding performance and participation. However, contradictory findings were revealed. Employees and employers were interviewed, and the employees noted difficulty in balancing their activities, stating that they worked shorter hours in favour of completing domestic chores and having time for sleep and rest (172). In a phenomenological study, participants who had had a brain injury considered work less important than they had previously; however, a feeling of belonging was as important as before (6). Hence, taking both perspectives into account, allowing for domestic and leisure tasks as well as work tasks (172), individuals find ways to reorganize their routines in relation to energy and capacity. The conclusion drawn from the findings in this dissertation is therefore, in balancing activities after disability, several of the participants chose to downsize at least one of the domains of home labour, leisure activities, or working hours in order to meet their capacity and endurance.

6.1.4 A view on occupation related to health

Participants' occupations should be visualized in light of an extended understanding of the concept. With reference to Jonsson (114), a second viewing of the findings about occupation asks for a supplementary reflection in relation to perceived health. In some respect, the findings reveal that the participants' habits and interests guided their choices reorganizing their current daily life activities. Therefore, two other distinguished areas of occupations emerged: *pending occupation*, and *reciprocity occupation*.

In *pending occupation* the findings showed that, through waiting for improvement, the participants set their lives on a hold. They described themselves as homebound feelings with a goal of recuperation from their shortcomings at work or in social life. Not being able to deliver work they considered satisfactory, they bided their time, staying at home and waiting for their capacity to improve. Participants made statements such as "I never have the feeling of being completely free, no" (P I), "Some days I manage to do some work, but others more or less nothing" (P II); "I feel as though I'm on pause. I go around waiting for it to be okay again, but it isn't okay" (P III). Through pacing activities, the participants managed to keep going. However, *pending occupation* is imbued with solitude and sorrow and is correlated with a low level of well-being.

On the basis of *reciprocity occupation* the participants expressed their willingness to counter perform, meaning they took up voluntary work and desired to do a whole day's work as they used to do. In this way, one can argue that the participants exchanged their services with compensation from pension or sickness benefits. Moreover, voluntary work involvement could make use of their skills for a socially good reason. It is important here to consider the participants in Paper I, whose compassion was steeped in socio-cultural heritage. One other participant

was more implicit in saying: "You are part of society, you are a citizen – not just a consumer" (P III). This draws the attention to the domain of participation, or "involvement in a life situation" (29), which is influenced by the environment, with or without adjustments or assistance, and here in particular by socio-cultural determinants. One of the Jonsson's categories (114), "social occupation", was considered a token for a high significance for well-being. *Reciprocity occupation* underlined this relationship with a social gradient, being considered a high indicator of well-being.

The two categories of occupation conceptualized by Jonsson (114) comprise time use as well as significance for well-being. The present studies found that spending too many hours or too few hours on a singular occupation or commitment (caring for a family member, work-related activities, or pacing activity) replicated; however, an uneven distribution of occupations of private nature, domestic labour, and work did not necessarily meet the participants' expectations on balancing activities and perceived well-being. Therefore, occupational patterns "are regular and predictable human occupation ways of doing, and occur when human beings organise activities and occupations" p. 4 (24), a fact that is verified by the participants' achievements when trying their utmost. On the subject of health-related occupation, one participant noticed: "I do some things because I do not want to become immobile" (P II). These feelings are of importance in the challenge to reconcile present life situations and indicate a high significance of well-being.

Moreover, the most important conclusion is that *pending occupation* and *reciprocity occupation* add significant information to the categorising of occupation. In particular, *pending occupation* embodies qualities such as *biding one's time* to be understood as active, but with patience, waiting for improvement. Similarly significant is *reciprocity occupation* embodying *social participation*.

In addition, feelings of uncertainty eventually cease to be barriers for the participants (P III). A qualitative study interviewing participants who had had a TBI (97), who shared experiences of being uncertain about the future, had similar findings. However, considering the triad doing-being-becoming, several elements in the environmental and even cultural influences are significant. Individuals' perceived good health plays an important role in the flourishing interaction between nature and culture as well as in affording confidence in that the individual can do what he/she perceives people usually do (107, 129, 131). Performing familiar customs and roles reflects an individual's goal-directed and valued activities, framed by a socio-cultural context, giving a sensation of well-being (181). Consequently, the variety of occupations the individuals choose gives meaning to the performers themselves p. 128 (124). Reviewing the present findings, the meaning of occupation as well as changing occupations makes sense

in the view of the influence that culture and social tradition have on the individual's understanding.

The findings' relevance for a health-related occupation drew attention to the theory of SOC. Clearly it is important to have a review of the theory, and its three components: comprehensibility (1), manageability (2), and meaningfulness (3), as follows:

“The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring through dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement” p. 19 (127).

Indeed, a few observations of the three key points mentioned above could be mirrored through the SOC theory. Manageability appears to be linked to the balance between “want to do” and “must to do” occupations. Adaptation to current life situations seems to depend on participants' level of control over the order and structure of everyday occupations. In their early attempts to orchestrate a work-life balance, participants with TBI (P III) were far from content. The question of meaningfulness could only be answered by the informal caregivers' enthusiasm in preparing and cooking food (P I). Further, the meaning of work was a strong motivator for RTW (P III) and even sustainability in the workforce (P II and III). In the context of this dissertation, comprehensibility is of great concern; however, a certain, specific answer for this question would be too presumptuous.

6.2 Discussion of methodology issues

Methodology is best discussed in light of the following attitude about data sampling for qualitative analysis: “Purposeful or theoretical sampling are commonly done to obtain qualitative material” p. 485 (182).

6.2.1 Invitations to participate and “How many interviews is enough?”

Exploring a person's eating and swallowing difficulties can be a delicate matter due to the feelings of shame and guilt; the subject is, therefore, rarely displayed or spoken of. Difficulties such as eating and swallowing ailments are not typically socially displayed, and consequently are seldom recognised publicly, but it is still important to give them attention. When medical registers were not a viable alternative, a snowball sampling technique, through which the participants introduced themselves, was used. However, the samples of participants in Studies

2 and 3 were conveniently drafted from registers. Accordingly, in this dissertation both snowball sampling and purposeful sampling met the requirements on credibility due to the participants' familiarity with the matter under consideration.

However, it is important to have an appropriate number of interviews to establish credibility and transferability. In most quantitative research the estimated numbers of informants are calculated based on validity and the generalisation of the outcomes. On the other hand, when conducting qualitative studies, other issues are considered. Usually qualitative studies, which are exploratory by nature to develop a certain theme, aim to reveal thoughts, feelings, and experiences (146, 183). In Study 1, the delicate matter of living with eating difficulties narrowed the sample size; in Study 2, just about one-fifth of the study sample answered the invitation letter positively. These criteria, as well as the context for Study 3, set the sample limit. By giving voice to the participants, purposeful samples corresponded to the research questions. One other important issue of the methodological approach is to reveal many possible perspectives while the data sampling and analysis are parallel and iterative. Finally, when the full saturation of the perspectives has emerged, the number of participants is known. Moreover, the objectives were to uncover individual experiences and to better understand these objectives; therefore, the exact number of participants could not be estimated beforehand.

6.2.2 Methods for data collection

Knowing participants were solely responsible for the actions taken in their private and social lives, slightly less attention was given to medical issues. Thus, adopting a client-centred view guided the designs of this dissertation, and diagnoses and disorders were of much less importance than the participants' narratives.

The interviews were performed using semi-structured guides. As an interviewer, I positioned myself as a listener. A researcher posing as listener distances him-/herself, creating space for the narratives (143). Short, positive phrased sentences with a single message were used in order to keep the participant on topic. During the interview sessions, these questions were built on one another, encouraging the participants to use reflexive thinking in building up their narratives (184).

Theoretical sampling is significant for grounded theory; however, in such research, the authors' inconsistent means of conducting theoretical sampling is frequently criticized (185). Theoretical sampling is intended to add information, and moreover tests emerging categories. Before conducting the second and third rounds of interviews, the previous data analysis was used to add questions to the original interview guide, contributing to the data. Before the last three interviews, emerging categories were found and were convenient in up-coming interview sessions. While approaching the theoretical sampling procedure as concisely as

possible, the extended interview guide and the test of emerging categories contributed to revealing any possible additional perspectives.

6.2.3 Methods for analysis

Qualitative methods require the investigator's engagement and creativity. In occupational sciences, deeper understandings of individual experiences require methods of analysis that allow the researchers to broaden the individuals' creative thinking (182). Obviously, with this dissertation's aim in mind, employing qualitative methods for data analysis was adequate.

The three methods used for analysis were constant comparison, content analysis, and grounded theory. These methods have a few comparable features, such as conjunctively introducing the steps of data handling. Initially, sequences of the transcribed text were marked and thereafter condensed into segments; however, they still match the original text. A constant comparison is useful for revealing similarities and differences. A rule for a constant comparative analysis has been defined as follows: "while coding an incident for a category, compare it with previous incidents in the same and different groups coded in the same category. ... This constant comparison of the incidents very soon starts to generate theoretical properties of the category" p. 106 (150). This constant back-and-forth procedure was mainly conducted in Papers I and III, and was found to be useful for the identification categories. Paragraphs of the text were narrowed into codes, and finally categories, and the data were at last discussed with a focus on deeper meaning. However, Nayar (155) asserts that grounded theory is overlooked when describing daily life actions and thoughts about these actions in the context of social processes and environmental influence. The findings in Paper III showed GT to be well suited for revealing individuals' actions and their thoughts about returning to work, as well as their mastery of everyday occupations. Additionally, the constant comparative analysis was useful for finding out more about relatives' experiences. In addition, a latent understanding gave a deeper meaning to the original findings in Paper II. In any case, there are critiques raised about the administration of GT (138, 156). One critique is the duration of time spent on analysis, given the meticulous procedure performed through several stages. The method is indeed time consuming, but writing notes from the very start of the process was useful in sorting out what mattered most, and the excerpted main concerns guided the steps of the process to follow. Thus, applying structured methods to analyse data met the appropriate level of compliance with the objectives of the study.

In this dissertation, which includes three individual studies, qualitative methods were employed for data analysis from data sampling comprised of 9, 14, and 8 participants, separately. In view of the transparency of the findings of 45

interviews⁶ should cover the need for trustworthiness. However, with a quantitative design in mind, the sample size might be a limitation if the results are not supported by investigations with large-scale data. Consider that the findings from this dissertation stem from qualitative studies only. The studies do not include investigations conducted within the same context that can confirm or reject the findings.

Conducting supplementary quantitative studies would encompass extended numbers of participants, which could produce outcomes expressed in a percentage of a population to be evaluated in terms of statistical significance. Such a study design will make it possible to compare the results from analogous research. Reliability and validity could be discussed and evaluated. A research design based on principles for a quantitative method is undoubtedly appropriate for an extended comprehension of individuals' changes in occupational patterns after disability. Statistical results following qualitative methods could reinforce the original findings in this dissertation. Of course, such a research strategy needs to be further planned and designed. In spite of the quantitative methods deductive in the present design, a single matter to consider is that, whenever a certain hypothesis is requested, it will offer the possibility of overlooked information. In randomized controlled (RCT) studies, a few variables are considered in relation to the objective.

At the time for the third study, The Norwegian Labour and Welfare Service (NAV) expressed a need for qualitative studies in order to receive findings based on the individual experiences. Of course, the use of a national registry of individuals with TBI would have increased the sample size. In that case, the findings would have met the demands on credibility and transferability almost completely for a specific country. Another limitation is that a SOC questionnaire has not been administered. That would have given a reliable view of the participants' comprehensibility, manageability, and meaningfulness of their arrangements made throughout their progress in understanding and controlling their life situations. It is important to note that the objectives in the three studies were to describe the participants' experiences and to broaden the knowledge about the matters in question. Thereby, the participants' coping strategies were briefly covered during data sampling. Certainly, highlighting the participants' experiences gave information about the phenomena they experienced. The methodology gave a broad understanding of the objectives.

6.2.4 Transferability of findings

Findings from qualitative studies are not and should not be generalisable. Through discussion of the findings in light of each study, the question of transferability was

⁶ In the third study 7 participants were individually interviewed 3 times.

raised. Despite the independence of the three studies in design and implementation, the final conclusion brought together observations that daily life activities, occupational identity, and life-style balance in the context of voluntary or paid work have similar elements. As such, the findings of the three projects may be brought together into a cohesive unit. One could argue that findings from a qualitative analysis could bear transferability for others in similar situations. This dissertation, which covers three projects independent of each other, shows that findings from qualitative methods based on individual experiences could very well be “applied universally” p.78 (155). However, bridging the findings from one context to another should occur at the reader’s discretion (157, 158).

One note that must not be neglected is my pre-understanding of the subject matter. Any researcher’s experience with the field of study and knowledge in data sampling and analysis ought to be controlled in order to explore new aspects of research questions (143). At the same time, experience as well as methodology is useful in analysing and exploring new domains of findings. If not, areas already revealed and published might once again be highlighted, sacrificing new scientific information that would have otherwise emerged. In conducting the interviews for the projects in this dissertation, I had no knowledge about the participants beforehand. Instead, the use of open-ended questions in a one-on-one communication setting inspired my creativity and reflexive attributes. The researcher’s objectivity is a matter of trustworthiness, and can be achieved through distinct methodological steps during the process (144). Qualitative and quantitative methods are complementary in interpreting and describing persons’ lived world and biopsychosocial conditions (142). Articulating persons’ thoughts, experiences, and expectations on an individual basis adds more information to normal objective investigations (142). Thus, the trustworthiness of these studies was enriched and confirmed by the systematic analysis procedure I conducted and by my creativity in bringing the findings to an inner meaning.

6.3 Conclusion

The overall aim of this dissertation was to explore individuals’ experiences regarding everyday occupations and adaptation to a changed life situation after disability. Some of the participants were in a more strained situation than previously experienced, which was a recurrent predicament. One potential reason for this could be the shortage of a balanced life-style. It is important to note that the findings indicate that, in balancing activities after disability, several of the participants chose to downsize at least one of the domains of activity (home labour, leisure activities, or working hours) in order to meet their capacity and endurance. In recreating occupational life after disability, household labour was not seen by participants as providing sufficient structure for the whole day. For persons still working, assignments in the workplaces seem to be the most significant place to reorder routines and roles. The findings add complementary

information to what can be interpreted from ICF domains. From the findings, it is clear that familiar customs and roles influence individuals' rehabilitation, and socio-cultural traditions guide individuals' choices of activities, which might be reflected in their occupational identities and social participation.

A deeper understanding suggests that the salient elements of this dissertation can be summarized as follows: Aside from alterations in daily occupations by practicality, embodied by the theory of occupational adaptation, other determinants could play a major role in the individuals' way of thinking about occupations. The findings indicate that the participants' minds and socio-cultural natures are of significance. On account of the individual's persistence in *sustaining autonomy* in the view of occupational theory, two distinguishing categories, *pending occupation* and *reciprocity occupation*, should be considered in light of the relationship between occupation and well-being.

6.4 Clinical implications and suggestions for the future

Finally, the results raise a few significant points that bring new evidence to the need for further research. Findings included problems that are not frequently focused on in rehabilitation research. All the papers include the participants' perceptiveness to occupational identity, and to achieving a work-life balance.

Firstly, returning to work ought to be a topic of discussion early on in the rehabilitation process. Secondly, in order to strengthen the individuals' engagement and motivation, the individuals themselves should be given the responsibility to set goals for returning to work or some other appropriate choice. Correspondingly, the relatives' needs and desires should be given utmost attention. Identifying goals will be helpful in the assessment of outcomes, an assessment that would in turn be helpful in the modification of goals if needed. Thirdly and finally, a satisfactory work-life balance is an important factor in promoting sustained engagement and commitment. Thus, incorporating relatives' special skills during the rehabilitation process, as well as the individuals' RTW process, early on could strengthen individuals' belief in their own skills, increase motivation, and promote perceived good health.

7 Ethical reflections

While performing individual interviews and addressing matters of personal characteristics, one cannot help but note the emotional and affective expressions that appear. Obviously that was a topic of concern, and the participants were informed in advance that, if necessary, they could seek professional treatment or follow-up steps of usual procedures. However, because several years had passed since the participants' onset of disability, the majority of the participants (Study 2) had likely discussed their pain with health professionals, and to some extent had

adjusted to their feelings. Sensitivity to the participants' mood and capacity required attentiveness and respect. Clearly, interviewing participants (P I) who had less time to adjust, it was important not to go profoundly into matters that made the participant uncomfortable. Likewise, in performing the interviews in the third study, due to the participants' digressive endurance with appurtenant articulation, difficulties limited the duration of the sessions. Of course, breaks in between helped. Even if not during the actual interview session, the interviewer addressed emotional effects with the participants to ensure that there would be no risk of any unpleasant side effects after the interviews. Unlike this, in Norway, the context of the third study, all residents are entitled to a general practitioner. Generally, rehabilitation services as well as following-up on consequences of a TBI lies on the municipalities; of course, it is still the individual's responsibility to call for a health examination. Therefore, in summing up each interview session, the participants were advised to call at their district health care centers for any needs that might arise from the interviews. In addition, a few participants explained that they, at any time, had access to a neuropsychologist from their rehabilitation unit.

Information about the studies was given both orally and in writing. Participation was voluntary, written consent obtained in every case, and participation could be interrupted at any time by the participants. Meeting places for the interview sessions were mutually agreed upon. The length of each interview was adjusted according to each participant's endurance. Precautions were taken in case feelings around troublesome and intriguing issues arose while the participants answered interview questions. If signs of such troubled feelings arose, the voice recorder was stopped. When things settled, the participant was again offered withdrawal from the study. Thus, the research measures closely follow the code of ethics.

Förmågan att kontrollera dagliga livets aktiviteter kan vara en utmaning för alla människor. Det kan bli en extra belastning efter sjukdom både för den som själv är drabbad och för de närmast anhöriga. Det övergripande syftet för den aktuella avhandlingen var att beskriva personers erfarenheter av ändringar i aktivitetsmönster efter sjukdom. Avhandlingen fokuserade på deltagarnas upplevelser av anpassning till en ny livssituation. Aktivitetsmönster i relation till att komma tillbaka i avlönat arbete var ett angeläget tema. Tre studier genomfördes oberoende av varandra. Kvalitativa metoder: konstant jämförande analysmetod, innehållsanalys och grounded theory användes för analys av transkriberad text: 45 intervjuer. Deltagarna intervjuades individuellt, tillsammans 31 deltagare (9 anhöriga till personer med ät- och sväljsvårigheter, 14 personer med sjukersättning, 8 personer med traumatisk hjärnskada). Deltagarna i den tredje studien intervjuades tre gånger under en sexmånadersperiod. En förändrad livssituation innebar att deltagarna mötte krav och förväntningar som de var oförberedda på. Brist på tid för egna aktiviteter var ett återkommande tema i samtliga studier. Deltagarna gjorde avkall på tid för egna intressen och ibland också tid för egen träning till förmån för sitt engagemang i det uppdrag de hade fått sig pålagt eller avlönat arbete. Detta kom till uttryck i teman som åskådliggjorde strategier för att hantera den nya situationen. Deltagarna framförde flera behov, bland annat råd och stöd för att nå resultat i sin rehabilitering. Deltagarnas förslag till åtgärder rörde sig om uppdatering av tekniker och strategier i nivå med nuvarande situation. Två år efter skadetillfället ansåg deltagarna som hade haft en traumatisk hjärnskada att de hade möjligheter att utveckla sina förmågor. Konklusion: resultatet visar att deltagarna hade en ojämn fördelning av aktiviteter (tid för egna aktiviteter, vård av anhörig, arbete).

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Participation in the workforce after a traumatic brain injury: A matter of control

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ABSTRACT

Purpose:

The aim of this study was to explore individual experiences in developing a mastery of daily activities and roles after a TBI with the objective of returning to work.

Method:

Eight 30-60-year-old men, who were employed at the time of injury were each interviewed three times over a six-month period. The first round of interviews was held 10-21 months after the injuries. Half of the participants had returned to work at least part time. Grounded theory was adapted for data analyses.

Results:

A single core category emerged: a desire for control: focusing on high-priority issues. Still two years after injury, the participants were uncertain about their abilities with respect to what was expected of them at work. The participants felt that they would do better as time progressed. A single core category emerged from the four mentioned above: a desire for control: focusing on high-priority issues.

Conclusions:

The participants' uncertainty about their efficacy cast doubt on their beliefs in improving their skills, finding a suitable balance between daily activities and work. Moreover, they wondered about the sustainability of their health and efficacy in a work context. Counseling to help sort out their priorities was pivotal. Wanting to control their own improvement, the participants asked for strategies and techniques to help with their progress. This issue could be taken into account in follow-up rehabilitation programmes. Additionally, the workplace might be the ideal context in which to develop the structures and routines necessary to master life in general.

Keywords: Traumatic Brain Injury; Life Style; Return to Work; Social Participation

INTRODUCTION

The persons often experience changes in their occupational capacity while regaining mastery of everyday life after a severe illness [1, 2]. Going about ones' occupational life with a disability is a process of adaptation of daily routines and activities. In addition, engagement in carrying out especially meaningful activities is of vital importance to a person's well-being [3]. The attainment of well-being with regard to an orientation of normality after disability is a strenuous endeavor, and people need support and guidance [4, 5]. Furthermore, there are assumptions that individuals after severe illness seem to reevaluate their preferences [6]. An interview study exploring the meaning of work found that participants did not value work as highly as they did before the injury; however, the social dimension of work, especially a feeling of belonging, remained important [7]. One other study explores how early pensioners working part time saw their future role as a worker [8]. In order to benefit as much as possible from their paid work, they reorganized their everyday activities in order to compensate for their reduced stamina. They did not do household tasks as thoroughly, nor did the participants take part in as much social life [8].

Individuals who have suffered a traumatic brain injury (TBI) enter into a process of adaptation that is an ongoing struggle through several years [3, 9]. Consequences from a brain lesion can cause difficulties in planning and shifting from one task to another [10, 11]. Possibly, a familiar environment will help in awkward situations. Changed executive abilities, emphasizing new identity as well as new routines, might cause stress to the individual and cause limitations in the health-related quality of life [12].

Several studies show a variety of perspectives following the aftermath of brain lesion, but the knowledge about different aspects and difficulties of everyday life in combination with

working life is sparse. In rehabilitation practice, patients experience a challenge in balancing ordinary daily activities in combination with wanting to maintain their capabilities. Deeper knowledge about the balancing and intensity of activities and patients' need to adapt to current situations after disability would be of great value. In particular, knowledge about people's occupational life and the adaptation to new routines with the purpose of returning to work after having a TBI have barely been explored. Consequently, the researchers gained incentive for further research. Therefore, the aim of this study is to explore individual experiences in developing a mastery of daily activities and roles after a TBI with the objective of returning to work.

MATERIALS AND METHODS

Design

The objective of this study is to capture the experiences of individuals with a TBI in developing a new mastery of daily activities and roles. These themes are what directed the authors to use a grounded theory (GT) method [13, 14]. The present study was conducted at Sunnaas Rehabilitation Hospital (SRH), the most specialized hospital in Norway in the field of physical medicine and rehabilitation. In addition to inpatient rehabilitation treatment programmes, there are follow-up programmes - four to six weeks of the hospital stay - with intensive training aimed at cognitive and physical functions. The hospital also offers other programmes of limited duration, for instance, specific functional evaluations of work-related ability and suitability for possessing a driving licence. Participants were recruited to the project according to principles for purposeful sampling [15]. Former in-patients in the rehabilitation programme during June 2010 – May 2011 (first draft) and June – Dec 2011 (second draft), was retrieved from the medical records by the second author (TH). All participants lived in the capitol region of Norway.

Materials

The data gathered for the objective under consideration were the individual interviews, which were conducted three times at three months intervals in order to capture any possible view of the matter in consideration. To support the interviews a semistructured interview guide was developed to cover the following issues: facilitators and obstacles in performing everyday activities, including those related to a return to work; furthering the balance of everyday activities; and the individual's future occupational life. The areas of concern were supported by open-ended questions, such as: What do you usually do from early morning until late? Tell me about your thoughts, and the purpose of having a job or position? If you do have a position, How would you describe your work assignment? How would you express what the meaning of work is to you? What, if any, hindrances or barriers do you experience when talking about returning to work? Could you describe what the concept *life balance* means to you? Where do you see yourself in five years? The interviewer's approach in conducting the interviews was guided by the intention of establishing rapport [16, 17], using open-ended questions, and encouraging talk about topics that were proposed by the participants themselves. In addition to the questions on the interview guide, the participants were asked to answer a set of questions on sociodemographic data, developed by the National Centre for Occupational Rehabilitation (in Norwegian: Rehabiliteringsenteret AiR). Accordingly, issues that were highlighted by the participants when answering the questionnaire were discussed during the actual interview beyond the interview guide but still remained under consideration for the objective of this study.

Ethical considerations

This study was approved by the National Committee for Research Ethics in Norway; 2011/925. The participants were informed verbally and in writing about the study, and assurances of confidentiality were given. Participation was voluntary, and written consent was obtained.

Participants

The data sampling was obtained, at the earliest, ten months after the injury, and eight men, aged 30-60 and fully employed at the time of injury, accepted the invitation to participate. One participant was on disability pension and was interviewed once. The level of consciousness was recorded through the Glasgow Coma Scale score (GCS) at the time of admission to intensive care: two men had minor, two men had moderate, and four men had severe injuries (Table 1). Furthermore, three participants had not passed neuropsychological tests for a driving licence. To our knowledge, and with one exception, a driving licence was not a necessity to commute for full-time work among those who did not pass the tests. No physical functional deficits were dominant; however, one man used a walking stick for balance when walking outdoors. The participants were skilled workers with full-time employment at the time of the injury. At the time of the first round of interviews, four men had returned to work; one man was in full-time work, and three men were in part-time work. Those mentioned had mainly taken up their former assignments in the same departments they worked in at the time of the injury. Three participants were on sick-leave, of whom two men were dismissed from former job assignments, and one man was on disability pension. Six months later when the third round of interviews took place, five men had re-entered their former employment, and another participant had temporary full-time work assignments for shorter periods (Table 1).

Insert Table 1 about here.

Procedure

In all, twenty-two interviews were conducted from January 2012 to March 2013 (Table 2). The interviews, which took 40 – 60 minutes, were digitally voice-recorded and transcribed verbatim. In addition to taking part in the interviews, the participants were invited to take a medical examination from a specialist in neurology, the second author of this article, before or after the interview sessions. Note that the medical assessments were not intended to be used in the study and thus were not included. The primary setting for data collection was the outpatient clinic at SRH. However, three interview sessions were conducted at the participants' workplaces at their own request. These participants were asked to contact health professionals to meet any possible medical and therapeutic needs.

Insert Table 2 about here.

Data analysis

Data collection and analysis were conducted in parallel, while interviewing, transcribing, and analysing the interviews, which were carried out by the first author (AJ). Generating the analysis process one salient feature was defined. The position, *an ongoing struggle through day and night*, was framed and defined as being significant for the participants' description of their trying to find new routines and mastery of activities in daily life. Furthermore, that concern was taken into consideration while more connected information was included in the sample of data.

Data analysis consisted of identifying and systematically comparing similarities and differences in the data in line with a constant comparative analysis [16]. Throughout, the categories that emerged were thoroughly questioned with the purpose of finding a pattern that illuminated the objective under consideration. First, the initial coding with the focus on labelling segments, which corresponded to critical incidents and actions expressed, was conducted. Second was a focused coding, in which hundreds of codes were sequenced into categories and labelled from an inner meaning, still using exactly the same wordings as in the texts. In a third step, categories and the initial codes were related to one another in order to give coherence to the analysis in progress, a so-called axial coding in the sense of making a reduction and clustering of categories. The most outstanding features were categories as follows: *facing up to the difficulties of a working life; pending time while accepting the slow rate of recovery; moderating activities to match current abilities; and attaining an adequate everyday life.*

Two central stages in conducting GT should be mentioned. First, throughout the entire process, notes were written whenever creative thinking brought new insight and knowledge to the data. Especially as the time came for the third step of analysis, described below, the notes were carefully read through in order to capture thoughts about emerging categories. As such, the memo-writing encouraged theoretical thinking and ideas during the coding process. Second, a central stage of the analysis process is theoretical sampling. Accordingly, theoretical sampling should be used, for instance, to keep the process moving towards the identification of variations of categories that emerge [13]. Referring to the statement, *theoretical sampling gives you the material to compare theoretical category with category*, p. 106 [13] in the present study, deeper knowledge on the participants' thinking about their own situations, was formed. These insights led to our understanding further that the participants

nursed a sense of self-estimated well-being related to participation. Therefore, during the theoretical sampling conducted through the last three interviews, experiences of mastering everyday activities were further penetrated, directing the participants to the categories under consideration. The theoretical sampling visualised the prospect the participants had in mind, although an ongoing struggle through day and night was apparent. In that respect the issue capturing the participants' uncertainty about the future was signalled. An excerpt of a deeper understanding of the four categories mentioned above was outlined into a single core category. Consequently the core category, *a desire for control: focusing on high-priority issues*, contributed to further comprehension about changes in daily activities. Throughout the process of analysing the data, the findings were discussed among the first and the fourth author (UJ) and also in the final step among all the authors until agreement was reached. In order to strengthen trustworthiness for the findings, a team of experienced professionals from the follow-up rehabilitation unit at SRH met regarding consensus about the improvements that participants in general have after leaving hospital.

FINDINGS

The consideration clause *an ongoing struggle through day and night*, revealed that the participants handled matters and tasks differently from the way they did before the injury. Verbalizing their experiences did not come easily to them. Eventually, four categories of exploring the aim, namely individual experience in developing a mastery of daily activities and roles after a TBI with the objective of returning to work, emerged. The categories were: facing up to the difficulties of a working life, pending time while accepting the slow rate of recovery, moderating activities to match current abilities, and attaining an adequate everyday life. The body of categories embraced different perspectives of the participants' adaptation to current capability. In facing up to the difficulties of a working life, a longing for a return to

former everyday life was apparent. Through a period of acceptance, the participants were in a tranquil state of mind exposing a patient attitude toward the slow rate of recovery. The third category, moderating activities to match current abilities, emphasized that the participants did their best to find a rhythm in daily routines. At last, in attaining an adequate everyday life, the participants expressed their desire to take part in society but still shared distrust in what the future might bring. Finally, a single core category emerged from the four previously mentioned, namely, *a desire for control: focusing on high-priority issues*. Understanding that the participants asked for counseling, we could see that they were enabling their persistence in their own abilities.

Facing up to the difficulties of a working life

The overall interests that highlighted the narratives were the participants' concern about return to work and their ambivalence in their abilities to keep going in the workforce. The participants delved into the matter of what people usually do and what is seen as an ordinary style of living. On that account, the year off work was described as a nuisance to them. Confronted with drawing a tableau of their doings for seven consecutive days, the participants said that it was incredible how little they did, yet they had the feeling of constantly being busy with something. The participants expressed their observations on the process of recovery in a reserved manner, saying that recovery was barely perceptible to them as *...it is getting better, but it takes so very much time*. In any case, one way of attaining a former role identity could be met by reclaiming former working routines, which could keep their identities inviolate. Therefore, when we raised the question about the meaning of work, they responded with several expressions of work's advantages; they spoke of a sociocultural as well as an individual fundament. The quotation below gives a general idea of the apprehension felt among those back at work.

It's to perform, to achieve something. And then there is getting some money for it. Getting positive feedback on what you do. And that you have a social network around you at work.

Additionally, the participants shared their reflections about the reciprocity involved in reclaiming one's post; to give back to society was important to them, as is apparent in the following utterance:

Well, when I think about meaning, I think you have an important job. You are part of society, you are a citizen – not just a consumer or on the edge of society where no one would notice if you disappeared.

Due to the participants' determination to take up work as soon as possible, they rushed the date for re-entry, although they were advised not to. One participant even chose to combine the follow-up rehabilitation period with vocational training at the workplace. Others showed - at an early stage - some reluctance in following doctors' orders to apply for a disability pension allowance. The participants regarded leading positions in their various fields highly and had hoped to attain them. However, re-evaluating their altered work abilities, the participants faced up to the fact that their former plans for a working career, eventually, would not come true.

I'm a little uncertain, I don't know. But I believe that in five years I will have come quite far and have managed to find a way to go, even if it is limited in relation to the

capacity I really had. I have realized that I may have the ability to work 70% or 80% or some reduced amount in relation to the 100% or 120% I actually have worked.

Probably, among the participants returning to work it was on the premise that they signal when to return to work, rather than when the professionals' indicated that they were able. When given the opportunity to have adjustments made at their work post, for instance, separate rooms to eliminate unwanted stimuli, the participants chose not to because they wanted to maintain collegial togetherness. Various re-engineering options were made available, such as taking long breaks for lunch that would allow for a rest or a slow walk in the neighbourhood, because a noisy lunchroom could be too stressful and would drain them of energy. However, the most applicable arrangements had to do with the number of working hours and the selection of tasks. Current official working hours were differentiated to adjust to their estimated capability. Eventually, a few participants worked longer hours to assure themselves of a satisfactory outcome to their tasks.

In order to become attractive on the job market, the participants considered various options. A few participants made quite radical arrangements, for instance, changing their living accommodations. These participants moved to districts close to the workplace or checked in at a bed and breakfast facility in order not to tire themselves out on transportation. One or two participants applied for complimentary courses. Those who did not return to their former employment attempted to take up meaningful interests, which reminded them of their former paid work. Thus, employment was not always highly regarded; that view came out as:

I find that what I am doing now is pleasurable. That I sit with my own tasks, and this is what I do and that's that. If I don't feel like it one day, I put it off to the next day. And it

goes just as well because there are no deadlines that have to be met. I don't know how it would work if I had those deadlines.

One participant took on temporary work assignments in line with previously enjoyed leisure time interests, while another one took up education again, even though it had been several years since the last professional training. Another participant favoured voluntary work, such as house maintenance.

Pending time while accepting the slow rate of recovery

Awaiting improvements, the participants were in a state of reconciling themselves and accepting the uncertainty they felt at leaving hospital. Throughout the days and nights, they tried to make the most out of their abilities, and beyond that they waited for things to get settled. The participants faced a solitary endeavor, in which they had to rely on their own determination for a possible recovery.

I think I've said it before, that I feel as though I'm on pause. I go around waiting for it to be okay again, but it isn't okay.

Among other feelings of uneasiness during the period of acceptance, the participants expressed a sense of vulnerability to changes in their daily activities. Their ability to take the initiative was far-off. Every now and then, they struggled at eating regularly. They quite simply forgot to eat, which troubled them, knowing that they needed to maintain their energy. Mainly, they showed persistence in increasing their physical strength with training schedules and time for rest and sleep. The participants appreciated support from their families and their social network's encouraging words. On the whole it became very much up to the participants

to surmount barriers relating to their ambition. However, with no one around, they could descend into a passive state, in which they did not pay much interest to ordinary matters. Anybody could have inspired them to do something, to clear away the dishes, for instance. Another intricate matter that also gave them the feeling of solitude was their vulnerability to stimuli. The decline in social activity made some of them frustrated and feeling uncomfortable in unfamiliar or larger gatherings. That isolation troubled them, particularly when they were in public places, because they found themselves somewhat reluctant to participate socially. Therefore, the participants' comments on this issue were that they were not as socially outgoing as they had been. Their homes became the place where they could unwind and recharge their batteries.

In order to increase their abilities to make things go smoothly and accurately, the participants expressed a desire to understand their progress. At the discharge from hospital, the participants felt they were entitled to their own judgements. Having achieved improvements, they asked for devices and information about how to design strategies that would be compatible with their improvements. Therefore, the participants would welcome advice on establishing an acceptable rate of recovery. Irrationally enough though, once they had drawn up plans and schedules and seemed to have everything figured out, they lacked the spark to get started.

No, I manage to take care of most things. But me, I feel I have no driving force or energy. I don't have any suggestions or solutions for putting things in order. Without that, [someone or something] must come and *Can you, can you?* And then I can do it.

More likely, the months following rehabilitation gave them plenty of time to think about their own situations. Their physical abilities had increased, and they managed to do some things with less strain; however, they asked for other more subtle and sophisticated methods to cope with their daily activities.

Moderating activities to match current abilities

The first period of a vacuum-like state was gradually transformed into a period of pushing boundaries. Still, the participants were not quite convinced that they could manage on their own. The participants' concerns involved not just their physical endurance, but also their abilities to keep their domestic lives going. Moreover, the participants did not feel that they had attained their style of living, which prompted the following utterance, in which the participant's need to sort out what to do is what mattered.

And that has been my challenge, when I have come home and not met anyone at home. And not met psychologists or therapists or doctors or whoever it might be. So I revolve in my own inactivity. And in a sense I'm locked in. Instead of being met, to be allowed to unburden myself but also to be confronted: *What are you actually doing?* I ask myself this and sort of avoid it. Being one's own therapist – this is a challenge. And I have missed meeting other people who also are thinking: *What should we do in future?*

Returning to work was a challenging period for the participants. Time for a good night's sleep was a must-do on a twenty-four-hour agenda. Even so, the next day could become a discomfort when not feeling fit enough for another day at work. Noteworthy is the following assertion: *I feel that I use as much as I can at work. And then when I come home, there is*

nothing left. This statement serves as an illustration of the effect the participants' engagement in paid work could have on housework and leisure-time activities.

The participants took actions to open up further possibilities in controlling their everyday lives. Moderating activities to match current abilities, the participants spent more time with family members and household chores. The season of the year influenced the activities in which they were interested. During the summer, they did not hesitate to take up more challenging tasks like maintenance work on the family house or weekend cottage or vehicles. The participants described themselves with enthusiasm as human beings that were... *a little slow to begin with but when I get going, I'm difficult to stop*. The participants, doubtful about their vocational lives asked themselves if they should continue to be part of the workforce, or would it be more appropriate for them to apply for a disability pension. It was too soon to say since they felt that they could do even better as time progressed, and they stressed that they would give this try-out period five years. Hopefully, they reasoned, there would be another three years to work things out.

The participants' ambivalence and uncertainty made them express the need for therapeutic sessions, which they thought might help to sort their priorities. In addition, medical examinations by a specialist would further explain their improvements. All that and the employers' positive attitude were highlighted as vital factors. In paid work situations, it was not that the participants asked for mentorship or coaching, but a weekly fifteen-minute follow-up session would do. Otherwise, they were very much left on their own. Another common statement they made was that they needed to curb their eagerness with respect to their own demands for fulfillment; this restraint might unburden them from tiredness.

Because I have to make my own private schedule, I must decide, get done what I need to do. Actually solve, identify and solve problems. And not only at work. There is something to do with private life that I have not got hold of yet, but must take with me home now.

Attaining an adequate everyday life

Facing up to the goal of attaining an adequate everyday life, the participants recognized that they did not quite manage to meet their expectations, especially at work. The most significant remark they made was that they were not fully satisfied with what they accomplished, though their principles told them the work was satisfactorily done. Perhaps some days they agreed that their work was fine, but on other days, far from it, and that uncertainty made them reconsider their predicament. Still, two years after injury, each and every one of the participants was uncertain about their efficiency with respect to what was expected from them in domestic life as well as at work, and that doubt made them linger on the subject.

One just can't manage to handle everyday life at work well enough to function efficiently. I have to get up from my chair and wander around a bit, and then I have to try to grab my thoughts and say: *Get a hold of yourself, don't sit like this. Try to systematize what you are going to do.* ... and after a round of this it can go well or the whole day can be horrible, as far as feelings are concerned.

In spite of the participants' devotion to work, they began to judge their efforts in relation to the advantages they experienced. Their fear of not taking care of their health perhaps could be a concern for them in the future. The participants commented on a decreased ability to endure and be effective, which they felt could jeopardize their jobs. Participants in their sixties

considered an early pension as a possible way out of their dilemma and, of course, also out of the job market.

When you get tired, you think it's all too much. You will wear yourself out. You will die young. It's just this that destroys the rest of life. In such situations, retirement can be seductive.

Nor were the younger participants confident that full-time work was manageable with a satisfactory family life.

If it becomes problematic, I'll scale down for a period, if necessary. But I am not intending to do so, because I intend to do a full-time job.

Finally, the question: "What will the future bring?" remained unanswered, in particular with respect to the participants' working prospects. The participants were in doubt. Their uneasiness cast doubt on their beliefs in themselves and their abilities to improve their work capacities, find a suitable balance between daily activities and work, and sustain their health and efficacy.

Thus, the main finding of this study, covering a period of approximately one to two years after TBI, was that the participants experienced this time as a period to carry out and test their own abilities and endurance. The participants were constantly trying to achieve their former capabilities, carrying on day by day meaningful activities and moderating domestic tasks and paid work. Being observant of abilities and asking for counseling seemed to be important for re-entry to the workforce and sustained efforts. Moreover, a few participants considered

education for alternative work just to become desirable on the job market. Considering the public's response as well as employers' decisions about the level of work ability caused stress for the participants because they felt they had not yet reached their optimal level of recovery. In accordance with the participants' narratives, one possible avenue to confronting barriers would be updated strategies and techniques in adapting to current capabilities. In addition, regular feedback and counseling might be a way to move forward. Consequently, the core category appeared to be *a desire for control: focusing on high-priority issues*.

DISCUSSION

The purpose of this study was to explore individual experiences in mastering daily activities and roles after a TBI with the objective of returning to work. From this study, four categories emerged: *facing up to the difficulties of a working life; pending time while accepting the slow rate of recovery; moderating activities to match current abilities; and attaining an adequate everyday life*. From these four categories, the single core category *a desire for control: focusing on high-priority issues* developed. Several elements of moderating features became apparent while the participants struggled to re-order their daily activities, including the need to understand their priorities. However, the theory of salutogenesis [18] suggests that a sense of coherence can be achieved if previous experience with controlling incidents is harnessed to deal with the new more extraordinary events, laying the foundation for perceived good health. A literature review [19] regarding the relationship between the salutogenic model and health identified certain key points. First, comprehensibility, manageability, and meaningfulness were highlighted as three components that can promote both physical and mental health. Another aspect is the theory of occupational adaptation [20, 21], which states that preferences for activities that one is engaged in before illness are of great importance if one needs to change roles afterwards. This means that skills in setting up goals in the context of one's

environment for the future can guide a person in establishing new activities and roles after a disability [20, 21]. According to the model of GT, one abstract way to articulate *how and why the participants construct meanings and actions in specific situations*, p. 130 [13] is to interpret the relationship between the two subjects in order to reach an extended knowledge of the matter under consideration. In the current study, a developing theory can be understood as follows: the interpretation of the findings based on the clause *an ongoing struggle through day and night* became comprehensible whenever the participants' desires and engagement were explained by the core category *a desire for control: focusing on high-priority issues*. In accordance with the theories presented above, the findings of this study focused on the participants' decisions regarding how to modify daily activities and roles, especially those choices intended to promote a return to work.

The core category *a desire for control: focusing on high-priority issues* highlighted in the present study is grounded in the participants' persistence in establishing strategies and techniques and requesting feedback and counseling to compensate for changed modalities in memory and endurance. One could argue that the participants' reduced abilities might negatively influence their social participation in family life as well as work. Lifestyle balance has been described as a continuum between the activities human beings want to spend time on and the activities they actually take part in [22]. The theory of lifestyle balance is one of a number of models based on the assumption that people experience well-being when involved in challenging activities that require competence and engagement [22, 23]. In such a model, performing especially meaningful activities is vitally important to one's well-being [24]. However, one other aspect to consider is their inaccurate assessment of their own skills. In the current study, the participants' efforts to accept everyday challenges might eventually result in meeting their expectations regarding well-being. For example, perceived good health might

influence one's self-efficacy and personal causation; that is, *the individual's unique awareness of capacity and effectiveness in relation to... (that person's)... desired outcome*, p. 42-3 [25] is crucial for returning to work. The desire to control what one does and when and how it is done is common among individuals who are recovering from a severe illness and consequently deserves consideration. An individual perspective has been highlighted in a study about re-entry to work after stroke [26], demonstrating the participants' mixed emotions and concerns regarding work arrangements, such as having someone to confide in and the option of performing less demanding tasks. The participants' lack of confidence when they spoke about control was also apparent. However, we believe that our study shows that mastery of everyday activities is very important to those who have experienced TBI, especially as it relates to *moderating activities to match current abilities* and *attaining an adequate everyday life*. The findings of this study, in which the participants demonstrated that focusing on success at work combined with a desire for control might be a marker for an individual's own improvement after a TBI.

In the present study, our assumption about balancing activities was derived from the categories *facing up to the difficulties of a working life* and *pending time while accepting the slow rate of recovery*. Changes in the participants' private lives, such as changing their living arrangements to allow them to do their best at work, made them push their limits of endurance. The participants frequently expressed unease about their ability to perform their work. The participants scheduled activities and sleep to ensure that they would have sufficient reservoirs of energy and would therefore feel pleased with their efforts at work. The participants held the unique viewpoint that work required them to balance a wide variety of issues, requiring plasticity in adaptation skills. A case study of a worker who had experienced TBI mentioned that the employer noticed that the worker had difficulty multitasking [27]. The

following elements, such as reconciliation with new identities, opportunities to try out one's capability versus the risk of failure, and support were determined to be crucial for returning to work [28]. However, in the present study, an individual's resources such as reflective thinking, awareness, and willingness to accept changes seemed to be valuable when the participants set goals and established outcomes of training after they were discharged from the rehabilitation unit. They also showed an interest in balancing domestic chores and self-care activities to ensure that they could fulfil expectations on task performance at work. In our study, questions about the amount of time spent on daily chores in relation to the participants' expectations regarding the benefit of improvement in structures and routines in daily life were not satisfactorily answered by the participants. During the first interview sessions, the participants gave vague answers in response to questions about housework. During the third interview, they said they were not observant enough about what needed to be done and therefore delayed what presumably should have been done. Observations [29] regarding the time spent on household tasks found that men spend fewer hours performing housework than women. In addition, some men and women consider household tasks to be secondary activities [29]. In the present study, which focused on the ten-month to 28-month period after suffering TBI, the participants' viewed housework, which required approximately two hours per day, as a secondary activity. We concluded that household chores and maintenance work on family house and vehicles alone were not sufficient to equip a TBI survivor with the necessary skills to create new structures or routines. The participants expressed a desire to have structure in daily life, and the workplace appeared to be the most appropriate environment in which to achieve former structure and routines. Activities and actions that are repeated frequently are internalized as former roles, and new roles can also be formed, expanding an individual's repertoire of roles. The environment can also affect how a person reacts to a changed life situation[30]. Additionally, a person's engagement in occupations

rather than a focus on performance has a positive effect on balancing daily life activities and roles [30, 31]. The participants in the present study indicated their desire to establish confidence in their own skills. It is clear that the participants felt insecure about their ability to perform at work. They also had no one to provide feedback about their decisions. However, there is an ongoing debate as to what might promote an individual's perceived self-efficacy, enabling confidence in his own skills, p. 202 [32]. In our opinion, the participants' *desire for control; focusing on high priority issues* might be achieved through modification of activities to balance occupations and roles. The results indicated that the participants, acknowledging the adversity of working with a disability, placed a higher priority on their performance at work than on their ability to accomplish household chores and participate in social activities.

Methodological considerations

The design of this study was descriptive with an explorative and listening approach. The interviews, three per participant, were performed consecutively over a six-month period. The conversations were not designed to be interventional. However, the interviews could be experienced as interventions since the participants expressed a need for someone to talk to. In general, the interview guide determined the topic of conversation during the first round of interviews. In addition, the early data analysis revealed issues that enriched the following sessions. The sessions were to begin with the interviewer asking questions and the participants responding. The participants were often very interested in the topics, and the amount of time spent talking about special topics increased as the interviews progressed. The interviewer encouraged the participants to expand on their experiences. Topics for which the participants had previously failed to provide adequate answers could be revisited at a subsequent interview after the participants had time to prepare themselves, rethinking and writing notes. In many ways, the third interview session was led by the participants, although,

the interviewer ensured that the objective of each question was met. There was a more relaxed atmosphere during the third session. This change in atmosphere was not due to the location because the locations varied. Accordingly, the interviews became conversational partnerships, in which therapeutic knowledge could be shared [33].

A maximum of two interviews were performed each day, and there was considerable time allowed for transcription and data analysis after each interview. The question of saturation depends on how well the data collected answered the question under consideration [14]. Accordingly, the theoretical sampling could enrich the perspectives of the objective [13]. In addition, the collegial peer-review, provision of the participants with information about the concise categories, and the literature review improved the trustworthiness of the study. The findings of a qualitative analysis cannot be generalised; however these findings certainly contributed to a deeper understanding of the final core category, which might help others in a similar situation. The concordance between the interviews and this paper is strengthened by our use of quotations from the participants' narratives within the appropriate context. However, we explicitly emphasize that the quotations chosen reflect the experiences of all of the participants unless specifically noted otherwise. Moreover, the quotations aim to give voice to a specific category that was mentioned by the majority of the participants albeit in varying ways.

Conclusion

The focus on the participants' attempts to improve their ability to match former standards was mainly expressed in the four categories: *facing up to the difficulties of a working life; pending time while accepting the slow rate of recovery; moderating activities to match current abilities; and attaining an adequate everyday life*; of these four categories, the core category *a*

desire for control: focusing on high-priority issues emerged as most important. The participants placed a higher priority on work performance than on domestic tasks or social interaction, indicating their aspiration to return to work and sustain the workforce. In assessing the participants' awareness of their need to adapt to their current capability and endurance, it became clear in that they would like help developing strategies to master everyday activities. Infrequent feedback decreased their confidence in their own skills, potentially jeopardizing their jobs. Thus, the workplace might be the ideal context in which to develop the structures and routines necessary to master life in general.

Clinical Implication

Two years after an injury, the participants were still assessing their abilities to perform at work and at home. They felt that they would improve with time. The participants could contribute to their own improvement by broadening their knowledge of strategies to make their daily routines compatible with their current abilities and asking for feedback and guidance. Medical and therapeutic counseling would also contribute to their well-being. In a multidisciplinary context, these tasks could be accomplished in rehabilitation programmes. A consequence of our main finding is that counseling about work-related issues should be considered to be an integral part of any rehabilitation programs after TBI.

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Conflicts of interest

No conflict of interest has been declared by the authors.

Author contributions

Annica Johansson collected and analysed the data and wrote the paper. Ulla Johansson supervised during the analysis. Tor Haugstad saw the participants during medical controls. All of the authors participated in designing the study and critically reviewed the final paper.

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Table 1. Demographic data, and work assignments

Demographic data			First interview		Third interview					
ID	GCS*)	Education (years)	Work position (white/blue collar)	Living arrangement	Living area	Time since injury (months)	Working hours (%)	Time since injury (months)	Working hours (%)	Disability pension (dip)
1	14	> 12	white	alone	urban	15	100	22	100	
2	10	≤ 12	blue	family	urban	21	27	28	40	
3	09	> 12	white	alone	urban	13	60	20	70	applied for a dp
4	7	> 12	white	alone	rural	15	0	21	0	
5	7	≤ 12	blue	alone	rural	19	0	unknown	0	on dp
6	7	> 12	white	alone	rural	15	0	21	100	
7	8	≤ 12	white	family	urban	10	40	16	100	
8	16	> 12	blue	family	rural	15	0	22	48	

*) GCS: severe 3-8, moderate 9-12, minor 13 -15, diffuse head injury 16

Table 2. The distribution of the interviews over the period for data sampling

ID												
	2012 Jan	Feb	Mar	Apr	May	July	Aug	Sep	Nov	Dec	2013 Mar	
1	I			II			III					
2	I			II		III						
3	I			II		III						
4		I	II				III					
5			I									
6					I			II	III*			
7					I			II*		III*		
8									II		III	

I, II, III) the first, second and third rounds of interviews; the two drafts respectively
 *) the interview conducted at the participant's workplace

