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WORKING LIFE IN PEOPLE WITH MULTIPLE SCLEROSIS

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THESIS FOR DOCTORAL DEGREE (Ph.D.)

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To Ylva and Siri, my children

Everything in life is possible.
Whatever life brings you,
curiosity and dedication
carry the extraordinary.

ABSTRACT

Background: Multiple sclerosis (MS) is a chronic disease in the central nervous system, usually with an onset in early adulthood with many years of working age ahead. The employment rate in people with MS (PwMS) is low and associated with low quality of life (QoL). The support for PwMS in working life is despite this limited and needs to be further developed for PwMS to maintain sustainable working life and long-term QoL.

Aims: The overall aim of this thesis was to build new knowledge for the development of interventions to support sustainable working life and QoL in PwMS. The aims for the included papers were: I) to explore predictors for employment status over 10 years; II) to describe and explore the lived experience and meaning of change in working life in PwMS; III) to make the Acceptance of chronic health conditions (ACHC) Scale available in Swedish; and IV) to explore patterns of change over 10 years in functioning and perceived impact of MS, as well as level of acceptance of MS and life satisfaction, in relation to employment status.

Participants and methods: In the exploration of predictors for employment status (Paper I) and patterns of change (Paper IV), 116 PwMS of working age were included from a 10-year follow-up of PwMS. A generalized ordinal logistic regression was used for exploring predictors and Wilcoxon signed rank test for patterns of change. Out of PwMS of working age, 15 PwMS were purposely selected for interviews concerning change in working life. The interviews were analysed with a phenomenological approach (Paper II). For the translation and cultural adaptation of the ACHC Scale, an additional 10 PwMS were recruited from a rehabilitation clinic, while the test of the psychometric properties of the Swedish version of the scale using Rasch analysis, was based in the 10-year follow-up including 148 PwMS of working age and older (III).

Results: Young age, full-time work, high frequency of activities in private life and fatigue were found to predict keeping employment after 10 years. Low perceived physical impact of MS predicted full-time work and full-time or part-time work after 10 years (Paper I). The meaning of change in working life was found to be characterized by a negotiation of what gives life meaning, a disrupted life course, finding meaning through taking control and altered life as usual (Paper II). The ACHC Scale was made available in Swedish with acceptable psychometric properties (Paper III). The PwMS still working after 10 years, were found to be more stable in functioning and perceived impact of MS and had a higher level of acceptance of MS and life satisfaction than the PwMS not working (Paper IV).

Conclusion: This thesis underlines the complexity of working life for PwMS. A holistic perspective is needed for supporting sustainable working life and QoL. Change in working life can be difficult for PwMS and early indicators of problems in working life are therefore valuable for initiating appropriate support for sustainable working life. Maintaining meaningful activities in private life while working, may possibly improve QoL by making the loss of the benefits of work less tangible when ending working life.

SAMMANFATTNING

Bakgrund: Multipel skleros (MS) är en kronisk sjukdom i det centrala nervsystemet som vanligen debuterar i ung vuxen ålder då det är lång tid kvar av arbetslivet. Stor andel av personer med MS (PmMS) arbetar inte och att inte arbeta är associerat med låg livskvalitet. Stöd för PmMS i arbetslivet är trots det begränsat och utveckling av insatser behövs för att stödja PmMS i ett hållbart arbetsliv med bibehållen livskvalitet.

Syfte: Det övergripande syftet med den här avhandlingen var att bygga ny kunskap som bas för att utveckla insatser för att stödja PmMS till ett hållbart arbetsliv med livkvalitet. Syftena för varje delarbete var: I) att undersöka prediktorer för grad av arbete över 10 år; II) att beskriva och undersöka PmMS levda erfarenhet och meningsskapande vid förändring i arbetslivet; III) att göra ”the Acceptance of chronic health conditions scale” (ACHC-skalan) tillgänglig på svenska; och IV) att undersöka förändringsmönster över 10 år med avseende på funktion och upplevd påverkan av MS, samt nivå av acceptans av MS och livstillfredsställelse, i förhållande till grad av arbete.

Forskningspersoner och metod: I studien av prediktorer (Paper I) och förändringsmönster (Paper IV) deltog 116 PmMS i arbetsför ålder från den 10-årsuppföljning av PmMS som avhandlingen baserades på. Generaliserad ordinal logistisk regression användes för att undersöka prediktorer (Paper I) och Wilcoxons teckenrangtest för att undersöka förändring över tid (Paper IV). Utav dessa personer, valdes 15 personer ut och intervjuades kring förändring i arbetslivet. Intervjuerna analyserades med fenomenologisk metod (Paper II). Vid översättning av ACHC-skalan rekryterades ytterligare 10 PmMS från en rehabiliteringsklinik, medan test av psykometriska egenskaper genomfördes med Rasch analys i en grupp på 148 PmMS från 10-årsuppföljningen inkluderande även äldre (III).

Resultat: Lägre ålder, heltidsarbete, hög frekvens av aktiviteter i privatlivet, och fatigue predicerade fortsatt arbete efter 10 år. Låg upplevd påverkan av MS predicerade heltidsarbete, samt heltids eller deltidsarbete (Paper I). Det som karaktäriserade förändring i arbetslivet för PmMS var en förhandling med sig själv om vad som ger mening i livet, bruten livsbana, meningsskapande genom att ta kontroll, samt förändrat vardagsliv (Paper II). ACHC-skalan översattes och testades och befanns inneha acceptabla psykometriska egenskaper (III). De personer som fortfarande arbetate efter 10 år hade en stabilare funktionsnivå och lägre upplevd påverkan av MS samt högre acceptans av MS och livstillfredsställelse än de som inte arbetade efter 10 år. (Paper IV).

Slutsats: I den här avhandlingen blev komplexiteten för PmMS i arbetslivet framträdande. Ett helhetsperspektiv behövs för att kunna stödja PmMS till ett hållbart arbetsliv med livskvalitet. Förändring i arbetlivet kan vara svårt för PmMS och tidiga indikationer på problem i arbetslivet är därför värdefulla för att kunna sätta in välriktat stöd för ett hållbart arbetsliv. Möjlighet att bibehålla meningsfulla aktiviteter i privatlivet medan man är aktiv i arbetslivet kan vara betydelsefullt för livskvaliteten efter avslutat arbetsliv, genom att känslan av förlust av arbetslivet kan minska.

LIST OF SCIENTIFIC PAPERS

I. **Forslin M, Fink K, Hammar U, von Koch L, Johansson S.** Predictors for Employment Status in People With Multiple Sclerosis: A 10-Year Longitudinal Observational Study. Arch Phys Med Rehabil. 2018 Aug;99(8):1483-1490.

II. **Forslin M, Fink K, Johansson U, Johansson S.** Meaning of change in working life in people with multiple sclerosis. Manuscript.

III. **Forslin M, Kottorp A, Kierkegaard M, Johansson S.** The Swedish version of the Acceptance of Chronic Health Conditions Scale for people with multiple sclerosis: translation, cultural adaptation and psychometric properties. J Rehabil Med. 2016 Nov 11;48(10):872-879.

IV. **Forslin M*, Conradsson D*, Fink K, Johansson U, von Koch L, Johansson S.** Employment status in relation to patterns of change in functioning, and to acceptance of multiple sclerosis and life satisfaction, in people with multiple sclerosis: a 10-year study. Manuscript.

* Shared first authorship.

LIST OF ABBREVIATIONS

ACHC Scale	Acceptance of chronic health conditions scale
DIF	Differential item functioning
EPP	Empirical phenomenological psychological method
HRQL	Health-related quality of life
ICF	International classification of functioning, disability and health
MS	Multiple sclerosis
PPMS	Primary progressive multiple sclerosis
PwMS	People with multiple sclerosis
QoL	Quality of life
RRMS	Relapsing-remitting multiple sclerosis
SPMS	Secondary progressive multiple sclerosis
VIF	Variance inflation factors

CONTENTS

1 INTRODUCTION

People living with multiple sclerosis (MS) are subject to many challenges, where one is working life. In my experience from working with people with MS (PwMS) in a rehabilitation setting as a physiotherapist, many PwMS struggle to maintain participation in working life and sometimes get to pay a high prize for doing so. The thought of ending working life has for many PwMS I've met been seen as a last resort when all other options are exhausted. When working life despite this approach still has come to an end, I've found that many have difficulties in finding new activities to engage in that can fill the gap of work and give new meaning to life.

This doctoral project was designed with the long-term goal to help improve PwMS' situation in working life and also in the transition out of working life. I got involved in this project due to my interest in the complex situation PwMS often are faced with, and my drive to improve the support for PwMS. In the case of working life and PwMS, my experience is that well-designed support often is lacking.

The thesis includes four papers, all with an underlying intention to improve PwMS' quality of life (QoL) both in working life and after ending working life. The first paper is focused on long-term predictors for working, the second on PwMS experiences of change in working life, the third on translation and testing of a scale assessing acceptance of MS, and finally, the fourth paper is focused on patterns of change over time, acceptance of MS and life satisfaction.

2 BACKGROUND

2.1 Theoretical and conceptual framework

This thesis has four overarching themes, which are given a theoretical background in this section: working life; functioning, disability and health; coping and acceptance of MS; and QoL. Further information relating to specific papers is introduced in their study contexts.

2.1.1 Working life

Working life is a complex part of life. For increased understanding of the aspects interacting in working life the Work ability house model (Figure 1) was used in this thesis. It is a multidimensional model, developed by Ilmarinen and coworkers (1-3), which core structures are based on a broad study of work ability (2). In this model, aspects that underlie work ability are depicted as a house with four interconnected floors. The three bottom floors represent individual resources and the top floor the demands and context of work. Based on the house model, work ability can be understood as the balance between the individual resources (the first three floors of the house) and the demands of work (the top floor). If the individual resources meet the demands of work, the work ability is good. If the resources are not sufficient, there is imbalance between resources and demands, resulting in decreased work ability.

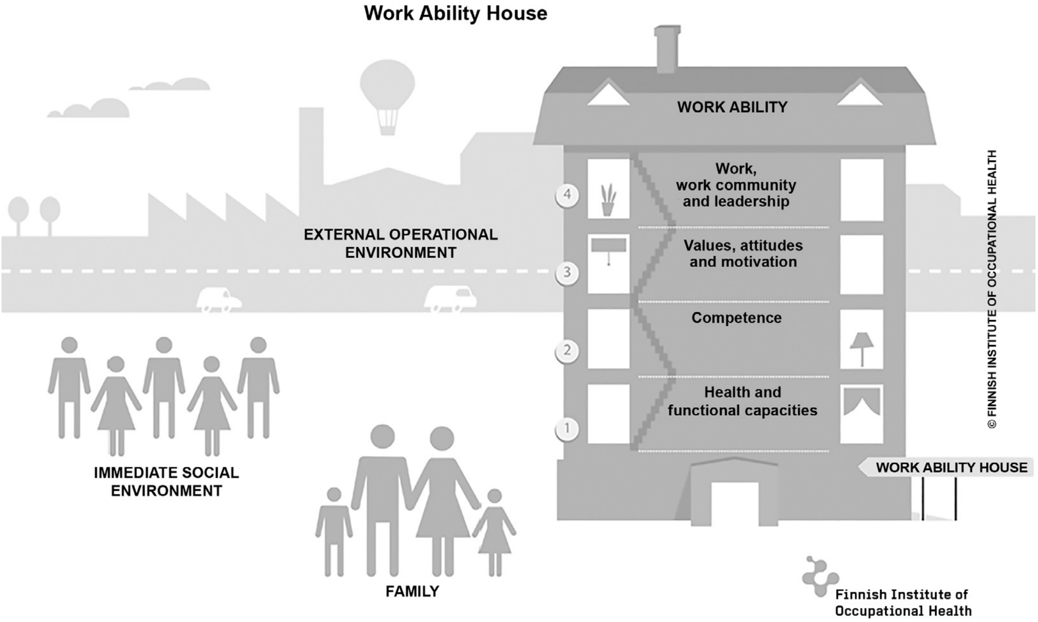

Figure 1. *The Work ability house, a multidimensional model of work ability.*

The house is placed in the context of the external operational environment, i.e. the context of society (1, 2), and in the context of life (4). The context of life includes family, immediate social environment and leisure activities outside of work (1-3), and can be thought of as an additional house placed in the yard of the work ability house (3). In this thesis, this additional house is referred to as private life.

For sustainable employability, work-life balance and lifestyle have been proposed to be added to the Work ability house model (5) and can be thought of as a balance between what is included in the work ability house and in private life. The concept of work-life balance is concerned with how well the multiple roles of life are balanced (6) and have been suggested to be beneficial for a sustainable working life (7).

The employment status of an individual, in this thesis is defined as quantity of work, can be understood as the result of all aspects interacting in Work ability house model: the four floors of the work ability house, the context of society and private life.

2.1.2 Functioning, disability and health

The Work ability house is a model focused on interacting aspects in the work ability of an individual. To enable a deeper understanding of functioning, disability and health based on a health condition, in this thesis MS, the International classification of functioning, disability and health (ICF; 8) was used. It is based in a biopsychosocial approach that has been found to be useful to describe the wide spectrum of consequences of MS for PwMS lives (9, 10).

In the ICF an individual’s health condition (diseases, disorders, injuries) and living context are thought to interact with, as well as constitute the basis for the level of functioning and disability (Figure 2). The contextual factors comprise personal and environmental factors. Personal factors represent an individual’s internal characteristics, e.g. age, sex, the background of an individual’s life and living including education, coping strategies, as well as other diseases. Environmental factors represent external factors affecting an individual, such as the physical, social and attitudinal environment that people live in, and can be both facilitating and act as barriers.

Functioning is classified in body functions/body structures, and activities and participation. Disability is classified in impairment of body functions/structures, activity limitations and participation restrictions. Body functions/body structures concern bodily functions, while activities and participation involve activities of the whole person, and the whole person’s participation in a social context. As activities and participation often are closely interlinked, they are presented together in the ICF, consequently in this thesis as well.

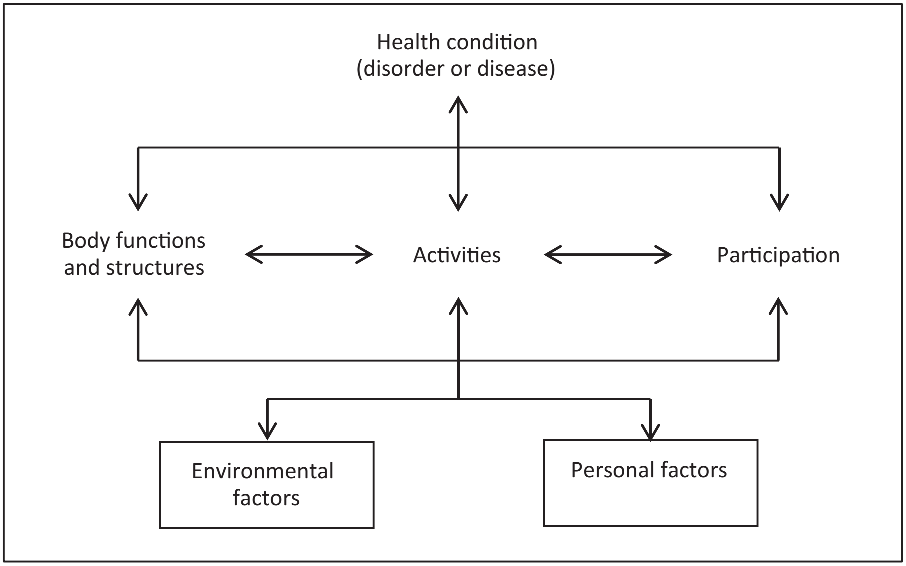

Figure 2. *Interactions between the components of the International classification of functioning, disability and health.*

2.1.3 Coping and acceptance of MS

Coping is a personal factor in the ICF model (8) and often defined as efforts to prevent or diminish threats, harm, and loss, or to reduce the associated distress (11). The most common distinction made in coping literature is between problem- and emotion-focused coping (11, 12) but the distinction between active and avoidant coping strategies have also increased in importance. In this distinction, different forms of problem- and emotion-focused coping strategies are included in both active and avoidant coping strategies (13, 14).

Acceptance is a emotion-focused coping strategy that can be considered to be active as well as passive. For the purpose of being able to measure acceptance in chronic health conditions, the Acceptance of chronic health conditions (ACHC) Scale was developed by Stuifbergen et al. (15). In this scale, acceptance of MS is defined as an approach where the disease is one of many aspects of an individual's life, and not necessarily defining who the person is (15). Acceptance is then not an act of passive resignation in a seemingly hopeless situation, but a sense of the chronic condition to be integrated in life, not hindering active efforts to improve QoL or finding better ways of leading life. Instead it can create a foundation for experiencing good health with existing disabilities.

2.1.4 Quality of life

QoL has become an increasingly important factor to consider in clinical settings and research, particularly regarding chronic health conditions where there is no cure for the affected (16), such as MS. QoL is defined by the World Health Organization as: “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (17). The concept of QoL is not incorporated in the ICF, but work in this direction has been encouraged. McDougall et al. (18) suggested that the ICF model can be expanded to include QoL, depicting it as encircling the original components of the ICF (Figure 3). From this perspective, an individual’s QoL is seen as a composite, emergent and changing phenomenon originating from all aspects included in the original ICF model, i.e. a person’s health condition, functioning and contextual factors.

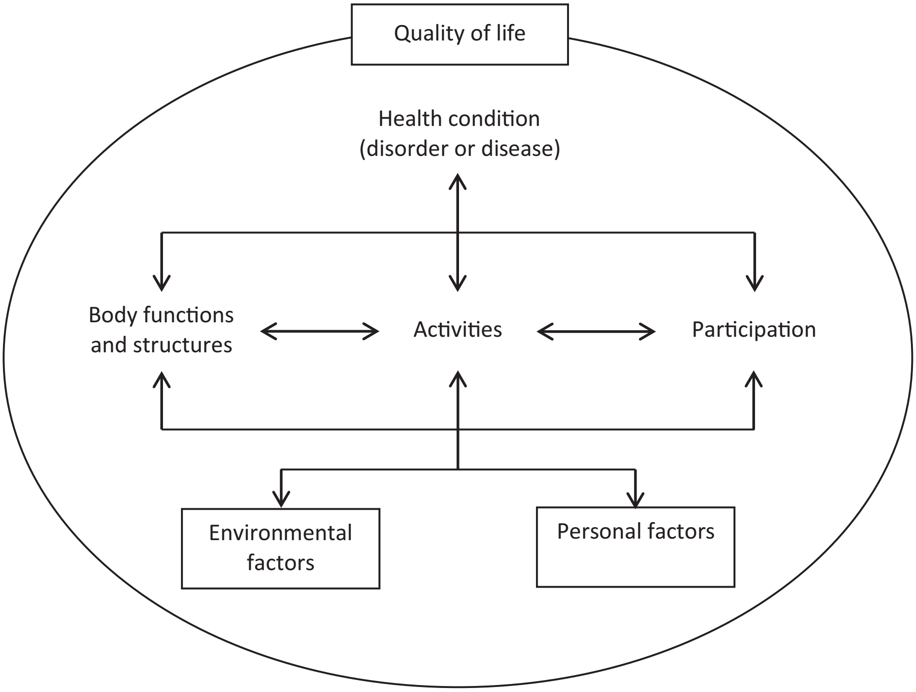

Figure 3. *Modified version of the interacting components of the International classification of functioning, disability and health, including quality of life. McDougall also suggested to include human development across time in the model, but this is not depicted here (18).*

As QoL is a complex concept, there are different ways of conceptualizing QoL in addition to the definition of the World health organization (17). The concept of health-related quality of life (HRQL) was introduced as a way to focus on how health, disease and treatments affect QoL (19). HRQL has been criticized for mostly concerning perceived health rather than QoL (16), and has both been confused with health status (20) and used interchangeably with the wider concept of QoL (21). Life satisfaction can on the other hand be regarded as a wider perspective on QoL. It refers to the level of satisfaction with all aspects of life, in relation to the ability to adjust aspirations and ambitions to one's capacity, and the level of achievements (22). Satisfaction with life has previously also been referred to as happiness (23) and is closely related to well-being (22).

Each definition of QoL may have its own value. However, the used aspect of QoL needs to be considered to make valid conclusions. In this thesis the concepts of QoL, HRQL, perceived health and life satisfaction were used depending on the concept that was used in the reference literature and the elected perspective in the papers included in the thesis.

2.2 Multiple sclerosis

2.2.1 Etiology and epidemiology

All the participants in this thesis have MS. MS is a chronic health condition, characterized by inflammation and degeneration in the central nervous system (24, 25). It is the most common disease causing neurologic disability in younger adults in western society, with a prevalence from 20/100.000 to 200/100.000 in Europe (26). Sweden is considered a high-risk country for MS with a prevalence of 189/100.000, with a female to male ratio of 2.35:1(27). The prevalence in Sweden has been found to be increasing over time (28). In the majority of cases, the onset is at 20-40 years of age (29, 30) and many live for a long time with the disease. The full picture of what causes MS is not known, but it is known that it results from interplay of genetic susceptibility and environmental risk factors (24).

The MS diagnosis is based on a set of clinical and laboratory criteria. According to the Poser criteria (31) at least two lesions in separate sites in the central nervous system, at separate time-points are needed for establishing the diagnosis of MS. The lesions can be identified through clinical examination, supported by findings from magnetic resonance imaging or cerebrospinal fluid. In the more recent McDonald criteria (32, 33), findings from magnetic resonance imaging can replace clinical findings as evidence of dissemination in place and time.

At the time of this study mainly three types of disease courses (phenotypes) in MS were defined and used: relapsing-remitting MS (RRMS), secondary progressive MS (SPMS), and primary progressive MS (PPMS; 34). Consequently, these are the phenotypes referred to in the studies of this thesis. Since then the phenotypes have been refined and separated into two major disease courses; the relapsing course and the progressive course, both of which are subcategorized in accordance with presence or absence of disease activity and progression (34, 35).

Approximately 80% of the PwMS are diagnosed with RRMS, which is characterized by intermittent relapses and limited disability progression (25). Out of these, 65% proceed to SPMS within 10 to 20 years after diagnosis, where incomplete recovery from relapses and neurodegeneration in time lead to progression and permanent disability. PPMS is experienced by 20% of the PwMS, causing progressive disability from the time of diagnosis (25).

2.2.2 Disability

Depending on where the lesions are localized in the central nervous system for each individual living with MS, different combinations of disabilities are experienced (9, 36). Common impairments in MS are decreased motor control (e.g. muscle weakness, spasticity and ataxia), sensory impairment, impaired vision, bowel- and bladder function, cognition, and furthermore, fatigue, depression and heat sensitivity (36). Activity limitations often include limited walking ability, fine hand use and the ability to perform both personal and instrumental activities of daily living. Restricted participation in social/lifestyle activities and working life often develops over time (9, 10).

2.2.3 Coping with MS

Living with MS has been described as living with constantly changing conditions, leading to a continuous struggle to maintain engagement in meaningful occupations and causing an altered perception of self, as well as having to live life differently (37). Coping strategies are used in the adjustment process. In literature concerning chronic conditions emotion-focused coping have previously been shown to be associated with distress while problem-focused coping has been associated with better adjustment and lower levels of distress (13, 38). In PwMS active coping strategies in general have been found to protect PwMS from experiencing depression (39) and there are indications of that active emotion-focused coping strategies, such as acceptance of MS, can offer positive effects (40-42).

2.2.4 Quality of life

In the literature concerning MS, QoL is often assessed through HRQL-measures. In MS, HRQL is generally low (43-45). It has been shown to be lower than in the general population and also lower than in other chronic conditions (21). PwMS also rate lower life satisfaction (40). In spite of the often high total load of disability, psychological aspects of HRQL correlates to physical disability only to some extent (43, 46). Previous research indicates that physical aspects of HRQL deteriorate over time while psychological aspects stay stable or improve (47), that may concern psychosocial adaptation or changed values (48, 49).

2.2.5 Disease management

Pharmacological treatment

In recent years much progress has been made in the development of more efficient disease-modifying treatments that decrease progression of the disease, but so far there is no cure to MS. The first disease-modifying treatment for MS was introduced in 1993 (50). Since then increasingly efficient drugs have been developed. Today, the goal for the disease-modifying treatments is to be so efficient that no evidence of disease activity can be found (35, 51).

From the start, disease-modifying treatments have been more effective in RRMS and are most efficient early in the disease course. Most disease-modifying treatments also have RRMS as an indication. In an increasing number of cases today, progression of MS can be halted at an early stage of the disease. The efficiency of disease-modifying treatments is limited in SPMS and PPMS, and for some people with RRMS, there are severe side effects of efficient disease-modifying treatment. This reduces the treatment options and increase risk of disease progression (35).

When permanent disability is established, symptomatic pharmacological treatment can be used to decrease its effects on daily life, e.g. fatigue, incontinence and spasticity. Symptomatic treatment has a varying degree of efficiency, depending on the drug and the disability treated (36).

Rehabilitation

Improved QoL have been emphasized as the overall goal of rehabilitation by the National Board of Health and Welfare in Sweden (52). This is believed to be accomplished through optimizing activity and participation, aiming to restore what is possible to restore, compensate for permanent loss of function and accommodation to changed living conditions. Since every individual with MS has a unique combination of disability and contextual factors, personalized interventions are needed in all phases of the disease (53).

Early in the disease course, rehabilitation is useful for learning about MS and how to manage the challenges following the disease. In later phases, it is more directed towards coping with the consequences of disease progression. Rehabilitation includes physical as well as psychosocial interventions (9). It can be delivered in out-patient and in-patient care (54), in individual and group settings and through interventions by single professions or multidisciplinary teams. Professions within the multi-professional team can be nurses, physiotherapists, occupational therapists, psychologists and physicians, but it is the needs of the PwMS that decide which professions to be active at a certain point in time (53).

A recent review of rehabilitation in PwMS by Khan and Amatya (55) presents evidence for physical therapy and multidisciplinary rehabilitation for improved activity and participation; for exercise-based educational programs to reduce fatigue; cognitive-behavioural therapy for treating depression and for information-provision interventions for improved patient knowledge. The evidence is limited for psychological and symptom management programs, and for other rehabilitation interventions the evidence is inconclusive, mainly due to limitations in methodology.

Health care for PwMS in Sweden

In Sweden, the county councils are responsible for providing health care services for its residents. The health care services are responsible for treating health conditions with the aim to retain or regain physical and mental health as far as is possible (56). There are approximately 20.000 PwMS in Sweden, with a higher prevalence in the northern parts. To a larger degree, competence concerning MS among health care professionals is concentrated to the larger cities, entailing that many PwMS do not have access to specialized MS-care, in respect to neurologists and other health professionals. There are also limitations in the granted types and amounts of rehabilitation for PwMS by the county councils. This limits the PwMS opportunities to maintain functioning and independence (57). The National Board of Health and Welfare in Sweden recommends multidisciplinary care to be available for PwMS in Sweden. Since the availability varies across the country, increased availability is needed (51).

2.3 Working life

2.3.1 Employment in PwMS

Many PwMS end working life early (58-61). Difficulties in getting and keeping an employment have been described (62), and among those still working many report changed roles at work and decreased working hours (63). In Sweden, 62% of the MS population has been reported to have full or partial disability pension compared to 14% in the general population (64). Sick leave is also common (65), often beginning before the diagnosis of MS is set (66-68). The low rate of PwMS working leads to increased societal costs (58, 60, 69, 70). However, PwMS does not only leave the work force, they also re-enter to some extent (71).

2.3.2 Factors associated with employment status

Personal factors and factors related to the health condition

Age has been shown to be associated with (72-74) employment status in PwMS. Declining participation in working life with older age is evident in the general population but it is considerably more pronounced in PwMS. This finding can be expected due to the progressive nature of MS over time (72) as overall MS-disability and longer MS-duration also are associated with not working (73, 75). Lower education level has been shown to be associated with not working (75) and in studies of coping and employment status, avoidant coping strategies have been found to be associated with leaving working life (76) and shorter time to unemployment (77).

Concerning values, attitudes and motivation in relation to working life in PwMS, there are indications that work is prioritized in PwMS for the benefits of work (59, 78), in addition to other aspects of life getting more important with increased disability (79).

Functioning and disability

Limited walking ability (80), and limited ability to carry out activities of daily living (81), have been reported to be associated with not working. Commonly reported impairments associated with not working are cognitive impairment (82), low energy level (fatigue; 59, 74, 75), low mood (depressive symptoms; 75) and mobility impairments (74).

Context of work

There are indications that PwMS who continue working are in a working situation where facilitating factors are present to a higher degree, such as accessibility, flexible work schedule and time off when needed (59). The most important factor for maintaining employment among PwMS has been suggested to be planning for effective symptom management in the workplace in advance (74, 83).

2.3.3 Quality of life and working life

Participation in working life has been described to be essential for QoL for PwMS, as well as for the general population, since it is important for the sense of identity, the sense of being useful, social interaction, and financial security (78, 84, 85). The already low HRQL in PwMS are reported to be even lower in PwMS not working (84, 86-88). It seems to be very important for PwMS to keep on working to maintain QoL, to the extent that it has been suggested as a health-promoting intervention for PwMS (89). Simultaneously, it seems that working come with difficulties. A well-functioning work-life balance has been reported to be positively related to life satisfaction as well as work satisfaction (90), but in PwMS there are indications that this work-life balance is challenged (78, 79, 91). Working has been described to induce costs in the form of increased fatigue and decreased activities in private life (78).

2.3.4 Support for PwMS in working life

PwMS may need support in several aspects of working life to be able to keep on working, maintaining work-life balance, adapting work and returning to work. Vocational rehabilitation involves interventions directed towards supporting people in working life. Evidence for the effectiveness of vocational rehabilitation is limited, due to few studies on PwMS and limitations in methodology (62, 92). In smaller studies often using qualitative methodology, important aspects of what is required in vocational rehabilitation have been identified, such as need of early preventive interventions (74). Generally, the focus of research has moved from how disabilities are associated with employment status to the impact of psychological factors. Despite available evidence the support for PwMS in working life is poorly developed (92).

Vocational rehabilitation in Sweden

In Sweden, the employer is responsible for the vocational rehabilitation of its employees and thereby provide for interventions enabling the employees to retain and regain their ability to work as far as is possible. The Swedish social insurance agency is responsible for determining need of vocational support and co-ordinate interventions from the health care services, the employer, the Swedish public employment service, social services and other possible parties, aiming for the patient to return to working or seeking work (56). There is no structured preventive support for people with chronic health conditions at risk of declining work ability and no nationwide support system specifically for PwMS. Knowledge of MS is limited among health professionals that are not specialized in MS (57), and from clinical experience even more limited in professionals outside of the health care services. This limits the understanding of what kind of support PwMS may be in need of and hampers development of interventions designed for PwMS. However, there are local efforts mainly based in the health care services where there is access to specialized MS care, improving PwMS situation in working life (93).

2.4 Rationale for the Thesis

MS is a chronic disease causing many challenges for those affected. Difficulty in adapting to changes caused by the disease is evident in the low QoL experienced by PwMS. It is known that the employment rate in PwMS is low, leading to increased burdens for society, and that unemployment is associated to low QoL in PwMS. The support PwMS have access to for maintaining a sustainable working life and QoL is despite this limited and needs to be further developed.

There is an existing knowledge base available for development of support, as presented in the background of this thesis, but there are also knowledge gaps to be filled. There are very few studies in a long-term perspective concerning predictors for employment status and studies of patterns of change in functioning and perceived impact of MS over time, in relation to employment status. There is also a lack of studies exploring activities in private life in relation to employment status in PwMS, making it possible to explore the factors that may be involved in work-balance, for sustainable employment in PwMS.

How change in working life is experienced and given meaning to by PwMS is unclear and reports on how values, attitudes and motivation are involved in decision-making in working life is inconclusive. Exploring the phases of change would be particularly important for understanding what PwMS are faced with that may lead to reduced employment.

There are indications of that acceptance of MS is of value for QoL and coping with changes in PwMS but its role in working life is insufficiently explored. At the beginning of this project, there was no test instrument available in Swedish for acceptance of MS, indicating a need for making this available to be able to explore acceptance of MS in relation to employment status. In order to get a wider perspective on QoL and employment status life satisfaction also need to be explored in relation to employment status

Increased knowledge of long-term predictors for employment status, patterns of change in relation to employment status and lived experience of change in working life would be valuable for identifying early indicators of problems in working life and for a deeper understanding of the challenges PwMS are faced with in working life and after ending working life. Together with findings concerning acceptance of MS and life satisfaction in relation to employment status, this may have potential to improve the basis for long-term planning of interventions for PwMS and development of support with appropriate timing, for PwMS to maintain sustainable working life and long-term QoL.

3 AIMS

The overall aim of this thesis was to build new knowledge that may contribute to the development of interventions to support sustainable working life and QoL in PwMS.

The aims for the included papers were:

I. To explore predictors for employment status after 10 years in a cohort of PwMS.

II. To describe and explore the lived experience and meaning of change in working life in PwMS.

III. To translate and culturally adapt the Acceptance of Chronic Health Conditions Scale for PwMS into Swedish, and to analyse the psychometric properties of the Swedish version.

IV. To explore patterns of change over 10 years in activities and participation, body functions and perceived impact of MS in subgroups of PwMS based on employment status, and to explore level of acceptance of MS and life satisfaction at the 10-year follow-up in the same subgroups.

4 PARTICIPANTS AND METHODS

4.1 Study design

In the papers included in the thesis, several different study designs were used. They are presented in Table 1.

Table 1. Overview of the study designs of the papers included in the thesis.

Paper	Aim	Design	Specific analysis method[a)]
I	To identify predictors for employment status after 10 years	Longitudinal study over 10 years using quantitative analysis	Generalized Ordinal Logistic Regression[b)]
II	To describe and explore the lived experience and meaning of change in working life	Interview study using qualitative analysis	The Empirical Phenomenological Psychological method
III	To translate and culturally adapt the ACHC Scale To analyze the psychometric properties of the ACHC Scale	Questionnaire development Cross-sectional study using quantitative analysis	Translation and back-translation, pre-test Rasch analysis
IV	To explore patterns of change in functioning, acceptance of MS and life satisfaction in relation to employment status	Longitudinal and cross-sectional study using quantitative analysis	Wilcoxon signed rank test Effect sizes

ACHC Scale: Acceptance of Chronic Health Conditions Scale

[a)] Descriptive statistics were used in all papers in the thesis.

[b)] In the published article of Paper 1, Mann-Whitney U test and chi-square test were also used for the purpose of comparing those who completed the 10-year follow-up with those who dropped out.

4.2 Participants and procedures

The included papers in this thesis were based on a 10-year follow-up of a cohort of PwMS (Figure 4) who were initially recruited for a 2-year longitudinal study of functioning, perceived health and satisfaction with the care (47, 94). Eligible for inclusion in the 2-year study were all people with a definite MS-diagnosis scheduled for an outpatient appointment with neurologists at the MS Centre at Karolinska University Hospital in Stockholm, Sweden, during the time period from February, 2002, to June, 2002. For inclusion in the 10-year follow-up, the participants who completed the 2-year study and alive were re-identified and contacted by an investigator. The participants were given oral and written information regarding the study and included after informed consent. A total of 155 PwMS were included in the 10-year follow-up.

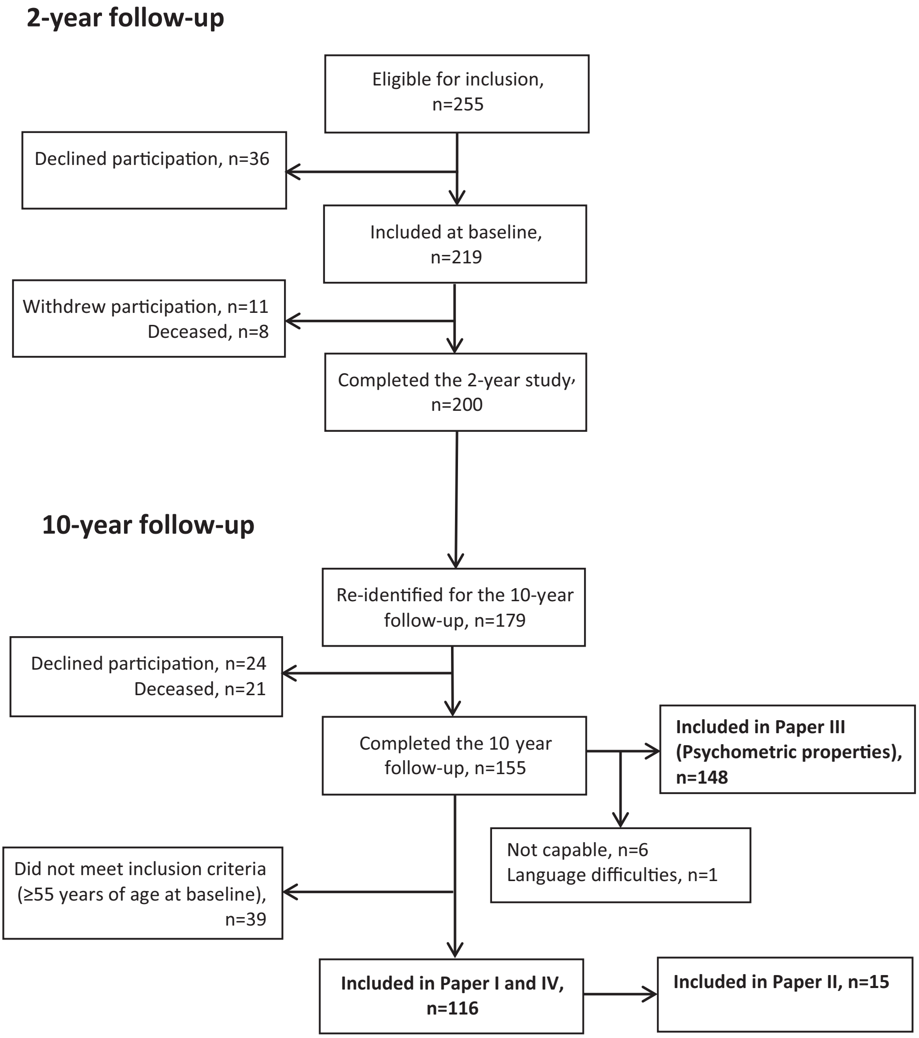

Figure 4. *Flow-chart for the people with multiple sclerosis in the research project which started in a 2-year follow-up, and continued in the 10-year follow-up, which this thesis is based on.*

Data collected at baseline in 2002 and at the 10-year follow-up in 2012, 10 years +/- six months after baseline was used in this thesis. At both points in time the data collection comprised a structured interview, self-reported questionnaires and performance-based tests, completed in a standardized order. The data collection took place at the MS Centre or in the participant's home and was guided by research physiotherapists. Each data collection took 1.5-2.5 hours. In a few cases, the 10-year follow-up data were collected via mail and telephone interviews, due to the PwMS having moved from the area. In addition, data was collected from medical records.

For the translation of the ACHC Scale in Paper III, 10 additional PwMS were involved, for specifics see paragraph 4.1.3.

4.2.1 Papers I and IV: Predictors of employment status, and patterns of change, acceptance of MS and life satisfaction

Eligible for inclusion in Paper I and IV were the PwMS from the 10-year follow-up who were of working age at the 10-year follow-up, i.e. younger than 55 years of age at baseline as the age of retirement in Sweden is 65 years of age up to present. A total of 116 PwMS were included in Paper I and IV (Table 2).

In Paper IV the PwMS were divided into four subgroups based on employment status at baseline and the 10-year follow-up: 1) full-time work at the 10-year follow-up; 2) part-time work at the 10-year follow-up; 3) declined from working at baseline to not working at the 10-year follow-up; and 4) no work, either at baseline or the 10-year follow-up.

Table 2. Baseline characteristics for all participants of working age in the 10-year follow-up (Paper I and IV) and the subgroups (Paper IV): those who worked full-time and part-time at the 10-year follow-up, those who had declined from working at baseline to not working at 10 years and those who did not work either at baseline or at the 10-year follow-up.

Baseline characteristics	**All, n=116 n (%), mean (SD)[1]**	**Full-time work, n=32 n (%), mean (SD)[1]**	**Part-time work, n=27 n (%), mean (SD)[1]**	**Decline to no work, n=28 n (%), mean (SD)[1]**	**No work, n=29 n (%), mean (SD)[1]**
Contextual factors					
Female	78 (67)	20 (63)	21 (78)	18 (64)	19 (66)
Age, years	41 (9)[1]	39 (8)[1]	36 (10)[1]	45 (7)[1]	43 (8)[1]
Education level					
Elementary school	25 (21)	2 (6)	4 (15)	7 (25)	12 (41)
High school	46 (40)	10 (31)	13 (48)	10 (36)	13 (45)
University/collage	45 (39)	20 (63)	10 (37)	11 (39)	4 (14)
Sedentary work[a)]	66 (57)	22 (69)	14 (52)	19 (68)	11 (38)
Living alone	29 (25)	9 (28)	8 (30)	7 (25)	6 (21)
Living with children <18 years	51 (44)	15 (47)	9 (33)	14 (50)	13 (45)
Immunomodulatory treatment	100 (86)	27 (84)	23 (85)	25 (89)	25 (86)
Health condition					
Disease course					
Relapsing remitting	85 (73)	31 (97)	24 (89)	17 (61)	12 (41)
Progressive	31 (27)	1 (3)	3 (11)	11 (39)	17 (59)
Time since diagnosis, years	12 (9)[1]	9 (8)[1]	9 (7)[1]	13 (10)[1]	15 (10)[1]
Overall MS-disability					
Mild, EDSS 0-3.5	81 (70)	31 (97)	23 (85)	17 (61)	10 (34)
Moderate, EDSS 4-6.5	24 (21)	1 (3)	4 (15)	8 (28)	11 (38)
Severe, EDSS 7-9.5	11 (10)	0 (0)	0 (0)	3 (11)	8 (28)
Activities and participation					
Employment status					
Full-time work	49 (42)	26 (81)	15 (56)	8 (29)	0 (0)
Part-time work	32 (28)	2 (6)	10 (37)	20 (71)	0 (0)
No work	35 (30)	4 (13)	2 (7)	0 (0)	29 (100)

n: number; SD: standard deviation; EDSS: Expanded Disability Status Scale (95)

[a)] Data collected two years after baseline and referred to actual type of work at baseline.

4.2.2 Paper II: Lived experience and meaning of change

Out of the 116 PwMS in working age in the 10-year follow-up, 15 PwMS were purposely selected for participation in the interview study (Table 3). Information from the 10-year follow-up was used to strategically identify PwMS with different background characteristics, who were known to have different sorts of experiences of change in working life, and who were able to share their experiences. The selected PwMS were approached with information via telephone and ordinary mail and were included after informed consent.

Table 3. Sample characteristics for the 15 participants in Paper II.

Sample characteristics	**All, n=15 n**
Contextual factors	
Female	10
Age (years)	
35–44	2
45–54	4
55–64	9
Education level	
Elementary school	2
High school	4
University/collage	9
Sedentary work	10
Living alone	8
Living with children <18 years	4
Health condition	
Time since diagnosis, years	
11–20	6
21–30	7
>30	2
Overall MS-disability	
EDSS 0–2	2
EDSS 2.5–3.5	5
EDSS 4–5.5	4
EDSS 6–7.5	4
Activities and participation	
Employment status	
Full-time work	4
Part-time work	5
No work[a)]	6

n: number; EDSS: Expanded Disability Scale (95)

[a)] No work includes unemployed (n=1), sick-leave (n=1) and disability pension (n=4)

The qualitative data were collected through interviews between September 2015 and April 2016. A semi-structured interview guide developed for this study was used. It comprised a set of open-ended questions, focusing on the PwMS concrete experiences of change in working life and areas of relevance for this, such as: “What is an ordinary day like for you?” and “How has working life changed for you?”. The questions were directed to current, past, possible future changes in working life and also experiences of absence of change. Follow-up questions were used to deepen the PwMS descriptions of their experiences, such as “Can you tell me more?” and “What was this like for you?”.

Each interview was digitally recorded and took from 1 to 2 hours. It was located at the MS Centre or in the participant’s home, depending on the choice of the participant. The author of this thesis conducted all of the interviews except one that was carried out by a researcher involved in the research project.

4.2.3 Paper III: Translation and psychometric properties of the ACHC Scale

Paper III was performed in two phases. In the first phase, the original ACHC Scale were translated into Swedish and culturally adapted in a stepwise procedure that involved translators, expert committee and 10 PwMS in a pre-test of the Swedish version of the scale. In the second phase, the finalized Swedish version of the scale was tested for psychometric properties in the PwMS from the 10-year follow-up.

Phase 1: Translation and cultural adaptation

The steps performed for the purpose of translation and cultural adaptation of the ACHC Scale (Figure 5) were based on recommended guidelines (96, 97). Firstly, the original scale was translated independently by three translators of Swedish origin, competent in American English. From the three independent translations, the translators produced a synthesis that the translators agreed on. The synthesis was then independently back-translated into English by two translators of American origin, competent in Swedish. All translators took notes throughout the translation process, describing aspects taken into consideration during the translation. In the next step, the translations and the notes were reviewed by an expert committee that comprised health professionals with extensive experience in care of PwMS both in out-patient and in-patient settings. In this review, conceptual, experiential, operational and idiomatic equivalence between the original and the Swedish synthesis was evaluated. Revisions were made and a Swedish version of the scale was produced, which in the next step was used in the pre-test.

For the purpose of the pre-test, 10 PwMS were recruited from a rehabilitation clinic (Table 4). They were selected and invited to participate by rehabilitation professionals at the clinic and were included after informed consent. In the pre-test they were asked to reflect on the instructions for the scale, each separate item and the scale as a whole, while filling it in. When the scale was completed, they were informed of the view of acceptance that the scale intended to reflect, and were asked to reflect upon if the items of the scale represented this intention. Based on the PwMS responses, some final revisions of wording were made before the final version of the Swedish ACHC Scale was decided upon.

Figure 5. *The process of translation and cultural adaptation into Swedish of the Acceptance of Chronic Health Conditions Scale in Paper III.*

Table 4. Sample characteristics of the 10 people with multiple sclerosis, who reflected on the Swedish version of the Acceptance of Chronic Health Conditions Scale in the pre-test in Paper III.

Sample characteristics	**All, n=10 n, range years[1]**
Contextual factors	
Female	8
Age	28-66[1]
<65 years of age	9
Living alone	3
Health condition	
Time since diagnosis	1-28[1]
Activities and participation	
Full-time or part-time work	3
Movement ability	
Walking without difficulty/with difficulty	5/2
Driving wheelchair without difficulty/with difficulty	2/3
Bedridden	1

n: number

Phase 2: Test of psychometric properties

Out of the 155 PwMS included in the 10-year follow-up described above, 148 PwMS completed the ACHC Scale and were thus included in the test of psychometric properties of the Swedish version of the ACHC Scale (Table 5). This sample included PwMS of working age as well as older.

Table 5. Sample characteristics of the people with multiple sclerosis who completed the Acceptance of Chronic Health Conditions Scale for analysis of psychometric properties in Paper III.

Sample characteristics	**All, n=148 n (%), mean (min-max)[1]**
Contextual factors	
Female	98 (67)
Age, years	52 (30-84)[1]
<65 years of age	116 (79)
Health condition	
Time since diagnosis, years	23 (11-52)[1]
Overall MS-disability	
Normal, EDSS 0	4 (3)
Mild, EDSS 1–3.5	61 (41)
Moderate, EDSS 4–5.5	18 (12)
Severe, EDSS 6–9.5	64 (44)
Activities and participation	
Full-time or part-time work (persons <65 years of age)	59 (51)

n: number; EDSS: The Expanded Disability Status Scale (95)

4.3 Collected quantitative data

The variables used in the specific papers are presented in Table 6.

Table 6. Collected quantitative data used in the thesis, Paper I-IV.

Variable	Data collection method	Paper			
		I	II	III	IV
Contextual factors					
Sex	Medical records	X	X	X	X
Age	Medical records	X	X	X	X
Education level	Interview	X	X		X
Type of work	Interview	X	X		X
Living alone	Interview	X	X	X	X
Living with children	Interview	X	X		X
Sense of coherence	Sense of coherence scale	X			
Acceptance of MS	Acceptance of chronic health conditions scale			X	X
Immunomodulatory treatment	Medical records	X			X
Health condition					
Disease course	Medical records	X			X
Time since diagnosis	Medical records	X	X	X	X
Overall MS-disability	Expanded disability status scale	X	X	X	X
Activities and participation					
Employment status	Interview	X	X	X	X
Activities in private life	Frenchay activities index, all items a)	X			
Domestic	Items 1-5				X
Outdoor	Items 6, 8, 10, 12 and 13				X
Leisure	Items 7, 9, 11 and 14				X
Movement ability	Interview			X	
Walking ability	Timed 25-foot walk test	X			X
Fine hand use	Nine-hole peg test	X			X
Body functions					
Cognition	Symbol digit modalities test	X			X
Fatigue	Fatigue severity scale	X			X
Depressive symptoms	Beck depression inventory	X			X
Quality of life					
Perceived impact of MS	Multiple sclerosis impact scale				
Physical		X			X
Psychological		X			X
Life satisfaction	Life satisfaction index, item 1				X

a) All items except the item concerning work (item 15), due to that it was measured separately in the variable employment status.

4.3.1 Contextual factors

Demographic characteristics

Data on sex and age was collected from medical records in all studies except for the pre-test in Paper III where it was collected through interview. Education level and type of work was collected through interview and categorized as elementary school (0-9 years), high school (10-12 years), university/collage (>12 years) and sedentary/physically demanding work, respectively. Living situation was collected through interviews on the current situation regarding living with a partner or other adult and living with children <18 years of age.

Sense of coherence

The 13-item version of the Sense of coherence scale was used to assess the sense of coherence with its three components comprehensibility, manageability and meaningfulness (98). The items are rated on a Likert scale from 1 to 7 and the score is summed. A higher score indicates a higher level of sense of coherence. The scale has previously been used in the MS-population (99, 100).

Acceptance of MS

The ACHC Scale (15) was used to measure acceptance of MS. It consists of 10 items and is scored on a 5-category Likert rating scale. Four of the items are positively worded, and 6 negatively worded. A summated score of the scale is used, where the positively worded items are coded in reverse. High level of acceptance is indicated by a high total sum score; consequently a low score indicates a low level of acceptance. A score of ≥30 was considered to describe medium to high level of acceptance of MS.

Pharmacological treatment

Immunomodulatory treatment was collected from medical records.

4.3.2 The health condition

Disease course and time since diagnosis was collected from medical records. Overall MS-disability was assessed by the Expanded disability status scale (EDSS; 95), which was rated by neurologist and collected from medical records. It is rated on a scale from 0-9.5 where a higher score indicates a more severe disability.

4.3.3 Activities and participation

Employment status

Data on employment status was collected through interviews regarding the current situation. It was categorized based on hours worked per week: full-time work (≥40h), part-time work (>0 to <40h) and no work (0h).

Activities in private life

Aspects of activities in private life (also referred to as social/lifestyle activities) were measured using the Frenchay activities index (101, 102). The index consists of 15 items rated on a Likert scale from 0 to 3 regarding how frequently the activity in each item is performed. A higher score indicates higher frequency. The item in the index concerning work was excluded from analysis in this thesis due to that it was measured separately. The total number of items in this thesis was therefore 14. The index was both used as one whole scale in which all of the items were summed on a scale from 0 to 42, and in three subdomains: domestic (0 to15), outdoor (0 to 15) and leisure activities (0 to 12). The subdomains were based in the original work of the index (101) and modified for the purpose of this study.

Movement ability

Movement ability was collected through interviews and categorized in walking with and without difficulty, and driving a wheelchair with and without difficulty.

Walking ability

The Timed 25-foot walk (103) was used to assess walking ability. It is a performance-based test in which the time to walk 25 foot (7.62 meters) is measured. It was reported in meters per second and walking aids were allowed, if needed. The PwMS who could not walk were reported to have a walking speed of 0 meters per second.

Fine hand use

Fine hand use was assessed by the Nine-hole peg test (104), in which nine pegs are to be inserted in a board with nine holes. When the insertion is completed the pegs are to be removed again before the task is completed. The manipulation of the pegs is to be done with one hand, one peg at a time. The time to accomplish this is measured and in this thesis reported as pegs per second with dominant hand. The PwMS who could not complete the task was reported as 0 pegs per second.

4.3.4 Body functions

Cognition

The Symbol digit modalities test (105) was used to assess cognitive function. It is a performance-based test that measures processing speed through complex scanning and visual tracking. The task is to combine geometric symbols with the correct number, according to a key that shows the correct combination of geometrical symbol and number. The score is based on the number of correct responses recorded within 90 seconds. The test was administered in written format, except for a few cases were it was performed verbally, due to limited fine hand use.

Fatigue

Fatigue was assessed using the Fatigue severity scale (106). It is a self-report questionnaire including nine items that are rated on a scale from 1-7. The mean score is used and a higher score indicates higher level of fatigue.

Depressive symptoms

The Beck depression inventory (107) was used for assessing depressive symptoms. It is a self-report questionnaire including 21 items rated on a Likert scale. A summed score from 0 to 62 is used and a higher score indicates more depressive symptoms.

4.3.5 Quality of life

Perceived impact of MS

The Multiple sclerosis impact scale consists of two subscales (108), and was used to measure the physical and psychological impact of MS. The physical subscale consists of 20 items concerning the physical impact of MS and 9 items concerning psychological impact. Each item is rated on a Likert scale from 1 to 5, where a higher score indicates higher impact of MS. The item-score is summed and transformed to a scale from 0 to 100, where a higher score indicates higher impact of MS.

Life satisfaction

The Life satisfaction index (23) encompasses 11 items concerning satisfaction with different areas of life. It is rated on a Likert scale from 1 to 6, where a higher number represents higher level of satisfaction. The first item of the Life satisfaction index, that measures satisfaction with life as a whole, was in this thesis used to measure satisfaction with life. The ratings 5 and 6 were considered to represent satisfaction with life.

4.4 Data analyses

4.4.1 Paper I: Predictors for employment status

In the analysis of predictors for employment status, baseline values were used as independent variables and were treated as continuous, except for age and employment status at baseline (Table 9). Employment status at the 10-year follow-up was used as the dependent variable, categorized as full-time work, part-time work, and no work. The independent variables and the categorization of the dependent variable were chosen based on previous research and clinical experience. The statistical analyses were performed using IBM SPSS version 22.0 (supplied by SPSS) and Stata 13 (supplied by StataCorp). The missing values were very few and were imputed jointly using single imputation with chained equations (109) using predictive mean matching (110). For the purpose of comparing those included in the study with those who dropped out Mann-Whitney U test and chi-square test were used on baseline data (presented in the published article included in the thesis, Paper I).

A generalized ordinal logistic regression (111) was used in the analyses of predictors, as implemented in the Stata package gologit2 (112). In univariate generalized ordinal logistic regressions, using a significance level of $p<0.05$. All independent variables were tested against the dependent variable. The importance of each independent variable for predicting employment status after 10 years was measured using McFadden R^2 (113); a value 0.20 was considered to be an important predictor (114). The univariate analysis was also depicted in graphs, showing the probability of working full-time, part-time and not working after 10 years based on baseline data in each independent variable (not included in the published article included in the thesis, Paper I).

For multivariate analysis, the independent variables with a $p<0.20$ in the single predictor analysis were included, except for overall MS-disability that was considered to be overlapping with other variables. By using backward elimination of variables with $p>0.20$ the multivariate model was then reduced into a final multivariate model. The cut off value was chosen in order to ensure that all important variables were included in the analyses.

Two sets of separate but linked results, with all participants included in each, were generated both in the univariate and multivariate analyses: predictors for full- or part-time work versus no work at the 10-year follow-up; and predictors for full-time work versus part-time or no work at the 10-year follow-up. The level of correlation between the independent variables in the multivariate analysis was assessed using variance inflation factors (VIFs) for the different variables. VIFs >2.5 were considered to be an indication of multicollinearity, i.e. strongly correlated variables (115).

4.4.2 Paper II: Lived experience and meaning of change

The interviews were analysed using the five steps (Table 7) described in the Empirical Phenomenological Psychological (EPP) method (116). The EPP method aims to identify the meaning structure of a phenomenon based in an individual's lived experience of the phenomenon. This was considered to be useful for the purpose of describing and exploring the experience and meaning of change in working life in PwMS. In phenomenology, previous knowledge and experience of the phenomenon is strived to be bracketed by the researchers, for the analysis to be as open as possible about how it appears to the participants of the study. In Paper II, the researchers therefore sought to be aware of their preconceptions of change in working life from their experience of meeting PwMS in healthcare settings and from previous research, and instead return to the participants' experiences. This attitude was maintained and scrutinized throughout the study.

Table 7. The steps of analysis in the Empirical Phenomenological Psychological method in Paper II.

Steps	Analysis
1	**Reading the transcribed interviews** The transcribed interviews were read carefully to get a good grasp of its content.
2	**Dividing the transcribed text into meaning units** A new meaning unit was formed each time the transcribed text shifted meaning.
3	**Interpreting meaning units** The meaning units were interpreted in relation to change in working life, and re-written in the researchers' own words.
4	**Forming a situated structure** The interpreted meaning units were synthesized into a summary of the characteristics of change for each interview, i.e. its meaning structure. This also included returning to the original interview text to assure that the situated structure was in coherence with the descriptions of the participants.
5	**Forming a general meaning structure** Based on the characteristics of change in working life identified in the situated structures of all the interviews a general meaning structure was formed. The general meaning structure was compared with the original interview texts and the situated structures to ensure that it was representative for the participant descriptions of the phenomenon.

The first four steps were carried out separately for each interview, while all interviews were analysed together in step five. Three of the authors read all the interviews in step one. Steps two to four were analysed by the author of this thesis and were then discussed in detail for each interview with the other authors, with a focusing on the phenomenon change in working life. In step five, the general meaning structure was formed through a joint analysis and discussion including all authors. This process included returning to the situated structures and the original interview texts. The characteristics of the general meaning structure were refined several times before a final meaning structure was formed where each individual characteristic of the phenomenon fitted with the other characteristics, and was coherent with the original descriptions in the interviews.

4.4.3 Paper III: Psychometric properties of the ACHC Scale

Psychometric properties of the ACHC Scale were analyzed using WINSTEPS Rasch analysis software (117). Rasch analysis is a modern test theory approach that can increase the information regarding a scale's properties compared to an analysis using a classical test theory approach (118, 119). An introduction to Rasch analysis can be found in dedicated articles and textbooks (118-121). In short, the Rasch model can convert the ordinal data pattern across items into interval measures, if the data meets certain criteria of validity and reliability (118).

In the ACHC Scale a generic rating scale is used and it can be assumed that the rating scale functions in the same manner across all items. The Andrich Rating scale model was therefore chosen as a method for analysis. A stepwise procedure was used in the evaluation of the psychometric properties of the ACHC Scale in this study (Table 8), which is described in detail elsewhere (122). The items were also assessed regarding how well they targeted the participants in this study, by using an item-person map (120).

When these steps were carried out and a version of the ACHC Scale with seven items had been reached, an additional Rasch approach was used to validate the ACHC-7 Scale. Within the Rasch model there is an underlying assumption of local independence between items. In order to reveal whether the item deletion generated the most optimal solution for the ACHC Scale, or if the item deletion was biased by local dependence among items, correlation of the residuals in all of the 10 ACHC items was calculated. Item clusters with correlations exceeding 0.2 above the mean item residual correlations was then grouped into so called "super-items" and was re-evaluated towards the similar criteria as earlier versions.

4.4.4 Paper IV: Patterns of change, acceptance of MS and life satisfaction

Patterns of change were explored within each of the subgroups: 1) full-time work; 2) part-time work; 3) declined from working to not working; and 4) no work. The within-group difference in functioning and perceived impact of MS between baseline and the 10-year follow-up were analysed using the Wilcoxon signed-rank test. Due to the multiple tests performed, the significance level was set at <0.01 to decrease the risk of Type 1 error. The magnitude of the within-group differences in the subgroups was calculated using non-parametric effect sizes based on the z-values from the Wilcoxon signed-rank test (effect size = $z/\sqrt{n}$). The effect sizes were categorized in small effect ≥ 0.1, medium effect ≥ 0.3, and large effect ≥ 0.5 (131). Acceptance of MS and life satisfaction were analysed descriptively for each subgroup and were presented as numbers (percentages) of PwMS reporting a medium/high level of acceptance of MS and satisfaction with life.

Table 8. Overview of the analytic process of the Rasch analysis in Paper III.

Step	Psychometric property	Statistical approach	Criteria
1	Rating scale functioning	Average measures for each step category and threshold on each item should advance monotonically (118)	z-values <2.0 in outfit mean square (MnSq) values for step category calibrations (122)
2	Internal scale validity: Item goodness-of -fit	Item goodness-of-fit statistics[a] (123)	Infit[b] MnSq values ≤1.4 and z-value <2.0 (124, 125)
3	Internal scale validity: unidimensionality	Principal component analysis of the residuals (126)	≥60 % of total variance explained by first component (e.i. acceptance) (127) Any additional component explains <5% of the remaining variance of residuals after removing first component (127)
4	Person-response validity	Person goodness-of-fit statistics	Person-goodness-of-fit infit values ≤1.4 and z-value <2.0 (124, 125) ≤5% of sample fails to demonstrate tolerable goodness-of-fit values (124)
5	Person-separation reliability	Person-separation index (128)	≥1.5 for group use and ≥2.5 for individual use (118)
6	Internal consistency	Cronbach alpha coefficient	≥0.7 for group use and ≥0.85 for individual use (118)
7	Differential item functioning (DIF)[c]	Mantel-Haenszel statistic (129)	P<0.01 with Bonferroni correction (129) No more than one item, or 5 % of items, is allowed to demonstrate DIF (125)

[a] In presence of item misfit, misfitting items were successively excluded until no misfit appeared.

[b] In this study the infit values were used in the analysis since they are considered to be more sensitive to item performance and more informative when exploring internal scale validity than the outfit values (130).

[c] Regarding gender, age, time since diagnosis and disease severity determined by the Expanded Disability Status Scale (EDSS; 95). Age and time since diagnosis were categorized in two groups based on the median in the cohort, and the EDSS scores were categorized based on illness severity, EDSS mild and EDSS moderate/severe.

4.5 Ethical Approval

The research has been carried out in accordance with the Helsinki declaration (132). The studies were approved by the ethical review board in Stockholm, registration numbers 2011/2068-31/5 and 2011/211-31/1.

5 RESULTS

5.1 Paper I: Predictors for employment status

In the univariate analyses for employment status (Table 9), all variables except sex, sense of coherence and part-time work were significant (significance level 0.05) concerning full-time or part-time work versus no work, and full-time work versus part-time or no work. Frequency of activities in private life and walking ability were the most important predictors for employment status 10 years later. Sex, age, education level, sense of coherence, depressive symptoms and perceived psychological impact of MS explained very little or nothing of the variance in employment status after 10 years.

In the graphs depicting the probability of working full-time, part-time and not working after 10 years, similar patterns were found in several variables (Figure 6). Low levels of disability at baseline corresponded to a high probability of working full-time after 10 years, and high disability levels corresponded to high probability of not working. Regarding the probability of working part-time after 10 years, the probability was the highest with moderately high baseline scores.

In the final multivariate model (Table 10) the following independent variables at baseline significantly predicted full- or part-time work after 10 years: young age, full-time work, high frequency of activities in private life, fatigue and low perceived physical impact of MS. Low perceived physical impact of MS at baseline also significantly predicted full-time work versus part-time or no work. The analysis of the correlation between variables revealed that frequency of activities in private life, walking ability, fine hand use, cognitive function, perceived physical and psychological impact of MS were strongly correlated with other independent variables, presenting with VIFs >2.5.

Table 9. Univariate analyses of predictors for working full- or part-time work versus no work, and for full-time work versus part-time or no work after 10 years in Paper I.

Independent variables	**Full- or part-time work vs no work**			**Full-time work vs Part-time and no work**			
Contextual factors	OR	(95% CI)	p-value	OR	(95% CI)	p-value	McFadden (adjusted)
Female a)	1.03	(0.49-2.16)a)	0.32	1.03	(0.49-2.16)	0.32	-0.01
Age	0.92	(0.88-0.96)	<0.001	0.97	(0.92-1.01)	0.14	0.05
Education level	2.39	(1.40-4.08)	<0.001	3.04	(1.57-5.90)	<0.001	0.05
Sense of coherence a)	1.01	(0.98-1.04)	0.45	1.01	(0.98-1.04)	0.45	-0.01
Health condition							
Overall MS-disability a)	0.49	(0.37-0.64)	<0.001	0.49	(0.37-0.64)	<0.001	0.17
Activities and participation							
Full-time work	24.77	(7.76-79.05)	<0.001	8.76	(2.68-28.59)	<0.001	
Part-time work	2.90	(0.93-9.01)	0.07	0.21	(0.09-3.03)	0.465	0.18b)
Activities in private life a)	1.25	(1.15-1.36)	<0.001	1.25	(1.15-1.36)	<0.001	0.21
Walking ability a)	12.67	(5.17-31.04)	<0.001	12.67	(5.17-31.04)	<0.001	0.20
Fine hand use a)	1.17	(1.10-1.25)	<0.001	1.17	(1.10-1.25)	<0.001	0.12
Body functions							
Cognitive function a)	1.11	(1.07-1.14)	<0.001	1.11	(1.07-1.14)	<0.001	0.18
Fatigue a)	0.52	(0.40-0.68)	<0.001	0.52	(0.40-0.68)	<0.001	0.11
Depressive symptoms a)	0.91	(0.86-0.96)	0.001	0.91	(0.86-0.96)	0.001	0.04
Perceived impact of MS							
Perceived physical impact of MS a)	0.94	(0.92-0.96)	<0.001	0.94	(0.92-0.96)	<0.001	0.18
Perceived psychological impact of MS a)	0.98	(0.97-0.99)	0.004	0.98	(0.97-0.99)	0.004	0.03

vs: versus; MS: multiple sclerosis; OR: odds ratio; CI: confidence interval

a) The same figures appear both in the Working vs Not working columns and the Working full-time vs Not full-time columns due to the statistical method used in a generalized ordinal logistic regression.

b) McFadden for employment status, including full-, part-time and no work.

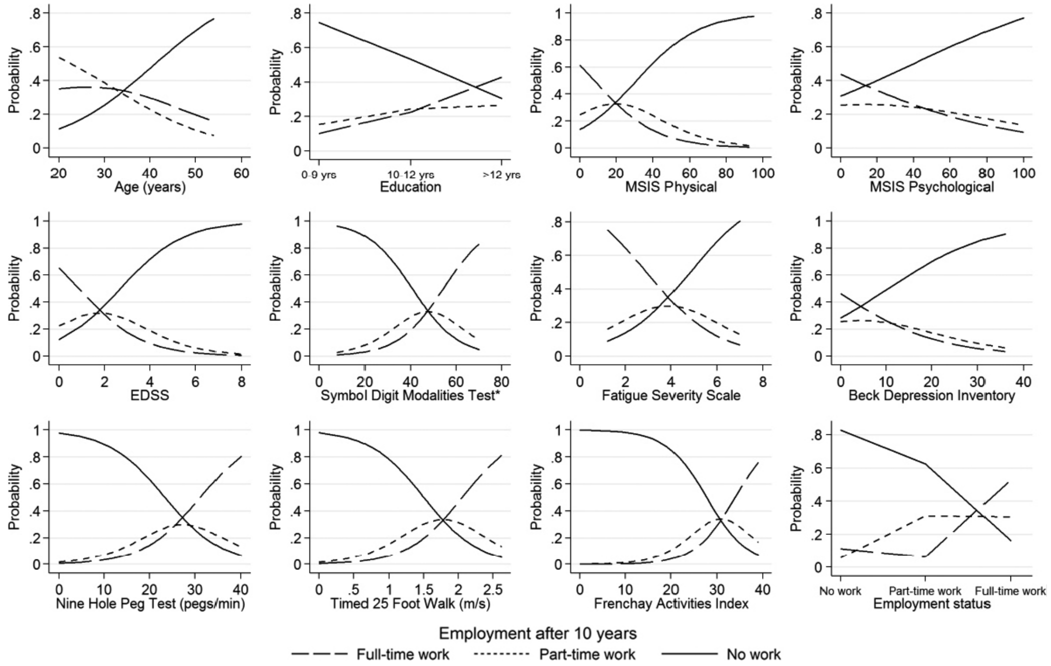

__Figure 6.__ Probability of full-time work, part-time work and no work after 10 years based on baseline data in Paper I. MSIS: Multiple Sclerosis Impact Scale; EDSS: Expanded Disability Status Scale.
** Number of correct responses was reported.*

Table 10. Final multivariate model of predictors for full- or part-time work versus no work, and for full-time work versus part-time or no work at the 10-year follow-up presented in odds ratios and p-values in Paper I.

Independent variables	**Full or part-time work vs no work**			**Full-time work vs part-time work or no work**		
Personal factors	**OR**	**(95% CI)**	**p-value**	**OR**	**(95% CI)**	**p-value**
Age	0.85	(0.76-0.94)	0.002	1.04	(0.97-1.12)	0.28
Education level [a)]	2.02	(1.00-4.06)	0.05	2.02	(1.00-4.06)	0.05
Activities and participation						
Full-time work	29.89	(4.05-220.6)	0.001	1.47	(0.26-8.26)	0.66
Part-time work	5.56	(0.97-31.95)	0.05	0.15	(0.02-1.26)	0.08
Activities in private life	1.33	(1.13-1.56)	0.001	1.07	(0.90-1.26)	0.46
Fine hand use [a)]	0.92	(0.82-1.03)	0.16	0.92	(0.82-1.03)	0.16
Body functions						
Fatigue	2.03	(1.08-3.84)	0.03	0.65	(0.38-1.10)	0.11
Perceived impact of MS						
Perceived physical impact of MS [a)]	0.95	(0.92-0.99)	0.02	0.95	(0.92-0.99)	0.02

vs: versus; MS: multiple sclerosis; OR: odds ratio; CI: confidence interval.

[a)] The same figures appear both in the Working vs Not working columns and the Working full-time vs Not full-time columns due to the statistical method used in a generalized ordinal logistic regression.

5.2 PAPER II: Lived experience and meaning of change

The participants described different types of change in working life, such as changed working hours, work contents, physical environment and attitudinal changes. Out of the descriptions of these lived experiences the general meaning structure of the phenomenon change in working life for PwMS was identified. The general meaning structure was found to consist of four main characteristics, describing the whole phenomenon from different perspectives. Two of the main characteristics are presented with sub-characteristics representing different aspects of these characteristics (Table 11).

Table 11. The four main characteristics that formed the general meaning structure of the phenomenon change in working life for people with multiple sclerosis in Paper II. Two main characteristics are presented with sub-characteristics representing different aspects of the characteristic

Negotiation of what gives life meaning • Strong incentives to keep working life going as usual • Struggling to maintain life as usual • Balancing working life and private life
Disrupted life course
Finding meaning through taking control • Taking control through acceptance • Taking control through medical treatment and taking care of self • Extending control through allies
Altered life as usual

Negotiation of what gives life meaning

A negotiation of what gave life meaning was presented when changes in work ability and ability to run the private life occurred. The participants experienced *strong incentives to keep on working as usual* as working gave a sense of value as a person, contributed to daily routines and a space outside MS and their private selves. There was also an experience of that it was their obligation to work, and if they did not have the opportunity to work it was destructive to sense of self. The incentives to work could however be reduced when disability made it difficult to work independently, e.g. not being able to write on one's own.

The strong incentives to work were intertwined with *struggling to maintain life as usual*, that generally meant to continue working. Frustration and anger were expressed concerning not being able to meet their own expectation, fear of not being good enough and worry about having a relapse. There was also a struggle to keep the effects of MS from showing, that gave way to a behaviour of avoidance. Holding on to walls for keeping balance, always being aware of where the closest bathroom is and continuously taking extra time to double-check their work for errors were strategies used to be able to continue working without making obvious changes. Change was resisted and challenged the sense of identity. Sometimes not acknowledging a disability that affected work also could lead to errors and distrust in the work-place.

As working was highly prioritized, a lot of energy was drained at work, leaving little energy for private life. Difficulties with *balancing working life and private life* were evident. The need of change to cope with life as a whole with decreasing resources was transferred from working life to private life, sometimes entirely. This happened more as a subconscious process, than as an active choice. Still, there was an awareness of how they should balance life for living a good life, but it was very difficult to accomplish. This led to frustration and a sense of resignation.

Disrupted life course

Change in working life was experienced as a disrupted life course. Every time there was a deterioration in MS that threatened working life a sense of losing control emerged. This concerned seemingly small disabilities and instantly overwhelming increases in disability. Problems also grew over time from itches of discomfort to problems that were impossible to ignore and where changes were inevitable. It was hard to deal with the realization that change in working life was not possible to avoid. The situation when the gap between what they wanted to do and what they could do got to large it caused pain, frustration and anger.

Finding meaning through taking control

A meaning in what was going on in life was found, when the participants perceived that they had control of their changing situation. *Taking control through acceptance* was described both by those who had found acceptance and those who had not. Finding acceptance for changed ability to continue working life as usual was a difficult process that could take long time, but in the end described as a way to move on with life. To be in a situation without room for the process of acceptance and where decisions of change in working life was forced became a source to great dissatisfaction, with a strong sense of losing control.

Taking control through medical treatment and taking care of self were ways of trying to keep their situation stable, to avoid changes in working life, and improve chances and hope to restore previous working situation. Optimized medical treatment could both be to take medication to prevent disease progress and improve functioning, and to not take medication due to massive adverse effects which made working difficult. Participants had an awareness of the importance of taking care of oneself for being able to work, by eating well, resting when needed, and exercising to keep health as good as possible. This was however difficult to accomplish.

Extending control through allies was described as making their working situation easier and improved ability to cope with change. Control was increased by finding persons at work who understood their situation and helped them to overcome difficulties. This was important also for persons with minimal disability. Support from family and healthcare givers gave the participants a frame of reference of when they could keep on going as usual and when change was needed. Having the possibility to be backed up and supported to cut down on work when it was needed, gave a sense of security. When there was a lack of allies the situation at work was more uncertain and lonelier, rendering a sense of losing control. It was also described as difficult to build trust with a new employer after having lost employment.

Altered life as usual

A new phase of life was described after a change had taken place, where new habits formed a new life as usual. Often it was not until a change had been lived that the participant became aware of its benefits. Benefits of reducing hours worked were described as being able to go grocery shopping, cooking, and doing valued activities, including exercising and being able to take breaks when needed to avoid getting exhausted. Even though it was possible to find new meaning in life after changes in working life participants described feelings of grief having lost an important aspect of life that they valued.

5.3 PAPER III: Translation and psychometric properties of the ACHC scale

5.3.1 Translation and cultural adaptation

The Swedish version of the ACHC Scale was considered to be a satisfactory equivalent to the original version in all of the reviewed aspects of equivalence (Table 12). Regarding the concept of acceptance described to be represented in the ACHC Scale, the Swedish version was considered to be equivalent with the original version. Both the expert committee and the PwMS in the pre-test did however reflect on the complexity of the concept of acceptance. It was described as a concept that could be interpreted in different ways, both in the sense of giving up and in the positive sense the scale was constructed to represent, and as such important to well-being. The PwMS also indicated that there may be different sorts of acceptance, i.e. intellectual and emotional, and that acceptance may change over time along with the challenges of MS and other demanding life events.

The conceptual and experiential equivalence were challenged in a few items but this could be solved by finding appropriate wordings for these items in Swedish, through reflection in the expert committee of the meaning they were thought to convey. Regarding operational equivalence there were some difficulties with the questionnaire concerning the labeling of the rating categories and a double meaning in one item, but the Swedish version was thought to operate in a similar manner in a Swedish as in the original context. During the translation process idiomatic equivalence was considered to have been achieved, though care had to be taken to assure that the items in the original version, that mainly were expressed based on spoken language, were expressed in a similar manner in the Swedish version.

Table 12. The Acceptance of Chronic Health Conditions Scale in the original version and the final Swedish version in Paper III.

		Original version	Swedish version
Instruction		Please respond to the following statements by circling the answer that most closely matches your attitude about having MS.	Vänligen svara på följande påståenden genom att ringa in det alternativ som stämmer bäst med din inställning till att ha MS.
Response categories	1	Strongly agree	Stämmer helt
	2	Agree	Stämmer
	3	Not sure	Osäker
	4	Disagree	Stämmer inte
	5	Strongly disagree	Stämmer inte alls
Items	1[a)]	I feel I've come to terms with my MS.	Jag känner att jag lärt mig leva med min MS.
	2	I'd give all the money I have to get rid of my MS.	Jag skulle betala vad som helst för att slippa ha MS.
	3	I think of my MS as a curse.	MS är som en plåga som drabbat mig.
	4[a)]	I can't conquer MS, but I can adept to it.	Jag kan inte vinna över MS, men jag kan anpassa mig.
	5	My fondest dream is that I'll awaken some morning without my MS.	Det jag önskar allra mest är att en morgon vakna utan MS.
	6[a)]	Having a disease like MS is just part of life.	Att få en sjukdom som MS är bara så som livet kan vara.
	7	My MS is a major focal point in my life.	Mitt liv kretsar mycket kring MS.
	8	I spend a lot of time wondering why I have MS.	Jag tanker mycket på varför just jag fått MS.
	9[a)]	I think of my MS as just a part of who I am.	MS har blivit som en del av mig.
	10	I think a lot about what my life would be like without MS.	Jag tanker mycket på hur mitt liv skulle vara utan MS.

MS: Multiple sclerosis

[a)] Reversely coded items.

5.3.2 Psychometric properties

The Rasch analysis demonstrated a version of the ACHC Scale including seven of the 10 items demonstrated acceptable psychometric properties. With further analyses a version including all items, two original items and three super-items, demonstrated the most favourable psychometric properties. This enabled including all items and use summated score. Key points leading to this result are presented below and in Table 13.

Table 13. Psychometric properties of the different item solutions of the Swedish version of the Acceptance of Chronic Health Conditions (ACHC) Scale, overview of the analytic process in Paper III.

ACHC Scale solutions	**ACHC-10**	**ACHC-9 Item 9 excluded**	**ACHC-8 Item 9 and 4 excluded**	**ACHC-7 Item 9, 4 and 6 excluded**
Rating scale functioning	Item 9 was disordered and failed to meet criteria Outfit *MnSq* *z*-value ranged from 0.77 to 1.30	All items met criteria Outfit *MnSq* *z*-value ranged from 0.73 to 1.39	All items met criteria Outfit *MnSq* *z*-value ranged from 0.74 to 1.42	All items met criteria Outfit *MnSq* *z*-value ranged from 0.83 to 1.63
Internal scale validity: Item goodness-of-fit	Item 9 failed to meet criteria, infit MnSq was 1.75 and z-value 5.6	Item 4 close to not meet criteria, infit MnSq was 1.29 and z-value was 1.9	Item 6 failed to meet criteria, infit MnSq was 1.42 and z-value 3.0	All items met criteria
Internal scale validity: Unidimensionality	First component failed to meet criteria, explaining 48.7% of total variance. Second component failed to meet criteria, explaining 14.0%.	First component failed to meet criteria, explaining 57.3% of total variance. Second component failed to meet criteria, explaining 10.8%.	First component failed to meet criteria, explaining 58.7% of total variance. Second component failed to meet criteria, explaining 9.2%.	First component met criteria, explaining 63.6% of total variance. Second component failed to meet criteria, explaining 9.0%.
Person-response validity	8.1% of sample failed to meet criteria.	8.1% of sample failed to meet criteria.	6.8% of sample failed to meet criteria.	6.8% of sample failed to meet criteria.
Person-separation reliability	Met criteria for group use, person separation index 1.6	Met criteria for group use, person separation index 1.9	Met criteria for group use, person separation index 1.9	Met criteria for group use, person separation index 2.0
Internal consistency	Met criteria for group use, Cronbach's alpha coefficient 0.80	Met criteria for group use, Cronbach's alpha coefficient 0.84	Met criteria for group use, Cronbach's alpha coefficient 0.84	Met criteria for individual use, Cronbach's alpha coefficient 0.85
Differential item functioning (DIF)				Item 2: easier to agree with for women than men (p<0.01) Item 7: easier to agree with for men than women (p<0.01)

Evaluation of the rating scale revealed that the 5-category generic rating scale met the criteria for acceptable rating scale functioning. In the evaluation of item goodness-of-fit to the Rasch model, items #9, #4 and #6 demonstrated misfit and were excluded in indicated order. This resulted in a seven-item version of the ACHC Scale (the ACHC-7 Scale) in which unidimensionality was indicated and person-response validity was close to satisfactory. The ACHC-7 Scale also demonstrated ability to separate between groups using the person separation index and between individuals when using the Cronbach's alfa coefficient. Differential item functioning (DIF) was demonstrated in items #2 and #7 with regard to sex in the ACHC-7 Scale. In order to ensure that the items that were excluded did not appear as misfits due to DIF, this was analysed and concluded that DIF was not a potential cause of the item misfit. The Rasch analysis demonstrated further that the ACHC-7 Scale targeted the PwMS of the study satisfactory, demonstrating an acceptable fit between the item difficulty and the ability of the subjects (Figure 7).

Calculation of the item residual correlations resulted in the creation of three super-items, combined out of the original 10 ACHC items: items #1 to #4; items #6 and #10; and items #7 and #9. The super-items included one each of the items that demonstrated misfit in earlier analysis. When the version with three super-items and two original items (#5 and #8) were re-evaluated, this version (now including all items) demonstrated overall stronger evidence of internal scale validity, unidimensionality and person response validity than the ACHC-7 Scale. It also met the criteria for group use, but not for individual use. These additional analyses made it possible to keep all items in the scale and use a summated score.

```
<high acceptance>|<more challenging items>
 90           XX  +
                  |
                  |
          XXXXXX  |
                  |
                  |
                  |
                  |
 80               +
                  |
                  |
                 T|                                               Item #2, 4/5[d]
                                                                  Item #5, 4/5
                  |
                  |
            XXXX  |
                  |                                               Item #3, 4/5
 70               +
                  |
          XXXXXX  |
                  |T
         XXXXXXX S|
                  |
            XXXX  |                                               Item #7, 4/5
                  |                                Item #5, 3/4[c] Item #10, 4/5
 60    XXXXXXXXX  +                                Item #2, 3/4   Item #8, 4/5
         XXXXXXX  |S
           XXXXX  |                 Item #5, 2/3[b]
                  |                 Item #2, 2/3   Item #3, 3/4
      XXXXXXXXXX  |
         XXXXXXX  |                                               Item #1, 4/5
        XXXXXXXX M|
      XXXXXXXXXX  |                 Item #3, 2/3
 50               +M
    XXXXXXXXXXXX  |  Item #5, 1/2[a]
            XXXX  |  Item #2, 1/2
              XX  |                                Item #7, 3/4
                                                   Item #10, 3/4
        XXXXXXXX  |
                  |  Item #3, 1/2                  Item #8, 3/4
          XXXXXX  |                 Item #7, 2/3
                                    Item #10, 2/3
           XXXXX  |S
 40      XXXXXXX S+                 Item #8, 2/3
              XX  |
                  |                                Item #1, 3/4
            XXXX  |
           XXXXX  |
                  |T Item #7, 1/2   Item 1, 2/3
                     Item #10, 1/2
           XXXXX  |
                  |  Item #8, 1/2
 30            X  +
                 T|
                  |
                  |
                  |  Item #1, 1/2
                  |
                  |
                  |
 20            X  +
<low acceptance>|<less challenging items>
```

Figure 7. *Person-item map of the seven items included in the final model of the Acceptance of Chronic Health Conditions Scale (ACHC-7) in a sample of people with multiple sclerosis with shown Thurstone thresholds: Each item is placed where there is a 50/50 chance of scoring each of the stated categories.*

[a] 50% chance to respond 1 or 2

[b] 50% chance to respond 2 or 3

[c] 50% chance to respond 3 or 4

[d] 50% chance to respond 4 or 5

5.4 Paper IV: Patterns of change in functioning and perceived impact of MS, and level of acceptance and life satisfaction

5.4.1 Patterns of change in functioning and perceived impact of MS

In the full-time and part-time subgroups, limitation in walking ability was significantly increased (Table 14; significance level <0.01) demonstrating large effect sizes (Figure 8). In the part-time subgroup there was also a significant decrease in outdoor activities in private life reflecting a large effect size.

In the subgroup declining from working to not working and the not working subgroup, there was a significant increase in limitation of both walking ability and fine hand use. The declining subgroup also decreased domestic and outdoor activities in private life significantly, demonstrating large effect size. In addition, there was a significant increase in perceived physical impact of MS in the declining subgroup.

5.4.2 Acceptance of MS and life satisfaction

At the 10-year follow-up, 29 PwMS (91%) in the full-time work subgroup reported medium to high acceptance of MS. The part-time, declining and not working subgroups reported medium to high acceptance of MS to a lesser extent; 24 PwMS (74%), 18 PwMS (64 %) and 18 PwMS (62 %), respectively. The pattern was similar in the ratings of life satisfaction, where 25 PwMS (78%) in the full-time subgroup rated satisfaction with life, the part-time subgroup15 PwMS (56%), the declining 10 PwMS (36%) and not working subgroup 10 (34%).

Table 14. Patterns of change in activities and participation, body functions and perceived impact of MS at baseline and at the 10-year follow-up in the subgroups of PwMS in Paper IV. The subgroups were: those who worked full-time and part-time at the 10-year follow-up, those who had declined from working at baseline to not working at 10 years, and those who did not work either at baseline or at the 10-year follow-up. Data is presented as median and interquartile range.

	Full-time work, n=32			**Part-time work, n=27**			**Decline to no work, n=28**			**No work, n=29**		
Variables	**Baseline**	**10-year follow-up**	***p*-value**	**Baseline**	**10-year follow-up**	***p*-value**	**Baseline**	**10-year follow-up**	***p*-value**	**Baseline**	**10-year follow-up**	***p*-value**
Activities and participation												
Frenchay activities index • Domestic (0-15)	13.0 (2.0)	12.5 (4.5)	0.023	14.0 (4.0)	12.0 (3.0)	0.391	11.0 (6.5)	8.0 (10.0)	0.006	9.0 (10.0)	3.0 (10.5)	0.041
Frenchay activities index • Outdoor (0-15)	12.0 (3.0)	11.0 (3.0)	0.019	11.0 (2.0)	9.0 (4.0)	0.008	8.0 (4.5)	3.5 (8.0)	0.002	5.0 (6.5)	3.0 (7.0)	0.017
Frenchay activities index • Leisure[a] (0-12)	7.5 (2.8)	7.0 (4.8)	0.611	8.0 (5.0)	7.0 (4.0)	0.759	6.0 (4.0)	5.0 (2.0)	0.116	5.0 (6.0)	5.0 (4.5)	0.321
Timed 25 foot walk (m/s)	1.90 (0.41)	1.73 (0.46)	<0.001	1.73 (0.42)	1.38 (0.75)	<0.001	1.52 (0.55)	1.31 (0.79	0.001	1.04 (0.74)	0.77 (0.71)	0.006
Nine-hole peg test (pegs/s)	0.46 (0.13)	0.46 (0.14)	0.458	0.44 (0.10)	0.41 (0.15)	0.375	0.37 (0.15)	0.36 (0.15)	0.005	0.34 (0.11)	0.30 (0.17)	0.001
Body functions												
Fatigue severity scale (0-7)	3.4 (2.3)	2.9 (2.2)	0.739	5.0 (2.2)	4.9 (2.3)	0.809	5.3 (0.9)	6.0 (1.6)	0.136	6.1 (1.9)	6.0 (1.7)	0.259
Symbol digit modalities test (n correct responses/s)	0.56 (0.14)	0.57 (0.22)	0.861	0.52 (0.19)	0.54 (0.26)	0.485	0.39 (0.21)	0.41 (0.21)	0.012	0.36 (0.21)	0.34 (0.28)	0.175
Beck depression inventory (0-63)	6.0 (6.0)	4.5 (5.0)	0.181	8.0 (11.0)	7.0 (8.5)	0.710	9.0 (6.0)	8.0 (6.3)	0.819	14.0 (9.8)	7.0 (8.5)	0.115
Perceived impact of MS												
Multiple sclerosis impact scale • Physical (0-100)	6.5 (19.0)	6.0 (13.0)	0.914	22.0 (30.0)	26.5 (40.3)	0.809	42.0 (28.0)	43.5 (35.8)	0.006	45.0 (32.0)	40.0 (27.0)	0.211
Multiple sclerosis impact scale • Psychological (0-100)	19.0 (30.0)	19.0 (23.0)	0.029	33.0 (39.0)	34.5 (37.5)	0.330	38.0 (36.0)	33.0 (34.0)	0.127	55.0 (46.3)	27.0 (41.5)	0.602

n: number; m: meters; s: seconds

[a] The item concerning work was excluded to only include leisure activities in private life.

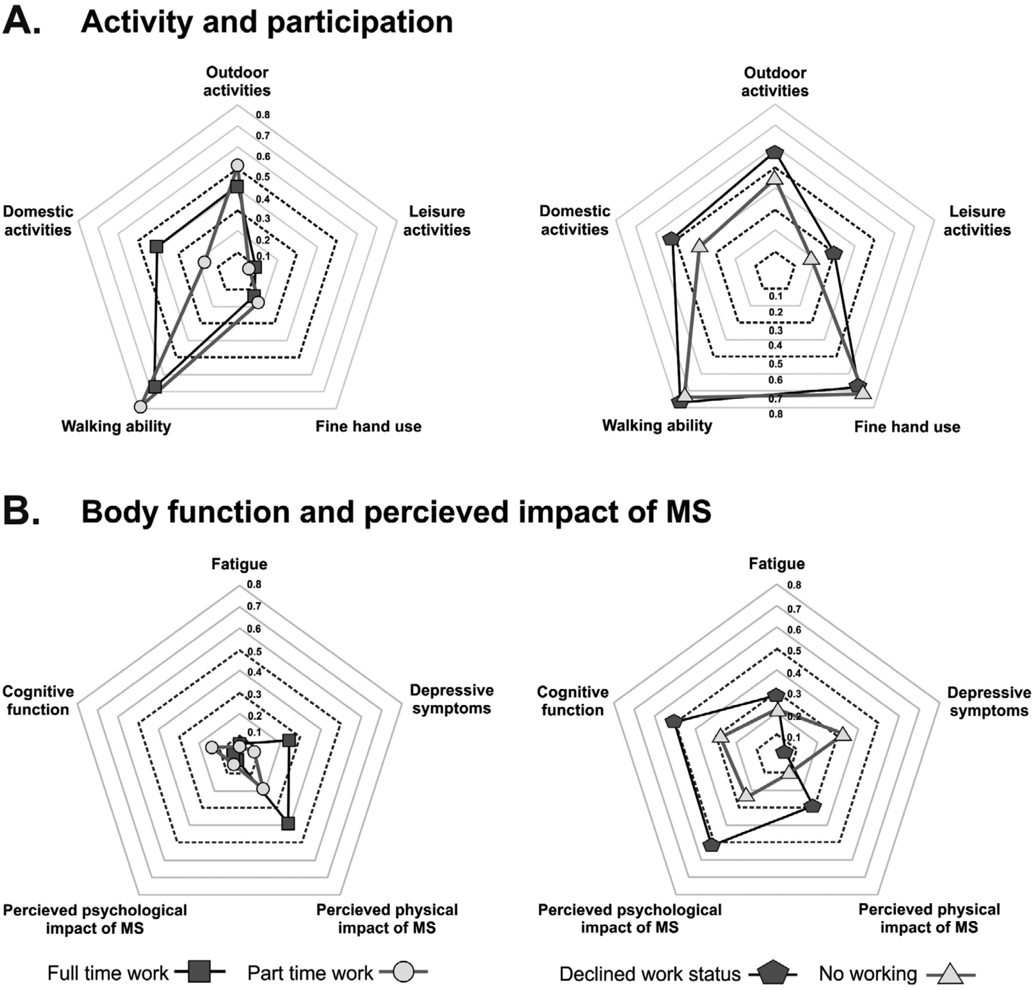

Figure 8. *Effect sizes of change in functioning and perceived impact of multiple sclerosis (MS) in Paper IV.*

6 DISCUSSION

6.1 Main findings

The overall aim was to build new knowledge that may contribute to the development of interventions to support sustainable working life and QoL in PwMS. In Paper I, we found that young age, full-time work, high frequency of activities in private life, fatigue and low perceived physical impact of MS were predictors for keeping employment after 10 years and that low perceived physical impact of MS also predicted working full-time after 10 years. The findings in Paper II revealed that the meaning of change in working life for the PwMS was characterized by a negotiation of what gives life meaning, a disrupted life course, finding meaning through taking control and altered life as usual. In Paper III, the ACHC Scale was found to be satisfactory translated and culturally adapted into Swedish, and to demonstrate acceptable psychometric properties for group use of a summed score including all 10 items. The PwMS still working after 10 years in Paper IV were found to be more stable in functioning and perceived impact of MS than the PwMS not working at the 10-year follow-up. Acceptance of MS and satisfaction with life was lower in the PwMS not working at the 10-year follow-up.

6.2 Results discussion

6.2.1 Contextual factors

Young age was a significant predictor for full- or part-time work (Paper I) in line with earlier reports (74, 133). However, age did not predict full-time work versus part-time or no work. In this sample the youngest participants had a higher probability of part-time than full-time work at the 10-year follow-up. The part-time subgroup was also the youngest in subgroup analyses (Paper IV). This may imply that younger PwMS to a lesser degree may advance to full-time work. Indications in line with this result have been observed in previous research, where younger and older PwMS were less likely to be employed than those of middle-age (134). The reasons for this are not certain, but since the times for building a career and a family coincide, it is possible that after a period of working part-time taking care of children, advancing to full-time work when the children have become older may be more difficult with a progressed disability over time. This would benefit from being explored further as young PwMS has a long time in working age ahead of them.

The time since diagnosis in our study differ from research reporting that PwMS end working life early after diagnosis (61). In our sample, more than 50% were still working at least 10 years since the diagnosis (Paper I). One reason for the higher employment rate in this sample may be that there is a support system in Sweden making part-time work possible.

6.2.2 Functioning and disability

Employment status

Working full-time at baseline predicted full- or part-time work after 10 years, but not working full-time versus part-time or no work (Paper I). This may be explained by that some of those working full-time at baseline were working part-time or were not working at the 10 year follow-up (Paper IV). Employment with an established trustful relationship with employer and colleagues also seemed to be an important factor for being able to deal with decreased ability at work and reducing working hours, but still being able to continue working (Paper II). It was described as a lot more difficult to get employed after not having an employment. It may therefore be important to support PwMS at their work-place early on to promote chances of keeping their employment, and that increased support is needed for PwMS who need to change employment or are unemployed for them to find appropriate employment. This may involve employers, social insurance services, employment services and health care professionals. As PwMS have been reported to not wish to use job-retention services until there is an employment crisis (74, 135) early signs of work-instability are important to observe and act on (133).

Strong incentives to work were described by the PwMS (Paper II). This is in line with other qualitative work where working has been found to be important for PwMS (78, 91), but there are also descriptions of working as not being as important as before MS (79, 91). It seems that MS can lead to a re-evaluation of what is valued in life, e.g. value of family and own health as being more important than working (79, 91). This was found in our study too but mostly after change had given space to other aspects of life (Paper II).

Activities in private life

High frequency of activities in private life at baseline predicted working 10 years later (Paper I). The high level of variance explained by activities in private life for employment status after 10 years indicates that a measure of activities in private life may be particularly valuable for understanding working life in PwMS, preferably in relation to level of fatigue. Even a small reduction in frequency may be useful as an early indicator of problems in working life (Paper I). These finding are in line with the PwMS experiences of difficulties with balancing working and private life while working (Paper II) and the decreased activities in private life found in the study of patterns of change where outdoor activities seemed to decrease before domestic activities (Paper IV).

Frequency of activities in private life has to our knowledge not previously been used as a predictor for employment status or studied for patterns of change in relation to employment status in PwMS (Paper I and IV). Increased fatigue from working, leaving little energy for managing private life has however been described in qualitative work (78), and aspects of private life, such as domestic and social life, have been identified by health professionals as factors influencing work ability (4). These reports strengthen the indications that work-life balance is a challenge for PwMS, and probably to a larger extent than in the general population since MS limits the PwMS resources.

Walking ability

In the study of patterns of change (Paper IV) walking ability demonstrated significant change in all subgroups in the analysis of patterns of change. Thus, walking appears to be an indication of disease progression present in all subgroups. Previously, a walking speed of 1.0-1.3 meters per second (6 to 8 seconds on the Timed 25-foot walk) have been reported to be associated to change in occupation (80). In our sample this occurred at a walking speed of 1.4 to 1.7 meters per second, i.e. the part-time subgroup. There may be differences in contextual factors in different counties accounting for this difference, but it is still evident that walking ability has an impact on employment status, including ambulatory PwMS with mild loss of mobility (136). Accessibility and attitudes both within the individual with MS and the environment may be key issues for walking ability not being a barrier for a continuing working life (Paper II). To start using walking aids or wheelchair may be difficult to accept for PwMS and lack of appropriate aids can therefore be an obstacle for continued working life. Evaluating level of acceptance of MS (Paper III) in this respect may be valuable for initiating support for coping with increased disability due to MS when immunomodulatory treatment has not halted the disease process enough for walking to not become a problem.

Fine hand use

It seems as problems with fine hand use appears to a higher degree in those who have ended working life (Paper IV). This is in line with previous research (65, 81) and the experience that working loses meaning when it is no longer possible for PwMS to use their hands independently e.g. when writing at work (Paper II). Limited fine hand use also slows down the pace of performing tasks at work such as writing and fine hand manipulation, which makes working difficult (81). This can become a problem on the working market where employers want fast and efficient employees.

Cognition

In the PwMS experience of change, impaired cognition was described as a major difficulty in working life making it difficult to make use of their competence (Paper II). Cognitive impairment caused uncertainty if completed tasks was carried out correctly, longer time for accomplishing their work and distrust from co-workers and employers. Both time and energy were spent in the struggle to cope with cognitive impairment. It is possible that if the rate of cognitive deterioration increase the difficulties at work become hard to overcome, resulting in an end to the PwMS working life. Early interventions would be beneficial, but this can only be done if the PwMS themselves have acknowledged their difficulties and are prepared to make changes at work (Paper II). In Paper I and IV however, impaired cognition did not predict employment status in multivariate analysis (Paper I) or change significantly over time (Paper IV). Previously, cognitive impairment has been reported to be associated with employment status (82, 137) and concern for memory and concentration difficulties (74), but the research is inconclusive (92). It is possible that many aspects influence employment status, and that the impact of cognitive impairment depends on the working and living situation as a whole.

Fatigue

Fatigue decreased the odds of full-time or part-time work in the univariate analyses but increased the odds in the multivariate model (Paper I). This result surprised us. Previous reports on fatigue are however inconclusive, reporting both fatigue to be associated with employment status (59, 74, 75), and not associated (138). In the PwMS descriptions of change in working life those working described experiences of fatigue as a major difficulty in working and private life (Paper II). Findings in line with this has also been found in previous qualitative research (78).

In the study of patterns of change (Paper IV) fatigue did not change over time in either of the subgroups, but there seemed to be differences in levels of fatigue between the groups. As the time since diagnosis was the same for the full-time and part-time subgroups, our results may indicate that those working full-time may have a disease course with a lower level of fatigue compared to the other subgroups. This may be in line with fatigue being identified as a contributor of decreased work ability (139) and a main driver for decreasing working hours (140).

These results indicate that fatigue has impact on PwMS in working life but interact in complex patterns with other aspects in life, which makes fatigue important to screen for in relation to other aspects of life such as work-instability and activities in private life.

Depressive symptoms

In the subgroup analyses there was no significant change in depressive symptoms in relation to employment status (Paper IV). Depression has previously been reported to be associated with employment status (75). In the PwMS' experience, not working was described as having lost something valuable in life (Paper II). Even though new meaning could be found in other aspects of life, dealing with what was lost was a challenge. From the descriptions of the PwMS it is likely that losing employment and also losing functioning could be reasons for depressive symptoms and support for coping with this is indicated.

6.2.3 Coping and acceptance

In the PwMS experience of change in working life (Paper II), acceptance was described as a means of taking control over a changing life situation, important for being able to move on with life. This is similar to what the ACHC Scale is described to represent (15) and to the reflections of the PwMS in the pre-test of the Swedish version of the scale (Paper III). The lower proportion of acceptance of MS in the PwMS in the part-time subgroup and the subgroups not working at the 10-year follow-up compared to the full-time work subgroup (Paper IV) may indicate that decreasing working hours and having ended working life is challenging to cope with for PwMS and that the degree of succeeding with this is limited. It is possible that the PwMS in the full-time work subgroup, that had a very high proportion of acceptance of MS, and also had a pattern of change with lower decrease in functioning, had not encountered as challenging changes because of MS as those who had decreased working hours or ended working life. In a study by Ford et al. (133), which also used the ACHC Scale, low levels of work instability, self –efficacy and younger age were found to predict job retention over a three-year study-period, but not acceptance of MS. In this sample the mean age was 10 years younger, they had a shorter time since diagnosis and a lower overall MS-disability. It would be of value to further study how acceptance of MS change with time and level of disability to increase the understanding of its impact on employment status.

In PwMS with cognitive impairment there are indications of higher degrees of maladaptive coping, as this may impair individuals' ability to use adaptive coping strategies (39). This may have affected the PwMS in our research project too, but fatigue seemed to affect the ability to cope more, because there was not enough energy for this kind of reasoning (Paper II).

6.2.4 Quality of life

Perceived impact of MS

Low perceived physical impact of MS was a predictor for both working full- or part-time and for working full-time. Furthermore, it was a stronger predictor than performance based tests (Paper I). Notably, the probability of not working was higher, than of working full- or part-time, already at a low level of physical and psychological impact. Higher perceived disability has also been reported to be related to more and more severe work-related difficulties (141). These results indicate that a measure assessing perceived physical impact of MS may be a sensitive and useful tool for identifying early indications of future difficulties in working life.

In the study of patterns of change, only the subgroup declining from working to not working was found to rate increased physical impact of MS. In the subgroup not working the impact was high also from the beginning of the study-period

(Paper IV). This result is in line with previous reports of that PwMS who do not work experience lower HRQL (86-88). It is however not clear if it is the lack of participation in working life that is the main reason for the low HRQL. Factors which have been found to have high impact on HRQL, such as limited walking ability, fatigue and depression (142), are also reported to be associated with not working (65, 74, 80) and present in the subgroups not working in our study. It is likely that decreased functioning is contributing to the low perceived physical impact of MS, as well as not working.

Life satisfaction

In the PwMS working full-time more than three quarters were satisfied with life, a little more than half of those working part-time were satisfied with life, and only approximately one third of those not working at the 10-year follow-up (Paper IV). This is in line with a report from Pack et al. (84) where employed PwMS tended to rate QoL close to one third of a standard deviation higher than those who were unemployed. Interestingly, they found that the difference between those working full-time and those working part-time was minor, no more than what could be expected by chance. In our sample the difference seemed to be larger, and may be due to possible cultural differences contributing to the conflicting emotions about cutting down on work found in our qualitative study (Paper II).

Measurements of life satisfaction have potential to include satisfaction with more aspects of life than measurements focusing on perceived impact on health (20). Our results indicate that this is the case for the PwMS in the studies of this thesis, which means that the value of other aspects of life may be underestimated when using measures of perceived impact on health or HRQL. In a study by Kuspinar et al. the top five domains PwMS identified as most negatively affected by MS was work, fatigue, sports, social life and relationships (20), out of which most are not covered by measures of perceived impact on health but may be included in ratings of life satisfaction.

It may be that when disease progression has caused irreversible disability, as is the case for the PwMS not working in this sample, other aspects impacting on the experience of life satisfaction may be more susceptible for change than the actual health condition. The challenged work-life balance found in Paper II may also play a role in the low QoL in PwMS not working. If it is not possible for the PwMS to maintain valued activities in private life due to prioritizing work, the loss of work may be even more detrimental to QoL than if other aspects of life could have been maintained while working. To be able to support PwMS to improve life satisfaction these aspects need to be explored further on the same time as existing disability is managed appropriately to minimize their negative impact on life.

6.3 Methodological considerations

6.3.1 Participants and procedures

It is recommended that PwMS have access to specialist neurological service (51). The sample this thesis is based on was recruited from such a setting. At baseline all PwMS with a scheduled appointment with a specialist neurologist were eligible for inclusion during a specific time period. These were then followed-up after 10-years. In consequence, all participants in this sample had at least 10 years since receiving their diagnoses and all were 30 years or older at the 10-year follow up. The sample can be considered to be representative for PwMS in regular contact with a specialized service and been diagnosed with MS some time ago.

For the study of psychometric properties of the ACHC Scale (Paper III), all PwMS of the 10-year follow-up were included, also those above 65 years of age. It would have been preferred if the sample also included PwMS with less than 10 years since diagnosis and younger than 30 years of age, but the sample was still represented a diverse group of PwMS.

In this thesis we sought to explore a wide range of variables and the ICF framework was used so that all domains included in the ICF were covered. Consequently, the variables included represented contextual factors, activities and participation and body functions. We also included QoL. Both patient-reported and performance based outcome measures were used in the quantitative analyses that strengthens the assessment base for the studies. For the purpose of exploring the PwMS work situation assessments concerning the context at the work-place would have been useful, but this was not possible to follow-up since it was not included in the study at baseline.

At baseline all data was collected at the neurology out-patient clinic. For the 10-year follow-up data was collected at the clinic or through home visits, depending on the choice of the participant. The different contexts for data collection may have influenced the PwMS, but data was collected in the same standardized order with the same sort of guidance regardless of place for data collection. In a few cases at the 10-year follow-up, data was collected via mail and telephone interviewing, due to the PwMS having moved from the area. For these PwMS the performance based tests were not possible to carry through, which meant data was missing for these PwMS. This was not optimal, but was considered to be a better choice than excluding them from follow-up. These settings for data collection contributed to a low number of drop outs.

6.3.2 Data analyses

In the study of predictors for employment status (Paper I), the statistical method generalized ordinal logistic regression was used to enable differentiation of PwMS working full-time, part-time and not working. This type of analysis is more complex than an analysis where the dependent variable is categorized in two levels but it was considered as more useful for exploring work-life balance and would relate better to a clinical context. The variables were carefully selected for making the multivariate model as valid as possible. Overall MS-disability was included in the univariate analyses, but excluded from the multivariate analysis. Its assessment was considered to be largely based in walking ability, for which we instead used a performance-based test instrument to assess.

The Frenchay activities index, which was used to assess activities in private life has been criticized concerning the possibility of outdated items, as it was developed decades ago (143). Further development of the index has been presented where differentiated means of transportation and use of mobile phone has been added, and also advanced rating options (143). These improvements may have been useful in our project, if they had been accessible at the time of data collection. However, based on descriptions in Paper II and habits of society of today, it is likely that items would have been more useful concerning social interaction at home and over the internet, shopping over the internet, and also exercising, which is not included in the original index but is an activity in private life with documented health benefits (144) in need of both time and energy to be beneficial.

Use of a multivariate analysis method enabled improved understanding of each variable in the context of the other variables included in the model, that is a strength of the study. It also came with some challenges concerning interpretation of the results. Activities in private life turned out to be the most important predictor for working after 10 years (Paper I). As this variable may be considered to be a compounded variable, resulting from level of functioning in other variables, e.g. walking ability, cognitive function and depressive symptoms we considered excluding it. However, frequency of activities in private life was considered to add something unique and was therefore kept in the model.

Walking ability, fine hand use, cognition and depressive symptoms were significant predictors in univariate analyses but not in multivariate analysis in addition they were strongly correlated with other independent variables and may in effect often be present on the same time in PwMS. All correlated variables may be useful for detecting higher odds for employment in the univariate analysis, but one or two may be enough in a multivariate model.

A result we were concerned about was fatigue as a predictor for working in the multivariate analysis but for not working in univariate analysis (Paper I). It should be noted that the levels of fatigue, using the Fatigue severity scale, in PwMS working full-time was below the cut-off for being considered as having fatigue. If this variable had been dichotomized using the cut-off for fatigue the results of the analyses may have turned out differently.

In Paper II a phenomenological approach was used for the design and analysis of the study. Using this methodology, rich and varied descriptions of the phenomenon are important. This was assured through the varying characteristics of the participating PwMS. The interview guide with open-ended questions and the interested and open attitude of the interviewer, led to rich descriptions of the participants' life stories and experiences. This was very useful in putting the studied phenomenon into the perspective of life as a whole. To ensure trustworthiness, triangulation between the researchers was used in the analysis process leading to the final meaning structure and we repeatedly returned to the interviews to confirm the consistency of the results with data. The researchers had different professions and experience of PwMS that may have improved both the credibility and confirmability of the findings. Some had extensive experience of MS and knowledge of the participants, while others did not. The researchers did however need to stay aware of their previous knowledge and experience to minimize its influence on the emerging meaning structure, as prior knowledge should be set aside (116). The findings were further discussed with health professionals experienced in rehabilitation for PwMS for consideration of transferability. It was found that the findings were in consistence with experiences they had of meeting PwMS, which also improved possibility of dependability.

The translation and cultural adaptation carried through (Paper III) was performed in a rigorous way, based in relevant literature (96, 97) that strengthens the quality of the Swedish version of the ACHC Scale. The translators and the expert committee were all competent in English, still adding a professional translator may have been beneficial. The final version of the scale may not have differed, but it may have taken a shorter time to accomplish the translation and cultural adaptation.

Rasch analysis was used for the evaluation of the psychometric properties of the ACHC Scale (Paper III). It was chosen in favour of methods based in classical test theory as it can increase the information on scale properties (118, 119). The stepwise methodology of the Rasch analysis had been tested and used previously (122) that helped secure the quality of the analysis process. The analyses resulting in the super-items were added to ensure that no items that should be included were excluded. This resulted in all items being kept in the scale.

The purpose of Paper IV was to explore clinically useful factors that may interact with employment status over time, and indicate where further research may be needed. Dividing the PwMS into subgroups based on employment status made it possible to identify aspects interacting in working life in PwMS not possible to identify when analysing the PwMS as one whole group. This benefited the intention with the research on the same time as it impact on the generalization of the results. To improve the reliability of the results, non-parametric statistics were used with a significance level of $p<0.01$. Using the subdomains of activities in private life enabled exploration of different aspects of activities in private life in relation to employment status and is thought to have made possible a deepened understanding for working life in relation to life as a whole.

6.3.3 Ethical considerations

There has been a continuous effort to protect the well-being and sense of security of the PwMS during the course of this research project. It was both time and energy-consuming for the participants to complete the data collections in this thesis. For a few persons it was very tiring. There was also a risk that the focus on assessing function and answering questions that may be perceived as disheartening or invasive of privacy would raise negative thoughts in the PwMS. Still, the dominating impression was that the participants valued the opportunity to help developing knowledge about the situation for PwMS, by taking part in this research project. The extra time talking to someone knowledgeable in MS, who showed interest in their situation, was also perceived to be valuable. During the data collection at baseline and the 10-year follow-up, the research physiotherapists took care in assessing the PwMS' ability to perform all the tests and still be able to get through the rest of the day. If not, some tests were excluded or a new appointment for the remaining tests was set up another day.

6.4 Conclusions

This thesis underlines the complexity of working life for PwMS, and that a holistic perspective is needed for understanding PwMS' situation in working life and for supporting sustainable working life and QoL.

Change in working life can be difficult for PwMS and involve a struggle with strong incentives to keep life going as usual. In this process, work-life balance can be challenged, sometimes to the extent that even basic needs in private life may be difficult to provide for. Frequency of activities in private life may therefore be useful to pay attention to for detecting early problems in working life and for predicting future risk of employment loss. Assessment of perceived physical impact of MS also seem to be a sensitive and useful tool for predicting future risk of employment loss and reduced working hours.

Proactive support would be valuable for PwMS to be better prepared for change instead of postponing taking action to when change is forced by problems not possible to ignore. When disability increases, e.g. limitations in walking ability, fine hand use and cognitive impairment, it is important to make sure the work-place is accessible, that attitudes allow for using aids, adapting work to ability and a slower pace of working if this is needed. Changes like these can be very challenging for PwMS and care should be taken to not underestimate its impact.

For PwMS to find meaning in change and improve their well-being in phases of change in working life, taking control over their situation through acceptance of their situation, self-care and finding support in allies may be helpful. An altered life can be established, but grief for what is lost may prevail as well as difficulties in finding meaning in other aspects of life. The ACHC Scale may be a useful tool for identifying PwMS with difficulties in coping with MS, indicating who is in need of increased support.

PwMS still working full-time after 10 years seem to have a more stable disease course, less challenging for coping with MS and satisfaction with life. A larger increase in disability and perceived physical impact of MS in PwMS declining from working to not working may be accountable for lower level of acceptance of MS and satisfaction with life, alongside loss of employment. The loss of meaningful activities in private life while working may also play a role for the low QoL when ending working life. Widening the view of what is valued in life at an early stage may be helpful for maintaining meaningful activities in private life, such as social interaction outside of work, exercising and pursuing a hobby. It is also of importance that this is allowed by society, as this may imply that decreased working hours are needed.

6.5 Clinical implications

In the management of MS, slowing down the disease progression is vital for maintaining work ability and QoL. The health care services need to support PwMS in maintaining functioning as far as is possible and minimizing the effects of permanent disability, for making the basis for work ability and QoL as good as possible. The ACHC Scale may be helpful in identifying when PwMS are in need of support to cope with the consequences of MS in working and private life.

Indications of problems in working life need to be identified early for being able to initiate appropriate vocational support. Screening for activities in private life and perceived physical impact of MS may be used for this purpose. Building a trustful relationship with the individual with MS, including working life, private life as well as managing MS, may be helpful for being able to offer proactive support and support in phases of change.

It is however not clear who should be responsible for the proactive support in working life for PwMS and detecting when interventions are needed. The employer is in Sweden responsible for vocational rehabilitation, but it is not likely employers have sufficient knowledge for this responsibility, neither the Social insurance agency nor the Public employment service. It is in the health care services, specialized in MS, the required expertise is available. Vocational rehabilitation interventions for PwMS therefor need to be planned and put in to effect in close collaboration with the health care services.

Improved work-life balance may have potential to prolong working life by making life as a whole more sustainable, and to improve QoL both while working and when working life has ended. Increased MS-disability may decrease an individual's total resources for managing different roles in life. This could be resolved, e.g. by granting more help in daily activities such as household work and facilitate transportation to save more energy for work, or by decreasing working hours to save more energy for meaningful and health-promoting activities in private life.

6.6 Future research

This thesis includes studies on working life in PwMS which add to the scientific basis for developing interventions aiming at sustainable working life with QoL. More research in this area is indicated concerning the role of work-life balance for work sustainability and QoL in PwMS both while working and after ending working life, as the previous research in this area is limited. This may also imply a need to further develop test instruments in this area.

For the ACHC Scale to be valid also in a younger population with more recent MS diagnosis and reliable concerning test-retest, additional research is also indicated. Acceptance of MS in relation to disability may also benefit from being explored further to increase the understanging of the impact of disability on ability to cope with MS.

The next step in research on PwMS working life is to focus on interventions which at an early stage prepare PwMS for possible change later on in working life, and how more flexible solutions can be implemented for employers and social security systems to enable PwMS to continue with a meaningful working life despite disability.

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