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ENGAGEMENT IN OCCUPATIONS  
IN PERSONS WITH MULTIPLE SCLEROSIS



# ENGAGEMENT IN OCCUPATIONS IN PERSONS WITH MULTIPLE SCLEROSIS

Eva Månsson Lexell

Akademisk avhandling

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Docent Kerstin Tham

Institutionen för neurobiologi, vårdvetenskap och samhälle  
Karolinska Institutet, Huddinge



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Abstract The overall aim of this thesis was to increase our knowledge of engagement in occupations in persons with Multiple Sclerosis (MS) in order to develop client-centred occupational therapy and rehabilitation. In study I, observations of the performance of self-care and household occupations were pursued in 44 participants, and study II identified self-perceived problems in performance of occupations in 47 participants. In studies III and IV, in-depth interviews with ten participants revealed experiences related to engagement in occupations and to the process of adaptation of engagement in occupations. The results showed that persons with MS can perceive problems related to all areas of occupations, and at different hierarchical levels. They can be dissatisfied with performance in occupations, especially related to self-care and household occupations and observational assessments confirm that performance in these occupations is impacted on. Furthermore, they can be independent in self-care but dependent in household occupations, and can have problems in their performance regardless of their age, disease severity, or their living arrangements. They can experience that they need to struggle continuously to manage occupations, and that this changes them as a person and make them live their lives differently than they had anticipated. In addition, they experience their adaptation of engagement in occupations as an ongoing, non-linear process, involving both themselves and their family, and they consider who would benefit the most, before they choose their adaptation of engagement in occupations. In summary, this thesis has shown that engagement in occupations in persons with MS is a complex phenomenon. All areas of occupations can be affected, and need to be addressed within occupational therapy and rehabilitation. Clients' own experiences needs to be elucidated in order to facilitate the reconstruction of self, identity and support the process of adaptation of occupations.		
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## List of Publications

This thesis is based on the following studies which will be referred to in the text by their Roman numerals:

- I. Månsson E & Lexell J. (2004). Performance of activities of daily living in Multiple Sclerosis. *Disability and Rehabilitation* 26:576–585.
- II. Lexell E M, Iwarsson S & Lexell J. (2006). The complexity of daily occupations in Multiple Sclerosis. *Scandinavian Journal of Occupational Therapy* 13:241–248.
- III. Lexell E M, Lund M L & Iwarsson S. (in press). A constantly changing life: experiences of persons with Multiple Sclerosis. *American Journal of Occupational Therapy*.
- IV. Lexell E M, Iwarsson S & Lund M L. The ongoing process of adaptation of engagement in occupations as experienced by persons with Multiple Sclerosis. Submitted.

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## Preface

This thesis is based on my experiences as a clinical occupational therapist (OT) in a team working with persons with chronic neurological diseases, especially Multiple Sclerosis (MS). At the beginning of my career, OTs focused on hand function and primary daily occupations, i.e., on issues related to personal hygiene, dressing and mobility. Even though many of the interventions focused on occupations, evaluations of body function were performed pre- and post rehabilitation, and were often only used as a measure of the outcome. In addition to this, the goals and interventions were established from the perspective of the therapists rather than from that of the persons with MS.

Gradually, along with new trends in rehabilitation and occupational therapy, I moved towards a more client-centred approach, also incorporating a range of assessments that captured different aspects of a person's occupational performance. Still, it was my experience that, from working at our department,

persons with MS experienced difficulties in all areas of occupations, and as a clinical OT I worked with all types of occupational issues. This was not sufficiently reflected in the literature, and yet all of the large outcome studies of rehabilitation for persons with MS have chosen instruments that focus on primary daily occupations.

Since this is a thesis in occupational therapy, I am directing it towards OTs but it is also written with other professionals in mind that meet clients with MS, in the hope that the knowledge gained from conducting this thesis will enhance occupational therapy and rehabilitation services for persons with MS. However, I started the journey of writing this thesis with the incentive of improving the lives of those living with MS. In the end, my greatest wish is that the knowledge gained will enhance their lives so that they may engage in those occupations they find meaningful and thereby live their lives to the full.



# Engagement in Occupations in Persons with Multiple Sclerosis

Eva Månsson Lexell

## Introduction

This thesis focuses on the engagement of persons with Multiple Sclerosis (MS) in occupations: engagement in occupations is a central concept in occupational therapy. This concept is used in clinical practise and in research to describe both the means and the ends of occupational therapists' work (Hasselkus, 2000), and is considered to be an important factor for health and well-being (Wilcock, 1998a; Townsend & Polatajko, 2007).

This thesis encompasses two major aspects of engagement in occupation, namely the 'performance of occupations' and the 'experiences of occupations'. These two aspects reflect the two-body practice of occupational therapy in which OTs try to connect the

biomedical view with the phenomenological view, as described by Mattingly and Fleming (1994). Interventions, in the biomedical view, are aimed at disease-related dysfunctions whereas the phenomenological view is concerned with how clients experience their illness and, consequently, interventions are directed towards the experience of being ill (Mattingly & Fleming, 1994). OTs have to handle both perspectives, which is reflected in this thesis.

There are several definitions of occupation that have been introduced by several authors over time, and which are sometimes congruent and sometimes conflicting. I will introduce different aspects of the concept of occupation, and present the definitions which I have chosen to use for this thesis.

## **Definitions and current trends on the concept of occupation**

Occupation has been defined as ‘groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)’ (Townsend, 2002, p. 34). The performance of occupations, e.g., the doing of tasks, has typically been defined as the outcome of the relationship between the occupation, the person and the environment (Townsend, 1997). This was further developed in 2007 when the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007) was presented, incorporating a broader perspective than that of performance alone. The concept of engagement in occupations is central to this thesis, and has been defined as the individual’s involvement in, and motivation to participate in an occupation even if the person cannot perform it independently (Townsend & Polatajko, 2007; Kielhofner, 2008). That is, instead of referring solely to *performing* occupations, one can instead talk of *having* occupations (Townsend & Polatajko, 2007), about which, little is known for persons with MS.

The importance of incorporating value and meaning in the concept of occupation has been emphasised by several authors (Hasselkus, 2002; Persson *et al.*, 2001). Occupations can be both purposeful and meaningful, where purposefulness refers to the goal or the reason for doing an occupation, and meaningfulness motivates and gives personal significance to the performance for the person concerned (Trombly, 1995; Fisher, 1998). Consequently, learning what is meaningful to our clients requires us to let him/her re-

count his/her personal experiences (Hasselkus, 2002), and also to categorise occupations according to their different dimensions of meaningfulness to the person, through the concepts of ‘doing, being, becoming, and belonging’ (Wilcock, 1998b; Hammell, 2004). These concepts include the performance aspect of fulfilling purposeful occupations (doing), how we experience our lives, contemplate, and develop a sense of self (being), our social context where occupations take place (belonging), and our hopes and wishes concerning what we will be, do, and contribute to others in the future (becoming). This way of categorising occupations is not commonly acknowledged by OTs active in the field of rehabilitation, and especially not for clients with MS.

In clinical practise, occupations are often categorised, typically into three occupational areas; i) self-care or activities of daily living (ADL) involved in taking care of oneself; ii) leisure or play, including hobbies, games, etc; and iii) productivity, including paid and unpaid work (Townsend, 2002; Kielhofner, 2008). Within the rehabilitation context, ADL is generally the group of occupations given most attention, and these occupations are further divided into personal activities of daily living (P-ADL) and instrumental activities of daily living (I-ADL). P-ADL includes tasks such as toileting, dressing, eating, grooming, ambulation and bathing. I-ADL refers to more complex tasks such as communication, shopping, transportation and domestic activities (i.e., cooking, house-keeping and laundry) (Lawton & Brody, 1969; Sonn & Åsberg, 1991). The different papers incorporated in this thesis, have used occupation as well as ADL, but I have chosen to use *occupation* consistently throughout this thesis when I am referring to activities that have meaning and purpose for the clients in question. However, my view of the relation between occupation and activity has to be further clarified.

Instead of categorising occupations according to areas, they can be hierarchically ordered, where, according to the CMOP-E (Townsend & Polatajko, 2007), the concept of occupation is viewed as the overarching concept (Polatajko *et al.*, 2004). This comprises a taxonomy including different levels of occupational performance: occupation, activity, task, action and voluntary movement/mental processes, i.e., the Taxonomic Code of Occupational Performance (TCOP). The levels are hierarchically ordered depending on their complexity, where activities are defined as the outcome of a set of tasks with a clear end-point. Occupations, on the other hand, are defined as being 'a set of activities that is performed with some consistency and regularity that brings structure, and is given value and meaning by individuals and a culture' (Polatajko *et al.*, 2004, p. 19). Another way of categorising occupations is by including a time perspective. Occupations can either be viewed 'here and now' (the micro or the meso perspective) or through a person's whole life situation (the macro perspective), as described in the Value, Meaning and Occupation Model (ValMO) (Persson *et al.*, 2001). In this model, the micro and meso perspectives are comparable to the levels of action, task and activity, described in the TCOP. For instance, the smallest micro level in the ValMO model is an operation, whereas similar examples are called actions in the TCOP. Actions/operations are made with the intention of accomplishing an occupation that has meaning and value for the person concerned. Moreover, in order to accomplish an occupation, a person must complete a number of goal-directed actions in a sequential order; these actions can also be referred to as skills (Fisher, 2006a). There are three different types of skills, motor skills, process skills and communication and interactions skills (Fisher, 2006a; Kielhofner, 2008). The different goal-directed skills are defined as actions that are intended to move oneself or task objects

(motor skills), organise things, place things in a logical sequence, or adapt one's performance (process skills), and actions involving social interactions with other people (communication and interactions skills) (Fisher, 2006a; Kielhofner, 2008).

In medical rehabilitation settings, the terminology adopted in the ICF classification (WHO, 2001) is widely used to describe the consequences of a disease or injury in relation to health. Consequently, OTs need to position the concept of occupation in conjunction with this terminology. The ICF classification provides a uniform terminology for functioning, disability and health in two major areas; Functioning and Disability, and Contextual factors. Functioning and Disability include two components; body structures and functions; and activity and participation. Contextual factors comprise environmental and personal factors. All these components interact with, and influence a person's health. The ICF defines activity as a person's execution of a task or action, and participation is defined as involvement in a life situation. The classification has acknowledged that activity and participation can be considered at the same time, while it may be difficult to separate them, regarding the individual and the social perspective (WHO, 2001). Some OTs use occupation and activity interchangeably, with the intention of facilitating the understanding between professions (Clark, 2002), but participation is also viewed as being incorporated within the concept of occupation (Law, 2002; Townsend & Polatajko, 2007). Yet, even if the definition of occupation is similar to the definition of participation in the ICF, i.e., 'involvement in a life situation', the ICF has been criticised for not fully incorporating the subjective experience of meaning. That is, when the coding scheme in the ICF is used, the coding is made from an outsider's perspective, excluding the subjective experience (Hemmingsson & Jonsen, 2005).



## **Reflections on occupation and its influence on identity and self**

Several authors within psychology and sociology have described theories on self and identity, but since this is a thesis in occupational therapy, my focus has been on these concepts from an OT perspective, that is, how they influence engagement in occupations. Christiansen (1999) introduced the connection between identity and occupation, and stated that occupations form our identity. Thus, by being occupied, we maintain and build our identity. He differentiated between identity and self, by saying that identity is the way we label ourselves in the context of others, and that identity is built from how we view ourselves; i.e., the self. In addition, he argued that occupations are influenced by self and identity through engagement in occupations, and through the process of interaction with others (Christiansen, 2004). Later, Kielhofner (2002), added to this by establishing the concept of occupational identity. He stated that our occupational identity is a composite of several factors, and linked some of the cornerstones of the model of human occupation – the volition, habituation and experience of the lived body – to the concept of occupational identity. Thus, occupational identity includes a synthesis of how we view ourselves in terms of our capacity and effectiveness for doing, our preferences regarding doing, our roles and relations, and possibilities arising from and restraints imposed by our surrounding environment. All of these reflect a person's experiences of self, over time, involving his perceptions of the past, present and future (Kielhofner, 2008). Furthermore, Charmaz (2002) added to the knowledge of how occupations are influenced by our sense of self. She argued that self and habits are closely related, because our habits are automatised within our behaviour, and thus, influence our self, and vice versa. Hence, when a person needs

to develop new routines and habits owing to chronic illness, this will involve the reconstruction of their self and identity.

## **Multiple Sclerosis**

MS is an inflammatory demyelinating disease of the central nervous system and one of the most common causes of disability among young and middle-aged men and women. In Sweden, there are about 12, 000 people living with MS with an annual incidence of about 300–500 new cases. The typical age of onset is 20–50 years and MS is twice as common among women as among men (Ryberg & Hillert, 2006). The course of the disease is unpredictable and has individual variations including relapses with total recovery to progressions leading to severe disability. In most cases, the disease begins with a relapsing-remitting course (RRMS), i.e., infrequent relapses that either lead to total recovery or leave some disability. After 10–15 years, most of those with MS gradually develop a more progressive phase, the secondary progressive course (SPMS), where the person develops a more pronounced disability over the years. A few people with MS have a disease that follows a more progressive course right from the beginning, known as primary progressive MS (PPMS) (Lublin & Reingold, 1996).

MS can lead to a large variety of impairments, for example paresis, sensory loss, fatigue, bladder dysfunction, cognitive dysfunction, spasticity, dysarthria, weakness and pain (Kesselring & Beer, 2005). Most of the physical impairments are well known, and the fact that about 50 % of all persons with MS suffer from cognitive impairments (Rao *et al.*, 1991a) is becoming more acknowledged. The most frequent cognitive impairments among persons with MS are related to memory (both recent and long-term), sustained attention, and abstract reasoning, and they can be prominent in all stages of the disease (Rogers & Panegyres, 2007). Fatigue is another

impairment which is very common: about 40% of the MS population report problems related to fatigue (Bakshi, 2003) and many of them experience exhaustion, specified as being different from physical tiredness or being in a depressed mood (Krupp, 2003).

## Consequences for and experiences of daily life

Some researchers have focused on disease-related impairments and their consequences on daily life. The impairments considered include cognitive problems (Rao *et al.*, 1991b; Amato *et al.*, 2006), and spasticity (Barnes *et al.*, 2003), but other investigations have considered such issues as whether measures of physical functioning can predict performance in occupations (Paltamaa *et al.*, 2007). Since all of these researchers focused on specific body functions, their aim was not to describe the general consequences for daily life. This has, however, been described by several other authors who gathered their data through either postal-surveys or structured interviews. These were not specifically targeted to occupations, but included questions that covered certain occupational areas. They reported that most of the participants had problems with self-care, and some with household occupations, too, and that many had had to give up some recreational occupations. In addition, many participants reported that they were in need of help, economically and practically, to manage their daily life (Cervera-Deval *et al.*, 1994; Rodriguez *et al.*, 1994; Midgard *et al.*, 1996; Gulick, 1998; Hakim *et al.*, 2000; McDonnell & Hawkins, 2001; Sundström *et al.*, 2003). Contrasting results were reported regarding ability to work, ranging from one investigation in which it was reported that almost all of the participants were able to work full-time (Rodriguez *et al.*, 1994) to another in which only 25% were able to do so (McDonnell & Hawkins, 2001). In addition, during the time in which the studies included this

thesis were accomplished, a multidisciplinary research group in Stockholm, Sweden, started to describe functioning, disability and health-related quality of life (HRQoL) in a population-based study of 166 persons with MS. The results were summarised in two separate theses (Einarsson, 2006; Gottberg, 2006) and showed that, where everyday occupations are concerned, about half of the participants were independent in terms of self-care, a third could manage their household occupations unaided, and about another third reported having no problems related to social/lifestyle occupations. HRQoL was negatively affected overall, but was particularly poor in the areas of home management, walking and recreation. The authors used the ICF framework as a guide for the collection of their data, which was obtained through different assessments conducted in home visits. It is, however, not clear if the assessments of daily occupations were obtained by observation or if the forms were used as interview guides or for self-reporting questionnaires.

Some studies have been conducted with the specific aim of gaining insight into the consequences that performance difficulties have on all types of daily occupations of those with MS. Two of these reported problems with occupations had an impact on each of the following: general mobility, employment, mobility in the community, maintaining the garden, and heavy housework (Finlayson *et al.*, 1998; Mosley *et al.*, 2003). Another study reported that half of the 30 participants with MS were dissatisfied with their occupations, and that those that were satisfied with their life were less tired, more independent in terms of self care, and more satisfied with their leisure time and housekeeping ability (Lundmark & Bränholm, 1996). The authors also concluded that these occupations appear to have an impact on the satisfaction experienced by their subjects. Still, these studies used questionnaires offering fixed alternatives, and therefore it is possible that there

are occupations that are problematic to people with MS that have not yet been captured. Furthermore, in addition to the self-reports, performance in occupations has been observed and assessed by professionals in only a few studies. These have often focused on self-care and have been conducted with the intention of comparing different assessment tools (Granger *et al.*, 1990) or evaluating the effects of rehabilitation programmes (Freeman *et al.*, 1997; Solari *et al.*, 1999; Khan *et al.*, 2008a). Doble and coworkers (1994) assessed performance in household occupations with the aim of describing the participants performance, and found that more than half of the 22 participants had problems in occupations related to household tasks. However, for most of their participants, the severity of their disease was mild and, since most of the clients that receive recurring rehabilitation have a disease with a more pronounced severity, there is a need for studies to be conducted on a sample comprised of those with a disease of more pronounced severity. Moreover, most of the results on performance in occupations have only been presented as a composite score, and hence, it is difficult to identify the items for which the participants had the most problems. Furthermore, none of these studies encompassed simultaneous assessments of the performance of both self-care and household occupations.

Some recent research has focused on experiences of living with MS, some of which has explored psychological aspects (Courts *et al.*, 2004; Miller, 1997), common physical symptoms such as fatigue or incontinence (Flensner *et al.*, 2003; Olsson *et al.*, 2005), the presence and meaning of chronic sorrow (Isaksson *et al.*, 2007b), and the experience of quality of life (Reynolds & Prior, 2003; Somerset *et al.*, 2002). These studies only briefly touched upon occupations, but they showed that common MS symptoms do influence engagement in occupations, and that being able to engage in occupations is important for

having a positive experience of quality of life and living with MS. Engagement in occupations has also been explored among women, of whom the majority had MS, focusing on the impact that occupations have on identity. This investigation revealed that changed or reduced occupations influenced the women's identity, made them strive to maintain their usual routines, and that the possibility of continued engagement in meaningful occupations could provide a source of positive identity for people living with chronic illness (Magnus, 2001; Reynolds & Prior, 2003). Reynolds and Prior (2003) also described that women with MS experience life as an ongoing process of negotiation to feel healthy. Others have focused on the role of the home environment and concluded that person-environment interactions influenced participants' experiences of engaging in occupations and the meaning their home held for them (Lund & Nygård, 2004). However, since previous studies only focused on certain aspects of the experience of engagement, or indirectly on occupations, the entire range of consequences of engagement in occupations remains to be explored in persons with MS.

### ***The concept of adaptation and adaptation to the MS disease***

People with a chronic illness, such as MS, have to adapt their lives to the changed circumstances that the illness imposes on them and, therefore, it is inevitable that adaptation is a major issue for these clients. Adaptation is a broad, general term for the different psychological and biological reactions based on the interaction between the person and his/her environment (White, 1974; Elfström, 2007). Different concepts of adaptation have been used by different disciplines, sometimes as synonyms, such as adaptation, adjustment, coping or mastery. Within occupational therapy, adaptation is viewed as being similar to

the broader definition of adaptation, but it is described in relation to occupations. Hence, occupational adaptation is defined as a process in which people act in order to manage occupational challenges (Schkade & Schultz, 1992). A person's experiences of previous occupational adaptations will also influence any novel challenges encountered in the future, and thus influence occupational functioning as too. Kielhofner (2002, 2008) described occupational adaptation as the outcome of the relationship between a person's perceived identity and achieved competence in occupations, gained by means of engaging in meaningful occupations within an environment, developing over time. Since occupational adaptation is a process, it develops over time. There is growing evidence that both the perceived identity and one's competence are effected by a disability, but it seems as if occupational competence is mostly effected (Mallinson *et al.*, 1998; Kielhofner *et al.*, 2001). Moreover, Polkinghorne (1996) also suggested that clients who experience decreased engagement in occupations tend to change their perception of themselves from what is known as an agentic self-identity to a victimic identity – meaning that they assume a passive identity and approach to societal participation. By regaining engagement in occupations, clients can retrieve their agentic self-identity and actively set and achieve life goals.

In the existing literature on persons with MS, the focus has been on revealing which types of coping strategies have been used, and how the level of disability and social support has impacted on the ability of those with MS to adjust (Brooks & Matson, 1982; Pakenham, 1999; McCabe *et al.*, 2004). Other studies of adaptation have shown that there are differences in how people with MS experience their lives, and that some are capable to put their lives back together, whereas others are not (Boeijs *et al.*, 2002). Antonak and Livneh (1995) argued that it is important to make a distinction between the adaptation

to a traumatic injury and that to a chronic disease, such as MS, owing to the uncertain nature of the MS disease. Furthermore, the anxiety related to a chronic disease seems to be oriented towards the future, whereas it appears to be more strongly oriented towards the past for those who have suffered a traumatic injury. The adaptation process has been the focus for previous research in persons with MS, showing that they go through a process of change from the initial 'falling ill' towards 'coming to terms' (Salick & Auerbach, 2006; Malcomson *et al.*, 2008). However, a meta-synthesis of persons living with a chronic illness like MS, has shown that they can change perspectives from having, what she referred to as their illness-in-the-foreground to having wellness-in-the-foreground (Paterson, 2001), implying that their adaptation might not be a linear process. However, even if all of the studies described above have come to include aspects of daily occupations, none of them have specifically focused on determining whether engagement in occupations had any implications for the adaptation process. Since engagement in occupations is an important goal in life, and is vital for well-being, this is of great importance when rehabilitation is planned and implemented, and therefore it is necessary to develop the knowledge base regarding the adaptation of engagement in occupations.

## **MS Rehabilitation**

According to the World Health Organisation, the 'rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination' (WHO, 2009).

This guideline postulates that rehabilitation professionals are organised into multi-or

interdisciplinary teams. The team members in the interdisciplinary team work in close connection with the client to achieve his/her goals, and they document these goals in an individualised rehabilitation plan. In a multidisciplinary team, different disciplines are present, but it is not necessarily the case that mutual goals are held (Lundgren & Molander, 2008). Both models occur within rehabilitation today, depending on the complexity of the programme, but also depending upon different traditions between countries and/or rehabilitation facilities.

There is a difference between the rehabilitation process for persons with MS compared with those who have suffered an acute injury, such as a brain injury or a spinal cord injury. Since MS is a chronic, progressive illness, persons with MS live with the knowledge that the illness can progress, and leave them with new problems in their daily life. For persons with MS, rehabilitation emphasises education and self-management with the aim of enabling the clients to learn to live their lives the best they can, given their disease.

In addition, it is stated that for persons with MS, rehabilitation should include at least a multidisciplinary approach (Thompson, 2005). The rehabilitation for persons with MS should always include an initial multidisciplinary team assessment to decide upon the best intervention, to plan a goal-oriented intervention programme, and to identify the way to evaluate the outcome, including the perspectives of the clients as well. (Thompson, 2000, 2005; National Clinical Advisory Board of the NMSS, 2008). Article 26 in the Convention on the Rights of Persons with Disabilities, approved in 2006 by the United Nations (Sveriges Regering, 2008), and regulated in several consensus documents concerning how the rehabilitation of process with persons with MS should be implemented. The European parliament approved a resolution from the European MS Platform (EMSP), the 'Code of Good

Practice on the Rights and Quality of Life of People Affected by Multiple Sclerosis', stating that all citizens with MS should be treated equally with other citizens (2004). The EMSP (2004) also stated that since the disease varies between different persons, it is vital that the rehabilitation is tailored to the different clients. They specified that the rehabilitation of persons with MS has to be planned to ensure that it corresponds with the different stages of the disease; the diagnostic, the early, the later, and the advanced stages.

Recently, the Swedish MS-association developed recommendations regarding the rehabilitation of persons with MS (Einarsson *et al.*, 2008), building on evidence from existing consensus documents in Europe, and USA. The Swedish consensus document divides rehabilitation into three different types; i) early rehabilitation includes information about the disease and the use of medication, self-management techniques and symptomatic interventions. These interventions are especially suitable within a neurological clinic that has the early contacts with the persons with MS; ii) Acute rehabilitation is offered to those who have relapses that result in disabilities which prevent them from returning to their home after a period at the acute neurological clinic. This type of rehabilitation includes interventions intended to achieve optimal functioning, and/or adaptations in order for them to return to their own homes; iii) recurrent rehabilitation is addressed to those persons with MS in whom a disability has developed that compromise their independence, but also for those who experience a decline in their ability to manage daily life. This type of rehabilitation includes several different professionals, and includes a combination of team interventions, such as the provision of compensatory solutions, symptomatic treatment, and performing exercises. This thesis includes clients that have been admitted for a comprehensive rehabilitation

programme, including both acute rehabilitation (the minority) and recurring rehabilitation (the majority).

Spokespersons within the field of rehabilitation in Sweden claim that rehabilitation programmes have had a biopsychosocial perspective since the 1980s (Borg *et al.*, 2006), and this is often well incorporated in programmes directed towards acute rehabilitation, such as rehabilitation required for brain injury or spinal cord injury. However, for clients with MS, it is often neurologists that have the primary responsibility for management, and, even if the intention is to adopt a biopsychosocial approach, this has not been fully incorporated in clinical practise. Early on, the importance of incorporating a more holistic view to enhance the outcome of rehabilitation for clients with MS, was emphasised from the field of psychology and sociology (Adams & Lindeman, 1974; Brooks & Matson, 1982). The development towards the ICF (WHO, 2001), has led to a greater awareness of how a disease or injury can affect a person, and that there are multiple personal and environmental components that can influence daily life. The ICF strives to incorporate both the medical model (in which all of the person's problems are caused by the disease or injury) and the social model (assuming that all of the problems are explained by factors in society), and thus influenced the view within rehabilitation. However, even if there are documents that promote a more holistic view, ways of incorporating these issues within practise have only just recently been discussed within the literature of rehabilitation (Ellis-Hill *et al.*, 2007; Griffiths, 2009). Moreover, since rehabilitation includes interventions that focus on how the client can live his/her life in best possible way without completely eliminating the underlying symptoms or impairments, assisting clients to adapt to their new life situation is often a central part in rehabilitation programme. However, not all programmes for persons with MS work with adaptation

in its whole sense, and there is still a need for more knowledge regarding adaptation in MS. Consequently, there is a need for further studies that describe this phenomenon and explore how the process of adaptation is manifested.

The outcome of multidisciplinary rehabilitation has been evaluated in several studies, and a recent Cochrane review (Khan *et al.*, 2007) concluded that there is strong evidence that in-patient rehabilitation is beneficial for the outcome, when measured in terms of activity and participation, but impairments did not improve. Interestingly, there was stronger evidence for programmes with a low intensity, implemented over a longer period of time. Only eight studies out of 44 were considered in the Cochrane review and many of them used the ICF framework when outcome assessments were chosen. Only assessments that covered self-care occupations were chosen for the evaluation of the component related to activity, and the component representing participation component was often measured in terms of quality of life or by means of handicap scales (Khan *et al.*, 2007). This shows that there is a lack of knowledge, both in the area of occupations, regarding problems related to other areas than self-care, but also regarding engagement in life situations, since previous studies have used handicap scales to measure components of participation. In addition, previous research has shown that there is a hierarchical relationship between different occupations, where often self-care occupations are easier to perform than other occupations (Spector *et al.*, 1987; Fisher, 2006a). Since much of the research in persons with MS and occupations relevant to them relies on self-care, there is a need to compare performance in self-care and performance in other occupations to determine whether there are differences in the performance of occupations by persons with MS.

## **Occupational therapy for persons with MS**

In a clinical bulletin from the American National MS Society, Finlayson (2006) described how the focus for occupational therapy with persons with MS is to enable participation in meaningful and valuable occupations. The OT addresses three broad areas of occupation, self-care; productivity, and leisure, where interventions are aimed at removing or reducing challenges that hinder participation, and are exemplified with interventions aiming at reducing impairment, overcoming obstacles in the environment, and techniques and strategies that can be directed towards enhancing occupational performance without improving body functions at the same time (Finlayson, 2006). A similar description is given by Tipping (2002), although she added examples of different assessment tools that would enhance the OT's work in a client-centred manner. However, in Europe, at least within MS rehabilitation, a more biomedical view prevails. According to the European MS parliament (EMSP), OTs should focus their interventions on "maintaining abilities, teaching new techniques and providing equipment which facilitate independence in personal care, reducing environmental barriers and providing resources to lessen disability" (EMSP, 2004, p. 35). Even though other occupational areas are mentioned in the general description, the quotation is the main suggestion for practise, reflecting, to a large extent, a biomedical viewpoint, where interventions are determined beforehand, and in which self-care is the focus of interventions and is used for the measurement of outcome. Most of the Swedish OTs practise is more congruent with the descriptions by Finlayson and Tipping, using a client-centred approach and different models of practise that focus on performance of occupation. However, since the focus has mainly been on the performance perspective, the importance of also including the client's

experience has not been emphasised.

Several theoretical models can be used to guide the clinical work with persons with MS, but it is preferably an approach when the OT starts her/his evaluation together with the client by taking a broad perspective of the client's life situation, then looking at problems in occupations, and later examining the cause, e.g., the underlying body functions (Trombly, 1993). Such an approach to practise also implies a client-centred approach to occupational therapy practise (Law *et al.*, 1995; Townsend, 1997), and has been influencing occupational therapy for the last decade. Nevertheless, even if the two main models in use today, i.e., the CMOP-E (Townsend & Polatajko, 2007) and the Model of Human Occupation (Kielhofner, 2008), have incorporated the concept of engagement, my experience is that occupational therapy practise for persons with MS has generally consisted of interventions intended to address problems in performance, and it is rare for clients' experiences of their occupational life to have served as a tool during the implementation of interventions. In addition, more and more, OTs have started to acknowledge that problems related to engagement in occupations can be explained by other factors than problems directly associated with the person, such as body functions, or to physical aspects of the environment. However, to develop guidelines developed by empirical data, further studies of engagement in occupations, especially for persons with MS, needs to be undertaken.

Overall, there is still little evidence concerning the outcome of occupational therapy interventions. The conclusions drawn from a Cochrane study (Steultjens *et al.*, 2003) and from a meta-analysis (Baker & Tickle-DeGnen, 2001) were that there is only a little evidence on the benefits of occupational therapy interventions aiming at enhancing body function, and self-care, and energy conservation courses. Thus, the authors concluded that there is an immediate need for studies of the

efficacy of occupational therapy interventions for persons with MS. Again, the results show that interventions regarding occupations within occupational therapy tend to focus on self-care. However, evidence-based medicine includes not only best research practise, but also clinical expertise and client's preferences (Taylor, 2007). To develop client-centred occupational therapy and rehabilitation we need to have more knowledge regarding occupations and those factors that influence engagement in occupations. Thus, there is a need for qualitative studies that reveal the clients' experiences.

## Aims

The overall aim of this thesis was to increase and strengthen knowledge about performance, and the experience of occupations in persons with MS considered for rehabilitation in order to further develop client-centred occupational therapy and rehabilitation for these clients.

The specific aims were:

- to describe the performance in self-care and household occupations, and to evaluate the relationship between the performance of these areas of occupations, and between performance in occupations and disease severity (study I)
- to describe which occupations were perceived as being difficult to perform on admission to rehabilitation, and to describe the self-perception of the importance of, performance of, and satisfaction with these occupations, and to investigate whether the reported occupations were related to sex, age, disease severity, and living arrangements (study II)
- to gain an enhanced understanding of experiences of engagement in occupations, and of the process of adaptation of occupations (studies III and IV)

## Methods

The design of this thesis developed as the different studies evolved, and can be seen as consisting of two parts, where the first part focused on the performance of occupations (studies I and II), and the second part focused on the participants' experiences of engagement in occupations (studies III and IV). In the studies of performance, objective assessments were used (study I), as well as a semi-structured interview that captured those occupations perceived as being difficult by participants with MS (study II). The studies of experiences of occupations (studies III and IV) used qualitative research questions to explore the participants' own experiences. An overview of the data collection and analysis, is presented in Table 1.

## Participants

All participants had clinically definite MS, representing primarily a secondary progressive disease course, but participants with relapsing remitting and primary progressive disease courses were included. The participants were selected from a rehabilitation unit where they had attended rehabilitation owing to their progression of the MS disease.

Study I and II were retrospective, and data were retrieved from a database at the rehabilitation unit. Study I included participants who had received rehabilitation from 1997–2002, and study II included participants who had been recipients of rehabilitation services from 1999–2001. During the period 1999–2001, some participants were included in both studies I and II simultaneously, and thus, six (1999), four (2000), and seven (2001) participants were included in both studies. The participants in Studies III and IV were different from those in studies I and II, as the data were gathered during 2006. Specific information on the participants is



**Table 1.** An overview of the design and data collection for the four studies included in the thesis.

	Study I	Study II	Study III	Study IV
Data collection	Observational assessments; FIM, AMPS, EDSS	Semi-structured interviews with COPM	Open-ended research interviews	Open-ended research interviews
Data analysis methods	Descriptive statistics, parametric and nonparametric statistics	Content analysis, descriptive, and non-parametric statistics	Constant comparative analysis	Constant comparative analysis

Note: The Functional Independence Measure (FIM), the Assessment of Motor and Process Skills (AMPS), the Canadian Occupational Performance Measure (COPM), the Expanded Disability Status Scale (EDSS).

described separately for studies I and II, and together for the participants in studies III and IV (Table 2).

### Study I

Between January, 1997 to December, 2002, 142 persons with MS were admitted for rehabilitation. From these, participants were selected using the following inclusion criteria: i) their MS disease should be stable, i.e., with no ongoing relapse; ii) moderate to severe disease severity score; iii) problems with occupations primarily related to their MS, and no additional diagnosis; iv) data available from observational assessments of performance of self-care as well as of household occupations on admission to rehabilitation. Seventeen persons were excluded since the severity of their disease was too low, and a further 11 persons had another diagnosis or their MS was not stable. In another 54 persons, no observational assessment of household occupations had been made. In 60 persons with MS, an observational assessment of household occupations had been accomplished, but amongst them another eight persons were excluded since their assessment had not been performed on admission. Eight persons did not want to be included in the study. Finally, 44 persons with MS were included, 12 men and 32 women.

### Study II

During the period January 1999–December 2001, 87 persons with MS had been admitted for rehabilitation. The inclusion criteria were that participants should have reported having difficulties with occupations on admission to rehabilitation, according to the standardised Canadian Occupational Performance Measure (COPM) (Law, 1998). In 37 of the 87 potential participants, no individual assessment of occupations was made on admission ( $n=18$ ), or other types of assess-

Table 2. Participant characteristics, studies I–IV.

	Study I	Study II	Study III–IV
Number of participants	44	47	10
Sex F/M, <i>n</i>	32/12	28/19	6/4
Mean age, (SD), <i>range</i>	51.9 (10.7) 29–69	49.4 (10.2) 22–69	53.4, (8.9) 41–67
Years since MS onset, (SD), <i>range</i>	20.0 (10.9) 1–45	16.0 (11.8) 0–50	16.7, (10.8) 4–31
Type of MS, <i>n</i>			
Relapsing remitting	7	7	2
Secondary progressive	33	37	8
Primary progressive	4	3	–
EDSS score, median, <i>range</i>	6.5, 6.0–8.5	6.5, 1.0–8.5	6.5, 5.0–8.0
Living arrangement, <i>n</i>			
Living alone		14	6
Living with other person		33	4
Vocational situation, <i>n</i>			
Working part time or full time	3	5	–
Working part time with part time temporary or permanent SC	7	7	1
Full temporary or permanent disability pension	31	31	7
Retirement pension	3	4	2

Note: SC= Sickness Compensation, EDSS= disease severity measured between 0 (normal) to 10 (death due to MS) (Kurtzke, 1983).

ments had been made ( $n=19$ ). Of the remaining 50 persons, two did not want to take part in the study and the COPM form was missing for one further potential participant. Finally, a total of 47 individuals (28 women and 19 men) were included.

### Studies III and IV

Studies III and IV included the same participants, selected from 38 persons with MS who had completed a period of interdisciplinary rehabilitation during 2005, but had been

discharged at the time of the participation in these studies. A purposive sampling strategy guided the selection of participants (Patton, 1990) using the following inclusion criteria: i) having limitations on occupational performance according to different ADL assessments conducted during the rehabilitation period; ii) having the ability to understand and actively take part in an interview dialogue; and iii) having no other diseases influencing occupational performance. Since a heterogeneous sample was sought, several factors such as age, sex and the type of limi-

tations on occupational performances underlay the choice.

Potential participants were first identified by a clinical OT, who used the inclusion criteria to select potential participants consecutively among persons admitted for rehabilitation during the specified period. The clinical OT then gave potential participants written information on the studies, asking them for consent to be contacted by the first author. All participants then received written and verbal information about the studies, were assured confidentiality, and thereby gave their written informed consent to participate.

In the first phase, nine potential participants were contacted, six of whom wanted to participate. When interviews with these people had been completed, another four persons were contacted, targeting to include additional participants to ensure that a heterogeneous sample was obtained. The ten interviews completed were found to have enough variety to ensure the quality of the studies, and therefore no further participants were included. That is, six women and four men with MS were included, of whom eight had secondary progressive MS and two had relapsing remitting MS. According to the assessments recorded during the rehabilitation period, the participants had difficulties with all areas of occupation (i.e., self-care, productivity, and leisure). All of them stated that they received assistance with performance in occupations from their family and/or friends, and seven received private help, social service and/or personal assistance. Six of the participants had a partner, three were divorced, and one was single, eight had children three of whom had children who were still minors. Every participant had received interdisciplinary rehabilitation at least once. Furthermore, without exception, they had received some kind of community-related intervention, such as exercises intended to reduce impairments, or the provision of assistive devices, or adaptations made to their housing.

## **Study context**

At the time of the data collection, the Department of Rehabilitation Medicine, Lund University Hospital had a team specialised in the rehabilitation of persons with chronic neurological disorders, such as MS. Yearly, about 100 persons received in- and outpatient rehabilitation, and 50 of those had MS. The team consisted of a physician, nurse, assistant nurse, physiotherapist, social worker and OT. A speech pathologist and a neuropsychologist were associated to the team, as well as a sports instructor and a recreational assistant. The team worked in an interdisciplinary manner in close co-operation with the client and his/her family and with each other to reach the client's goals. The Department of Rehabilitation Medicine has been successively accredited according to Carf standards, internationally recognised standards regarding the quality of rehabilitation services.

## **Data collection**

### **Participant characteristics**

In all of the four studies, information on the participants' sociodemographic situation was obtained, such as their age, sex, and vocational situation. Information about living arrangement was included in studies II – IV and in studies III and IV, the type and amount of social service assistance was obtained as well. In addition, information about their MS disease was obtained (MS type, years since the onset of MS and disease severity).

### **Disease severity**

The Expanded Disability Status Scale (EDSS) is a neurologic measure of MS and rates disease severity on a scale of 0 (normal) to 10 (death due to MS) (Kurtzke, 1983). Scores between 0 and 3.5 indicate that the person with MS is fully ambulatory, whereas scores of 4.0 and above indicate limitations in ambula-

tion. Persons with EDSS scores 6.0 can walk approximately 100 meters with or without rest, but need a unilateral assistance. Those with an EDSS 6.5 can walk about 20 meters with bilateral assistance, whereas individuals with EDSS 7.0 and 7.5 are essentially restricted to a wheelchair and can only walk about 5 meters with aid (EDSS 7.0), or only a few steps (EDSS 7.5). Persons with EDSS scores 8.0 and 8.5 cannot walk at all and are restricted to bed or to a chair much of the day and use a wheelchair for ambulation.

## Performance of occupation

### *Observation of performance*

#### *Functional Independence Measure (study I)*

The Functional Independence Measure (FIM) is a well established instrument for rating of the amount of assistance required to perform P-ADL (Granger *et al.*, 1990). It consists of 18 items separated into two domains: the motor domain and the cognitive domain. Each item is scored on a seven-level Likert scale. A score of 1 or 2 indicates complete dependence (total or maximal assistance), 3 to 5 modified dependence (moderate or minimal assistance, or supervision), 6 modified independence, and 7 complete independence. The FIM motor domain consists of 13 items, assessing self-care, sphincter control, transfers and locomotion; summed scores range from 13 to 91. The FIM cognitive domain consists of five items, assessing communication and social cognition; summed scores range from 5 to 35. A summed score  $\geq 78$  in the motor domain and  $\geq 30$  in the cognitive domain indicate complete or modified independence.

#### *The Assessment of Motor and Process Skills (study I)*

The Assessment of Motor and Process Skills (AMPS) is an assessment for both self-care

and household occupations, measuring two components of occupational performance – 16 ADL motor and 20 ADL process skills – which are the observable goal-directed actions necessary for completion of ADL tasks (Fisher, 2006a, b). The ADL motor skills are actions a person carries out to move him or herself or objects during the performance of ADL. The ADL process skills are logical actions a person carries out to perform ADL tasks over time, to select and use appropriate tools and materials, and to adapt his or her performance when problems occur. The administration of AMPS involves four steps: i) interviewing the client and deciding which tasks to perform; ii) setting up the test environment; iii) observing the ADL tasks; and iv) scoring the performance and interpreting the results. The 16 ADL motor and 20 ADL process skills in each of the two or three tasks are rated on a four-point ordinal scale according to the level of i) effort; ii) efficiency; iii) safety; and iv) independence in the performance. A score of ‘1’ represents markedly deficient performance that impedes the action; ‘2’ ineffective performance; ‘3’ questionable performance; and ‘4’ competent performance. The raw ordinal scores are converted into interval data by a many-faceted Rasch analysis, and are presented graphically as an ADL motor and a process ability measure on two linear scales. High positive ADL motor and process ability measures indicate that clients are more able, whereas low and/or negative ability measures indicate that clients are less able (Fisher, 1993). There are cut-off criteria on both the ADL motor (2.0 logits) and process ability (1.0 logits) scales. Clients with logits below the cut-off on the ADL process ability scale are at risk of not performing occupations safely, efficiently and independently enough to live by themselves in the community.

## **Self-perceived performance**

### *Canadian Occupational Performance Measure (study II)*

The Canadian Occupational Performance Measure (COPM) is an individualized, client-centred measure designed to capture a client's self-perception of his/her performance of daily occupations (Law, 1998). The COPM includes three occupational areas, each comprising three subcategories: i) self-care (personal care; functional mobility; community management); ii) productivity (paid/unpaid work; household management; play/school); and iii) leisure (quiet recreation; active recreation; socialisation). The OT uses the COPM as a semi-structured interview and helps each client to identify those daily occupations that he/she finds difficult to perform. These occupations are noted in the COPM form, within the appropriate occupational area and subcategory. Thereafter, the client is asked to rate the importance of each occupation on a 10-point Visual Analogue Scale (VAS), ranging from 1 (not important) to 10 (most important). Finally, the most important occupations are prioritised and rated according to the client's self-perceived performance and satisfaction on the VAS ranging from 1 – “not able to do” (performance) or “not satisfied” (satisfaction) – to 10 – “able to do extremely well” (performance) or “extremely satisfied” (satisfaction), respectively.

## **Experience of occupations**

### *Qualitative research interviews*

For studies III–IV, qualitative research interviews based on a few questions with an open-ended format were used. The interviews included questions concerning how the participants experienced their engagement in occupations, and how they adapted their engagement.

Every participant was asked to recount

his/her experiences in as much detail as he/she wished. When clarification was needed, follow-up questions were posed, using the wording provided in the relevant participant's own descriptions. In study III, the participant was asked to reflect on if, and if so, how occupations had changed, and how that influenced his/her daily life. In study IV, questions were focused on how the person had adapted to the changed engagement in occupations, and how this had influenced his/her interaction with family and friends, and life overall.

## **Procedure**

Data for studies I and II were retrieved retrospectively from the participants' medical records. The assessments were undertaken during the participants' rehabilitation period, and obtained within the first week of admission. All assessments were part of the regular rehabilitation period. The physician rated disease severity with the EDSS, the FIM score was decided after a consensus had been reached by the treating interdisciplinary rehabilitation team, and the COPM and the AMPS assessments were conducted by different clinical OTs, in the team.

When the OT used the COPM to facilitate the identification of occupations that person with MS perceived difficult to perform (study II), she placed the occupation in question under the appropriate area and subgroup in the COPM, according to the person's preferences. For example, “working in the garden” could be considered either as household management within the occupational area of productivity, or as active recreation within the occupational area leisure. In addition, according to the COPM manual (FSA, 1999); when all of the occupations that the person perceived him or herself to have difficulties with had been identified, the person was asked to rate the importance of each of the occupations and thereafter

choose the most important occupations. In this study, the participants had the opportunity to choose as many occupations as they preferred, without the limit of five stated in the manual being imposed. This aside, the administration of the COPM followed the ordinary procedures.

For studies III and IV, all data were obtained at the time of the interview. An EDSS assessment was performed after every interview had been completed to describe the severity of the disease for each participant. The interviews were undertaken by the author in the participants' homes and all interviews were tape recorded and thereafter transcribed verbatim. The mean length of the interviews was 82 minutes (range 38–133 minutes).

## **Ethics**

The Ethics Research Committee, Lund University, approved the first two studies and the Regional Ethical Review Board in Lund, Sweden, approved the latter two. On admission to rehabilitation, all clients were asked to provide their informed consent that data collected during their rehabilitation could be used in management reports and research. On recommendations of the Ethical Review Board, a letter was sent to all potential participants containing information on each of the specific studies, to ensure that the consent was informed. All participants in the four studies were ensured confidentiality, and ensured that they could withdraw from participating at any time, without any influence on future rehabilitation.

## **Methods for analysing data**

### **Statistics**

In all of the four studies, descriptive statistics were used to present the background information and results for some typical variables. Parametric statistics were used when

data had a normal distribution and were on an interval level, whereas data that was skewed or were obtained on an ordinal level, used non-parametric statistics. Significance levels lower than  $p < 0.05$  were considered significant. All statistical analyses were accomplished by means of SPSS version 11.0.

The participants in studies I and II were divided into groups according to their ability to ambulate, as determined by the EDSS scores, to allow evaluations to be made of the relationship between performance in occupations and disease severity. In study I, correlations were used to test the relationship between self-care and household occupations (Pearson's correlation coefficient) and between disease severity and performance in self-care and household occupations, respectively (Spearman's rank correlation coefficient). A non-paired t-test was used to test sex differences for age and the number of years since the onset of MS (study II), and a one-way ANOVA with appropriate post-hoc tests was used to analyse differences in performance in occupations between men and women and among groups of participants, according to EDSS scores (study I).

The Mann-Whitney U test was used to analyse the differences in disease severity between men and women (study II) and to evaluate the differences for the total number of reported occupations in each of the three COPM occupational areas among subgroups (study II). A Kruskal-Wallis test was used to evaluate differences for the total number of reported occupations in each of the three COPM occupational areas in relation to disease severity (study II).

### **Content analysis**

In study II, data from the semi-structured COPM interviews were used. The different occupations, from here on called units of occupations, the participants perceived difficult to perform needed to be systematised to en-

able a detailed description to be made. The systematisation followed the general principles of a manifest content analysis (Downe-Wamboldt, 1992) and was accomplished by scrutinising each of the reported units of occupations within every COPM subcategory separately, grouping them into similar single occupations (e.g., 'dressing', 'showering' etc.). Thereafter, all units within a particular single occupation were classified as either actions or operations, according to the different levels – the macro, meso, micro – in the ValMO concept (Persson *et al.*, 2001). For example, 'showering', 'washing body parts' and 'holding the soap', all deal with 'showering', but represent different units. The following hierarchy was used when all reported units of occupations were systemised: i) COPM occupational area; ii) COPM subcategory; iii) single occupation; iv) action; and v) operation. The systematisation was discussed and validated with the other authors, in an iterative process. In case of disagreement, discussions with the second author (a senior occupational therapy researcher) successively led to consensus.

### **The constant comparative method of grounded theory**

In studies III and IV, the constant comparative method of grounded theory (Strauss & Corbin, 1998) was chosen. Grounded theory has its theoretical roots in symbolic interactionism, a sociological theory that view humans as active beings where interactions with others and within themselves continually shape and develop the person. Thus, to understand the human being, he has to be studied within the context where these interactions take place (Charon, 2007).

Strauss and Corbin (1990) presented their first version of grounded theory, which was further edited in 1998 (Strauss & Corbin, 1998). They described how, before a theory can be developed, the constituents of the

theory have to be understood, which involves the steps of describing, conceptual ordering and theorizing. Describing is performed when a narrative is depicted, but not interpreted, and conceptual ordering is performed when data are classified and ordered to get a general sense of the picture, whereas theorizing mean the constructing of data into a systematic scheme that integrates different concepts which explain and predict events. Even if the main aim of grounded theory is to generate a theory from the empirically gathered data, the researcher can stop before the stage of theory generation is reached, and settle with describing and conceptual ordering the data (Strauss & Corbin, 1998). The method uses both an inductive and a deductive approach, where the researcher starts inductively when data are collected and initial relationships in the data are found. Thereafter, the deductive process proceeds, wherein the initial data is scrutinised and compared with existing theories so that theory can be developed or further advanced. During such analyses, grounded theory uses constant comparisons as the method of comparing all data, on all levels – codes, dimensions, properties and categories – for similarities and differences.

Since studies III and IV aimed to reveal experiences of interactions and processes and their meaning during engagement in occupations and of adaptation during engagement, such as person-environment-task interactions, the constant comparative method of grounded theory was found to be suitable. In both studies the analysis started when all data had been gathered, hence it did not follow the general principles of grounded theory. In both studies the author started the analysis by reading each interview carefully to gain an understanding of its content. A line-by-line analysis followed, and clusters of text reflecting similar experiences relevant to the focus for the specific study were coded; this process continued until all text was coded. The analysis then moved on to a comparison of

the codes, gathering those with similar content until every interview contained a set of preliminary categories. This was performed separately for each participant. The analysis then continued by comparing the codes and the preliminary categories for all interviews, identifying similarities and differences, and thereby determining the properties and dimensions of the final categories. The analysis was performed in an iterative process together with the co-authors. As a final step, all three authors agreed on the text. The preliminary results for both studies were presented and discussed at a seminar with professionals from the same discipline (study III), or from different disciplines (study IV), experienced in qualitative research which lead to further refinements of the analysis.

## Results

### *Performance of occupations*

#### Self-care occupations

The results from the assessment of self-care, showed that the mean motor, cognitive, and total FIM scores (of 73, 33 and 106, respectively) were identical for the 44 men and women. The summed score for the FIM motor scores revealed 20 participants to be independent and 24 to have some degree of dependence. For the FIM cognitive sum score, 41 of the participants had scores indicating that they were independent, whereas three had scores indicating dependence.

When each of the items were scrutinised, six of the 13 motor items had a generally lower mean score than the other seven items, for both sexes (Table 3). The items were bathing, dressing lower body, different types of short transfers, and locomotion on stairs. Locomotion on stairs had the lowest mean value of all items. The main means of transportation for nine men and 10 women was a

hand-propelled wheelchair. All of the cognitive scores, with the exception of the item comprehension, were very high for both sexes. The mean score for the communication items were lower than for the other cognitive items, because those who wore eyeglasses received a low score ( $n = 31$ ).

#### Household assessment

A total of 90 different household tasks were performed during the AMPS assessments: meal preparation ( $n=38$ ), table setting ( $n=7$ ), house cleaning ( $n=15$ ), making beds ( $n=7$ ), laundry ( $n=17$ ), shoe polishing ( $n=1$ ) and plant care ( $n=5$ ). In Figure 1, the results from the AMPS assessments of the 44 participants are presented. Without exception, the ADL motor ability measure was below the cut-off criterion of 2.0 (range  $-0.7$  to  $1.5$ ). Fourteen of the participants (32%) had an ADL process ability measure above the cut-off criterion 1.0, and for six of these 14, the value was above 1.3 (the upper end of risk zone). Thirty individuals (68%) had an ADL process ability measure below or on the cut-off criterion of 1.0; of these, 11 had an ADL process ability measure below 0.7 (the lower end of risk zone) and 19 were in the risk zone (0.7 to 1.0). There were no significant differences between the sexes.

#### Self-perceived occupations

The results showed that 44 persons with MS reported a total of 366 units of occupations that they perceived difficult to perform (median 8, range 3–15; Table 4). The highest number was found in the occupational area self-care (51%), followed by productivity (30%) and leisure (19%). The three COPM subcategories household management (26%), personal care (21%) and functional mobility (20%) accounted for two thirds of all the units of occupations that the participants perceived to be difficult to perform. They



**Table 3.** The mean of the 13 motor items and the five cognitive items in the Functional Independence Measure (FIM) for the 44 men and women with MS.

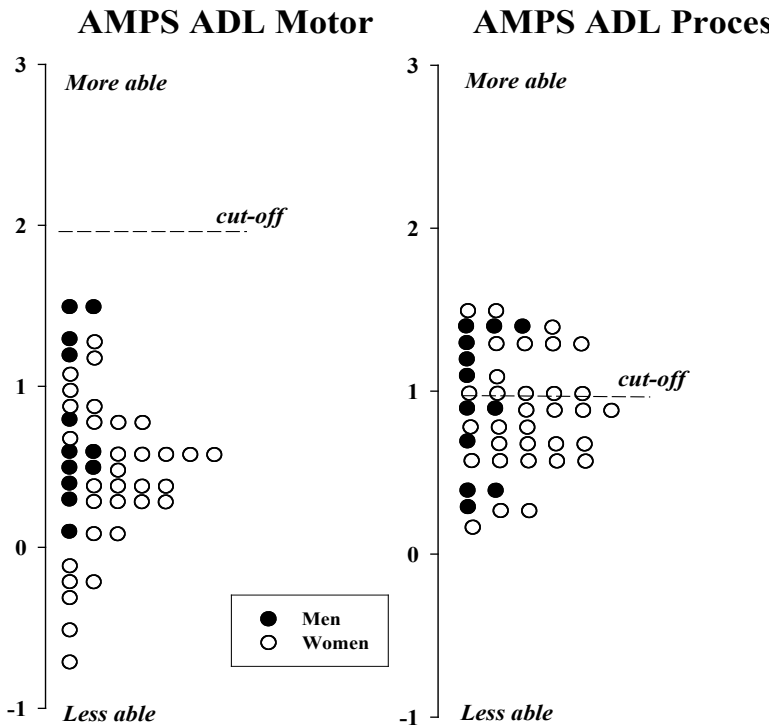
	Men ( <i>n</i> =12)	Women ( <i>n</i> =32)	% scores 6 or 7*
<b>FIM Motor domain</b>			
Self care			
A. Eating	6.4 (5–7)	6.3 (4–7)	84
B. Grooming	6.5 (6–7)	6.4 (4–7)	98
C. Bathing	5.4 (3–7)	5.6 (3–7)	68
D. Dressing – upper body	5.9 (4–7)	6.2 (4–7)	86
E. Dressing – lower body	5.4 (1–7)	5.0 (1–7)	70
F. Toileting	5.8 (2–7)	5.6 (1–7)	89
Sphincter control			
G. Bladder management	6.4 (6–7)	5.4 (1–7)	82
H. Bowel management	6.6 (5–7)	6.4 (2–7)	93
Transfers			
I. Bed, Chair, Wheelchair	5.2 (1–6)	5.3 (1–6)	73
J. Toilet	5.2 (1–6)	5.4 (1–6)	77
K. Tub, Shower	5.2 (1–6)	5.4 (1–6)	73
Locomotion			
L. Walk/Wheelchair	5.8 (3–6)	5.6 (1–6)	82
M. Stairs	3.1 (1–6)	4.2 (1–6)	46
Mean ±SD (range) items A–M	73 ±11 (41–84)	73 ±13 (33–84)	79 ±13 (46–98)
<b>FIM Cognitive domain</b>			
Communication			
N. Comprehension	6.2 (6–7)	6.1 (4–7)	93
O. Expression	6.8 (6–7)	6.8 (5–7)	96
Social Cognition			
P. Social Interaction	6.7 (5–7)	6.7 (6–7)	98
Q. Problem Solving	6.8 (6–7)	6.7 (2–7)	93
R. Memory	6.7 (6–7)	6.6 (2–7)	93
Mean ±SD (range) items N–R	33 ±1 (30–35)	33 ±3 (20–35)	95 ±2 (93–98)
Total (mean ±SD; range)	106 ±11 (75–118)	106 ±15 (64–118)	

\*Scores of 6 and 7 represent modified and complete independence, respectively.

prioritised 238 units of occupations (median 5, range 2–7), within eight of the nine COPM subcategories.

When the units of occupations within the different COPM subcategories were analysed in more detail, the results showed that they were classified as ‘single occupations’ (*n*=197), ‘actions’ (*n*=143), and ‘operations’

(*n*=16). Ten units of occupations were classified as a COPM subcategory (e.g. community management). Within the occupational area of self-care, the most frequently reported units were related to dressing, transferring, walking, and shopping. For productivity, the majority of the reported units of occupations (86%) were classified in the sub-



Note: Each data point represents the combined assessments from the two or three I-ADL tasks performed. The cut-off criterion of 2.0 for the ADL motor scale and 1.0 for the ADL process scale are indicated.

Fig. 1. Graphical presentation of the Assessment of Motor and Process Skills (AMPS) ADL motor and ADL process ability measures for the 44 men and women with MS.

category household management, mostly related to cooking and cleaning. Leisure included a wide variety of single occupations, related to both quiet and active recreations, and socialisation. In Table 5, single occupations within the three COPM occupational areas (self-care, productivity and leisure) are presented and examples of actions and operations are given in the following text.

Among the occupations prioritised by the participants, functional mobility and paid/unpaid work were rated as being the most important, whereas quiet recreation was rated the least important. The largest range in ratings was in household management and

the smallest in paid/unpaid work. The average ratings of performance were generally low; the lowest was in active recreation and the highest in paid/unpaid work. For satisfaction, the mean ratings were also generally low; the lowest were in active recreation and socialisation.

### Relationship between self-care and household occupations

There were significant positive relationships between the FIM motor scores and the AMPS ADL motor ability measures ( $r=0.38$ ;  $p=0.01$ ), between the FIM cognitive scores

**Table 4.** All reported and prioritised occupations which the 47 individuals with MS perceived as difficult, and their ratings of importance, performance and satisfaction, presented for each COPM occupational area and COPM subgroup.

	All occupations ( <i>n</i> =366)			Prioritised occupations ( <i>n</i> =238)			
	<i>n</i> (%)	Importance		<i>n</i> (%)	Importance	Performance	Satisfaction
<b>Self-care</b>							
Personal care	78 (21)	8.1 (3–10)		56 (23)	8.6 (5–10)	4.2 (1–9)	3.5 (1–8)
Functional mobility	71 (20)	8.9 (3–10)		54 (23)	9.3 (5–10)	3.3 (1–8)	2.4 (1–10)
Community management	38 (10)	7.2 (1–10)		19 (8)	8.5 (4–10)	2.7 (1–6)	2.5 (1–5)
Total	187 (51)			129 (54)			
<b>Productivity</b>							
Paid/unpaid work	13 (3)	8.5 (2–10)		6 (3)	9.5 (9–10)	4.3 (1–9)	3.8 (1–10)
Household management	95 (26)	7.7 (2–10)		60 (25)	8.4 (3–10)	3.4 (1–9)	3.6 (1–10)
Play/school	2 (1)	5.0 (3–7)		0	–	–	–
Total	110 (30)			66 (28)			
<b>Leisure</b>							
Quiet recreation	25 (7)	6.8 (1–10)		13 (5)	8.0 (5–10)	3.2 (1–7)	3.4 (1–6)
Active recreation	29 (8)	8.2 (2–10)		18 (8)	8.9 (5–10)	1.3 (1–4)	1.1 (1–2)
Socialisation	15 (4)	8.8 (4–10)		12 (5)	8.9 (4–10)	2.4 (1–5)	1.3 (1–4)
Total	69 (19)			43 (18)			

Note: Values for importance, performance and satisfaction are presented as mean, minimum and maximum.

**Table 5.** Reported single occupations ( $n=366$ ) from the assessment with the Canadian Occupational Performance Measure (COPM) in the three occupational areas of self-care, productivity and leisure among 47 individuals with MS.

<b>Self-care</b> ( $n=187$ )
Personal care ( $n=78$ ) <sup>a</sup>
Dressing ( $n=39$ ) Showering ( $n=12$ ) Grooming ( $n=11$ ) Feeding ( $n=6$ ) Toileting ( $n=5$ ) Other ( $n=2$ ) Medication ( $n=1$ )
Functional mobility ( $n=71$ ) <sup>b</sup>
Transferring ( $n=22$ ) Walking outdoors ( $n=11$ ) Walking in general ( $n=9$ ) Walking longer distances ( $n=9$ ) Walking indoors ( $n=7$ ) Walking in stairs ( $n=7$ ) Walking while carrying ( $n=6$ )
Community management ( $n=38$ ) <sup>a</sup>
Shopping ( $n=21$ ) Getting to service facility ( $n=4$ ) Travelling with a car ( $n=5$ ) Getting in/out from dwelling ( $n=2$ ) Banking ( $n=1$ ) Biking ( $n=1$ ) Driving a 3-wheeled scooter ( $n=1$ ) Going by bus ( $n=1$ )
<b>Productivity</b> ( $n=110$ )
Paid/unpaid work ( $n=13$ ) <sup>a</sup>
Performing physically demanding work tasks ( $n=8$ ) Doing desk-work ( $n=3$ )
Household management ( $n=95$ )
Cooking complex meals ( $n=23$ ) Cleaning floor ( $n=19$ ) Making bed ( $n=6$ ) Dusting ( $n=5$ ) Ironing clothes ( $n=5$ ) Laying table ( $n=4$ ) Baking ( $n=3$ ) Cleaning windows ( $n=3$ ) Hanging laundry ( $n=3$ ) Making tea or coffee ( $n=3$ ) Preparing breakfast ( $n=3$ ) Preparing micro-wave food ( $n=3$ ) Cleaning toilet/bathroom ( $n=2$ ) Caring for plants indoors ( $n=2$ ) Cleaning in general ( $n=2$ ) Gardening ( $n=2$ ) Mangling clothes ( $n=2$ ) Washing laundry ( $n=2$ ) Cleaning car ( $n=1$ ) Doing dishes ( $n=1$ ) Mending clothes ( $n=1$ )
Play/school ( $n=2$ )
Studying ( $n=2$ )
<b>Leisure</b> ( $n=69$ )
Quiet recreation ( $n=25$ )
Doing paperwork ( $n=6$ ) Reading ( $n=3$ ) Renovating/decorating house ( $n=3$ ) Taking care of pets ( $n=3$ ) Playing instrument ( $n=2$ ) Repairing things ( $n=2$ ) Sewing ( $n=2$ ) Crocheting ( $n=1$ ) Knitting ( $n=1$ ) Photographing ( $n=1$ ) Weaving ( $n=1$ )
Active recreation ( $n=29$ )
Walking and being in nature ( $n=8$ ) Gardening ( $n=3$ ) Playing ball sports ( $n=3$ ) Doing excursions ( $n=2$ ) Walking dog ( $n=2$ ) Biking ( $n=1$ ) Bird watching ( $n=1$ ) Dancing ( $n=1$ ) Decorating house ( $n=1$ ) Doing sports in general ( $n=1$ ) Fishing ( $n=1$ ) Getting to allotment garden ( $n=1$ ) Going to theater/cinema ( $n=1$ ) Jogging ( $n=1$ ) Skiing ( $n=1$ ) Taking trips ( $n=1$ )
Socialisation ( $n=15$ )
Communicating with other people ( $n=5$ ) Visiting friends/relatives ( $n=5$ ) Doing things with children ( $n=4$ ) Going to church ( $n=1$ )

Note: <sup>a</sup>For two of the reported difficulties no particular occupation were specified, <sup>b</sup>the term 'walking' was referred to even if mobility devices were used during locomotion

and the AMPS ADL process ability measures ( $r=0.36$ ;  $p=0.018$ ), and between the FIM motor scores and the AMPS ADL process ability measures ( $r=0.46$ ;  $p=0.002$ ) whereas the relationship between the FIM cognitive scores and the AMPS ADL motor ability measures was not significant ( $r=0.14$ ).

Eighteen individuals had a FIM cognitive score and an AMPS ADL process ability measure above the cut-off for both assessments, indicating that they were independent. In twenty-two participants, the FIM cognitive score indicated independence, but their AMPS ADL process ability measure was below the cut-off criterion, indicating the opposite; compromised independence. In three participants, both their FIM scores and their AMPS ADL process ability measure were below cut-off, indicating that they needed help to live in the community. Finally, in one of the participant's scores, the FIM cognitive score was lower than the cut-off, and the AMPS ADL process ability measure was in the risk-zone of  $\pm 0.3$  from the cut-off at 1.0.

### Relationship between performance in occupations and disease severity

There was a significant relationship between the EDSS and the FIM motor scores ( $\rho=-0.61$ ;  $p<0.001$ ) but not between the EDSS and the FIM cognitive scores ( $\rho=-0.15$ ). There was no significant relationship between the EDSS scores and the AMPS ADL motor ability measures ( $\rho=-0.01$ ), or between the EDSS scores and the AMPS ADL process ability measures ( $\rho=-0.21$ ).

The FIM motor scores for the group of persons with EDSS 7.0–8.5 were significantly different from those for the groups with EDSS 6.0 ( $p=0.002$ ) and EDSS 6.5 ( $p=0.004$ ), but no significant differences were found between the two groups with EDSS 6.0 and 6.5 (Table 6). There were no significant differences between the three groups for the FIM cognitive scores, the AMPS ADL motor ability measures or the AMPS ADL process ability measures.

**Table 6.** The Functional Independence Measure (FIM) and the Assessment of Motor and Process Skills (AMPS) for the 44 men and women with MS grouped according to their ability to ambulate based on their Expanded Disability Status Scale (EDSS) score\*

	EDSS		
	6.0 ( <i>n</i> =14)	6.5 ( <i>n</i> =13)	7.0–8.5 ( <i>n</i> =17)
FIM			
Motor domain	79 (66–84)	78 (71–83)	64 (33–84)**
Cognitive domain	33 (31–34)	34 (32–35)	32 (20–35)
AMPS			
ADL Motor	0.5 (-0.1–1.3)	0.5 (-0.5–1.1)	0.6 (-0.7–1.5)
ADL Process	1.0 (0.4–1.5)	1.0 (0.6–1.5)	0.8 (0.2–1.4)

\*Persons with EDSS 6.0 walk with assistance on one side whereas persons with EDSS 6.5 walk with bilateral assistance. Persons with EDSS 7.0–8.5 are essentially restricted to wheelchair (7.0–7.5) or perambulate in a wheelchair much of the day (8.0–8.5).

\*\*The FIM motor scores for the group of persons with EDSS 7.0–8.5 was significantly different from the groups with EDSS 6.0 ( $p=0.002$ ) and EDSS 6.5 ( $p=0.004$ ).

## Reported occupations in relation to sex, age, disease severity and living arrangement

There was a significant difference between the sexes in terms of self-care ( $p=0.042$ ) – men reported significantly more units of occupations as being problematic than women – but there were no significant differences for productivity or leisure. No significant difference was found between the younger and older persons for any of the three occupational areas. The number of reported occupations in the three occupational areas was not significantly related to disease severity or the participants' living arrangement.

## *Experiences of engagement in occupations and the process of adaptation in occupations*

### Experiences of engagement in occupations

The findings relating to how the participants experienced their engagement in occupations formed the core category “essentials of a constantly changing life” representing the continuum the participants described (study III). The core category was comprised of four categories: *decreasing engagement in meaningful occupations, constantly struggling for engagement in occupations, being a different person, and living life differently* (Figure 2). The participants experience was that *their engagement was constantly decreasing*, as they could no longer perform occupations according to their personal preferences, and the number of occupations to choose between was decreasing, in addition to which, and that their opportunity to plan and balance occupations over time was affected. This forced them to *struggle continuously to maintain their engagement*, and the struggle was described as being determined by three forces, society, other

people and/or body restrictions. None of the forces were more salient than the others, but all were described as being ongoing and dynamic, with different and variable intensity, and not necessarily all applying at the same moment. The struggle imposed by society could restrict engagement in occupations, and determine how the occupations were carried out. The struggle also aimed at maintaining social relations, outside the family, and was directed at other people's attitudes, which could influence engagement in occupations, positively and negatively. They also struggled because of the restrictions imposed by their bodies, and several stated that their lost physical condition made them feel uncertain and anxious about failure when engaged in occupations. They nourished a hope of regaining their past body condition again, and for some, this was a prerequisite for engaging in certain occupations again. They revealed that the struggle made them feel like *they were a different person*, which had a negative influence on their self-confidence, and thereby influenced their self-perception and their capacity to perform other occupations. Thus, their personal identity was altered. The struggle also required them to construct a *different life from the one they had lived before*, but there were variations in how the participants experienced their lives. Some said they lived a restrained life where occupations no longer were experienced as contributors to well-being in the way they had before. Other said their life was not much of a life and a few even said that they lived solely to survive. In addition, they said they had to live on positive life experiences, for instance by thinking of past experiences that were joy-full. They also stated that their private lives had diminished, and some of those who were dependent on social services experienced the assistance as an intrusion into their private family life.

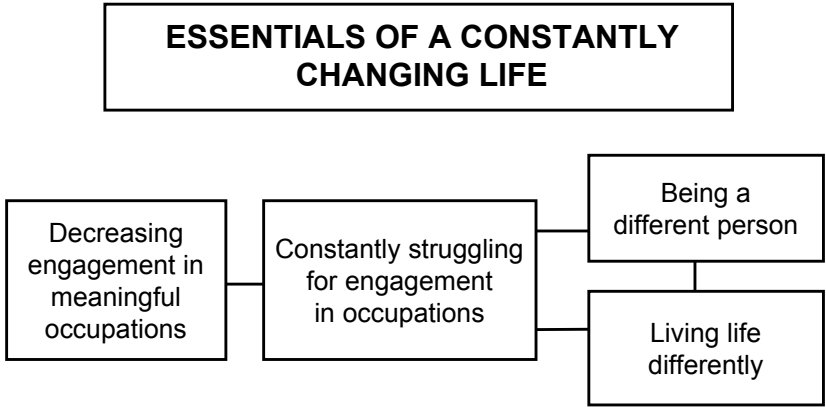


Fig. 2. The participants’ experiences of engagement in daily occupations formed the core category ‘Essentials of a constantly changing life’, and its four underlying categories

### Experiences of the process of adaptation of engagement in occupations

The participants’ experience of the process involved in the adaptation of their engagement in occupations was that it was an ongoing, non-linear process. The findings formed two main categories: “*adapting occupations to achieve a desired self*” and “*adapting occupation to achieve a desired family life*”, which the different adaptations of engagement strived to achieve. Each of the two main categories represented separate processes, but whenever occupations simultaneously pertained to the person’s own needs and those of his/her family, the participant considered who would benefit the most before the adaptation was chosen. They also described how they had the experience of going back and fourth between the different subcategories, of each main category, if the circumstances for initially making the adaptations to their in occupations had changed (See Figure 3). Some subcategories were more prominent for some persons, since each participant described his/her own unique dynamic process. An overview of the main categories, subcategories and properties is presented in Table 7.

The first main category; “Adapting occupations to achieve a desired self” reflected the different actions the participants undertook in order to achieve a desired self, depending on which of the subcategories the adaptations were aimed towards. At first, adaptations were made to *preserve each participant’s former capable self*, where the participants tried to engage in occupations as before and concealed shortcomings in their occupational performance, but they also challenged their ability and refused to take on the identity of a person with a disability. Later, when they had realised that they could no longer preserve those occupations that constituted their former capable self, they described how they changed their focus with the aim of finding their changing self. As a consequence, adaptations were now directed towards *finding a changing self*, searching for occupations that supported feelings of capability, and avoiding occupations where there was a risk of failure. The participants strived to be independent in their occupations for as long as possible, and they described themselves as being receptive to other people’s views and said that, through interactions with others, they had learned new ways of adaptation. They perceived the process of adaptation of engagement in occupations as

**Table 7.** An overview of the two main categories “Adapting occupations to achieve a desired self” and “Adapting occupations to achieve a desired family life” and their subcategories and properties.

Main categories	Adapting occupations to achieve a desired self	Adapting occupations to achieve a desired family life
<b>Subcategories</b>	<i>Struggling with adapting occupations to preserve the former capable self</i>	<i>Striving to adapt occupations to find a changing self</i>
<b>Properties</b>	<p>Struggling to engage in occupations as before</p> <p>Concealing shortcomings in occupational performance</p> <p>Challenging one's ability</p> <p>Refuse to take on an identity as a person with a disability</p>	<p>Striving to adapt occupations to find a desired family life</p> <p>Protecting their family from burden and feeling ashamed</p> <p>Striving to share family life and responsibilities as usual</p> <p>Striving to fulfil personal needs</p> <p>Striving for the children to view their parents as capable persons</p>
	<p>Searching for occupations supporting feelings of capability</p> <p>Avoiding occupations where one is at risk of failure</p> <p>Striving for independence in occupations</p> <p>Learning adaptations in occupations through interactions with others</p> <p>Finding adaptations in occupations through a process of trial and error</p> <p>Striving to avoid stigma</p> <p>Becoming prepared to manage new challenges in occupations</p>	<p>Adapting occupations to live a changed family life</p> <p>Sharing a changed family life</p> <p>Passing over all responsibility to the partner</p> <p>Making personal sacrifices to protect the family life</p>
	<p>Controlling the prerequisites for occupations</p> <p>Ignoring shortcomings and focusing on possibilities</p> <p>Occupations that support wellbeing</p> <p>Being a representative for others with MS</p> <p>Accepting modifications in occupations</p> <p>Choosing a life in solitude</p>	



a process of trial and error, where they tried to avoid stigma and explained how they had become prepared to manage new challenges in occupations, constantly. Finally, when they felt that they had found their new self, further *adaptations were aimed at sustaining a life with the changed self*. This was maintained by means of constantly making little adaptations to everyday occupations, such as always controlling the prerequisites for occupations, ignoring shortcomings and focusing on possibilities, and by choosing occupations that supported wellbeing. They also said they could now be a representative for others with MS and that they had accepted modifications in occupations. A few also chose to live a life of solitude as a way to live with their changed self.

The second main category; “Adapting occupations to achieve a desired family life”, comprised two subcategories: *striving to adapt occupations to find a desired family life* and *adapting occupations to live a changed family life*, both reflecting the adaptations made to engagement in occupations connected to as-

pects of the participants’ family life. When the participants had the experience that their decreasing engagement in occupations was taking away their former family life, they aimed their adaptations in occupations towards finding a family life that could accommodate the circumstances associated with their changed life. The analysis revealed that they protected their family from feeling their illness to be a burden on them and from feeling ashamed, and they strived to share family life to undertake responsibilities as usual, and to enable the children to view their parents as capable persons. In addition, they also said they strived to fulfil their own personal needs. When they had learned to live a changed family life that fitted in with the changed circumstances, the adaptations they made to their occupations were aimed at maintaining this changed family life, such as sharing a changed family life. Some also passed over all responsibility to their partner, and a few even said they made personal sacrifices to protect the family life of their family, even to the extent of excluding themselves if necessary.

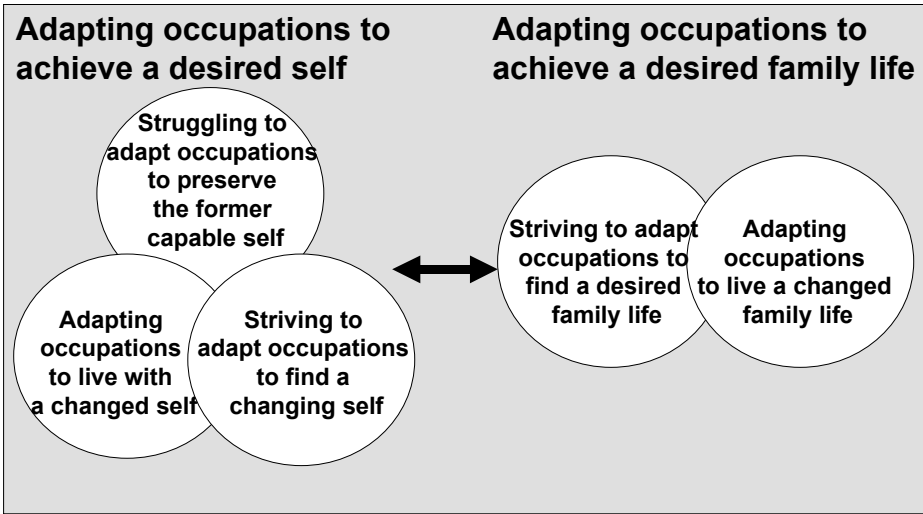


Fig. 3. The ongoing, nonlinear process of adaptation of engagement in occupations pertaining to the person’s self as well as those of his/her family.

## Summary of main findings

The main findings from the four studies can be summarised as follows. Persons with MS can:

- perceive problems with occupations related to all areas of occupations, at different hierarchical levels, and experience that they have only a few alternative occupations to engage in
- be dissatisfied with performance in occupations, especially related to self-care and household occupations, which is also confirmed by objective assessments
- be independent in self-care but dependent in household occupations
- have problems in their performance of occupations regardless of their age and disease severity or their living arrangements
- experience that they need to struggle continuously to manage everyday occupations, and that this changes them as persons and make them live their lives differently than they had anticipated
- experience their adaptation of engagement in occupations as an ongoing, non-linear process, involving both themselves and their family, and they always consider who will benefit the most before they choose the most suitable adaptation to improve their engagement in occupations

## Discussion

This thesis focused on the broad concept of engagement in occupations. Thus, the performance and the experiences of occupations in persons with MS were explored by means of different methodological approaches. The results highlight how complex the engagement in occupations is for these persons, and demonstrates that engagement in occupations can be markedly influenced, both in the way it is performed and experienced. Furthermore, the studies reveal that persons with MS ex-

perience their lives as constantly changing. This has a considerable impact on the sense of identity and of self of those with MS and on how they live their lives. In addition, it has implications for how adaptations to occupations are undertaken because the process of adaptation is non-linear and ongoing. These main findings will provide the standpoint for the discussion.

### *A decreasing engagement in occupations*

Reflecting the results, persons with MS can have problems with engagement in occupations both from the point of view of how the occupations are performed (studies I and II) and in terms of the way they are experienced (study II and III). Not surprisingly, the observational assessments showed that persons with moderate to severe MS had greater limitations to their performance in occupations, compared to healthy persons (study I). It was noteworthy that half of the persons with MS had such notable limitations on their performance of self-care occupations that they were assessed as being dependent. At the same time, 2/3 of the participants had so much difficulty performing household occupations that their independence in the community was at risk of being compromised; something that could easily be overlooked since the ability of persons with MS to perform household occupations has seldom been assessed. By observing the participants' performance of both self-care and household occupations, the results revealed not only in which occupations persons with MS had problems, but also to what extent their performance was affected. Furthermore, the correlations between the assessment scores for self-care and household occupations (study I) indicated a relationship between the two occupational areas, but limitations in the performance of household occupations were more pronounced than those for self-care. This suggests that a person with

MS can be independent in terms of self-care, but still be unable to perform household occupations satisfactorily. The fact that self-care occupations are generally more difficult to perform than household occupations, is well known within ADL literature (Spector *et al.*, 1987; Fisher, 2006a; Jakobsson, 2008), but this knowledge has not fully been incorporated in the management of MS or specifically addressed during rehabilitation. To date, the majority of all of the outcome studies conducted have relied on assessments of self-care to evaluate aspects of the performance of occupations (Khan *et al.*, 2007; Khan *et al.*, 2008a). The results of study I emphasise that it is important to consider also household occupations for persons with MS.

The results from the interviews, semi-structured (study II), as well as open-ended (study III), confirmed the results from the observational assessments. However, it also broadened the knowledge by revealing that persons with MS can perceive themselves to have problems with all areas of occupation (self-care, productivity and leisure) (study II), even though self-care occupations accounted for half of the reported occupations, productivity accounted for a third, with household occupations being the largest subcategory. Overall, the results from study II confirmed those obtained by Finlayson *et al.* (1998) who reported that persons with MS can encounter problems in all areas of occupations. Study II also revealed a novel finding that the participants perceived a wide variety in the different occupations that was reported, on different hierarchical levels. Interestingly, about 20% of all the reported occupations they perceived difficult to perform were classified as leisure, an area that is given less attention to within the literature on the health professions (Neumayer & Wilding, 2007). As was pointed out by Lundmark and Brännholm (1996), this is an important area to consider along with household occupations. These results show the importance for professionals to consider

all areas of occupations during rehabilitation, and the importance of acknowledging personal differences. The wide range of difficulties encountered in all occupational areas also have implications for life as a whole and for being able to balance different occupations in life, which has proven difficult for persons with MS (Matuska & Erickson, 2008).

Study I only included persons with moderate to severe MS, therefore it was not surprising that there was a relationship between the FIM motor score and disease severity, since the EDSS, especially in the range of 5.0 to 8.5, focuses wholly on ambulation. The results from this first study regarding the performance of occupations showed a more pessimistic view of the participants' ability to perform occupations than the studies included in Einarsson's (2006) thesis, the most recent description of the daily occupations of those with MS in Sweden. However, Einarsson's studies included more participants, a large variation in disease severity and seem to have relied a great deal on self-reporting instead on observational measures; they also used other assessments tools for self-care and household assessments than in the studies included in this thesis.

During the interviews, the participants also revealed how their performance was influenced (studies II and III), which forced them to struggle constantly against different forces to be able to continue to be engaged in occupations that they found meaningful (study III). One fairly recent study reported that struggling is a common experience among persons with MS (Reynolds & Prior, 2003), and more specifically, other publications have stated that struggling to get the services, benefits, and assistive devices that persons with MS need, is not uncommon (Wollin *et al.*, 2006; Edmonds *et al.*, 2007). The current study (study III) showed that participants' struggle also pertained to their possibility to maintain their engagement in meaningful occupations, which, to a large extent,

was associated with conditions imposed by their immediate social environment. This is in agreement with previous studies of other populations demonstrating the significance of a supportive environment for engagement in occupations (Lund & Nygård, 2004; Isaksson *et al.*, 2007d; Nyman & Lund, 2007). Again, since the participants stressed that much of their engagement in occupations, including the adaptations, was dependent on other persons (studies III and IV), they may need help to handle conditions that their social environment imposes on them, and to be able to determine the optimal choice for them and their families.

The results from the first two studies reported in this thesis, based on observational assessments of performance (study I) or subjectively reported by the participants (study II), have contributed in a different way to the understanding of problems related to the performance of occupations. From the observational assessments, information was obtained regarding the quality of the performance and the level of independence, whereas the subjective reports gave an insight into how occupational performance was perceived by the participants themselves. While the aim of this thesis was not to compare these two perspectives, it is worth noting that previous literature has shown that persons with MS report more problems regarding daily occupations than professionals (Goverover *et al.*, 2005), and that professionals and clients not always agree on their functioning (Rothwell *et al.*, 1997). In addition, professionals' observations of what they consider to be a problem in occupational performance may not always correspond to the experience of the clients, and, the contrasting situation may arise where the clients may experience other occupations to be problematic, but the problems be overlooked by the professionals. This emphasises the importance of gathering information on a client's occupations, from the perspective of the client as well as from that of the professional.

## ***Engagement in occupations influences self and identity***

In study III, experiences of engagement in occupations were described, and the participants emphasized that not being able to engage in their previous occupations in a satisfactory way had a negative impact on their self and their sense of identity. The result is in agreement with previous studies which have shown that chronic disease (Charmaz, 1983, 2002; Magnus, 2001; Laliberte-Rudman, 2002; Hvalsøe & Josephson, 2003; Öhman & Nygård, 2005; King *et al.*, 2006; Salick & Auerbach, 2006) influence a person's sense of self and their identity. The growing body of studies showing specifically how the MS disease influences a person's self and identity (Boeije *et al.*, 2002; Reynolds & Prior, 2003; Dilozenzo *et al.*, 2007; Isaksson *et al.*, 2007b) suggests that these are important issues that need to be addressed when persons with MS meet health care professionals, especially during rehabilitation. In addition, a previous study has shown that people can experience that their self and their identity is influenced not only by a disease, but by having to use an assistive device, alone (Lund & Nygård, 2003).

The results of study III also showed that the decreasing engagement in occupations made the participants strive to feel competent by searching for other occupations in which they could engage. However, studies of engagement in occupations conducted among persons with Alzheimer's disease or with mental illness found that previous occupations were identified as contributing to autonomy and were identified as ways of communicating personal identity (Hvalsøe & Josephson, 2003; Öhman & Nygård, 2005). To help a person with MS to reconstruct his/her identity, it is important to find occupations that can facilitate his/her experience of competency, not necessarily by holding on to those previously performed. This also raises other

concerns regarding the type of occupations that these persons can choose between. Often, people present themselves to others by the type of work or the type of leisure they pursue (Christiansen, 2004; Unruh, 2004). The majority of the participants whose occupations and experiences comprise this thesis had received a disability allowance or retirement pension. In study II, they reported having difficulties with performing leisure occupations. This suggests that they may need help to find new occupations that can fill the gap created by the loss of those occupations that they can no longer engage in, and which would enable them reconstruct their identity as capable, competent individuals.

The participants in study IV said that their adaptation of engagement in occupations was, partly, driven by the determination to achieve a desirable sense of self. This confirms previous research conducted on persons with other diagnoses, revealing that one's sense of self, identity, and engagement in occupations were all related and that the reconstruction of the new 'self' was crucial for successful occupational adaptation during rehabilitation (Bontje *et al.*, 2004; Klinger, 2005). The use of assistive devices, especially for walking, was found to influence the participants' sense of self (study III) as well as the adaptation process involved in finding their changing self (study IV), confirming the results by Lund and Nygård (2003). This suggests that when a person with MS has to use an assistive device, some interventions need to be directed towards helping them to reconstruct their self.

In addition, many of the adaptations that the participants said they undertook when they were trying to preserve their former self (study IV), were short-sighted, aiming towards solving an instantaneous problem or hiding the underlying issues. These adaptations often only facilitated engagement in occupations for a limited period of time, leaving the participants to solve the real issue later

on, in the next step in the process of adaptation. Furthermore, the adaptations made to engagement in occupations did not end when the participants experienced that they had found their new self. Instead, adaptations had to be made continuously by the clients in an ongoing battle to avoid having to start the process all over again. Again, this emphasises the importance of including the client's own experiences in clinical practise, so that professionals can capture where the client is in the adaptation process. A recent Swedish thesis on a specific occupational therapy method indicated that once clients' with a psychiatric disorder were able to tell their own experiences, they became aware of turning points and changes in their everyday life (Gunnarsson, 2008). Furthermore, in a group of clients with stroke, an increased awareness of disability has been shown to be related to improvements in the performance of occupations (Ekstam *et al.*, 2007). Awareness therefore seems to be a turning point for successful rehabilitation, and since this has not been studied among persons with MS, it would be an interesting target for future research.

### ***Adaptation is an ongoing non-linear process***

The results from study IV showed that the participants experienced their adaptation of engagement in occupations as an ongoing, non-linear process. The results are similar to those suggesting that persons living with a chronic disease continually shift their perspective between having their illness-in-the-foreground to having their wellness-in-the-foreground (Paterson, 2001), and that adaptation is an ongoing process for persons with chronic illness (Charmaz, 1995; Thorén-Jönsson, 2001). However, the existing literature has described the adaptation of persons with MS as a linear process, going from 'falling ill' towards a 'coming to terms' (Salick & Auerbach, 2006; Malcomson *et al.*, 2008).

Antonak and Livneh (1995), stated that ‘the person’s response to rehabilitation opportunities will be limited if he or she has not made a successful adaptation to the disease and its subsequent disabilities’ (p.1103). Instead, in my opinion, rehabilitation should facilitate adaptation, and, perhaps, also be one of the major foci of rehabilitation. The fact that persons with MS adapt their occupations differently depending on the aim of the adaptation, and also that they continually have to face new challenges is important knowledge for professionals working with clients with MS. This knowledge may help them to be prepared to suggest appropriate interventions and enable them guide their clients through the rehabilitation process with a more client-centred approach.

The ability of all people, with or without a disability, to cope and to adjust has been said to vary in accordance with behavioural and social factors (Elliott & Warren, 2007). Since cognitive impairment is common among persons with MS and can lead to a reduced strategy application ability, a more pronounced difficulty can be encountered in adapting to non-routine tasks (Birnboim & Miller, 2004). Thus, this has implications for the ability of persons with MS to adjust to a decreasing engagement in occupations, especially since habits are closely connected to occupations (Charmaz, 2002). King *et al.* (2006) argued that persons with a chronic illness might be in greater need of cognitive support – affirmation from others about who they are and what they can achieve – than persons in general, since they often doubt themselves and their abilities. Cognitive support might therefore be more important to this group of people than for people in general. In addition, persons with MS, have problems related to problem solving and seeking support (McCabe *et al.*, 2004). This and the results from study IV emphasises the need to not only educate or inform our clients, but to also to work in close cooperation with them

in real life situations, with affirmation of engagement in occupations.

### ***The family is prioritised during adaptations of engagement in occupations***

The results from study IV revealed that the family is central when making adaptations to engagement in occupations. Furthermore, the participants always considered who would benefit the most before they chose the most suitable adaptation to improve their engagement in occupations, which led to the implementation of adaptations that prioritised their family’s needs over their own. This is different from previous studies of families adopting the carer perspective when a partner or parent has MS (Heward, 2006) or from the investigations of the children’s experience (Turpin *et al.*, 2008), the children’s ability to adjust to stress (Pakenham & Bursnall, 2006), or how living with the MS affects family life and life in general (Courts *et al.*, 2004). In these investigations, the reasons why a client chose certain adaptations over others was not described. In a recent study, women with MS explained that their family was a strong motivator, and the dependence of the children and their expectations gave an incentive to struggle on with daily life (Olsson *et al.*, 2008). Even if the physical and social environment are important factors for influencing adaptations to occupations (Schkade & Schultz, 1992; Spencer *et al.*, 1996; Kielhofner, 2008), the fact that family issues could be a stronger drive for introducing such adaptations than the needs of the individual has not been put forward before. Hence, the results of study IV add to the body of knowledge available for the development of theories about adaptation to occupations. However, even though all of the participants in study IV had family relations, only a few of them had children who were still minors living at home. Choices concerning adaptations to occupations that

owed their result to family and children were especially evident in those with children who were minors. This indicates that studies are warranted of participants with different family constellations to elucidate the differences in the choices that are made when influenced by consideration of different family relations. Since it is evident that clients will make different choices, the importance of working in a client-centred manner to probe each client's and his/her family's priorities can not be over-emphasised.

## Methodological and conceptual considerations

### *Studies I and II*

All of the participants in this thesis were recruited from one rehabilitation clinic, and do not, therefore, represent the whole population of persons with MS. Consequently, it is not possible to generalise the results from studies I and II to all people with MS. In the first two studies where data was retrieved from the database at the rehabilitation unit, a retrospective design was used. This impacted on the number of possible participants, since some of the assessments had only been performed during a certain period of time. For instance, data on the performance of household occupations had not been gathered for all the clients that received rehabilitation, owing to a lack of trained and calibrated raters. This explains the relatively large number of participants (54 out of 144) for whom no observational assessment of household occupations was made, who were, thus, ineligible to participate in the study. In about 2/3 of the clients who had received rehabilitation from January, 1999 – December, 2001, no standardised assessment of occupational performance had been performed on their admission, as a result

of which, they could not be included in study II. Besides the fact that they were ineligible to participate, this raises some concern about how data are collected in clinical practise; this might have affected the results. Still, the results from studies I and II were congruent with those of other studies of reported or observed performance in occupations (Finlayson *et al.*, 1998), even if Doble and co-workers included persons with MS with a less pronounced severity of MS (1994).

In study I, observational assessment tools for self-care and household occupations were chosen to describe performance, and it should be noted that the aim was not to enhance the knowledge of the assessment tools. The choice of tools was primarily guided by the fact that they were already used within the clinical setting, and, in addition, the FIM is widely used within rehabilitation. However, previous studies have shown that the FIM may not be adequate when it is necessary to differentiate between clients who are more or less independent in self-care (Cohen & Marino, 2000). This was also seen in study I, with a substantial ceiling effect on the FIM. Since the AMPS can be used to assess occupational performance throughout a greater range of tasks and with different levels of difficulty, it is able to avoid floor and ceiling effects. The AMPS, on the other hand, has been criticised for being time-consuming, but my own experience is that this is mainly a problem when it is first incorporated into the OT's practise, as the OT gets accustomed to it. Nevertheless, a trained and calibrated OT rater is required to perform the assessment, which can be a problem in clinical practise.

In study I, the assessments of self-care and household occupations were examined by looking at the correlations between them, but it can be difficult to analyse the results from these correlations since the two assessments measure separate things. The FIM can be used to measure the level of independence, whereas the AMPS measures goal-directed

skills. This has to be taken into consideration when the results from the correlations are interpreted. Another concern is that neither of these assessments covers the whole spectrum of occupations, which was actually the reason that study II was conducted. Since the participants in study II reported problems with other areas of occupation, future studies that aim to describe occupational performance from an observational perspective should strive to include assessments that cover all areas of occupations. In addition, when global outcome of rehabilitation is measured, it is recommended to use measures that cover more than parts of the occupational repertoire. The goal attainment scaling (GAS) has been proven useful in inpatient rehabilitation for clients with MS, and measures clinically important change in overall functioning (Khan *et al.*, 2008b).

In study II, the COPM was used to gather data on occupational performance, and for most of the participants, there was no problems with the data collection. However, there have been discussions regarding the inter-rater agreement of the COPM, mainly regarding the procedure in which occupations are to be prioritised (Eyssen *et al.*, 2005). In the current study, every participant was interviewed by one OT, but, it is possible that the quality of this interview may still have influenced the data, and that, for example, if the interviews had been performed on another occasion, the participants may have perceived different occupations as being difficult to perform. Another issue worth noting is that many of the occupations that were perceived as difficult were related to mobility, which has been emphasised before (Brandt, 2005; Löfqvist, 2008), even if mobility itself is not regarded as an occupation. Since mobility was an item in the COPM, units of occupations related to this subcategory were classified accordingly. Previous research has shown that mobility is a major problem for persons with MS (Hobart *et al.*, 2001; Paltamaa *et al.*, 2007) and there is a possibility that many of the problems in

occupations encountered by the participants of study II, arise as a result of constraints on mobility. This underlines the importance of not only mapping out the occupations clients perceive themselves to have problems with, but to also unravel why an occupation is perceived as being difficult. On the other hand, if only mobility is captured and assessed, without targeting those occupations where mobility is undertaken, the client's engagement in that occupation may not be enhanced. Again, this implies that professionals need to use different assessment tools that target different aspects and it is of great significance that professionals in different disciplines collaborate in teams, in order to help clients with the many faceted problems they experience.

The EDSS has received a considerable amount of criticism as, besides mainly measuring aspects of ambulation, it has been shown to have poor psychometric properties (Hobart *et al.*, 2000). Nevertheless, it is still viewed as being a good descriptor of disease severity for persons with MS (Thompson, 2002). However, since it does not capture cognitive problems, there is a risk that clients who have these problems will still have scores representing only minimal disease severity. This is especially relevant to study II, where some of the participants had lower EDSS scores, as it is possible that the EDSS did not capture the whole spectra of disease severity. The disease severity was also used to divide the participants in studies I and II, according to their ability to ambulate. This differentiation was made to allow for evaluations of the relationship between performance in occupations and disease severity, but owing to the limited data available, no power calculations on the groupings of participants according to their EDSS scores was made. Therefore, these results should be interpreted with caution.

In study II, the data consisted of short statements or specific words related to the participants' perception of difficulties encountered with their occupational performance,



and therefore the choice of manifest content analysis was appropriate. The content analysis was guided by the micro and meso levels in the ValMO concept (Persson *et al.*, 2001). A difficulty encountered during the analysis was the construction of appropriate terminology for each 'single occupation'. The ValMO concept did not provide such information and does not specify precisely when an occupation should be classified as a single occupation or an action. The ValMO concept was therefore mostly used as a guiding framework in the second step of the analysis (Downe-Wamboldt, 1992). The analysis was mainly performed by the first author, but to strengthen the trustworthiness of the analysis and the results, it was discussed with and validated by the other authors.

In addition, the COPM focuses on performance of occupations, which can make it less relevant to clients who no longer perform occupations themselves, making it difficult to use the COPM with such participants. In line with the development of the Canadian model, the CMOP-E (Townsend & Polatajko, 2007), where engagement has been incorporated in the model, the COPM could be developed to incorporate the concept of engagement as well.

### **Studies III and IV**

The aim of studies III and IV was to reveal the experiences of persons with MS from their perspective, and, as it is an approach that has proven to be suitable for revealing personal experiences, a qualitative design was chosen. Owing to the qualitative design of the studies, the results cannot be generalized to all persons with MS, but they might be transferable to other persons in the same situation (Lincoln & Guba, 1985). The trustworthiness of the analysis and the results of the two studies in terms of their credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985; Graneheim & Lundman, 2004),

will be discussed in this next section.

It is a possibility that the clinical OT selected participants with a similar background, even though the author had the final choice of participants. The purposive sampling guided the selection of participants to ensure that they would reflect a variety of experiences. Although it had not been planned at the outset, for practical reasons, the participants were selected in two phases. Thus, the interviews and analysis did not follow the general principles of grounded theory, i.e., using theoretical sampling where the interviews and analysis are performed simultaneously and continue until saturation occurs. This could have yielded more extensive information and widened the perspectives of engagement and adaptations of engagement in occupations. However, the data collected in these studies, were judged to be sufficiently comprehensive because the background of the participants was diverse and extensive and, in addition the interviews were rich in information, which enhances the credibility of data. Furthermore, the credibility was further enhanced since all of the interviews were tape-recorded and transcribed verbatim. The qualitative research interviews were conducted with an interview guide comprised of a few questions (Kvale, 1997), developed together with the co-authors. Thus, the participants were able to recount their own stories concerning their experiences, and follow-up questions beyond the interview guide were posed when appropriate. Follow-up interviews with each of the participants were not made. It is possible that they could have extended their stories, and, that some topics could have been elaborated on more extensively if follow-up interviews had been conducted. At the end of the interviews the participants came back to the initial topics, and it is likely that saturation in data may have been obtained and therefore additional interviews might not have yielded new information. Nevertheless, as the participants were telling their stories retrospectively, it is

possible that the experiences of previous episodes they recounted had changed owing to the time that has lapsed.

The analysis was performed according to the constant comparative method (Strauss & Corbin, 1998) and was conducted by the author and the co-authors, together, in an iterative process. Initially, all interviews were read and re-read several times, and notes were made in all of the interviews about the content, both initially and during the coding process. During the coding process, extensive data was available, so data regarding adaptation of engagement in occupations was saved separately, and was further analysed in study IV (Strauss & Corbin, 1998). It is important to acknowledge that the analysis can be influenced by the author's prior knowledge in the field (Kvale, 1997; Strauss & Corbin, 1998) which can influence the dependability in the data. However, it is also possible that the author's experience in the field may have enhanced the quality of the data. Through experience of having interviewing clients with MS, and by being familiar with the occupations they have problems with, the authors may have enhanced how the data was gathered, and thereby the quality of data. In this respect, it is worthwhile noting that all of the authors who performed the analysis were OTs, and it is possible that if someone else, with another area of expertise, had performed the interviews as well as the analysis, the results would be different. With this in mind, the author has made a conscious effort to maintain an open mind and to capture the experiences as they were told by the participants. This is reflected in the quotations that are presented in the text to highlight some of the results thereby improving the confirmability of the studies. Since the results were presented and discussed at a seminar with professionals from the same discipline (study III), and from different disciplines (study IV), experienced in qualitative research, the credibility of the studies were further enhanced.

According to Strauss and Corbin (1998) a researcher implementing the constant comparative method of grounded theory should initially work inductively to reveal patterns in data, with little or no knowledge of the field. Later in the process, data should be scrutinised against existing research and theories so the latter can be developed or new theories can emerge, i.e., the deductive phase. These steps were also followed in studies III and IV, where, initially, the experiences of the participants were used to determine the pattern of codes and categories, without further elaborating on existing research and theories. Later, the categories were scrutinised in order to identify a core, or main categories, hence the deductive phase moved the analysis forward. Then the results from the participants' experiences were related to existing theories and, consequently, the names of the core and main categories were related to those of existing theories. Yet, the content within each core and main category remain congruent with the participants' experiences.

### *Conceptual considerations*

Categorisation of occupations is sometimes necessary to get an overall picture of perceived problems of occupations, as in study II. Recently the categorisation of occupations has been debated within the discipline of occupational therapy, where it has been stated that some occupations are not possible to categorise according to their purpose, i.e., self-care, productivity or leisure (Hammell, 2004; Jonsson, 2008). This was also found in study II, since an occupation can sometimes be related to several categories. Instead, it has been suggested that the meaningfulness of engaging in an occupation should be paid more attention (Hammell, 2004; Jonsson, 2008), and occupations should be categorised according to different dimensions of their meaningfulness to the person, through the concepts of 'doing, being, becoming, and belonging' (Wil-

cock, 1998b; Hammell, 2004). These concepts include the performance aspect of fulfilling purposeful occupations (doing), how we experience our lives, contemplate, and develop a sense of self (being), the social context where our occupations take place (belonging), and our hopes and wishes concerning what we will become, do, and contribute to others in the future (becoming). Jonsson (2008), on the other hand, suggests that occupations should be categorised according to the persons' experience of well-being by using seven experienced-based categories to describe the meanings that occupations hold to those engaging in them; i.e., engaging, basic, social, relaxing, regular, irregular, and time-killing. The categories that are the most important and contribute to well-being should be addressed. However, this way of reasoning is not commonly acknowledged by OTs active in the field of rehabilitation, and in particular those working with clients with MS.

Unruh (2004) suggested that for OTs to help their clients find their occupational identity again, the clients must have the opportunity to grieve for what is lost, and that OTs need to understand which occupations are the most meaningful to their clients. Further, Doble and Santha (2008) elaborated on how clients' most meaningful occupations can be acknowledged by OTs. They argued that OTs have been focusing too extensively on performance, and clients' subjective experiences have been overlooked. Instead they suggest that OTs should explore clients' experiences of what are meaningful occupations to them, to enable the OTs to help them to find occupations that constitute and improve well-being. Hence, interventions would not only include the doing perspective, but also the being, belonging and becoming. This is not only relevant for persons with MS, and examples of how this concept can be implemented with persons with different diagnoses have been presented (Rebeiro *et al.*, 2001; Lyons *et al.*, 2002; Isaksson, 2007c; Gunnarsson, 2008),

suggesting that the adoption of this approach will enhance the outcome of rehabilitation and occupational therapy.

## Conclusions and clinical implications

This thesis were related to two aspects of engagement in occupations, performance and experiences, showing that engagement in occupations is a complex phenomenon for persons with MS. Regarding the performance in occupations, the results show that those with MS can have greater problems with performance in occupations compared to the problems encountered in healthy people of a similar age. In addition, problems in the performance of occupations cannot be explained by age, disease severity, or living arrangements, alone. Moreover, they can be independent when they perform self-care occupations but have limitations when they perform household occupations, requiring a more comprehensive approach to assessment than is currently used. As independent living requires that a person can perform both self-care and household occupations, health care professionals managing clients with MS should be attentive to these limitations and their implications for independence in society.

Persons with MS can perceive themselves to have difficulties with a variety of occupations related to all aspects of daily life, and that they can experience dissatisfaction with their performance of occupations. Therefore, in clinical practise, rehabilitation professionals are recommended to use assessment tools that capture the complexity of daily occupations, and to individualise the assessments and interventions so they correspond to those problems perceived by the client. Furthermore, gathering information on a client's occupations from the client's perspective as well as from that of the professional will ensure that a broader picture of each client's en-

agement in occupations is captured. When global outcomes of rehabilitation are evaluated, it is not recommended that assessment tools capturing aspects of self-care occupations be used alone.

Persons with MS constantly have to struggle to maintain engagement in occupations, which, to a large extent, is influenced by societal regulations and other people's attitudes. In addition, they stress that much of their engagement in occupations is dependent on other persons. Consequently, professionals working with clients with MS are recommended to address the social conditions that influence meaningful occupations for each specific client, and adopt a wider perspective to work towards a change in attitudes and regulations in society.

Persons with MS experience a change in their sense of self and in their identity, owing to their decreasing engagement in occupations and the struggle they undertake to maintain their engagement. In addition, some of the adaptations they make to continue engagement in occupations are aimed towards achieving a desired self. The results from this thesis, together with the growing knowledge of how chronic diseases such as MS influence a person's identity and self, suggests that a changing sense of self and identity are important and need to be addressed by rehabilitation professionals. OTs should support clients to reconstruct their identities, by helping them to find occupations that can facilitate their experience of competency, which are meaningful, and bring a feeling of well-being for the clients. This challenges clinicians to change their clinical practice from the focus of performance in occupations to the broader perspective of engagement in occupations.

Finally, adaptations are not only directed towards the participant's self, but also towards his/her family, and whenever occupations simultaneously pertain to the person's own needs as well and those of his/her family, both are considered before an adaptation

is chosen, and often the family's needs are prioritised. It is crucial that rehabilitation settings incorporate issues related to adaptation into their programmes, since interdisciplinary rehabilitation is well suited to work with adaptation. Gaining knowledge of, and being able to recognise the different adaptations persons with MS undertake to achieve their various underlying aims, can facilitate suitable interventions that help clients' with issues of adaptation, in a client-centred manner. To be able to meet each client's specific needs it is crucial that professionals from different disciplines work together, in an interdisciplinary fashion. This means that each discipline needs to determine which interventions are most suitable for them to implement, otherwise the team will not be able to use its full potential or co-operate fully to meet the client's goals. For OTs, this means that we need to consider what is most important for our clients where engagement in occupations is concerned. Interventions need to correspond with these issues, not only aiming to improve performance in occupations, but also acknowledging our clients' experiences of their daily occupations.

## Future research for persons with MS

During the time in which the work presented here was conducted, several other theses have been presented on persons with MS living in Sweden, describing functioning and disability, quality of life and the experiences of those living with the disease (Einarsson *et al.*, 2008; Gottberg, 2006; Isaksson, 2007a; Olsson, 2007). Along with the work presented in this thesis, this body of research has contributed to the knowledge base regarding the performance of occupations, and the experiences of those living with MS, including engagement in occupations. However, there are still areas that need to be studied further

if one is to fully understand how occupations influence the lives of for people with MS. For example, since leisure was such an important area of concern for the participants, and as it has been given less attention in previous studies, there is a need to further explore experiences of leisure among persons with MS and to investigate why they have problems engaging in their leisure occupations. Nevertheless, building on the existing knowledge base, future studies should aim at measuring the outcome of different interventions and investigate which interventions are the most effective for persons with MS.

Today there is evidence to support the efficacy of rehabilitation for persons with MS (Khan *et al.*, 2007), but since the assessment tools that were used to measure occupations were intended to measure effects on self-care, it is most likely that the interventions recommended were directed towards self-care occupations as well. Since there is now evidence demonstrating that persons with MS have problems related to all areas of occupations, there is a need to find assessment tools that capture all of these aspects, and future studies of the outcome of interventions will, hopefully, reveal that rehabilitation is effective for performance in diverse areas of occupations. It also remains to be determined if certain in-

terventions are more efficient than others, for example, for different types of rehabilitation (early, acute and recurrent), or during different stages in the clients' process of adaptation. Clinical practice needs to incorporate programmes where the intention is to help clients to adapt to their current life, but there is still little knowledge about which interventions influence the possibility to adapt, and this warrants further investigations. In addition, there is a need to develop assessment tools that can measure whether rehabilitation contribute to the clients' ability to adapt, i.e., examining adaptation as the measure of the outcome of rehabilitation, and occupational therapy interventions.

For occupational therapy practice, there is a lack of research regarding the efficacy for persons with MS, and, thus, there is a need to plan and implement studies aiming at exploring its efficacy. There is also a need for OTs to move away from the consideration of performance towards a perspective that considers well-being, but there is a lack of instruments that can facilitate this. The results of study III provided some of the knowledge base, and by building on the ideas from Doble and Santha (2008) and Jonsson (2008), future research could be directed towards the development of such an instrument for persons with MS.

## Svensk sammanfattning (Swedish summary)

### *Engagemang i aktiviteter hos personer med multipel skleros*

Denna avhandling har studerat engagemang i aktiviteter hos personer med multipel skleros (MS), vilket innebär att både görandet, dvs utförande, och den egna upplevelsen av att vara delaktig i aktiviteter omfattas. Begreppet aktiviteter omfattar allt från personlig vård (hygien, påklädning, förflyttningar), sköta hushållsgöromål eller sitt arbete, men också att kunna delta i fritidsaktiviteter tillsammans med familj och vänner.

MS är en inflammatorisk, autoimmun sjukdom och kan leda till en rad olika funktionsnedsättningar såsom pareser, känselbortfall, trötthet, blåsstörningar, kognitiva nedsättningar, spasticitet, svaghet m.m. Sjukdomen kan också inverka på personens möjligheter att kunna utföra olika vardagliga aktiviteter, i och utanför hemmet och därmed personens möjligheter att leva ett välfungerande liv. Trots att sjukdomen är en av de vanligaste orsakerna till funktionshinder hos yngre och medelålders vuxna, finns det få studier som har belyst engagemang i aktiviteter hos personer med MS.

Inom arbetsterapi och rehabilitering har man i huvudsak fokuserat på själva utförandet av aktiviteter och de studier som har kartlagt vilka aktiviteter som är problematiska att utföra har främst beskrivit svårigheter i olika aktivitetsområden och därför saknas beskrivningar av specifika aktiviteter. I övrigt har man främst studerat svårigheter med att utföra personlig vård, både när utförande är bedömt av professionella och när det rapporteras av personerna själva, t.ex. via enkäter. Under de senaste åren har forskare för-

sökt beskriva hur personer med MS själva upplever specifika funktionsnedsättningar men också hur det är att leva med MS sjukdomen och hur de upplever sin livskvalitet. Trots att dessa studier inte direkt fokuserade på dagliga aktiviteter visade det sig att personerna upplevde att vanliga MS symtom influerade deras engagemang i aktiviteter. Engagemang i aktiviteter hade också positiva effekter på hur de upplevde sin livskvalitet. Andra studier har visat att kvinnor med MS upplever att en förändrad eller minskad aktivitetsrepertoar inverkar på deras identitet, vilket gjorde att de höll fast vid tidigare rutiner för att försöka fortsätta att vara aktiva i meningsfulla aktiviteter. Mänskliga relationer har även visat sig ha betydelse för hur man upplever engagemang i aktiviteter men dess hela spektrum är inte belyst hos personer med MS.

Personer som lever med en kronisk sjukdom måste anpassa sitt liv efter de nya förutsättningar som sjukdomen innebär. När man studerar anpassning hos personer med MS har man visat att graden av funktionshinder och socialt stöd inverkar på möjligheterna till anpassning men att det också finns skillnader i hur personer med MS upplever sina liv och hur de förmår att anpassa sig. Det finns också studier som menar att anpassningsprocessen hos personer med MS är linjär, medan andra hävdar att personer med en kronisk sjukdom byter perspektiv från att ha sjukdomen i fokus till att ha hälsa i fokus. Dessa studier har inte inkluderat aspekter av aktiviteter men eftersom engagemang i aktiviteter har stor betydelse människors liv, är det viktigt att studera om och hur engagemang i aktiviteter har någon betydelse för anpassningsprocessen. Dessutom är anpassningen en viktig del i rehabiliteringen vid MS och därför behövs mer kunskap om den anpassning som dessa personer behöver gå igenom för att klara att leva ett så aktivt liv som möjligt och hur rehabiliteringen bidrar till denna anpassning.

## Studie I–IV

Det övergripande syftet med mitt avhandlingsarbete var att öka och fördjupa kunskapen om utförande av aktiviteter och om erfarenheter av aktiviteter hos personer MS. Syftet var också att denna nya kunskap skulle kunna utveckla klient-centrerad arbetsterapi och rehabilitering. Avhandlingen har också fokuserat på att beskriva utförandet i personlig vård- och hushållsaktiviteter och att utvärdera relationerna dem emellan, samt mellan dem och sjukdomsgraden. Mer specifikt var syftet att beskriva vilka aktiviteter som personer med MS själva upplever sig ha svårigheter att utföra och hur de upplever sitt utförande. Vidare var syftet att få en fördjupad kunskap om hur personer med MS upplever sitt engagemang i aktiviteter och anpassningsprocessen av engagemang i aktiviteter. Deltagare till de fyra delarbetena rekryterades från en rehabiliteringsklinik där de varit inskrivna för rehabilitering.

I delstudie I deltog 44 personer med MS, där deras utförande i aktiviteter bedömdes av arbetsterapeut. Resultaten visade att personer med MS har nedsatt förmåga jämfört med friska personer och att personer med MS kan vara självständiga avseende förmågan att utföra personlig vård men kan behöva hjälp för att utföra hushållsgöromål. Slutsatsen från denna studie var att både personlig vård och hushållsgöromål behöver bedömas för att kunna avgöra om en person är självständig eller ej.

I delstudie II, som innefattade 47 personer med MS, användes ett bedömningsinstrument som utgår från en semi-strukturerad intervjuguide, för att kartlägga vilka vardagliga aktiviteter som personer med MS själv upplever sig ha svårigheter att utföra. Hushållssysslor, som matlagning, städning, tvätt och diskning, upplevdes som mest problematiska, men man angav även svårigheter med personlig vård, förflyttning och fritidsaktiviteter. Medelvärden i skattningarna

av utförande och tillfredsställelse var generellt låga. Det fanns en skillnad mellan män och kvinnor avseende rapporterade aktiviteter; män rapporterade fler problem med personlig vård än kvinnor.

I delstudie III–IV djupintervjuades tio personer med MS, med olika bakgrund, som alla hade svårigheter att utföra vardagliga aktiviteter. Intervjuerna genomfördes utifrån en intervjuguide där deltagarna fick berätta om och på vilket sätt som deras engagemang i aktiviteter hade förändrats och dess inverkan på dagliga livet (delarbete III). De fick också berätta om hur de hade anpassat sig för att få ett förändrat engagemang att fungera och hur det influerat deras relation till familjen och vänner och till livet i stort (delarbete IV). Resultatet i delarbete III visade att deltagarna upplevde att deras liv konstant förändrades då deras engagemang i aktiviteter försämrades. Försämringen gjorde att de ständigt behövde föra en kamp mot olika krafter: samhälleliga, andra personer och mot kroppens begränsningar. Sammantaget innebar det att deras jag och identitet förändrades vilket tvingade dem att leva ett annat liv än de tänkt sig. Resultatet av delarbete IV visade att deltagarna upplevde att deras anpassning av engagemang i aktiviteter var en icke-linjär, pågående process, som dels syftade till att vidmakthålla sin eget jag, dels att vidmakthålla ett önskat familjeliv. När de upplevde problem relaterade till både egna jaget och familjen, övervägde man för- och nackdelar med olika typer av anpassningar där ofta familjen drog det längsta strået. Anpassningar som riktades mot det egna jaget syftade antingen till att bevara sitt tidigare kapabla jag, därefter till att finna sitt förändrade jag och sedan till att bibehålla sitt nya jag. Anpassningen av aktiviteter i relation till familjelivet beskrevs på ett liknande sätt och inleddes när de upplevde att deras möjligheter att bibehålla sitt nuvarande familjeliv blivit svårt. Anpassningen riktades då mot att återfå ett fungerande familjeliv igen och därefter mot att försöka vidmakthålla det fa-

miljeliv man uppnått. Slutsatsen av delarbete III-IV är att personer med MS kan behöva få hjälp med insatser som i hög grad innefattar deras sociala miljö, dvs andra personer som influerar, för att de ska kunna få ett fungerade engagemang i aktiviteter. Dessutom behöver professionella bli bättre på att fokusera på hela klientens engagemang i aktiviteter, dvs både görandet och den egna upplevelsen av att vara delaktig, samt konsekvenser för hans/hennes liv, jag och identitet. Personer med MS har olika syften med sina anpassningar, beroende på var i anpassningsprocessen han/hon befinner sig, och därifrån måste professionella utgå från när interventioner planeras och genomförs tillsammans med klienterna.

## **Konklusion**

För att kunna klara ett självständigt boende behöver en person med MS både kunna sköta personlig vård och hushållsgöromål, men för att hjälpa honom/henne att vara aktiv måste fokus också vara på alla typer av aktiviteter. En person med MS som erhåller rehabilitering ska också ha möjlighet att själv få identifiera vilka aktiviteter han/hon upplever sig ha svårigheter med att utföra. Arbetsterapeu-

ter behöver bedöma utförandet av dessa aktiviteter och därefter är det viktigt att båda bedömningarna beaktas då det ger en bredare bild av aktivitetsproblemen. Det är dock viktigt att fokus inte enbart riktas mot själva utförandet i aktiviteterna utan att också personen med MS själv får berätta hur de upplever sitt engagemang i aktiviteter. På så sätt fångas inte enbart själva görandet av aktiviteterna utan också personens möjligheter att delta i aktiviteterna, trots att han/hon kanske inte själv kan utföra dem. Eftersom engagemang i aktiviteter till stor del påverkas av sociala omständigheter är det viktigt att dessa faktorer också beaktas, både för den enskilda klienten och på samhällsnivå. Det är vanligt att personer med MS upplever att både deras jag och deras identitet förändras och det är viktigt att få hjälp med att hitta sig själv och sin nya identitet under en rehabiliteringsperiod. Under en rehabiliteringsperiod bör de därför få hjälp med att hitta aktiviteter som känns meningsfulla och som gör att de känner sig kapabla. Det är också angeläget att rehabilitering för personer med MS innefattar åtgärder som syftar till att hjälpa personerna att anpassa sig så att de kan leva sitt liv så bra som möjligt.



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# Paper I



# Performance of activities of daily living in multiple sclerosis

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## Abstract

**Purpose:** To assess the performance of activities of daily living (ADL) in individuals with moderate to severe multiple sclerosis (MS).

**Method:** A total of 12 men and 32 women with MS (Expanded Disability Status Scale, EDSS, 6.0–8.5) were studied. The performance of personal ADL (P-ADL) and instrumental ADL (I-ADL) was assessed with the Functional Independence Measure (FIM) and the Assessment of Motor and Process Skills (AMPS).

**Results:** Twenty-four of the 44 individuals were rated dependent in P-ADL by the FIM motor score, mainly due to limitations in some areas of self-care and in transfers and locomotion. Only three individuals were rated dependent by the FIM cognitive score, indicating no or little cognitive disability. Two thirds of the individuals who were rated independent/modified independent in P-ADL by the FIM were rated dependent in I-ADL by the AMPS. Only the FIM motor score was significantly related to the EDSS score, indicating that ADL performance and disease severity is weakly related.

**Conclusions:** Moderate to severe MS reduces the ability to perform both P-ADL and I-ADL. An individual with MS can be independent in P-ADL but still unable to perform I-ADL satisfactorily. Assessments of both P-ADL and I-ADL are advocated to evaluate ADL performance in order to implement appropriate management strategies for individuals with MS.

## Introduction

Multiple sclerosis (MS) is an inflammatory demyelinating disease of the central nervous system and one of the most common causes of disability among young and middle-aged men and women. As the disease progresses the ability to perform activities of daily living

(ADL) is reduced.<sup>1</sup> Limitations in ADL performance in MS have a great impact on personal independence and quality of life<sup>2,3</sup> and on the social roles of the individuals and the well-being of their families.<sup>4</sup> A major aim of the management of individuals with MS is to minimize the impact of the limitations in ADL. An increased knowledge of ADL performance among individuals with MS could improve the management strategies and so enhance their ADL performance and thereby maintain independency in society.

ADL is usually divided into personal activities of daily living (P-ADL) and instrumental activities of daily living (I-ADL). P-ADL includes tasks such as toileting, dressing, eating, grooming, ambulation and bathing. I-ADL refers to more complex tasks such as communication, shopping, transportation and domestic activities (i.e., cooking, housekeeping and laundry).<sup>5</sup> Several studies have described the impact of MS on ADL. McDonnell *et al.*<sup>6</sup> used the Incapacity Status Scale (ISS)<sup>7</sup> and the Environmental Status Scale (ESS)<sup>8</sup> and assessed disability and handicap in 248 individuals with MS (mean disease duration 18.5 years) in Northern Ireland. Only 71 of the 248 individuals were fully independent in dressing, bathing and feeding, 86 required assistance with ADL for at least 1 h per day, and 81 required assistance to drive a car or to use public transportation.<sup>6</sup> Using the same assessment tools, Midgard *et al.*<sup>9</sup> found that one third of 124 individuals with MS (mean disease duration 7.8 years) in Norway needed assistance in stair-climbing, 25% needed aids for locomotion, and up to 16% needed assistance in self-care. Similar results were obtained in a study of 162 individuals with MS (median disease duration 15.4 years) in Minnesota, USA.<sup>10</sup>

The Functional Independence Measure (FIM), a generic tool that assesses P-ADL,<sup>11</sup> is designed to determine the amount of care a person needs by assess-

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sing what a person does. It consists of 18 items separated into two domains: the motor domain and the cognitive domain. Several studies have used the FIM to assess limitations in P-ADL in individuals with MS<sup>12</sup> and improvements following inpatient rehabilitation.<sup>13–15</sup> In these studies, the effects on P-ADL have been reported as the summed scores of the motor and cognitive domains of FIM. As some items in the FIM are more affected than others, the summed FIM scores may not adequately describe ADL limitations in MS. Furthermore, studies of limitations in ADL have assessed individuals with mild as well as moderate and severe MS. Studies of more homogeneous groups of individuals with MS and a more detailed description of the individual problems in ADL may increase our knowledge of the effects of MS on ADL performance.

Only one study has addressed the effects of MS specifically on instrumental activities of daily living (I-ADL). Doble *et al.*<sup>16</sup> evaluated the I-ADL performance in 22 community-dwelling individuals with mild to moderate MS, using the Assessment of Motor and Process Skills (AMPS). The AMPS is a world-wide used occupational therapy assessment tool, designed to evaluate both P-ADL and I-ADL.<sup>17</sup> It measures two components of occupational performance—ADL motor and process skills—which are necessary for completion of ADL tasks. The AMPS assessment indicates if and why the ADL performance is affected, and provides information of the person's ability to live independently in the community. Doble *et al.*<sup>16</sup> reported that more than half of the 22 individuals had problems performing I-ADL tasks. As this study was performed on individuals with mild to moderate MS, our knowledge of I-ADL performance in moderate to severe MS is not known.

From clinical practice, it is well known that an individual with MS can be independent in some P-ADL tasks but limited in I-ADL tasks. As independent living requires a high level of P-ADL as well as I-ADL performance, health care professionals would benefit from knowing the effects of MS on both P-ADL and I-ADL. To the best of our knowledge, no study has assessed limitations in both P-ADL and I-ADL in individuals with MS.

The aims of this study were (1) to assess the performance of P-ADL and I-ADL in men and women with moderate to severe MS using the FIM and the AMPS; (2) to evaluate the relationship between the performance of P-ADL and I-ADL by comparing data on the FIM and the AMPS, and (3) to explore the relationship between ADL performance and disease severity.

## Materials and methods

### SUBJECTS

A total of 44 individuals, 12 men and 32 women with clinically definite MS,<sup>18</sup> were studied. Data for these men and women were retrospectively obtained from our database that included 142 individuals with MS admitted for rehabilitation in the Department of Rehabilitation at Lund University Hospital from January 1997 to December 2002. All individuals had been admitted due to their disease progression that has led to various impairments, limitations in activity and restrictions in participation. The 44 men and women were selected using the following inclusion criteria: (1) stable in their MS with no ongoing relapse; (2) an EDSS score of 6.0 to 8.5; (3) activity limitations primarily related to their MS, with no additional diagnosis, such as major depression or limb fractures, that would impact on their ADL performance; (4) an assessment with both the FIM and the AMPS made on admission to rehabilitation. Written informed consent was obtained from each of the 44 individuals, and the study was approved by the Research Ethics Committee of Lund University, Sweden. The characteristics of the 44 individuals with MS are summarized in table 1.

### THE EXPANDED DISABILITY STATUS SCALE (EDSS)

EDSS is a measure of the neurologic impact of MS.<sup>19</sup> It rates disease severity on a scale of 0 (normal) to 10 (death due to MS). Scores between 0 and 3.5 indicate individuals with MS who are fully ambulatory, whereas scores of 4.0 and above indicate limitations in ambulation. Individuals with EDSS scores 6.0 need assistance on one side and can walk approximately 100 m with or without rest. Those with EDSS 6.5 can walk about 20 m with bilateral assistance, whereas individuals with EDSS 7.0 and 7.5 are essentially restricted to a wheelchair and can only walk about 5 m with aid (EDSS 7.0) or only a few steps (EDSS 7.5). Individuals with EDSS scores 8.0 and 8.5 cannot walk at all and are restricted to bed or chair or perambulated in a wheelchair much of the day. The median EDSS score was 7.0 (6.0–8.0) for the 12 men and 6.5 (6.0–8.5) for the 32 women. To allow for an evaluation of the relationship between disease severity and ADL performance, the 44 individuals were divided into three groups according to their ability to ambulate: (1) individuals who are able to walk with unilateral assistance (EDSS 6.0;  $n = 14$ ); (2) individuals who are able to walk with bilateral assistance (EDSS 6.5;  $n = 13$ ); and (3) indivi-

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**Table 1** Characteristics of the 44 men and women with MS

	Men (n = 12)	Women (n = 32)
Age (years)		
Mean (± SD)	47.9 (7.6)	53.3 (11.4)
Range	36–58	29–69
Years since MS onset		
Mean (± SD)	17.3 (5.3)	21.0 (12.2)
Range	8–29	1–45
Type of MS (N)		
Relapsing remitting	1	6
Secondary progressive	10	23
Primary progressive	1	3
Vocational situation (N)		
Working part time or full time with no disability pension	3	0
Working part time with part time temporary or permanent disability pension	4	3
Full temporary or permanent disability pension	6	25
Old-age pension	0	3

duals who are unable to walk and restricted to a wheelchair (EDSS 7.0–8.5;  $n = 17$ ).

#### FUNCTIONAL INDEPENDENCE MEASURE (FIM)

The FIM rates the amount of assistance required to perform P-ADL.<sup>11</sup> It consists of 18 items separated into two domains: the motor domain and the cognitive domain. Each item is scored on a seven-level Likert scale. A score of 1 or 2 indicates complete dependence (total or maximal assistance), 3 to 5 modified dependence (moderate or minimal assistance, or supervision), 6 modified independence and 7 complete independence. The FIM motor domain consists of 13 items, assessing self-care, sphincter control, transfers and locomotion; summed scores range from 13 to 91. The FIM cognitive domain consists of five items, assessing communication and social cognition; summed scores range from 5 to 35. A sum score of 78 and above in the motor domain and 30 and above in the cognitive domain indicates complete or modified independence.

#### THE ASSESSMENT OF MOTOR AND PROCESS SKILLS (AMPS)

The AMPS measures two components of occupational performance—16 ADL motor and 20 ADL process skills—which are the observable goal-directed actions necessary for completion of ADL tasks.<sup>17</sup> The ADL motor skills are actions a person carries out to move themselves or objects during ADL performance. The ADL process skills are actions a person carries out to logically perform ADL tasks over time, to select and use appropriate tools and materials, and to adapt his or her performance when problems occur. The

AMPS has been standardized cross-culturally for healthy individuals and for individuals with different diagnoses. The AMPS has been found to be reliable,<sup>20, 21</sup> valid<sup>22–24</sup> and usable in Sweden.<sup>25</sup>

The administration of AMPS involves four steps: (1) interviewing the person and deciding which tasks to perform; (2) setting up the test environment; (3) observing the ADL tasks; and (4) scoring the performance and interpreting the results. The aim of the initial interview is to identify P-ADL or I-ADL tasks that the person normally performs in his/her environment. The person is then offered three to five tasks of appropriate difficulty out of 83 P-ADL and I-ADL tasks in the AMPS manual, and selects two or three tasks for the observation. The 83 tasks in the AMPS manual are ranked according to difficulty: very easy, much easier than average, easier than average, average, harder than average and much harder than average. The AMPS can thereby assess low and high functioning persons without floor and ceiling effects.<sup>17</sup> Before the observation, the person and/or the examiner is familiarized with the assessment environment. Finally, the person is asked to perform the tasks as he/she would normally do them, and the examiner observes and takes notes of the performance.

After completing the observation, the examiner assesses the performance in each of the two or three tasks according to the AMPS manual. To complete a specific ADL task, a person must perform both different ADL motor skills (e.g., lifting an iron, reaching for a shirt, gripping a sleeve) and ADL process skills (e.g., choosing the shirt, organizing the workspace efficiently and noticing/responding to wrinkles). The 16 ADL motor and 20 ADL process skills in each



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of the two or three tasks are rated on a four-point ordinal scale according to the level of (1) effort; (2) efficiency; (3) safety; and (4) independence in the performance. A score of '1' represents markedly deficient performance that impedes the action; '2' ineffective performance; '3' questionable performance; and '4' competent performance. After the examiner has rated the performance, the raw ordinal scores from the two or three tasks are analysed and converted into interval data, logits, by a many-faceted Rasch analysis.<sup>26,27</sup> These logits are presented graphically as an ADL motor and a process ability measure on two linear scales: high positive ADL motor and process ability measures indicate that persons are more able, whereas low and/or negative ability measures indicate that persons are less able.<sup>17</sup>

The ADL motor and process ability measures accommodate several aspects of the observation, such as the difficulty of the motor and process skills, the challenges of the tasks and the person's performance during the ADL tasks, all of which are computed in the same linear metric and on the same scale. Thereby, the ADL ability measures for each individual are adjusted for the difficulty of the tasks actually performed, which determines where on a continuum of ability the individual is placed. Thus, the individual's performance capacity across tasks of greater or lesser difficulty than those on which he/she was observed can be predicted.<sup>17</sup>

A person scoring below 2.0 logits (cut-off criterion) on the ADL motor scale might need a greater level of effort when performing ADL tasks than a well/healthy person.<sup>17</sup> A person scoring below 1.0 logits (cut-off criterion) on the ADL process scale, with a possible risk zone of  $\pm 0.3$ , indicates that the individual cannot perform the ADL tasks safely, efficiently and independently and is at risk of not being able to live independently in the community. The mean AMPS motor and process ability measures for healthy adults are 3.2 and 2.2 logits, respectively.

PROCEDURE

On admission, each of the 44 individuals was examined and assessed with the EDSS by the physiatrist (JL). During the first 3 days, each individual was rated with the FIM by a consensus opinion of the treating interdisciplinary rehabilitation team. Within the first week of rehabilitation, the occupational therapist (EM) assessed each individual with the AMPS. The AMPS was part of the regular occupational therapy assessment, where the therapist and individual together

identified problems with occupational performance. Individuals who identified ADL problems that were covered by the AMPS were then assessed. In this study, only the results from assessments of I-ADL tasks are included. Each AMPS assessment was completed within 45–60 min, depending on the ability of the individual and the type and number of tasks performed: 42 individuals chose to perform two tasks each and two individuals chose to perform three tasks each.

DATA AND STATISTICAL ANALYSIS

For each of the 44 individuals, four measures of ADL performance were available: the FIM motor and cognitive scores, and the AMPS ADL motor and process ability measures. Pearson's correlation coefficient was used to assess the relationships between the FIM motor and cognitive scores and the AMPS ADL motor and process ability measures. A one-way ANOVA with appropriate *post-hoc* tests was used to analyse differences in ADL performance between men and women, and between the three groups of individuals, grouped according to their ability to ambulate. Spearman's rank correlation coefficient was used to assess the relationship between the EDSS scores and the AMPS ADL motor and process ability measures, and the relationship between the EDSS scores and the FIM motor and cognitive scores. Results are presented as means, standard deviation, minimum and maximum. Significance levels smaller than 5% are considered significant. All statistical analyses were done with SPSS version 11.0.

Results

FIM MOTOR AND COGNITIVE SCORES

The mean motor, cognitive and total FIM scores were identical for the men and the women: 73, 33 and 106, respectively (table 2). For both the men and the women, the mean scores for six motor items—C (self care; bathing), E (self care; dressing—lower body), I (transfers; to/from bed, chair, wheelchair), J (transfers; to/from toilet), K (transfers; to/from tub/shower) and M (locomotion; stairs)—were generally lower than for the other seven motor items. For these six motor items, the proportions of individuals with scores of 6 or 7 were also lower compared with the other seven motor items (table 2). Item G (Sphincter control; bladder management) was lower for the women than for the men. For item L (locomotion; walk/wheelchair), 9 men and 10 women used wheelchair as their main form of transportation; a

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**Table 2** The mean of the 13 motor items and the five cognitive items in the Functional Independence Measure (FIM) for the 44 men and women with MS

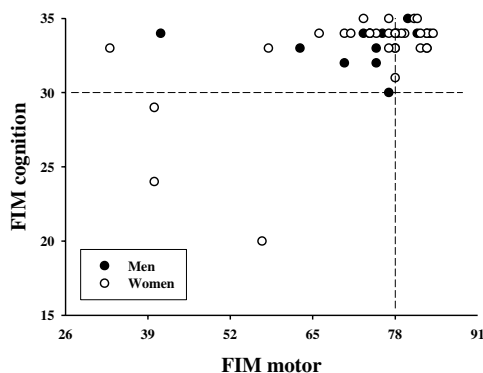
	Men (n = 12)	Women (n = 32)	% scores 6 or 7*
<b>FIM Motor domain</b>			
Self care			
A. Eating	6.4 (5–7)	6.3 (4–7)	84
B. Grooming	6.5 (6–7)	6.4 (4–7)	98
C. Bathing	5.4 (3–7)	5.6 (3–7)	68
D. Dressing – upper body	5.9 (4–7)	6.2 (4–7)	86
E. Dressing – lower body	5.4 (1–7)	5.0 (1–7)	70
F. Toileting	5.8 (2–7)	5.6 (1–7)	89
Sphincter control			
G. Bladder management	6.4 (6–7)	5.4 (1–7)	82
H. Bowel management	6.6 (5–7)	6.4 (2–7)	93
Transfers			
I. Bed, Chair, Wheelchair	5.2 (1–6)	5.3 (1–6)	73
J. Toilet	5.2 (1–6)	5.4 (1–6)	77
K. Tub, Shower	5.2 (1–6)	5.4 (1–6)	73
Locomotion			
L. Walk/Wheelchair	5.8 (3–6)	5.6 (1–6)	82
M. Stairs	3.1 (1–6)	4.2 (1–6)	46
Mean $\pm$ SD (range) items A–M	73 $\pm$ 11 (41–84)	73 $\pm$ 13 (33–84)	79 $\pm$ 13 (46–98)
<b>FIM Cognitive domain</b>			
Communication			
N. Comprehension	6.2 (6–7)	6.1 (4–7)	93
O. Expression	6.8 (6–7)	6.8 (5–7)	96
Social Cognition			
P. Social Interaction	6.7 (5–7)	6.7 (6–7)	98
Q. Problem Solving	6.8 (6–7)	6.7 (2–7)	93
R. Memory	6.7 (6–7)	6.6 (2–7)	93
Mean $\pm$ SD (range) items N–R	33 $\pm$ 1 (30–35)	33 $\pm$ 3 (20–35)	95 $\pm$ 2 (93–98)
Total (mean $\pm$ SD; range)	106 $\pm$ 11 (75–118)	106 $\pm$ 15 (64–118)	

\*Scores of 6 and 7 represent modified and complete independence, respectively.

majority self-propelled in their wheelchair 50 m or more, and hence had a score of 6. Item M had the lowest mean and the highest number of individuals with scores of 1 ( $n = 16$ ; 36%). The total number of scores of 7 for items A–M was 112 (out of 572; 20%) and of 6 was 337 (59%).

The FIM cognitive scores for items O (communication; expression), P (social cognition; social interaction), Q (social cognition; problem solving) and R (social cognition; memory) were very high for both the men and the women (table 2). The mean score for item N (communication; comprehension) was lower than for the other four cognitive items, because individuals wearing eyeglasses receive a score of 6; 31 individuals had a score of 6 for this item. Three women had summed FIM cognitive scores below 30, and also scores below 6 for items N, O, Q and R. For items N–R the total number of scores of 7 was 151 (out of 220; 69%) and of 6 was 57 (26%).

In figure 1, the summed FIM motor and cognitive scores are plotted for each individual. The lines at 78 for the FIM motor and at 30 for the FIM cognitive



**Figure 1** Graphical presentation of the Functional Independence Measure (FIM) motor and cognitive scores for the 44 men and women with MS. The lines at 78 for the FIM motor scores and 30 for the FIM cognitive scores represent complete or modified independence. Note that several individuals have the same FIM motor and cognitive scores, therefore the total number of data points does not add up to 44.

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tive domains represent complete or modified independence. The highest summed FIM motor score was 84; 20 individuals had a sum score of 78 or above while 24 had 77 or below. Six individuals had a summed FIM cognitive score of 35 and 21 of 34; 41 had a sum score of 30 or above and 3 had 29 or below. Three women had both FIM motor and cognitive scores below the two lines.

AMPS ADL MOTOR AND PROCESS ABILITY MEASURES

A total of 90 I-ADL tasks were performed during the AMPS assessments: meal preparation ( $n = 38$ ), table setting ( $n = 7$ ), house cleaning ( $n = 15$ ), bed making ( $n = 7$ ), laundry ( $n = 17$ ), shoe polishing ( $n = 1$ ) and plant care ( $n = 5$ ).

In figure 2, the AMPS assessments of the 44 individuals are presented. All had an ADL motor ability measure below the cut-off criterion of 2.0; the highest was 1.5 and the lowest  $-0.7$ . Fourteen individuals (32%) had an ADL process ability measure above 1.0, and 6 of these were above 1.3 (upper end of risk zone). Thirty individuals (68%) had an ADL process ability

measure below or on the cut-off criterion of 1.0: 11 had an ADL process ability measure below 0.7 (lower end of risk zone) and 19 were in the risk zone of 0.7 to 1.0. The mean AMPS motor ability measure was  $0.8 (\pm 0.5)$  for the men and  $0.4 (\pm 0.5)$  for the women. The mean process ability measure was  $1.0 (\pm 0.4)$  for the men and  $0.9 (\pm 0.3)$  for the women. There were no significant differences between the men and the women.

RELATIONSHIP BETWEEN AMPS AND FIM

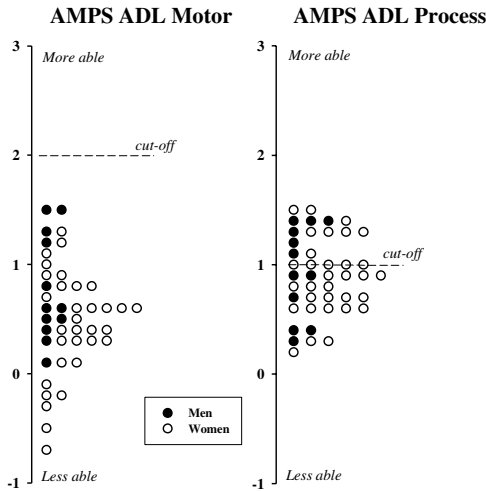
There were significant positive relationships between the FIM motor scores and the AMPS ADL motor ability measures ( $r = 0.38$ ;  $p = 0.01$ ) and between the FIM cognitive scores and the AMPS ADL process ability measures ( $r = 0.36$ ;  $p = 0.018$ ). The relationship between the FIM motor scores and the AMPS ADL process ability measures was also significant ( $r = 0.46$ ;  $p = 0.002$ ) whereas the relationship between the FIM cognitive scores and the AMPS ADL motor ability measures was not significant ( $r = 0.14$ ).

Eighteen individuals had a FIM cognitive score of 30 or above and an AMPS ADL process ability measure above the cut-off criterion of 1.0. One individual had a FIM cognitive score of 30 and an AMPS ADL process ability measure of 1.1. Twenty-two individuals had a FIM cognitive score of 30 or above but an AMPS ADL process ability measure below the cut-off criterion of 1.0. The remaining three individuals had a FIM cognitive score below 30 and an AMPS ADL process ability measure below 0.7.

RELATIONSHIP BETWEEN EDSS, FIM AND AMPS

There were significant differences between the FIM motor scores for the group of individuals with EDSS 7.0–8.5 and the groups with EDSS 6.0 ( $p = 0.002$ ) and EDSS 6.5 ( $p = 0.004$ ), but no significant differences between the two groups with EDSS 6.0 and 6.5 (table 3). There were no significant differences between the three groups for the FIM cognitive scores, the AMPS ADL motor ability measures or the AMPS ADL process ability measures.

There was a significant relationship between the EDSS scores and the FIM motor scores ( $r = -0.61$ ;  $p < 0.001$ ) but not between the EDSS scores and the FIM cognitive scores ( $r = -0.15$ ). There was no significant relationship between the EDSS scores and the AMPS ADL motor ability measures ( $r = -0.01$ ), or between the EDSS scores and the AMPS ADL process ability measures ( $r = -0.21$ ).



**Figure 2** Graphical presentation of the Assessment of Motor and Process Skills (AMPS) ADL motor and ADL process ability measures for the 44 men and women with MS. Each data point represents the combined assessments from the 2 or 3 I-ADL tasks performed. The cut-off criterion of 2.0 for the ADL motor scale and 1.0 for the ADL process scale are indicated.

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**Table 3** The Functional Independence Measure (FIM) and the Assessment of Motor and Process Skills (AMPS) for the 44 men and women with MS grouped according to their ability to ambulate based on their Expanded Disability Status Scale (EDSS) score\*

	EDSS		
	6.0 (n = 14)	6.5 (n = 13)	7.0–8.5 (n = 17)
FIM			
Motor domain	79 (66–84)	78 (71–83)	64 (33–84)**
Cognitive domain	33 (31–34)	34 (32–35)	32 (20–35)
AMPS			
ADL Motor	0.5 (–0.1–1.3)	0.5 (–0.5–1.1)	0.6 (–0.7–1.5)
ADL Process	1.0 (0.4–1.5)	1.0 (0.6–1.5)	0.8 (0.2–1.4)

\*Individuals with EDSS 6.0 walk with assistance on one side whereas individuals with EDSS 6.5 walk with bilateral assistance. Individuals with EDSS 7.0–8.5 are essentially restricted to wheelchair (7.0–7.5) or perambulate in a wheelchair much of the day (8.0–8.5).

\*\*The FIM motor scores for the group of individuals with EDSS 7.0–8.5 was significantly different from the groups with EDSS 6.0 ( $p = 0.002$ ) and EDSS 6.5 ( $p = 0.004$ ).

## Discussion

A major management aim of individuals with MS is to enable them to perform ADL as satisfactorily as possible and thereby remain as independent as possible in society.<sup>28</sup> This requires that they can perform P-ADL as well as I-ADL. Despite the well-known effects of MS on ADL performance, few studies have described and assessed the limitations in ADL. In this study, both P-ADL and I-ADL performance were assessed in a selected group of individuals admitted for rehabilitation due to their MS-related disability. Our results show that men and women with moderate to severe MS have similar limitations in the performance of P-ADL, mostly related to parts of self-care, transfer and locomotion. The results also show that the quality of their I-ADL performance is considerably reduced and that individuals with MS may be independent in P-ADL but still unable to perform I-ADL satisfactorily.

About half of the individuals were rated as dependent by the FIM, i.e., a FIM motor score of 77 or below. This is consistent with the disease severity—the average time since MS onset was 20 years and the median EDSS score 6.5. Our results are somewhat higher than the previously reported median motor FIM scores of 67<sup>13</sup> and 61.5.<sup>14</sup> Although the disease severity was similar to the present study, both these studies<sup>13,14</sup> included individuals with EDSS 9.0 and reported FIM motor scores as low as 13, indicating that they were completely dependent with maximal assistance. As individuals with EDSS 9.0 cannot perform ADL tasks they were excluded from our study.

As expected, some FIM motor items were more affected than others: items related to bathing, lower-body dressing, transfers and locomotion were most affected. Sharrack *et al.*<sup>29</sup> assessed 25 MS patients

(EDSS 0–7.5) and also found that these FIM motor items were more affected than the other motor items. These results are consistent with the disease severity, where lower limb function in moderate to severe MS is affected to a large extent. Several of the individuals in the present study had accessed community resources and received appropriate mobility aids. Therefore, the mean score for item L (walk/wheelchair) was not as low as the other mobility items. More than a third of the individuals had a score of 1 for stair locomotion (item M), but many could still move around independently indoors using a wheelchair. Thus, reductions in the summed FIM motor score is accounted for by only a few items, which, in turn, may not be that relevant to these individuals' overall ADL-performance. As mobility is more easily improved than other items in the FIM, this raises concern about the use of FIM as a global ADL outcome measure in MS rehabilitation studies.

More than 60% of the individuals had FIM cognitive scores of 34 or 35 and only 3 individuals were rated as dependent, i.e., a FIM cognitive score of 29 or below. In a previous study of 201 MS patients with EDSS 5.0–9.0, the mean FIM cognitive score on admission to rehabilitation was 30, ranging from 11 to 35.<sup>30</sup> These authors argued that the FIM cognitive score has limited usefulness for the measurements of cognitive disability in MS patients. MS is known to lead to cognitive dysfunction,<sup>31</sup> but few studies have actually assessed the relationship between cognition and ADL in MS. The FIM has been shown to be useful for the assessment of cognitive disability in stroke and traumatic brain injury.<sup>32,33</sup> Thus, the high FIM cognitive scores in our study implies that a majority of the individuals did not have a significant disability with regard to communication and social cognition. Another reason for the high

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FIM cognitive scores in the present study may be that our sample represented a selected subgroup of individuals with moderate to severe MS. Further studies are needed to assess the impact of cognitive impairments in MS on ADL performance.

With the AMPS, the performance of I-ADL was assessed in tasks that the individuals together with the therapist had selected. Thus, these tasks were relevant to the individuals and represented tasks that they had problems performing. A majority were domestic I-ADL tasks related to meal preparations, laundry and house cleaning, which are tasks that individuals with MS have reported difficult to perform.<sup>1</sup>

Our study is, to the best of our knowledge, the first that has presented quantitative assessments of I-ADL performance in individuals with moderate to severe MS. The I-ADL performance was considerably lower than that for healthy individuals<sup>17</sup> and for individuals with mild to moderate MS.<sup>16</sup> The low ADL ability measures in our study are not unexpected, given the disease severity of the 44 individuals. Motor impairments, such as reduced neuromuscular strength and endurance—characteristic of moderate to severe MS—can compromise the ability to complete ADL tasks and lead to low AMPS ADL motor ability measures. Cognitive impairments related to, for example, perception, memory and executive functioning, could result in ADL process skill deficits. Problems in ADL motor skills can also lead to increased demands on ADL process skills, because the ability to use alternative or compensatory strategies is reduced. As a majority did not have a marked cognitive disability as assessed by the FIM, the reduced ADL process ability measures is most likely related to their physical impairments. As we did not assess motor and cognitive impairments, limitations in ADL performance can only be indirectly related to deficits in physical and cognitive functioning.

The correlations between the FIM scores and the AMPS ADL ability measures indicate a relationship between P-ADL and I-ADL performance. Previous studies have shown a relationship between FIM motor and cognitive scores and AMPS ADL motor and process ability measures in elderly people diagnosed with dementia or mild memory impairment.<sup>22</sup> In this study, limitations in I-ADL were more pronounced than in P-ADL. The low AMPS ADL motor ability measures indicated that none of the individuals were able to perform any of the tasks without substantial effort, but 20 were rated independent in P-ADL (FIM motor score of 78 and above). Similarly, 30 individuals had an AMPS ADL process ability measure on or below the cut-off criterion of 1.0 and a further eight

were in the risk zone of 0.3 logits, but as many as 41 were rated independent with a FIM cognitive score of 30 or above. The ADL process ability measure has been found to discriminate between individuals who are able to live independently in society and those who require assistance.<sup>17,34</sup> Thus, for a majority of the individuals in this study, the quality of the I-ADL performance was reduced to such a degree that their ability to live independently in the society could be compromised. This shows that an individual with MS can be independent in P-ADL but can have limitations in I-ADL, which may not be evident from assessments of P-ADL alone.

Even though many of the limitations in ADL can be explained by the severity of the MS, only the FIM motor score was significantly related to the EDSS score and only the FIM motor score discriminated between the group with the highest EDSS scores and the other two groups. As EDSS in the range of 5.0 to 8.5 focuses wholly on ambulation, it was not surprising that only the FIM motor score correlated significantly with the EDSS score. Our results are similar to those reported by Cohen *et al.*<sup>35</sup> who investigated the relationship between the EDSS and ADL performance from self-reports in 43 individuals with MS. They found a strong correlation between the EDSS and total ADL performance, but the ADL domain of 'mobility' fully accounted for this relationship.

ADL performance is a broad concept that encompasses several domains: personal care, household tasks, work and leisure.<sup>36</sup> Notwithstanding their advantages, both the FIM and the AMPS give a somewhat limited view of ADL performance. The FIM is one of the most widely used P-ADL assessment tools, however, previous studies have shown that the FIM score may not adequately assess individuals who are more or less independent in P-ADL.<sup>37</sup> This is also seen in the present study with a substantial ceiling effect of the FIM. With the AMPS, ADL performance is evaluated throughout a greater range of ADL tasks of both lesser and greater difficulty. Thereby, the AMPS avoids floor and ceiling effects. However, the AMPS can only be used to assess a selected number of I-ADL tasks. To obtain a comprehensive understanding of ADL performance in MS, self-reports, proxy-reports, interview methods as well as methods that rely on direct observations of ADL performance may have to be combined.<sup>38</sup> Further studies are needed to establish the most appropriate tools that can evaluate the spectrum of activity limitations that occur in MS. Future studies should also be prospective and include a larger sample size to allow for more detailed inferences.

## Conclusions

Moderate to severe MS affects the ability to perform both P-ADL and I-ADL. Individuals with MS can be independent in P-ADL but can have limitations in I-ADL, which is not evident from assessments of P-ADL alone. As independent living requires a high level of both P-ADL and I-ADL performance, health care professionals managing individuals with MS should be attentive to these limitations and their implications for self-reliance in society. Assessments of both P-ADL and I-ADL are advocated to evaluate ADL performance among individuals with MS and to implement management strategies that allow these individuals to maintain a high level of ADL performance and thereby their independence in society.

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## Paper II



Erratum in paper II:

Page 85, in Table III under the heading “community management – travelling with a car” should be  $n=5$

ORIGINAL ARTICLE

## The complexity of daily occupations in multiple sclerosis

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### Abstract

The aims of this study were to describe which self-care, productivity, and leisure occupations individuals with multiple sclerosis (MS) perceive as difficult to perform on admission to rehabilitation and the individuals' own perception of the importance of, performance of, and satisfaction with these occupations. Whether the reported self-care, productivity, and leisure occupations were related to sex, age, disease severity, and living arrangements was also investigated. Forty-seven men and women (mean age 49.4 years) were assessed with the Canadian Occupational Performance Measure (COPM) on admission to rehabilitation. The individuals reported 366 occupations (median 8, range 3–15), which were categorized as self-care (51%), productivity (30%), and leisure (19%). Three COPM subcategories—household management (26%), personal care (21%), and functional mobility (20%)—accounted for two-thirds of the reported occupations. All prioritized occupations ( $n=238$ ; median 5, range 2–7) had high ratings for importance and the ratings for performance and satisfaction were generally low. Men reported significantly more occupations related to self-care than women, but no significant difference between the sexes could be found for productivity and leisure. No significant differences between the occupational areas were found when age, disease severity, or/and living arrangements were included in the analysis. In conclusion, individuals with MS perceive difficulties with occupations related to all aspects of daily life. This underscores the need to use assessment tools that capture the complexity of daily occupations.

**Key words:** *Activities of daily living, multiple sclerosis, outcome assessment, patient-centred care, rehabilitation*

### Introduction

Despite it being one of the most common causes of disability among young adults (1), our knowledge of the consequences of multiple sclerosis (MS) for daily occupations is limited. As a main aim of the management and rehabilitation of individuals with MS is to enable them to continue to engage in meaningful and purposeful daily occupations, detailed knowledge of the individuals' own perception of their occupational performance will facilitate the design and implementation of effective interventions.

Occupation, often used interchangeably with the terms activity and participation in the International Classification of Functioning, Disability and Health (ICF) (2), includes performance in three main areas: self-care, productivity, and leisure (3). Many individuals with MS have reported that they require assistance with daily occupations and are unem-

ployed or retired (4–7). Standardized objective methods have been used to assess different aspects of daily occupations in individuals with MS and have shown that their performance is significantly reduced compared with healthy individuals (8–12). Three surveys have used self-reports to describe specific difficulties with daily occupations. One study focused on preferences with practised occupations. Those who were satisfied with their life were less tired, more independent in self-care, and more satisfied with their leisure situation and housekeeping ability (13). In another study, 78% of the individuals with MS experienced difficulties with at least one occupation. The most frequently reported occupations were mobility, work, community mobility, meal preparation and cleanup, dressing, talking, bathing, and grooming (14). A survey of 430 individuals with MS found that yard work, employment, heavy housework, and going up and down

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stairs were the most difficult occupations to perform (15). Since most results reported in the literature are based on composite scores from standardized assessment tools or questionnaires with fixed alternatives, detailed knowledge is not available of the occupations that individuals with MS perceive as difficult to perform. This means that we also have limited knowledge of differences in reported occupations between men and women and relationships with age, disease severity, and living arrangements.

The Canadian Occupational Performance Measure (COPM) (16) is a measure that is designed to capture a client's self-perception of occupational performance. With the COPM, the individual identifies occupations in which difficulties are experienced and the performance and satisfaction with the most important occupations are scored. Although used increasingly, the COPM has not been applied to provide a detailed description of how individuals with MS perceive their occupational performance.

The aims of this study were to describe which self-care, productivity, and leisure occupations individuals with MS perceive as difficult to perform on admission to rehabilitation and the individuals' own perception of the importance of, performance of, and satisfaction with these occupations. We also investigated whether the reported self-care, productivity, and leisure occupations were related to sex, age, disease severity, and living arrangements.

**Material and methods**

*Sample*

A total of 47 individuals (28 women and 19 men) with clinically definite MS were included in this retrospective study. All individuals had been referred for rehabilitation due to their disease progression, and on admission to rehabilitation they reported difficulties with daily occupations primarily related to their MS. Following written informed consent, data on sex, age, years since MS onset, type of MS, living arrangements, and vocational situation together with assessments of disease severity and daily occupations for the 47 individuals were obtained from their medical records. The characteristics of the 47 individuals are summarized in Table I. The Ethics Research Committee, Lund University, Lund, Sweden approved the study (LU-284-02).

*Assessments*

*Expanded Disability Status Scale (EDSS)*. On admission to rehabilitation, the treating physician rated each individual with the Expanded Disability Status Scale (EDSS) (17). The EDSS is a measure of the neurological impact of MS and rates the disease

Table I. Characteristics of the 47 individuals with MS.

	Men	Women
Sex	19	28
Age (years)		
Mean (±SD)	48.0 (9.4)	50.3 (10.8)
Range	22–60	30–69
Years since MS onset		
Mean (±SD)	15.4 (9.9)	16.4 (13.1)
Range	1–32	0–50
Type of MS (N)		
Relapsing remitting	1	6
Secondary progressive	18	19
Primary progressive	0	3
EDSS score		
Median	6.5	6.5
Range	1.0–8.0	3.0–8.5
Living arrangements		
Living alone	8	6
Living with other person (partner, husband/wife, parent)	11	22
Vocational situation (n)		
Working part time or full time, with no disability pension	4	1
Working part time, with part-time temporary or permanent disability pension	3	4
Full temporary or permanent disability pension	11	20
Not working (old-age pension, unemployed, housewife)	1	3

severity on a scale of 0 (normal) to 10 (death due to MS). The median EDSS score was 6.5 for both the men and the women. To allow for an evaluation of differences between reported occupations and disease severity, the 47 individuals were divided into three groups based on their EDSS score: (i) EDSS 0–5.5 (n=7) represents individuals with mild MS; (ii) EDSS 6.0–6.5 (n=25) represents individuals with moderate MS; and (iii) EDSS 7.0–8.5 (n=15) represents individuals with severe MS. EDSS scores between 0 and 5.5 indicate the early stages of the disease with no assistance during walking. EDSS scores 6.0 and 6.5 indicate the need for unilateral or bilateral assistance and an ability to walk 100 m or less with or without rest. Individuals with EDSS scores 7.0 and 7.5 have severely restricted walking ability whereas individuals with EDSS scores 8.0 and 8.5 cannot walk at all and are restricted to bed or chair or perambulated in a wheelchair much of the day.

*Canadian Occupational Performance Measure (COPM)*. The COPM is an individualized, client-centred outcome measure designed to capture a client's self-perception of performance in daily occupations (16). The COPM includes three occupational areas, each comprising three subcategories:

(i) self-care (personal care; functional mobility; community management); (ii) productivity (paid/unpaid work; household management; play/school); and (iii) leisure (quiet recreation; active recreation; socialization). It can be used with clients with a variety of disabilities and has been found to be both valid and reliable (18–21).

In this study, the Swedish version of the COPM (22) was administered by the treating occupational therapist on admission to rehabilitation. First, the individual reported in a semi-structured interview those daily occupations that he/she found difficult to perform. During the interview, every occupation that the individual reported was noted in the interview guide, within the appropriate COPM occupational area and COPM subcategory. Second, the individual rated the importance of each occupation on a 10-point Visual Analogue Scale (VAS), ranging from 1 (not important) to 10 (most important). In the third and final step, the most important occupations were prioritized and rated according to the individual's self-perceived performance and satisfaction on the VAS ranging from 1, "not able to do" (performance) or "not satisfied" (satisfaction) to 10, "able to do extremely well" (performance) or "extremely satisfied" (satisfaction).

#### Data treatment

Data from the COPM assessments were retrieved from the interview guides and entered into a database. The total number of reported occupations and the number of prioritized occupations were summed for each COPM subcategory. For each of the nine COPM subcategories, the mean, minimum, and maximum of the VAS ratings of importance for all occupations together with the ratings of importance, performance, and satisfaction for the prioritized occupations were calculated.

As the COPM interview followed a semi-structured format, no given response alternatives for occupations were presented. Thus, the individuals could identify different perspectives of a particular occupation. For example, "showering", "washing body parts" and "holding the soap", all deal with the occupation "hygiene" but represent different perspectives of this occupation. According to the ValMO concept (23) there are three different, but interacting, perspectives of occupational performance: (i) the macro; (ii) the meso; (iii) the micro. The macro perspective comprises a person's total life-course repertoire of occupations and the meso perspective includes single occupations, e.g. "having breakfast". The micro perspective includes two components of occupations: actions (e.g. "drinking coffee") and operations (e.g. "lifting the cup"),

where operations are components of actions (23). Since the structure of the COPM does not allow for a classification of reported occupations within a COPM subcategory, the ValMO concept was applied. The following hierarchy was used when all reported occupations were classified: (i) COPM occupational area; (ii) COPM subcategory; (iii) single occupation; (iv) action; and (v) operation.

The classification was accomplished in two steps. The first step was completed during the interview when the individual and the occupational therapist classified the reported occupations according to COPM occupational area and COPM subcategory. Since it was possible to place some occupations under different headings, the individual always made the final decision. For example, "working in the garden" could be considered either as household management within the occupational area productivity, or as active recreation within the occupational area leisure (23). The second step in the classification was completed at a later stage by the first author (EML). All occupations within a COPM subcategory were grouped into similar occupations (e.g. "dressing", "showering" etc.). Thereafter, all occupations within a particular single occupation were classified as either actions or operations. The classification was validated and discussed with the other authors in an iterative process. In the case of disagreement, discussions with the second author (a senior occupational therapy researcher, SI) successively led to consensus.

#### Statistical analysis

Sex differences for age and years since MS onset were tested using a non-paired *t*-test and for EDSS using the Mann-Whitney U-test; no significant differences between the men and the women were found. To test whether the distribution of prioritized occupations was different from the distribution of non-prioritized occupations, a chi-squared test of independence was used. The COPM ratings are ordinal data, but according to the manual and in general practice they are treated as continuous variables. The Mann-Whitney U-test was used to evaluate differences for the total number of reported occupations in each of the three COPM occupational areas between (i) men and women; (ii) young and old individuals (below or above the median age of 51 years); and (iii) the reported living arrangements (living alone and living with partner, husband/wife, or parent). A Kruskal-Wallis test was used to evaluate differences for the total number of reported occupations in each of the three COPM occupational areas in relation to disease severity (mild, moderate, and severe MS). Significance levels

smaller than 5% are considered significant. All statistical analyses were done with SPSS version 11.0.

**Results**

*Number and ratings of reported occupations*

The 47 individuals reported a total of 366 occupations (median 8, range 3–15) that they perceived as difficult to perform (Table II). The highest number of occupations was found in the COPM occupational area self-care (51%), followed by productivity (30%), and leisure (19%). The three COPM subcategories household management (26%), personal care (21%), and functional mobility (20%) accounted for two-thirds of all the occupations that the individuals perceived as difficult to perform. The individuals prioritized 238 occupations (median 5, range 2–7), within eight of the nine COPM subcategories. There was no significant difference in the distribution of occupations among the nine COPM subcategories between the prioritized occupations and the non-prioritized occupations.

In comparison with the non-prioritized occupations, the mean ratings of importance were higher for the prioritized occupations in all subcategories. Among the prioritized occupations, functional mobility and paid/unpaid work were rated as the most important, whereas quiet recreation was rated the least important. The largest range in ratings was in household management and the smallest in paid/unpaid work. The average ratings of performance were generally low; the lowest was in active recreation and the highest in paid/unpaid work. For satisfaction, the mean ratings were also generally

low; the lowest were in active recreation and socialization.

*Reported occupations in relation to sex, age, disease severity and living arrangements*

There was a significant difference between the sexes for self-care ( $p=0.042$ )—men reported significantly more occupations than women—but no significant differences for productivity and leisure. No significant difference was found between the younger and older individuals for any of the three occupational areas. The number of reported occupations in the three occupational areas was not significantly related to disease severity or living arrangements.

*Description of reported occupations within the three COPM occupational areas*

The majority of the reported occupations were classified as “single occupations” ( $n=197$ ) or “actions” ( $n=143$ ). Sixteen occupations were classified as “operations” and 10 occupations were classified as a COPM subcategory (e.g. community management). In Table III, single occupations within the three COPM occupational areas (self-care, productivity, and leisure) are presented and examples of actions and operations are given in the following text.

*Self-care*

In this area, the most frequently reported occupations were classified as single occupations or components (actions or operations) of the single

Table II. All reported and prioritized occupations that the 47 individuals with MS perceived as difficult, and their ratings of importance, performance, and satisfaction, presented for each COPM occupational area and COPM subgroup.

	All occupations ( $n = 366$ )		Prioritized occupations ( $n = 238$ )			
	$n$ (%)	Importance	$n$ (%)	Importance	Performance	Satisfaction
<b>Self-care</b>						
Personal care	78 (21)	8.1 (3–10)	56 (23)	8.6 (5–10)	4.2 (1–9)	3.5 (1–8)
Functional mobility	71 (20)	8.9 (3–10)	54 (23)	9.3 (5–10)	3.3 (1–8)	2.4 (1–10)
Community management	38 (10)	7.2 (1–10)	19 (8)	8.5 (4–10)	2.7 (1–6)	2.5 (1–5)
Total	187 (51)		129 (54)			
<b>Productivity</b>						
Paid/unpaid work	13 (3)	8.5 (2–10)	6 (3)	9.5 (9–10)	4.3 (1–9)	3.8 (1–10)
Household management	95 (26)	7.7 (2–10)	60 (25)	8.4 (3–10)	3.4 (1–9)	3.6 (1–10)
Play/school	2 (1)	5.0 (3–7)	0	–	–	–
Total	110 (30)		66 (28)			
<b>Leisure</b>						
Quiet recreation	25 (7)	6.8 (1–10)	13 (5)	8.0 (5–10)	3.2 (1–7)	3.4 (1–6)
Active recreation	29 (8)	8.2 (2–10)	18 (8)	8.9 (5–10)	1.3 (1–4)	1.1 (1–2)
Socialization	15 (4)	8.8 (4–10)	12 (5)	8.9 (4–10)	2.4 (1–5)	1.3 (1–4)
Total	69 (19)		43 (18)			

Note: Values for importance, performance, and satisfaction are presented as mean, minimum, and maximum.

Table III. Reported single occupations ( $n=366$ ) from the assessment with the Canadian Occupational Performance Measure (COPM) in the three occupational areas of self-care, productivity and leisure among 47 individuals with MS.

Self-care ( $n=187$ )	
Personal care ( $n=78$ ) <sup>a</sup>	
Dressing ( $n=39$ ) Showering ( $n=12$ ) Grooming ( $n=11$ ) Feeding ( $n=6$ ) Toileting ( $n=5$ ) Other ( $n=2$ ) Medication ( $n=1$ )	
Functional mobility ( $n=71$ ) <sup>b</sup>	
Transferring ( $n=22$ ) Walking outdoors ( $n=11$ ) Walking in general ( $n=9$ ) Walking longer distances ( $n=9$ ) Walking indoors ( $n=7$ )	
Walking on stairs ( $n=7$ ) Walking while carrying ( $n=6$ )	
Community management ( $n=38$ ) <sup>a</sup>	
Shopping ( $n=21$ ) Getting to service facility ( $n=4$ ) Travelling with a car ( $n=3$ ) Getting in/out from dwelling ( $n=2$ ) Banking ( $n=1$ )	
Biking ( $n=1$ ) Driving a three-wheeled scooter ( $n=1$ ) Going by bus ( $n=1$ )	
Productivity ( $n=110$ )	
Paid/unpaid work ( $n=13$ ) <sup>a</sup>	
Performing physically demanding work tasks ( $n=8$ ) Doing desk-work ( $n=3$ )	
Household management ( $n=95$ )	
Cooking complex meals ( $n=23$ ) Cleaning floor ( $n=19$ ) Making bed ( $n=6$ ) Dusting ( $n=5$ ) Ironing clothes ( $n=5$ ) Laying table ( $n=4$ ) Baking ( $n=3$ ) Cleaning windows ( $n=3$ ) Hanging laundry ( $n=3$ ) Making tea or coffee ( $n=3$ ) Preparing breakfast ( $n=3$ )	
Preparing microwave food ( $n=3$ ) Cleaning toilet/bathroom ( $n=2$ ) Caring for plants indoors ( $n=2$ ) Cleaning in general ( $n=2$ )	
Gardening ( $n=2$ ) Mangling clothes ( $n=2$ ) Washing laundry ( $n=2$ ) Cleaning car ( $n=1$ ) Doing dishes ( $n=1$ ) Mending clothes ( $n=1$ )	
Play/school ( $n=2$ )	
Studying ( $n=2$ )	
Leisure ( $n=69$ )	
Quiet recreation ( $n=25$ )	
Doing paperwork ( $n=6$ ) Reading ( $n=3$ ) Renovating/decorating house ( $n=3$ ) Taking care of pets ( $n=3$ ) Playing instrument ( $n=2$ )	
Repairing things ( $n=2$ ) Sewing ( $n=2$ ) Crocheting ( $n=1$ ) Knitting ( $n=1$ ) Photographing ( $n=1$ ) Weaving ( $n=1$ )	
Active recreation ( $n=29$ )	
Walking and being in nature ( $n=8$ ) Gardening ( $n=3$ ) Playing ball sports ( $n=3$ ) Doing excursions ( $n=2$ ) Walking dog ( $n=2$ ) Biking ( $n=1$ ) Bird watching ( $n=1$ ) Dancing ( $n=1$ ) Decorating house ( $n=1$ ) Doing sports in general ( $n=1$ ) Fishing ( $n=1$ ) Getting to allotment garden ( $n=1$ ) Going to theatre/cinema ( $n=1$ ) Jogging ( $n=1$ ) Skiing ( $n=1$ ) Taking trips ( $n=1$ )	
Socialization ( $n=15$ )	
Communicating with other people ( $n=5$ ) Visiting friends/relatives ( $n=5$ ) Doing things with children ( $n=4$ ) Going to church ( $n=1$ )	

Note: <sup>a</sup>For two of the reported difficulties no particular occupations were specified, <sup>b</sup>the term 'walking' was referred to even if mobility devices were used during locomotion.

occupations "dressing", "transferring", "walking", and "shopping". "Dressing" included actions mostly related to upper and lower body dressing. "Transferring" included six different types of actions: "to and from toilet"; "in and out of bath tub"; "in and out of car"; "from one chair to another"; "in and out of bed"; and "turning in bed". Functional mobility comprised a number of various aspects of walking ( $n=49$ ), classified as single occupations or actions. "Shopping" included both actions and operations, all required to accomplish the goal of shopping, e.g. "gathering products", "handling food bags", "handling food carriers", "paying" and "manipulating money".

#### Productivity

A majority of the reported occupations (86%) in this area were classified in the subcategory household management. "Cooking" and "cleaning" accounted for more than half of the reported single occupations and components of occupations; the two most frequently reported single occupations were "cooking complex meals" and "cleaning the floor". "Cooking complex meals" also included a variety

of actions ("using the oven") or operations ("holding on to a vegetable during peeling"). The single occupation "cleaning the floor" included actions related to "mopping" or "vacuuming". Eight individuals accounted for the 13 single occupations and actions reported in the subcategory paid/unpaid work and one woman reported the two actions ("writing on keyboard" and "taking part in lectures") in the single occupation "studying" within the subcategory play/school.

#### Leisure

This area included a wide variety of single occupations. The individuals classified similar occupations differently. For example, "decorating house" was classified as quiet recreation by some individuals and as active recreation by others. Most single occupations related to "quiet recreation" were indoor occupations, whereas most occupations related to "active recreation" were outdoor occupations. The most frequently reported single occupation was "walking and being in nature". Single occupations in the subcategory socialization were mostly related to "social involvement".

**Discussion**

In order to meet the rehabilitation needs of individuals with MS, we have to understand the individuals' own perception of their occupational performance. In this study we used the COPM to identify occupations that individuals with MS perceived as difficult to perform on admission to rehabilitation. The most commonly reported occupations were related to household management, and about half of the occupations were concerned with personal care and functional mobility. All the prioritized occupations had high ratings for importance but, in general, the ratings for performance and satisfaction were low.

The individuals reported a broad range of occupations that they found difficult to perform. If the interview had been done during other circumstances or in a different environment, other occupations might have been identified. This has been seen in stroke patients, where 56% of the occupations reported during the first interview were reported during the second (18). In a study of the reproducibility of the COPM, 66% of the activities prioritized at the first assessment were also prioritized at the second assessment (20). Furthermore, as the sample in the present study was fairly small and comprised a selected group of individuals admitted for rehabilitation, the results might not be applicable to all individuals with MS.

Descriptions of the prevalence of difficulties in daily occupations may not take into account the importance and meaning of every occupation (15). This was accommodated to some extent here as the individuals prioritized occupations that were most important to them and also rated the importance of them. There were no differences in the distribution of occupations among the subcategories of all reported occupations and those that the individuals prioritized. This indicates that no particular COPM subcategory was more prevalent when the individuals were asked to select their most important occupations. The importance within each COPM subcategory varied, but the individuals rated the importance of the reported occupations generally high, indicating that many individuals with MS want to engage in meaningful and purposeful occupations.

Our results are in general agreement with studies that have described the consequences of MS for daily occupations using standardized assessment tools. Many individuals with moderate to severe MS report difficulties in personal care and functional mobility, such as dressing, showering, grooming, feeding, toileting, transfer, and locomotion (15). This is evident when instruments such as the Functional Independence Measure (FIM) or the Barthel Index

(BI) have been used to assess ADL performance (8,12,24). It is not surprising that most occupations reported in this and in previous studies are related to personal care and functional mobility, as these occupations are necessary for independent living. This also shows that standardized assessment tools are useful and depict many, but not all, aspects of daily occupations that are important to individuals with MS.

The finding that more than two-thirds of occupations classified as functional mobility were related to various aspects of walking, together with the high ratings of importance, is also in agreement with previous studies (15). Individuals with MS often identify walking as one of the most important occupations. Two prevalence studies have demonstrated that about 75% of individuals with MS experience mobility problems (25,26). When a patient-based measure of the impact of MS—the Multiple Sclerosis Impact Scale (MSIS-29)—was developed (26), walking was identified as a key component and used to form a specific measure of the impact of MS on walking, the Multiple Sclerosis Walking Scale (MSWS-12) (27).

Occupations related to household management were the most commonly reported and accounted for almost one-third of all occupations. This is in agreement with Finlayson et al. (15) who presented a high prevalence of problems with housework among individuals with MS. Other studies confirming these results have, however, not described which occupations related to household management individuals with MS perceive as difficult to perform. The fact that “cooking” and “cleaning” were the two most commonly reported occupations in this study is not surprising. The ability to manage one's own household (often referred to as instrumental activities of daily living, I-ADL) is another basic requirement of independent living. It has been shown that individuals with MS can be independent in personal ADL (P-ADL) but unable to perform I-ADL satisfactorily, and so may be at risk for living independently (9,12). Thus, healthcare professionals managing individuals with MS must be attentive to limitations in household management and their implications for self-reliance in society. These results also show clearly the need to use tools that capture more than just basic P-ADL when individuals with MS are assessed.

As a minority of the 47 individuals (about 25%) were working, few occupations related to work were reported. However, the high ratings of importance imply that these individuals perceived their work as a very important occupation. It is well-known that the progression of MS affects the ability to work and to stay employed, and many individuals with MS, even

at a relatively young age, get disability pension (4–6,28). These results emphasize the need to address issues of employment in individuals with MS.

Even though the number of reported occupations in each of the three subcategories within the occupational area of leisure was low, it accounted for about 20% of all the prioritized occupations. Leisure included a variety of occupations, representing the wide range of personal interests among these 47 individuals (cf. Table II). Interestingly, the ratings of importance were high for all three subcategories and the ratings of performance and satisfaction for active recreation and socialization were low. This implies that leisure occupations constitute a substantial and important part in the everyday life of individuals with MS. Hakim et al. (6) reported that only 3% of individuals with severe MS continued to visit friends and engage in social activities outside their home. In addition, two recent studies have shown the importance of social support from the social network to enable a person with a disability to participate in occupation (29,30). Few studies have explored the impact of MS on leisure and this indicates the need to work also on issues of leisure in individuals with MS.

This study identified those occupations that individuals with MS perceived as difficult to perform, but the reasons why were not further explored. The ratings give some indication of the individuals' perception of their performance and of their satisfaction with the reported occupations. Even though the actual numbers cannot be compared between individuals, the ratings suggest that they perceived significant difficulties with the reported occupations and that their performance was clearly unsatisfactory. To apply effective interventions, the identification of occupations that an individual perceives as difficult to perform must be complemented by a performance analysis using other instruments, for example the Assessment of Motor and Process Skills (AMPS) (31).

The only difference with regard to age, sex, disease severity, and living arrangements was found in the area of self-care: the men identified significantly more occupations than the women. As there were no significant differences between the men and the women with regard to their age, years since MS onset, and EDSS scores, these factors do not explain why the men identified more self-care occupations. One study of individuals with MS admitted to nursing facilities also reported that men were more likely to experience dependence in ADL (32), and a study of the elderly has shown that men are more dependent in bathing, dressing, and cooking (33). In contrast, an age- and sex-stratified prevalence study of physical disabilities and handicap in the general

population showed that women reported more difficulties than men with self-care, mobility, and aspects of transfers (34). These results and the limited knowledge of gender variations in daily occupations in the MS population warrants further studies.

The present study is, to the best of our knowledge, the first that has used the COPM to identify, classify, and describe occupations that individuals with MS perceive as difficult to perform. To enable a detailed classification of the reported occupations, the structure and hierarchy of the COPM was combined with the ValMO concept. The important clinical and practical finding was that the individuals reported different perspectives of particular occupations. This emphasizes the need to perform thorough assessments of occupational performance to capture the complexity of daily occupations in individuals with MS. We do not, however, suggest that occupational therapists in their everyday clinical practice use a combination of the COPM and the ValMO concept. The COPM and the ValMO concept were combined during the classification of the occupations to enable a detailed description of the reported occupations. A difficulty during the classification was the construction of an appropriate terminology for each "single occupation". The ValMO concept did not provide this information and does not specify precisely when an occupation should be classified as a single occupation or an action. This had, however, a limited impact on the overall results and was mainly a practical problem. Further development of the ValMo concept is imperative in order to use it in clinical practice.

In conclusion, on admission to rehabilitation individuals with MS perceive difficulties with a variety of occupations related to all aspects of daily life. Rehabilitation professionals are therefore recommended to use assessment tools that capture the complexity of daily occupations in order to plan appropriate interventions so that individuals with MS can engage in meaningful and purposeful daily occupations.

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## Paper III

## Paper IV

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